

INDUSTRY PROFILE ON

Wheeled

Mobility

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**RERC on Technology Transfer
University at Buffalo**



Acknowledgment

The Industry Profile on Wheeled Mobility

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Table of Contents

	Section	Page
	Abstract	3
	Introduction	4
Chapter	Industry Overview	
1	Wheeled Mobility Demographics <i>Jennifer Flagg</i>	7
2	Comparative Analysis <i>Jennifer Flagg</i>	30
	Expert Chapters	
3	Legislation and Funding <i>Barbara Crane, Jean Minkel</i>	50
4	Voluntary Industry Standards for Wheelchair Technology: A Model for Successful Advancement of Assistive Technology <i>Douglas Hobson, Peter Axelson</i>	79
5	Wheelchair Transportation Safety <i>Gina Bertocci, Mary Ellen Buning</i>	126
6	Accessible Public Transportation <i>Katherine Hunter-Zaworski</i>	152
7	Interpretive Overview: Wheeled Mobility <i>Linda Elsaesser</i>	185
	Stakeholder Perspectives	
8	Research Perspective: Mobility and Seating/Posture <i>Stephen Sprigle, Laura Cohen, Kim Davis</i>	236
9	The Clinician's Perspective <i>Susan Johnson Taylor, Jan Furumasu</i>	258
10	Supplier Perspectives <i>Daniel Lipka</i>	288
11	Parents' Perspectives of Assistive Technology <i>Jan Furumasu</i>	313
Appendix	Appendices	
A	Wheeled Mobility Consumer Needs	327
B	National Organizations and Associations	330
C	Conferences and Tradeshows	332
D	Manufacturer Index	333

Abstract

Purpose: The *Industry Profile on Wheeled Mobility* is a very broad and accessible compilation of knowledge pertaining to the wheeled mobility industry and marketplace. The *Industry Profile* is relevant to the development and refinement of public policy, legislation, grants, products, clinical practice, service delivery, third-party payment, standards, product delivery, and research programs. Anticipating that industries and markets constantly evolve, the *Industry Profile* includes many recommendations across all topics.

Method: The *Industry Profile* includes primary research, secondary research and invited chapters. Primary research is based on expert interviews and consumer focus groups. Purposive sampling was used to identify and recruit all interview and focus group participants, broadening and deepening knowledge representation. Focus group participants were expert users of manual wheelchairs and power wheelchairs. Interview participants include expert manufacturers, clinicians, researchers and suppliers. All focus groups and interviews were structured, scripted and moderated in a manner that helps to ensure full coverage of issues, facilitates data analysis and encourages free and open dialogue. Secondary research includes identification, review, compilation and analysis of data obtained from public sources. Secondary sources included government publications, studies and databases, trade journals, research publications, industry and manufacturer websites and product literature. Experts on wheeled mobility were drawn from academe, industry, product suppliers and service delivery. These experts contributed chapters and perspectives in nine topic areas.

Results: The *Industry Profile* has five expert chapters on: funding and legislation, standards, accessible public transportation, wheelchair transportation safety, along with an interpretive overview. There are four stakeholder perspectives chapters on: research related to mobility and seating/positioning, the role of clinicians in service delivery, mobility product supply and parent's perspective on mobility. The *Industry Profile* includes two additional chapters on: market demographics and a comparative analysis of consumer and expert perspectives focused on the strengths and weaknesses of current products and direction of and need for technology and product development. Finally, the *Industry Profile* includes compilations of manufacturers, their contact information and products; conferences and trade shows, and national organizations.

Conclusion: This *Industry Profile* fills an important need for critical stakeholders of the wheeled mobility industry and market. However, this *Industry Profile* cannot be regarded as fully complete or fully up to date. Many important topics are not covered in depth. As a consequence, this *Industry Profile* should be regarded as a foundation for future studies of an important and evolving industry and market.

KEYWORDS

Wheeled Mobility, Wheelchairs, Scooters, Seating, Positioning, Legislation, Medicaid, Medicare Modernization Act, American's with Disabilities Act, Reimbursement, Wheelchair Transportation, Standards, International Classification of Functioning Disability and Health, Service Delivery, Rehabilitation Engineering, RESNA, Assistive Technology Professional, Occupational Therapist, Physical Therapist, NRRTS

Introduction

An industry profile is a collection of knowledge pertaining to a “market,” and the “industry” serving this market. The commonly used phrase “wheeled mobility” connected to both a market and an industry is undefined. However, the International Classification of Functioning, Disability and Health (ICF) includes “using a wheelchair” to describe “devices designed to facilitate moving or [to] create other ways of moving around,” i.e., mobility. The U.S. Department of Health & Human Services, U.S. Food and Drug Administration (FDA), classifies wheelchairs as medical devices with wheels that are “intended for medical purposes to provide mobility to persons restricted to a sitting position.”

For the purpose of this profile, the “wheeled mobility market” includes “persons who use manual wheelchairs, power wheelchairs or scooters on a full- or part-time basis; and it includes the structures and processes that enable these products to reach their intended market.” The “wheeled mobility industry” includes “manufacturers of wheelchairs and scooters, and components and accessories of these devices, and the suppliers of these products, components and accessories.”

The *Industry Profile* is an accessible compilation and presentation of available knowledge on the wheeled mobility industry and marketplace. It is intended to be a reference document for policy makers, clinicians, suppliers, manufacturers, researchers, market analysts and students.

The *Industry Profile* is divided into three parts: the Overview, Expert Contributions and Stakeholder Perspectives. The *Industry Profile* draws from secondary sources such as published research, trade journals, manufacturer websites, product literature and public databases. It also draws from primary sources, including expert interviews, consumer focus groups and expert-authored chapters.

The Overview comprises this introduction and two chapters pertaining to market demographics and a comparative market analysis.

- The **Market Demographics** chapter includes data sources, manual wheelchair, power wheelchair and scooter usage, market growth trends and projections, and market share by product type. Device usage is discussed from the perspective of age, gender, race, ethnicity, employment status and income level. Industry leaders, their market share and trends are discussed. Important gaps in market research, data and terminology are identified. Recommendations are made on how these gaps might be closed. The company profiles include a listing of wheeled mobility manufacturers, their market segments, product lines and contact information.
- The **Comparative Analysis** chapter compares and contrasts the perspectives of wheeled mobility users (obtained through focus groups) to the perspectives held by manufacturers, suppliers, clinicians, and researchers (obtained through expert interviews). Especially considered are the strengths and weaknesses of current products and needs for future technologies and products.

The **Expert Contributions** comprise five chapters written by wheeled mobility content experts. These chapters include legislation and funding, standards, wheelchair transportation safety, accessible public transportation and interpretive overview.

- The **Legislation and Funding** chapter describes the current third-party payment system for wheeled mobility devices. It discusses the impact of third-party payment on manufacturers, suppliers, clinicians and product end-users.
- The **Standards** chapter presents the history and rationale for industry, voluntary, regulatory and international standards. The chapter contains an excellent, detailed presentation on the standards-development process. The authors argue that standards benefit users of mobility devices, clinicians, researchers, mobility device manufacturers and healthcare funding agencies.
- The **Wheelchair Transportation Safety** chapter discusses key elements of safe transportation for wheelchair-seated passengers within public and private environments. It presents current voluntary industry standards and their application to wheelchairs and restraints. Future development of standards for seating, private vehicles and buses is covered. The chapter closes with practical challenges to standards compliance and future research directions.
- The **Accessible Public Transportation** chapter argues that safe and accessible public transportation enables individuals with disabilities to participate fully in education, employment, recreation, independent living and other essential life activities. A logical, abstract and comprehensive model for public transportation systems is used to frame all discussion in this chapter.
- The **Interpretive Overview** chapter presents the holistic nature of wheeled mobility service delivery. Discussion spans clinician education, research and development, service delivery administration and refinement, standards and guidelines for practice, devices and service delivery, terminology, outcome measures, knowledge translation and medical standards of care.

The Stakeholder Perspectives comprises three chapters on research perspectives, clinician's perspectives, supplier's perspectives and parent's perspectives.

- The **Research Perspective** chapter includes results from the 2007 Mobility Rehabilitation Engineering Research Center, State of the Science Conference. Four critical research needs are discussed for both mobility and for seating/posture.
- The **Clinician's Perspective** chapter describes the knowledge of human function, clinical evaluation skills and knowledge of product features that are aspects of the services provided by occupational and physical therapy practitioners. Mobility devices enable individual to complete activities of daily living and engage in valued occupations. The critical role of clinicians in obtaining appropriate mobility devices is described.
- The **Supplier's Perspective** chapter examines the process by which individuals with mobility impairments obtain mobility devices. The chapter considers the roles of manufacturers, suppliers, and clinicians in this process. Types and sources of mobility devices and funding for their purchase are discussed. The future impact of competitive bidding (required by the Medicaid Modernization Act) is considered.

- The **Parent's Perspective** chapter considers the roles and perceptions of parents, as mothers and fathers, as advocates and as caregivers. Pediatric mobility devices and special considerations pertaining to mobility for children are discussed. The chapter concludes with general and specific recommendations for pediatric mobility devices.

The *Industry Profile on Wheeled Mobility* is a first step toward a comprehensive and accessible, compilation and presentation of knowledge pertaining to the wheeled mobility market and industry. Some critical topics are well covered, while other topics receive little attention. An important contribution of the *Industry Profile* is to identify gaps in knowledge where further research is needed. It is our hope that the 2009 *Industry Profile on Wheeled Mobility* will serve as an embryo from which a deeper and more comprehensive understanding of the wheeled mobility market and industry can grow.

The Industry Profile on Wheeled Mobility is available in an accessible format on the T2RERC website at <http://t2rerc.buffalo.edu/>. The Industry Profile will also be available through the affiliated websites of contributing authors. A listing of all sites and forms of dissemination will be listed on the T2RERC website.

Chapter 1

Wheeled Mobility Demographics

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Contents

	Section	Pg
1.1. Introduction	8
1.1.1. Data Sources	8
1.1.2. Data Analysis Reports	10
1.2. National Wheelchair Usage Estimates and Growth	11
1.2.1. Types of Wheeled Mobility Devices in Use	15
1.2.2. Wheelchair Usage by Age	17
1.2.3. Wheelchair Usage by Gender	18
1.2.4. Wheelchair Usage by Race and Ethnicity	19
1.2.5. Wheelchair Usage and Employment Status	20
1.2.6. Income Level and Mobility Device Use	21
1.3. Health Status, Functional Limitations and Mobility Device Usage	22
1.4. Wheelchair Usage and Home Accessibility Features	23
1.5. Wheelchair Manufacturer Market Share Information	24
1.6. Gaps and Needed Research	25
References	27

1.1. Introduction

The wheeled mobility industry in the U.S. is large and diverse, consisting of a primary market of end users and secondary markets of payers (i.e., reimbursement sources such as private and public health insurance), suppliers (i.e., wheeled mobility manufacturers and durable medical equipment (DME) dealers), and providers (i.e., clinicians and rehabilitation engineers). Yet, few surveys quantify the magnitude and growth of wheelchair sales and use. In comparison to other disability segments, wheeled mobility is relatively well documented. However, the national surveys that collect wheeled mobility information have not employed consistent methodology, making it difficult to combine data and identify trends. Furthermore, data for the most recent large study was collected in 2002.

This section of the IP addresses the wheeled mobility market in general by introducing the reader to two large-scale longitudinal surveys that gathered information regarding the use of wheeled mobility devices in the United States. Specific data regarding the secondary markets in the industry is lacking. Therefore, the discussion focuses on four reports that analyze longitudinal survey data. The data relates to the primary market of end users. Included in this discussion are market projections and growth estimates for the overall wheeled mobility market. Gaps in available research are also identified.

1.1.1. Data Sources

The two primary sources for national statistics regarding wheeled mobility device use in the United States are the U.S. Census Bureau's Survey of Income and Program Participation (SIPP) and the National Center for Health Statistics' (NCHS) National Health Interview Survey (NHIS).[1][2] Both surveys have historically been administered recurrently; however, wheeled mobility is not always a covered topic. The latest versions of these surveys relevant to wheeled

mobility are the 1980 NHIS, 1990 NHIS-AD (Assistive Devices), 1994 NHIS-D (Disability), and the 1996 and 2002 SIPP.

Both the NHIS and SIPP collected data from the same U.S., civilian, non-institutionalized population, and used similar but not identical methodologies for data collection and reporting. Differences between these surveys include variations in years of study, sampling, scope, and level of detail gathered. For example, the NHIS-D uses separate categories for reporting manual wheelchair, electric wheelchair, and scooter use, while the SIPP lumps all three into one single group. The surveys also use somewhat different inclusion criteria for who is considered disabled, and who is considered a wheelchair user. Table 1.1., highlights a sample of joint strengths and weaknesses common to the most recent versions of the NHIS-D and SIPP surveys as well as important differences between the two surveys.

Table 1.1. *Comparison of NHIS-D (1994) and SIPP (2002)*

	NHIS-D (1994)	SIPP (2002)
Population	Non-institutionalized U.S. population (Does <i>not</i> include nursing homes)	Non-institutionalized U.S. population (Does <i>not</i> include nursing homes)
Level of Device Detail	Separate categories for manual wheelchair, electric wheelchair, and scooter	Single category for manual or electric wheelchair or electric scooter
Definition of Wheelchair Users	Must have been, or must be expected to be, using the device for 12 months or longer	Stated that they used a wheelchair at the time of the survey
Total Population Estimate	261,539,000	282,873,000
Wheelchair Users Estimated	1.6 million	2.7 million

It is vitally important that national surveys such as these continue and expand. However, establishing common terminology and methods would greatly strengthen and extend the value

and interpretability of national surveys. Researchers should consider the methods and definitions used in past surveys in an effort to produce results that can be compared over time.

1.1.2. Data Analysis Reports

Several authors have reported findings based on data gathered by the NHIS-D and SIPP. The reports offering the most comprehensive coverage of the wheeled mobility industry are Mobility Device use in the United States by H. Stephen Kaye, Taewoon Kang, and Mitchell LaPlante, and Demographics of Wheeled Mobility Device Users by Mitchell LaPlante.[3][4] Additional publications of interest include Trends and Differential Use of Assistive Technology Devices by J. Neil Russell, Gerry Hendershot, Felicia LeClere, L. Jean Howie, and Michele Adler; Americans with Disabilities: 1997 by Jack McNeil; Americans with Disabilities: 2002 by Erika Steinmetz; and Trends and Issues in Wheeled Mobility Technologies by Rory Cooper and Rosemarie Cooper.[5][6][7][8]

Table 1.2., details the primary data sources used by each of these studies, as well as the topics covered by each. This table is intended to be used as a guide to locating more in-depth information from source documents. Many, but not all, of these findings are covered in the remainder of this chapter.

Table 1.2. Topics Covered in Wheeled Mobility Reports

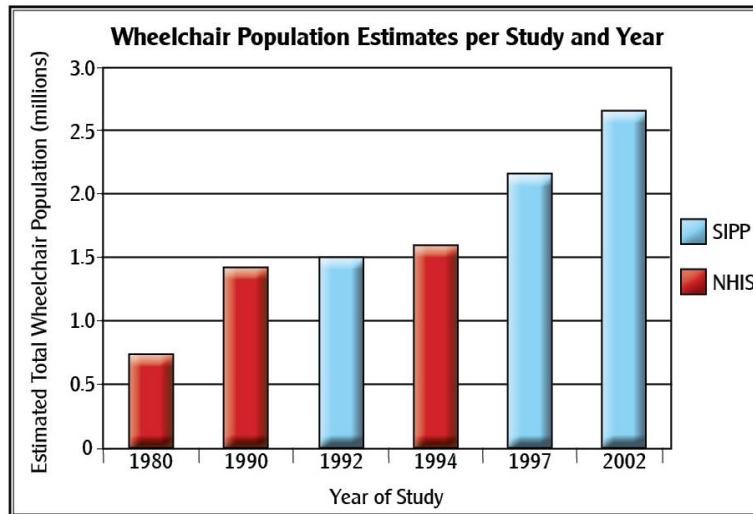
First Author (Year of Publication)	Russell (1997)	Kaye (2000)	McNeil (2001)	Cooper (2003)	LaPlante (2003)	Steinmetz (2006)
Dominant Data Source	NHIS-D 1994, 1990, 1980	NHIS-D 1994	SIPP 1997	N/A	NHIS-D 1994, SIPP 1997	SIPP 2002
Total Users	X	X	X	X	X	X
Usage Trends	X			X		
Type of Wheelchair		X		X		
Age	X	X	X		X	X
Gender		X	X		X	X
Race Ethnicity		X			X	
Education Level		X				

Employment Status		X	X		X	X
Income Level		X	X		X	X
Poverty Status		X			X	
Regional Location		X				
Setting of Residence		X				
Health Status		X			X	
Degree of Functional Limitation		X			X	
Type of Functional Limitation		X			X	
Type of Health Condition		X			X	
Home Accessibility Features		X			X	
Home Accessibility Difficulties		X			X	
Public Transportation Difficulties		X		X	X	
Health Insurance Coverage		X				
Hospitalization History		X			X	

1.2. National Wheelchair Usage Estimates and Growth

The two most recent approximations regarding the use of wheelchairs in the U.S. resulted from the 1994 NHIS-D, which estimated that there were 1.6 million wheelchair users in the U.S., and the 2002 SIPP, which reported that there were 2.7 million. Figure 1.1., offers a graphical depiction of the total wheelchair user population for 6 years of data collected by the NHIS-D and the SIPP.

Figure 1.1. Wheelchair users in the U.S.



Growth in the wheeled mobility marketplace results from many factors, including advances in trauma treatments leading to higher survival rates, a rise in the incidence of diabetes and obesity, growth in the general population, growth of the elderly population as the baby boomer generation ages into retirement and increased accessibility in residential and public settings. [4][3] No single factor is solely responsible. Additionally, advances in spinal cord injury treatments, decreases in reimbursement and device abandonment may inhibit market growth. Further research is needed to fully understand growth trends in this dynamic industry.

While causative factors that influence the rate of growth are critical, this analysis focuses on the magnitude of growth rather than the causes. Compiling the 1994 NHIS-D and 2002 SIPP suggests a total market growth of 69% in the number of wheelchair users over the course of eight years, translating to approximately 8.6% linear growth per year. Readers should note that these estimates include only those wheelchair users living in the community, as opposed to those who reside in institutions, such as nursing homes. Growth related to the institutionalized population is likely to be significant; however such data is not currently available. Additionally, differences

in methodology and terminology between the reporting surveys reduce confidence in these projections.

A report published in 1997 by the NCHS compares data from the 1980 NHIS, the 1990 NHIS-AD, and the 1994 NHIS-D. According to this report, age-adjusted wheelchair usage grew 65% from 1980 to 1990 (6.5% average growth per year), and an additional 11% from 1990 to 1994 (2.8% average growth per year). Growth during the 14-year period from 1980 to 1994 was just under 80%, suggesting an average growth of 5.7% per year.

Growth estimates based on SIPP data are similar to NHIS-D figures. As demonstrated in Table 1.3., wheelchair use grew 44% from 1992 to 1997 (8.8% average growth per year), and another 26% from 1997 to 2002 (average growth of 5.2% per year). These figures show total growth of 81% over the ten-year period, with an average growth rate of 8.1% annually.

However, readers should take note of the significant drop in average growth experienced during the 1997-2002 period. Understanding correlations to and causes for the dramatic change in the rate of market growth in this period would improve the industry’s ability to more accurately predict future market growth.

Table 1.3. *Estimated Growth Rates (SIPP-based)*

Years	Total Growth for Period	Average Growth per Year
1992-1997	44% (over 5 years)	8.8%
1997 to 2002	26% (over 5 years)	5.2%
1992 to 2002	81% (over 10 years)	8.1%

Table 1.4. (below) uses the minimum (5.2% per year) and maximum (8.8% per year) SIPP average growth rates to project the total number of wheelchair users in years beyond 2002. These figures suggest that as of 2003 (at 8.8% growth) or 2005 (at 5.2% growth) there were more than three million wheelchair users, and that number will rise to four million between 2006

and 2011. Interpreting this table, the 8.8% growth rate is more proximate (1997-2002) than the 5.2% growth rate (1992-1997) and may for that reason provide a better estimate of market size.

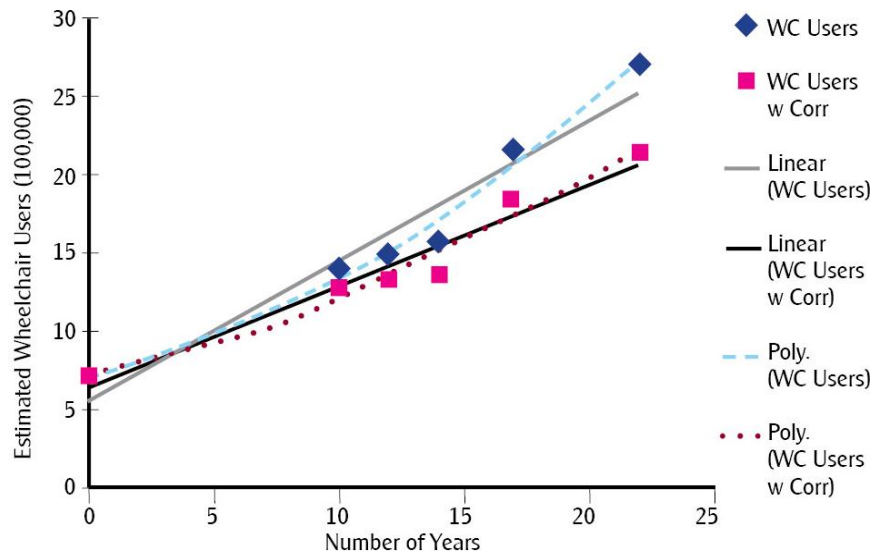
Table 1.4. *Total Number of Wheelchair Users*

Year	Total Users (5.2% growth/year)	Total Users (8.8% growth/year)
2002	2,707,000	2,923,560
2003	2,847,764	3,180,833
2004	2,995,848	3,460,746
2005	3,151,632	3,765,292
2006	3,315,517	4,096,638
2007	3,487,924	4,457,142
2008	3,669,296	4,849,370
2009	3,860,099	5,276,115

(Based on estimated growth rates using SIPP data)

Figure 1.2., depicts a linear and second order polynomial projection of wheelchair users. This chart includes data points from both the NHIS-D and SIPP surveys with correction for population growth (WC Users w Corr) and without correction for population growth (WC Users). Readers should keep in mind that the trend analysis and forecasting are essentially curve-fitting to a small set of data points. This type of forecast is inherently unreliable for longer than a few years out. Additionally, certain factors are likely to bias forecasts upward or downward. For example, as depicted in Figure 2.2., correction for population growth biases the forecast upwards. Other biasing factors are not explicitly reflected in this forecast.

Figure 1.2. Projected number of wheelchair users (linear and polynomial model).



1.2.1. Types of Wheeled Mobility Devices in Use

According to the 1994 NHIS-D data, approximately 84% of all non-institutionalized wheelchair users used a manual wheelchair; 9% used a power wheelchair; the remaining 8% used a scooter.[5] More recent estimates developed by Cooper and Cooper suggest that approximately 70% of all people who use a wheelchair utilize a manual wheelchair; 15% use power wheelchairs and the remaining 15% are scooters users.[8] These estimates are based on the authors' secondary research combined with their experience in the field. The figures statistically unreliable and should be used cautiously when making market projections. Cooper and Cooper do not explain the 67% increase in power wheelchair users and the 87% increase scooter users as compared to the NHIS-D data. However, Cooper and Cooper include wheelchair users living in institutional settings, while the NHIS-D estimates excluded this population. [8]

Cooper and Cooper also developed further breakdowns of the types of manual and power wheelchairs in use by the U.S. population.[8] Their estimates stated the total market size for various categories of wheelchairs, and suggest a total population of just over two million

wheelchair users. Readers should be aware that these categories reflect CMS coding definitions as they existed in 2003. These categories and their definitions have subsequently been updated. Figures 1.3. and 1.4. reflect Cooper and Cooper’s market size figures transformed into percentages, such that they can be applied to current estimates of the total number of wheelchair users in the United States. The figures in these tables include wheelchairs purchased specifically for individuals living in institutions (such as nursing homes). However, they do not include wheelchairs sold directly to institutions for general transport purposes, such as sales to airports, shopping centers, etc.

Figure 1.3. Manual wheelchairs.

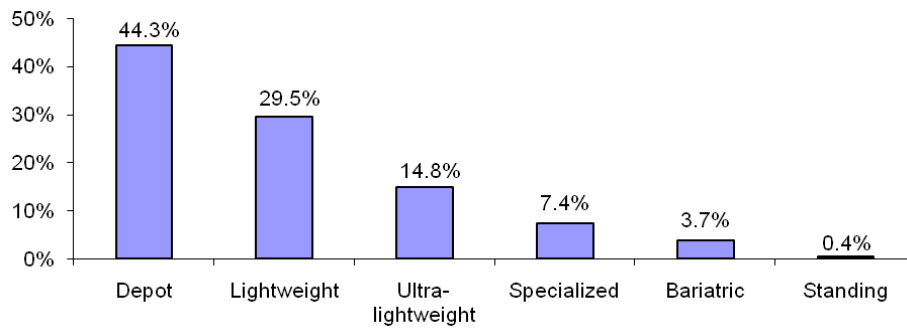
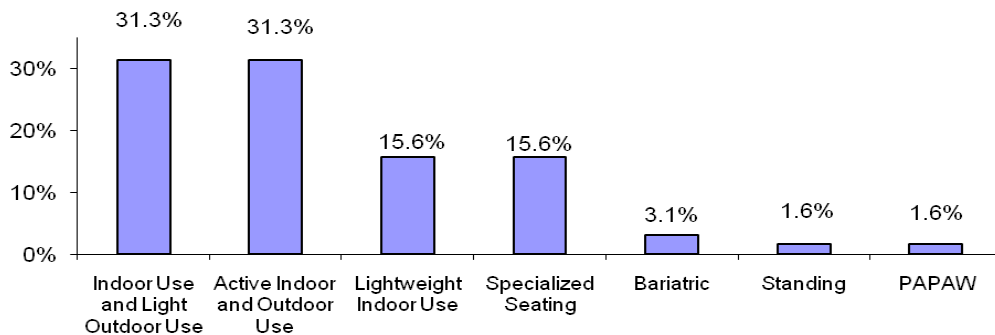


Figure 1.4. Power wheelchairs.



The vast majority of power wheelchairs sold are either indoor use and light outdoor use wheelchairs (31.3%), which are defined as an “electric powered wheelchair designed for both indoor and outdoor use in ADA environments in good weather” or active indoor and outdoor use

wheelchairs (31.3%), defined as “electric powered wheelchairs designed for daily use in both indoor and outdoor environments in all kinds of weather. These wheelchairs may also be used on natural surfaces.” Lightweight indoor use wheelchairs (“electric powered wheelchairs designed primarily for indoor use, e.g., home, assisted living facility”) and specialized seating wheelchairs (“an electric powered wheelchair that includes power seat functions”) each account for 15.6% of purchases of power wheelchairs. The remainder is split between bariatric (3.1%), which are “electric powered wheelchairs intended to be used by individuals with a body mass in excess of 250 pounds,” standing (1.6%), which are “electric powered wheelchairs that hold the occupant in the standing position” and PAPA W (1.6%), that are “pushrim activated power assisted wheelchairs.”

1.2.2. Wheelchair Usage by Age

Both The NHIS-D and the SIPP consistently agree that wheelchair use increases significantly with age. [1][2] Four studies have used the NHIS-D and SIPP’s aggregate figures to identify the total number of wheelchair users within various age groups who use manual wheelchairs, power wheelchairs and scooters. Unfortunately, each study used its own boundaries to define the age groups, with the primary similarity being the measurement of the 65-and-over age group. Table 1.5. highlights a sample of these findings. Readers should be wary of comparing these data sets. Aside from differing age categories, there are significant discrepancies between the totals for similar age groups. For example, there is no clear explanation for why the 15-to-24-year-old age group nearly doubled from the 1997 SIPP to the 2002 SIPP.

It should also be noted that these figures are at odds with Cooper and Cooper’s estimates that state that 15% of all wheelchair users utilize power wheelchairs, 15% use scooters and that the remaining 70% use manual wheelchairs. [8] However, the NHIS-D and SIPP estimates

exclude all people living in institutions, such as nursing homes and assisted living facilities, while Cooper and Cooper’s estimates account for these groups. Further research that includes wheelchair users in institutions and explores the factors impacting these estimates would be an important contribution to research in the field, and would have implications for manufacturers and service providers alike.

Table 1.5. *Manual or Power Wheelchair and Scooter Users by Age Group*

First Author and Year of Study	Dominant Data Sources	Age Groups	Any Wheelchair and or Scooter	Manual or Power Wheelchair	Scooter
Russell 1997	NHIS-D 1980, 1990, 1994	<44	347,000	335,000	12,000
		45-64	418,000	365,000	53,000
		65+	938,000	863,000	75,000
		Total	1,703,000	1,563,000	140,000
Kaye 2000	NHIS-D 1994	<18	97,000	97,000	0
		18-64	728,000	650,000	78,000
		65+	975,000	911,000	64,000
		Total	1,800,000	1,658,000	142,000
McNeil 2001	SIPP 1997	6- 14	70,000	-	-
		15-24	95,000	-	-
		25-64	843,000	-	-
		65+	1,216,000	-	-
		Total	2,224,000	-	-
Steinmetz 2006	SIPP 2002	6-14	77,000	-	-
		15-24	186,000	-	-
		25-64	1,002,000	-	-
		65+	1,519,000	-	-
		Total	2,707,000	-	-

1.2.3. Wheelchair Usage by Gender

The few studies that analyze wheelchair use as it relates to gender conclude, overall, that more women than men use wheelchairs. [3][4][6] This is generally attributed to the fact that women’s life expectancies are longer than men’s, and women have also been found to have higher rates of mobility impairments.[4] However, age groups usage rates vary significantly from study to study. For example, according to the Steinmetz analysis, amongst children ages 15

years and under, more males (54,000) than females (23,000) use a wheelchair or electric scooter. [7] On the contrary, McNeil claims that amongst children ages 6 to 14, more females (40,000) than males (30,000) use a wheelchair. [6] An investigation into the samples of the surveys producing these results may shed light on the conflicting values. Regardless, future research efforts should be mindful of the importance of accurate measures of gender in relation to wheelchair use for those who are developing products and services to meet the unique needs of each group.

1.2.4. Wheelchair Usage by Race and Ethnicity

Two studies, by Kaye, et al. and LaPlante, discussed wheelchair use in relation to race and ethnicity.[3][4] Kaye produced a ranking of wheelchair and scooter use across races, based upon the proportion of each racial group who were wheelchair or scooter users.[3] The results of Kaye's analysis are presented in Table 1.6. Similarly, LaPlante described the rate of wheelchair use amongst races and ethnicities in terms of number of wheelchair users per thousand individuals in each group. [4] Neither analysis distinguishes between wheelchair types, but Kaye's offers a separate ranking for scooter use.

LaPlante states that Native Americans have the highest rate of wheelchair use (eight of every thousand Native Americans use wheelchairs); six out of every thousand Caucasians and six out of every thousand African Americans are wheelchair users, and four of every thousand Asian American are also wheelchair users.[4] LaPlante also analyzed wheelchair use by individuals of Hispanic origin and found that people of Hispanic origin were less likely to be wheelchair users (four of every thousand) than people of non-Hispanic origin (six of every thousand).[4]

Table 1.6. *Ranking of Wheelchair and Scooter Use by Race and Ethnicity* [3]

Rank	Wheelchair Use	Scooter Use
1	Native American	Caucasian
2	Caucasian	Asian Pacific Islander
3	African American	African American
4	Other	Native American
5	Asian/Pacific Islander	Other

1.2.5. *Wheelchair Usage and Employment Status*

Kaye produced a relatively comprehensive analysis of employment amongst 18-to-64-year-olds. Statistics include the percentage of individuals included in the labor force, the percentage of individuals who are employed and unemployed and the unemployment rate, which is the proportion of labor force participants who are unemployed. Table 1.7. offers a sample of the data reported by Kaye in this analysis. These figures demonstrate that far fewer wheelchair users are employed or seeking employment than their non-disabled peers. [3] Further, for those seeking employment face additional barriers, a dynamic that contributes to a higher unemployment rate.

Scooter users are not included in these estimates because Kaye cited the figures as having low statistical reliability; the standard error exceeded 30% of the estimate.

Table 1.7. *Employment Statistics Ages 18-64*

	Non-Device Users	Wheelchair Users*
In labor force	79.6%	20.4%
Employed	76.2%	17.4%
Unemployed	3.4%	2.9%
Unemployment rate (Proportion of labor force who are unemployed)	4.4%	14.4%

Adapted from Kaye, et al. (2000)

27*Wheelchair Users includes manual and power wheelchairs

Although LaPlante’s findings agree with Kaye, showing 17% to 18% employment of wheelchair users, McNeil and Steinmetz’s conclusions demonstrate increased employment of wheelchair users over time. The 1997 SIPP reported employment of 22.2% of all wheelchair users, as compared to the 2002 SIPP, which reported 29.5% employment of wheelchair users, representing an increase of nearly 33% in employment. No explanation has been provided for the increase, although increased accessibility and accommodations resulting from federal legislation may be a contributing factor.

1.2.6. Income Level and Mobility Device Use

Despite reported growth in the employment of wheelchair users, the SIPP results indicate that the mean and median earnings of wheelchair users actually decreased by approximately 20% between 1997 and 2002, while earnings for people without disabilities rose by nearly 6%. Table 1.8. highlights income levels for wheelchair users compared to people who do not have disabilities. Although the SIPP reports do not explain the decline in income over time, it is interesting to note that working wheelchair users’ earnings were very similar to their non-disabled peers in 1997. However as of 2002, wheelchair users were earning significantly less.

Table 1.8. *Mean and Median Income Level*

Study Year	Non-Disabled		Wheelchair Users	
	Median Income	Mean Income	Median Income	Mean Income
McNeil 1997	\$23,654	\$31,053	\$21,240	\$28,307
Steinmetz 2002	\$25,046	\$32,870	\$16,670	\$22,695

Kaye’s study indicates that the rate of use of all mobility devices (including manual and power wheelchairs and scooters) increases as income decreases. [3] However, as income decreases, the use of manual wheelchairs increases significantly more than use of power

wheelchairs and scooters. Kaye speculates that this may be related to the high cost of power wheelchairs and scooters, which would prohibit individuals in lower income brackets from being able to afford such devices. They may instead rely on manual wheelchairs. [3]

1.3. Health Status, Functional Limitations and Mobility Device Usage

LaPlante and Kaye reported on health status amongst mobility device users, and both described alarming rates of “poor” health status. [3][4] LaPlante found that 11.9% of wheelchair users and 11.2% of scooter users rated their health as very good to excellent, while an overwhelming 40% of wheeled mobility users rate their health as poor. [3] In comparison, only 2% of people who do not use wheeled mobility devices rated their health as poor. The study also indicates that wheeled mobility users were seven times more likely to be hospitalized in the previous year. Similarly, Kaye found that 60% (ages 18-64) to 70% (ages 65 and over) of wheelchair users described their health status as “fair” or “poor.”[3]

In addition to health status, data regarding the functional limitations experienced by people who use wheeled mobility devices has been analyzed by LaPlante and Kaye.[3][4] Table 1.9., highlights a small sample of the functional limitation data collected by the 1994-1995 NHIS-D. These figures are particularly important because they represent medical needs that are being met with the use of mobility devices, which serves to more clearly define the segments of the wheeled mobility market.

Table 1.9. *Wheelchair Users’ Functional Limitations*

Functional Limitation	Wheelchair Users Experiencing Limitation
Some Difficulty Only Walking a Quarter Mile	15.7%
Unable to Walk a Quarter Mile	78.5%
Some Difficulty Only Climbing Stairs	24.7%
Unable to Climb Stairs	63.7%
Some Difficulty Only Standing for 20 Minutes	25.8%

Unable to Stand for 20 Minutes	61.0%
--------------------------------	-------

LaPlante also described conditions that cause mobility impairments.[4] LaPlante stated that multiple sclerosis and paralysis were the most common causes for younger (non-elderly) wheelchair users, while arthritis, stroke, and multiple sclerosis were the most common causes for the elderly.[4] Readers should keep in mind that the causes of limitations leading to the use of wheelchairs are very segmented. No one or two causes account for a large portion of wheelchair use. The top three causes for the elderly (stroke, arthritis and multiple sclerosis) only account for 26% of wheelchair use when combined. In fact, the top ten causes, combined, only account for 49% of wheelchair use. They include absence of lower extremity, paraplegia, orthopedic impairment, various forms of heart disease, cerebral palsy, rheumatoid arthritis and diabetes.

1.4. Wheelchair Usage and Home Accessibility Features

LaPlante used data from the NHIS-D to compare the presence of accessibility features in the homes of people with disabilities who use wheeled mobility devices (including manual wheelchairs, power wheelchairs, and scooters) versus the presence of those features in the homes of people with disabilities who do not use wheeled mobility devices.[4] Table 1.10. highlights findings from LaPlante’s analysis, and includes figures regarding the magnitude of unmet needs for accessibility features amongst wheeled mobility device users. While many people who use wheeled mobility devices have necessary accessibility features, a substantial portion of these individuals, ranging from 5.1% to 11.6%, lack one or more of these features.

Table 1.10. *Percentage of Homes Containing and Needing Accessibility*

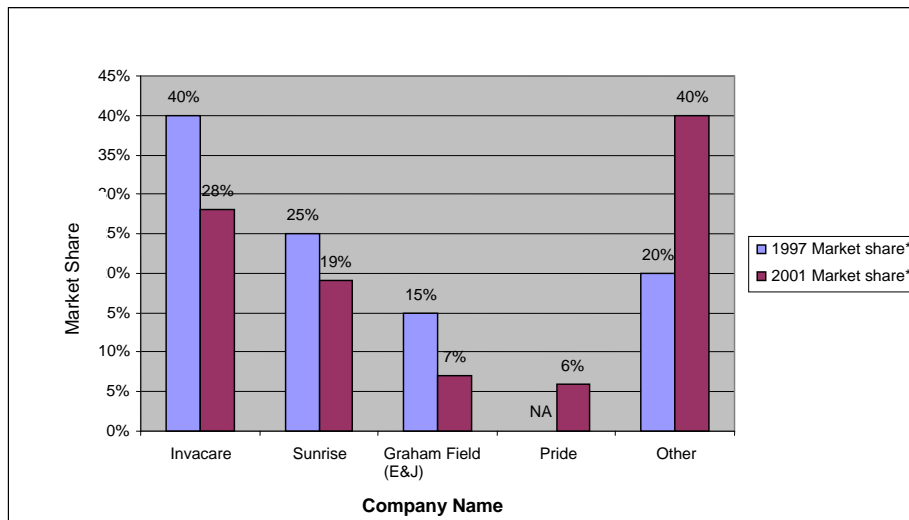
Features	Have Features		Need Features
	People with Disabilities Who Do Not Use Mobility Devices	Wheeled Mobility Device Users	Wheeled Mobility Device Users
Bathroom modifications	6.8%	36.5%	11.6%
Ramps or street-level entrances	7.6%	35.5%	9.8%
Accessible parking or drop-off site	15.8%	32.0%	5.1%
Railings for persons with disabilities	15.1%	31.2%	9.5%
Widened doorways or hallways	5.6%	20.6%	8.9%
Automatic or easy-to-open doors	4.6%	12.8%	8.0%
Elevator, chair lift, or stair glide	2.9%	12.7%	6.2%
Kitchen modifications	1.0%	7.4%	7.5%

1.5. Wheelchair Manufacturer Market Share Information

Market share distribution in the wheelchair industry changed dramatically from 1997 to 2002, with smaller companies capturing market shares once held by industry leaders. As shown in Figure 1.5., in 1997, Invacare (40%), Sunrise (25%), and Graham Field (15%) controlled 80% of the market. The remainder was held by smaller companies. [9][10]

By 2001, Invacare (28%), Sunrise (19%), Graham Field (7%), and Pride (6%) controlled only 60% of the market, while the “other” category of smaller manufacturers had grown more than any single company; accounting for 40% of the total industry. It is unclear whether lost market share is a result of increased competition from small manufacturers or shrinking market segments related to enhanced niche offerings. Furthermore, no formal surveys identify whom each company sells to, what types of products are sold, or who provides payment for the devices.

Figure 1.5. Market share 1997 and 2001. [9][10]



It is likely that other shifts have taken place in the wheeled mobility marketplace since 2001. Unfortunately, recent market share data is unavailable. The following assumptions include the authors' speculation based on observations of the wheeled mobility marketplace. Industry leaders' products tend to correspond to the largest market segments. Therefore, they may diversify to produce other durable medical equipment to compensate for lost mobility market share. Specialty products, including products such as specialized seating and standing wheelchairs are likely to be introduced by smaller manufacturers in pursuit niche markets. Further, increased international competition, and modular product designs such as mix and match seating may contribute to the fragmentation of market segments. Additional research is needed to identify specific causal factors.

1.6. Gaps and Needed Research

Despite the breadth of the NHIS-D, and the relative newness of the SIPP, there is a significant need for new research in several wheeled mobility topic areas. Current data lacks

consistency over long periods of time, which makes it difficult to understand trends and growth rates. Furthermore, no data is available regarding wheelchair users' transitions from manual to power wheelchairs. Data regarding the wheelchair manufacturer market share is scarce. And little to no data combines estimates for institutionalized and non-institutionalized populations of wheelchair users.

LaPlante also established that current research does not differentiate between power and manual wheeled mobility devices, nor is information available regarding reasons people choose specific types of wheeled mobility devices. [4] The reasons for prescription and selection of various types of wheeled mobility products would constitute an important contribution to research. As a result of existing definitions and legislation, the educational and vocational outcomes that are widely surveyed and reported cannot justify funding to purchase wheeled mobility devices. Medical research beyond these functional outcomes would support why wheeled mobility devices are being used, and would justify funding of products that meet the definitions set forth by the U.S. Food and Drug Administration for Class II medical devices, which are “intended for use in the diagnosis of disease or other conditions, or in the cure, mitigation, treatment, or prevention of disease, in man or other animals.”[11]

Another factor that has implications for the wheeled mobility market, which has not been considered by current research is the impact of organizational structural and standardized or non-standardized processes that effect outcome measures such as improved health status and increased quality of life. [12] An understanding of how outcomes relate to the quality of healthcare delivery can help identify effective practices that can become industry standards. Additionally, those outcomes can also be used to measure healthcare quality as it relates to improved medical care and quality of life outcomes among consumers. [13]

Finally, it is well known that legislation, particularly when it impacts reimbursement, can have major consequences in the marketplace. However, little has been reported regarding the ways in which the Medicare Prescription Drug Improvement and Modernization Act (MMA) and competitive bidding have shaped the wheeled mobility marketplace. The Agency for Healthcare Research and Quality (AHRQ) recently responded to the need for such research by publishing a series of research objectives that will be explored with grant support in 2009 and 2010. [14] One of the priority research objectives states “finding a way to improve the value of healthcare – i.e., reducing waste or unnecessary costs while improving quality – is a high priority...”[14] This is but one example of the type of funding that should be leveraged by researchers. Although the priorities do not focus specifically on wheeled mobility, researchers can argue that many wheeled mobility device users belong in the “underserved populations” category, which is of particular interest to AHRQ. Exploration of these research gaps will not only benefit researchers but will also have implications for consumers, clinicians, manufacturers, policy makers and medical equipment suppliers, while also spurring the creation of new standards and technologies.

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Chapter 2

Comparative Analysis

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Contents

Section	Pg
2.1. Introduction	31
2.2. End User Focus Group: Sampling and Demographics	31
2.3. End User Focus Group: Data Collection Techniques	33
2.4. Expert Interviews: Sampling and Demographics	34
2.5. Expert Interviews: Data Collection Techniques	35
2.6. Results: Unmet Needs and Strengths and Weaknesses of Current Technology	36
2.6.1. Manual Wheelchairs	36
2.6.1.1. Unmet needs	36
2.6.1.2. Strengths and weaknesses of available technology	38
2.6.2. Power Wheelchairs	39
2.6.2.1. Unmet needs	39
2.6.2.2. Strengths and weaknesses of available technology	40
2.6.3. Seating and Positioning	40
2.6.3.1. Unmet needs	40
2.6.3.2. Strengths and weaknesses of available technology	41
2.6.4. Wheelchair Transportation Safety and Public Transportation	42
2.6.4.1. Unmet needs	42
2.6.4.2. Strengths and weaknesses of available technology	43
2.6.5. Additional Unmet Needs	43
2.7. Results: Needed Research and Barriers and Carriers	44
2.7.1. Needed Research	44
2.7.2. Barriers and Carriers	45
2.8. Discussion	47

2.1. Introduction

The T²RERC conducted primary market research in the wheeled mobility industry with an overarching goal of identifying unmet needs related to five topic areas: manual wheelchairs, power wheelchairs, seating and positioning, wheelchair transportation safety and public transportation. We conducted all research between April and December 2007. End users of wheeled mobility products participated in two focus groups, and experts – including manufacturers of wheeled mobility products, researchers, suppliers, and clinicians – participated in individual expert interviews. This work was conducted to inform academia and industry of the challenges faced by end users, caregivers, service providers and suppliers of existing wheeled mobility products. Many of the identified unmet needs represent significant market opportunities for businesses and research opportunities for academia. Standards and funding reforms provide the context for research, market opportunities and product development. The following discussion leads the reader through the market-research process, the results from focus groups and expert interviews and a discussion of the implications of these findings.

2.2 End User Focus Group: Sampling and Demographics

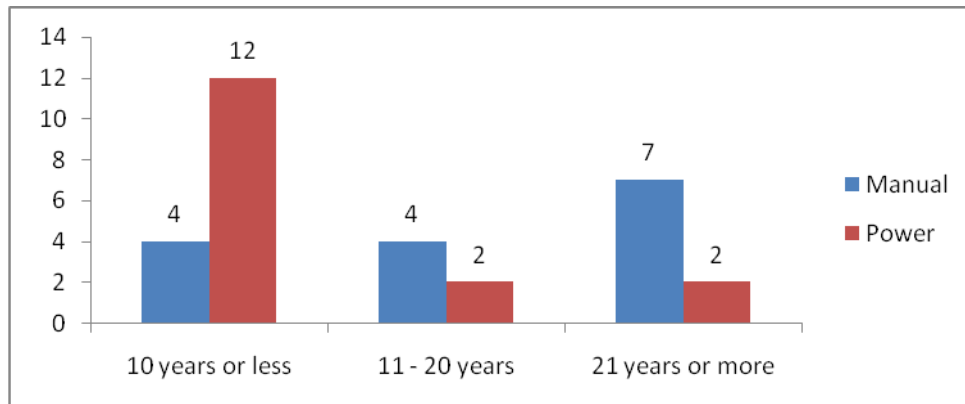
The Western New York Independent Living, Inc. (WNYIL) was retained to provide focus group services. The WNYIL has extensive experience working with consumers with disabilities. It also has fully accessible focus-group facilities. The project team began by purposive sampling to identify focus-group participants from the WNYIL's consumer database, which contains demographic information on more than 6,000 people with disabilities in the Western New York area. In order to have been considered for inclusion in the focus group, participants must have used a manual and or power wheelchair for at least two years. Additional criteria ensured that the sample represented adults from various age groups who had a range of limitations, leading to

the use of manual and power wheelchairs. The sample group also included people who did and did not use specialized seating. The sample was biased toward end users with diverse experience and knowledge of manual and power wheelchairs. The sample was biased toward end users with diverse experience and knowledge of manual and power wheelchairs. Although there is some risk of loss of generalizability in using participants who have a number of years experience using wheelchairs, the rich composition of the group was intended to uncover long-standing, fundamental problems in the industry. In total, 23 manual and power wheelchair users were recruited to participate in one of two focus groups. Participants were compensated for their time and participation, and transportation was offered to those who requested such accommodations.

Nine participants took part in the first discussion on December 4, 2007, and 14 participants took part in discussion on December 5. Among the participants were seven manual wheelchair users, and 16 power wheelchair users, eight of whom had transitioned from using a manual wheelchair to a power wheelchair. The groups included 16 females and seven males. In terms of race, 18 participants identified themselves as white, and five as African American. The majority of participants were between the ages of 41 and 64 (74%), while 17% were 40 years old or younger, and only 9% were over the age of 65. The most common disabilities of participants included cerebral palsy (seven individuals) and multiple sclerosis (five individuals). Nine participants had differing disabilities, including amputation of limb, scoliosis, spinal cord cyst, spinal cord injury, lupus, neuromuscular disease, spasticity, degenerative arthritis and back injury. The remaining two participants did not identify a single disability as leading to wheelchair use. Level of experience in using wheelchairs was the most important consideration for inclusion in the focus groups. A reasonable assumption was made that individuals with more experience using wheelchairs were more likely to have used a wide range of wheelchair products and accessories across more diverse roles and contexts. Figure 2.1., depicts the number of years

that participants stated they had used each type of wheelchair. Six of the eight participants (75%) who had transitioned from manual to power wheelchairs had used manual wheelchairs for at least 20 years.

Figure 2.1. Participant experience with manual and power wheelchairs



2.3. End User Focus Group: Data Collection Techniques

The focus group moderator developed a script in collaboration with the IP project team. It contained questions related to five technology areas, including manual wheelchairs, power wheelchairs, seating and positioning, wheelchair transportation safety and public transportation. Following the completion of requisite non-disclosure and human subjects testing paperwork, participants in both groups were asked to take part in a discussion led by a trained moderator. For each of the five wheeled mobility technology areas, participants were asked to identify: their unmet needs, available state of the art technology that they believe could meet those needs and the strengths and weaknesses of the available technology.

Following the identification of unmet needs, participants described the technologies and products that they currently use to meet those needs. Participants then voted on the existing technologies that they felt were most critical. The technology in each of the five technology

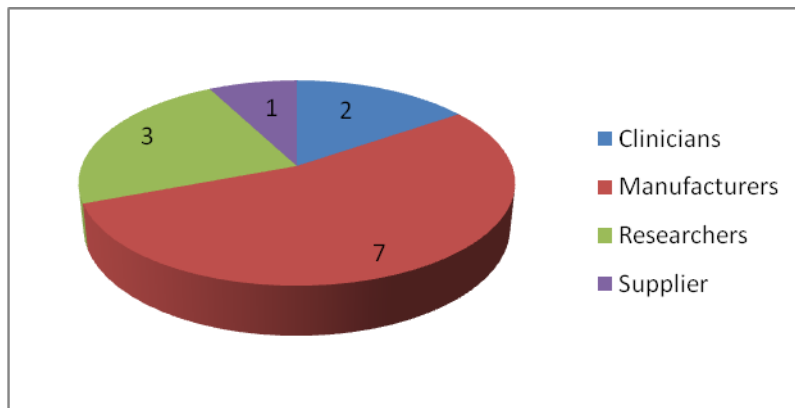
areas that received the highest number of votes was carried through the remainder of the discussion. The strengths and weaknesses of these technologies were discussed in more depth.

2.4. Expert Interviews: Sampling and Demographics

The T²RERC project team, which carried out recruitment and interviews, employed purposive (expert) sampling to ensure that knowledge representation would be deep and diverse. Interview participants included manufacturers, suppliers, clinicians and researchers from across the U.S. These participants had expertise in manual wheelchair systems and propulsion, power wheelchair systems, emerging technologies and propulsion systems, seating and positioning, the supply chain and reimbursement policies.

Figure 2.2. details participant distribution. A total of 13 individuals participated in the expert interview process. Manufacturers were over-sampled to ensure that all five technology areas were well represented by individuals knowledgeable of current and emerging technological that will impact the industry and market in the near future.

Figure 2.2. Expert backgrounds



2.5. Expert Interviews: Data Collection Techniques

Prior to the phone interview, participants were briefed about their roles as experts in the context of the Industry Profile Project. Participants were given a list of interview questions prior to the actual call so that they could reflect and develop responses (Table 2.1.). At the start of each interview, participants were given another brief introduction to the project. They were informed of interview protocols including that conversations would be recorded and transcribed to ensure accuracy. The participants' interview transcripts were returned to them so that each could verify accuracy and provide helpful annotations.

Table 2.1. *Expert Interview Questions*

Expert Interview Questions
<i>Needs Identification</i>
1. What mobility needs are poorly met?
2. Why are these needs important?
3. Who is most affected?
4. In which roles and contexts are these needs most critical?
<i>State of the Practice</i>
5. What products now address these needs?
6. What are the strengths and weaknesses of these products?
<i>Future Technology and Products</i>
7. What new or improved products are needed?
8. What research and technology is needed?
9. What barriers delay product development?
10. How might these barriers be overcome?

All interviews were conducted between April and June 2007. Two primary interviewers and a note-taker participated in each call. The two interviewers followed the scripted questions, ensuring that all major topics were covered and encouraging free flow of conversation. The note-taker captured not only discussion topics but also the tone and emphasis placed on these topics. Notes were reviewed by the two interviewers and used to annotate the interview

transcript. Remaining interview ambiguities were resolved by calling or emailing interviewees or through post-interview annotations by the interviewee.

2.6. Results: Unmet Needs and Strengths and Weaknesses of Current Technology

Data from end users and experts were quantified and analyzed separately, then compared to identify differences in the perceptions of unmet needs and strengths and weaknesses of products and technologies. To better understand their similarities and differences, end user and expert responses are summarized in a cross-tabular fashion for each of the five technology areas. As demonstrated in the resulting tables, there is congruence between unmet needs identified by end users and experts. Readers should note that experts were also given the opportunity to branch out and discuss issues beyond wheelchair design such as service delivery, CMS reform and training or education for end users, which are detailed in the Additional Unmet Needs segment of this chapter.

2.6.1. *Manual Wheelchairs*

2.6.1.1. *Unmet needs.*

During focus-group discussions, end users identified a large number of unmet needs related to manual wheelchairs. In both focus groups, end users were then asked to vote for what they believed to be their most significant unmet needs. The four areas of *unmet need* that received the most combined votes included manual wheelchairs with a better stride ratio when pushing, manual wheelchair propulsion systems that remain clean, portable manual wheelchairs that are easier to collapse and open, and manual wheelchairs that are lighter weight. For the fourth priority, it is unclear whether end users want all manual wheelchairs to be lighter, or if they want current lightweight manual wheelchairs to be more available and affordable.

To facilitate a comparison between end user and expert responses, all expert comments related to *unmet needs* and *needed technology* were grouped into three categories, which are based on the top need areas according to end users: propulsion, transportability, and light-weight. Within these groupings, the “lightweight” category was the highest priority unmet need according to experts, with propulsion systems and transportability following.

Table 2.2. highlights specific needs reported by end users and experts for the top three need areas, followed by other aspects of manual wheelchairs that are also in need of improvement. Appendix A provides a rank order listing of manual wheelchair needs as articulated by end users.

Table 2.2. *Unmet Needs Related to Manual Wheelchairs*

Sub-theme	End User Responses Stakeholders Need	Expert Responses Stakeholders Need
Propulsion	<ul style="list-style-type: none"> · Push rims cleaner with better grip · Adjustable push rims 	<ul style="list-style-type: none"> · N/A
	<ul style="list-style-type: none"> · All manual wheelchairs should be easier to self-propel · Adjustable stride ratio to prevent carpal tunnel 	<ul style="list-style-type: none"> · Easy to push on carpeting · Geared propulsion systems · Ergonomically correct propulsion systems
	<ul style="list-style-type: none"> · Allows the user to push other items 	<ul style="list-style-type: none"> · N/A
	<ul style="list-style-type: none"> · N/A 	<ul style="list-style-type: none"> · Appropriate funding, which is currently lacking for alternative propulsion systems
Transportability	<ul style="list-style-type: none"> · Improve ease and safety of portable wheelchair folding and unfolding 	<ul style="list-style-type: none"> · Reduce injuries to wheelchair users and caregivers from lifting wheelchairs into cars and trunks
Lightweight	<ul style="list-style-type: none"> · N/A 	<ul style="list-style-type: none"> · Stronger at lower cost · Improved safety · Improved stability
	<ul style="list-style-type: none"> · All manual wheelchairs should be lighter 	<ul style="list-style-type: none"> · N/A
Tires	<ul style="list-style-type: none"> · All-season, all-terrain winter tires · Easy to push on snow, grass and 	<ul style="list-style-type: none"> · Pneumatic tires for softer ride · Improved rolling resistance

	mud	
	· Front casters should be more stable and durable	· N/A
	· Self-cleaning tires	· N/A
Other components	· N/A	· Changes to axle position · Adaptations to wheelchair base or camber
	· Shocks	N/A
	· N/A	· Address comfort and quality of life · Pediatric wheelchairs that grow with children to avoid placing them into large wheelchairs that they will “grow into”
	· N/A	· Combination of features and price needs to change
Applicable to manual and power	· Prevent tipping when leaning forward	· Anti-tip devices
	· Standardized parts · Able to repair independently	· N/A
	· Customize the location of features	· N/A

2.6.1.2. Strengths and weaknesses of available technology.

Propulsion systems dominated the discussion of existing technology for both end users and experts alike. Specific technologies mentioned by participants include Pushrim Activated Power Assist Wheelchairs (PAPAW) such as Emotion or Quickie Extender, geared hubs such as Magic Wheels, one-arm drives, and lever-drive wheelchairs, such as the Wijit.

When asked about the strengths and weaknesses of these technologies, participants stated that PAPAWs are too heavy, which makes them difficult to transport; they lack communication between the hubs, causing tracking problems. They are often too expensive. Geared hubs were thought to be useful only when going uphill. They add width to the wheelchair and were labeled as heavy, costly and complex. Participants stated that one-arm drive wheelchairs can be cognitively challenging because they are not intuitive. They tend to have low weight capacity –

only 250 pounds – and are impractical for outdoor use. Lever-drive wheelchairs were described as beneficial for those with limited arm strength because they maximize the muscles available. However, lever-drive wheelchairs are not useful for individuals who have limited use of their hands. Furthermore, lever-drive attachments are often incompatible with certain wheelchair frames. They also tend to widen the frame, which can cause maneuverability and accessibility problems.

2.6.2. Power Wheelchairs

2.6.2.1. Unmet needs.

Power wheelchairs were discussed by focus-group participants and experts; however the listing of unmet needs was significantly shorter than that for manual wheelchairs. The areas receiving the highest number of end-user votes were better waterproofing of batteries, hand controls and wires, technology to look behind and or around and longer lasting batteries. The only comments provided by experts that were specific to power wheelchairs were on the topic of batteries and are included in Table 2.3. However, consumers suggested many needed improvements related to power wheelchairs, including safety concerns, modifications to controllers and the addition of smart-controls. Appendix A provides an analysis of end user power wheelchair needs, ranked by priority.

Table 2.3. *Unmet Needs Related to Power Wheelchairs*

Sub-theme	End User Responses Stakeholders Need	Expert Responses Stakeholders Need
Batteries	· Longer lasting batteries	· Batteries with a longer life span
	· Easier and faster changing of batteries	· Easily charged by end user
	· Lightweight batteries for travel	· Lightweight batteries
	· N/A	· Lithium batteries
	· N/A	· Solar charging
	· N/A	· New power source <ul style="list-style-type: none"> ○ Safe ○ Inexpensive

		<ul style="list-style-type: none"> ○ Day long life ○ Low maintenance ○ Many recharge cycles ○ Airplane safe
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2.6.2.2. Strengths and weaknesses of available technology.

When asked about technologies that are currently available to meet these needs, experts stated that alternative power sources have been developed using chemical fuels such as propane, butane, micro fuel cells, and ultra-capacitors. These power sources can be combined with standard batteries to provide a charge that lasts ten times longer than a standard battery alone. However, these technologies are currently not readily available in the marketplace.

2.6.3. Seating and Positioning

2.6.3.1. Unmet needs.

End users and experts felt that comfort and quality of life can be significantly and positively impacted by available seating and positioning systems. However, end users and experts also agreed that many aspects of seating and positioning can be improved. Among the highest priority unmet needs were adjustability and customization of seating systems. There is a need to prescribe appropriate seating systems for children so that they are not given a large wheelchair that they will eventually grow into. Precision fitting for wheelchair users of all ages will enhance an individual’s comfort, stability and function. Additionally, end users should be able to adjust their seating and positioning throughout the day. Improved selection and fitting of seating and positioning systems is imperative as injuries can be caused by or exacerbated by inappropriate or poorly fitted seating and positioning systems. Proper and well fit seating systems are also critical to the preservation of an end user’s remaining functional abilities. Table 2.4. provides a sample of end user and expert comments related to seating systems. A rank order outline of the end user seating and positioning needs is provided in Appendix A.

Table 2.4. *Unmet Needs Related to Seating and Positioning*

Sub-theme	End User Responses Stakeholders Need	Expert Responses Stakeholders Need
Customization	<ul style="list-style-type: none"> · Ability to independently adjust pre-set customized seating positions · Ability to independently adjust length (depth) of seat · Ability to independently customize (replace or reconfigure) seat back without specialized tools 	<ul style="list-style-type: none"> · N/A
	<ul style="list-style-type: none"> · Seating should maintain user's position all day and prevent slouching 	<ul style="list-style-type: none"> · Improvements (comfort, cleanliness, washability) toommel
	<ul style="list-style-type: none"> · N/A 	<ul style="list-style-type: none"> · Fitting should be more precise to enhance an individual's comfort, stability and function. · Ensure appropriate prescription of wheelchairs for children
Footrests and Armrests	<ul style="list-style-type: none"> · Method to move armrests and foot pedals out of the way · Adjustable length armrests · Ability for user to adjust size and elevation of footrests 	<ul style="list-style-type: none"> · More thought should be given to the design of components such as armrests, footrests and leg rests (they seem like an afterthought rather than a well designed system components)
	<ul style="list-style-type: none"> · Durable armrest material that prevents cracking 	<ul style="list-style-type: none"> · N/A
Ergonomics	<ul style="list-style-type: none"> · N/A 	<ul style="list-style-type: none"> · Integration of seating system and wheelchair design would eliminate redundancy and increase efficiency of propulsion · Method for reliably identifying the optimal seat height

2.6.3.2. *Strengths and weaknesses of available technology.*

Many seating and positioning technologies and products that are available were noted and discussed. Experts felt that current seating systems, if properly selected and fitted, can help prevent and treat pressure sores. However they stated that the developmental effects of static positioning systems are still unknown, and the inability to adjust static seating systems throughout the day was considered to be a problem. Experts discussed products that can enhance

comfort and function, including Hip Grip, which is a dynamic pelvic support that provides stability and full range of motion. Stretchable materials used on seating and positioning technologies were viewed favorably, as they enhance comfort and range of motion. Foam blocks for footrests absorb shock from movement, and ankle huggers allow movement within a controlled range. Standing wheelchairs, such as the Levo product line, were considered helpful, however obtaining reimbursement for such devices is difficult. End users were concerned with the durability and maintenance of seating systems. End users were interested in seating and positioning products that could be manipulated without tools. Users desired independent adjustability for the seat and seatback, armrest length, seat depth, and size and elevation of footrests. They believed that ease of customization would enhance their comfort and quality of life.

2.6.4. Wheelchair Transportation Safety and Public Transportation

2.6.4.1. Unmet needs.

Although wheelchair transportation safety and public transportation were treated as separate technology areas, the unmet needs and technologies identified by participants were similar enough that the two topics have been combined. While the experts were not particularly vocal in these areas, end users expressed a number of concerns. The highest priority unmet needs in wheelchair transportation safety and public transportation included improved access to buses, trains, and planes, safer lifts and quicker, more efficient lockdown systems (similar to Q'Straint systems). In particular, end users are unsatisfied with current restraint systems on public transportation because non-wheelchair users often have to climb on and around wheelchair users in order to ensure proper securement of wheelchair users. Solutions to these problems may decrease caregiver stress and increase wheelchair user independence.

Table 2.5. depicts end user and expert needs related to transportation safety and public transportation. An outline of consumer needs related to these areas is provided in Appendix A.

Table 2.5. *Unmet Needs Related to Wheelchair Transportation Safety and Public Transportation*

Sub-theme	End User Responses Stakeholders Need	Expert Responses Stakeholders Need
Public Transportation	More accessible locations (wheelchair spaces) on buses, trains and planes	N/A
	Public vehicles that allow wheelchair users to get on or off at all locations using any door	N/A
	Wheelchair accessible bathrooms on public transportation	N/A
	Wider airplane aisles	N/A
	Ability for a wheelchair to maneuver between train cars	Ability to explore environment on public transportation
	N/A	Universal standards for integration of mobility devices into transit system

2.6.4.2. Strengths and weaknesses of available technology.

The only two products mentioned by participants in relation to transportation were the IBOT and certain Invacare wheelchairs that can be used as vehicle seats. The IBOT was thought of as versatile and accessible and can maintain stability while climbing stairs. Its primary weakness was reportedly its prohibitive cost. Invacare products elicited no negative responses, but they were looked upon positively for their adaptability to vehicles.

2.6.5. Additional Unmet Needs

Experts were asked to identify unmet needs in the wheeled mobility industry without the limitations of the previously discussed categories (manual, power, seating and positioning, etc.). As such, experts voiced concerns about service delivery, the need to reform payment systems such as the Centers for Medicare and Medicaid Services (CMS), and improving training and or education for consumers. Specific statements are detailed in Table 2.6. below.

Table 2.6. *Additional Unmet Needs*

Sub-theme	Expert Responses Stakeholders Need
Service Delivery	<ul style="list-style-type: none"> · Standardized assessments · Assessment locations should try to mimic real world environments · More time per assessment · Reform of credentialing system · Recognition of rehabilitation team · Increase understanding of how to use and access new technology · Improve match of technology to person to increase functional movement · Training on proper adjustment and set up of wheelchairs · Access to qualified people to assess and instruct clients · Trial use of devices · Training for device use · Training in maintenance of devices · Propulsion monitoring systems
CMS Reform	<ul style="list-style-type: none"> · Recognize value of durability, functionality, etc. of high quality products · Allow purchase of higher quality products to eliminate need for repairs · Increase reimbursement level for repairs · Allow for reimbursement of multiple power and or manual wheelchairs to one user · Documentation on most efficient way to leverage CMS funding · Reduce paperwork burden
Training and Education for Consumers	<ul style="list-style-type: none"> · Education regarding seating and positioning options · Increase awareness and knowledge of available products · Provide wheelchair skills training for users and caregivers · Reduce incidence of uninformed choices

2.7. Results: Needed Research and Barriers and Carriers

2.7.1. Needed Research

Experts were asked to specifically identify needed research that might be used to meet end user needs. They responded with a keen interest in studies that could be used to help reform the reimbursement systems. For example, in order to properly support medical necessity claims, research must demonstrate the physical and financial benefits of using higher-end equipment. Showing payers that a higher-cost product can last longer than a cheaper one, or result in fewer injuries, could positively impact reimbursement policies. Additionally, many participants

vocalized a need for research on functional outcomes, such as how the body reacts to certain technologies from a biomechanical, proprioceptive or developmental standpoints.

Experts also called for materials research to investigate metals other than aluminum and titanium. They also suggested researching non-metals such as reinforced plastic or glass-fiber-filled plastics. Others suggested logging data to correlate wheelchair usage and needed changes in design and function. Lastly, experts called for increased funding for the integration of innovations into products. Small Business Innovation Research grants were mentioned specifically.

2.7.2. Barriers and Carriers

To complete the interviews, the experts were asked to identify barriers that might inhibit new product development in the industry. They were then asked to suggest ways to overcome those barriers. Public reimbursement policy was the top barrier to new product development, according to nine of the 13 experts. They noted specific challenges, including difficulty obtaining reimbursement for devices such as power-assist wheelchairs and difficulties in developing new HCPCS (Healthcare Common Procedure Coding System) codes.

Participants suggested conducting research studies to provide evidence that appropriate (perhaps more sophisticated or expensive) wheeled mobility, seating and positioning technologies reduce injury rates and severity. Consequently, while purchase costs may increase, overall societal costs may be drastically reduced. For example, power-assist wheelchairs may reduce repetitive-strain injuries. Attendant to strain injuries are medical and rehab costs, lost wages and taxes and an earlier transition to expensive powered mobility.

Overall, these experts would like to see an evidence-based reimbursement policy that pragmatically accounts for the full costs to all stakeholders and society. To address the challenge of developing new HCPCS codes, participants suggested developing a new universal coding

scheme. One expert stated that such a system is under development, however no further details were provided.

Participants stated that expenses incurred when supplying wheelchairs to end users increased manufacturer and supplier costs, increased product prices to end users and insurers, decreased profit margins and decreased U.S. manufacturer competitiveness with respect to overseas manufacturers. For example, one participant remarked that extensive work needed to obtain device reimbursement equated to a need for more staff, which in turn drove up device prices and cut into profit margins. This is a challenging problem for U.S. businesses in competition with overseas manufacturers who produce less expensive products. To overcome this barrier, experts suggest that non-governmental agencies conduct research with the objective to improve reimbursement process efficiency. Study outcomes would be used to streamline the reimbursement process, saving time and money, particularly for suppliers and end users.

The high cost of customizing wheeled mobility devices was also noted as a barrier. Distributors are under pressure by manufacturers to increase sales volume, which leads distributors to focus on a limited line of products, decreasing the demand for specialty components and driving up specialty component prices. As a potential solution to this problem, one expert recommended developing a bulk buying system for suppliers. Bulk purchasing would make high quality components more readily available to clinicians and more affordable to end-users. A bulk purchasing strategy will reduce pressure from large manufacturers on suppliers to purchase common but less appropriate off-the-shelf components and equipment. This strategy would allow suppliers to make customized components and equipment available to service providers and end users at reasonable prices. Suppliers would ultimately increase their profits from the sale of customized wheelchairs.

Experts recognized that good innovations often exist, but those innovations simply fail to make it to the marketplace. Regulations imposed by organizations, such as the Federal Aviation Administration (e.g., mandatory standards on power wheelchairs) and the International Organization for Standardization (e.g., voluntary safety and performance standards) were cited as creating barriers to new product development. Experts suggested including other parties, outside of the regulating bodies, in reforming in these systems.

Languishing patents often prevent manufacturers from implementing good designs. Useful inventions with patents must be licensed from the patent holder. If terms cannot be reached with the patent holder, the invention cannot be used in a wheelchair design. In some cases, the patent holder is unwilling to reach a reasonable agreement on terms. In other cases, a patent may be held by a competitor.

Manufacturers wanted to work collaboratively with the university research community. They believed that it was especially important that industry-university collaborations start early in the product development cycle. Manufacturers also noted that federal agencies must support industry-university collaboration through grant solicitations and oversight.

Finally, experts stated that the end users' lack of product awareness is a significant barrier. End user education is needed to ensure that consumers make informed choices. This is an important issue, which is revisited in the discussion section of this chapter.

2.8. Discussion

End user focus groups and expert interviews identified an important set of unmet needs for the wheeled mobility industry. The focus groups and interviews also provided an assessment of currently available technology, identifying strengths and weaknesses and recommendations for research and development efforts. Barriers to technology refinement and development were

discussed. Solutions for overcoming these barriers were solicited. In addition to the needs discussed in detail through the results section, two critical needs became clear: the third-party payment system needs reform and consumers need better education.

As a result of the market's current pricing and third-party payment structure, manufacturers are naturally more responsive to pressures from third-party payers than end-user needs. The third-party payer system also impacts other key stakeholders negatively. Principle among these stakeholders are suppliers (who occupy the supply chain between manufacturers and end-users) and service providers (who are considered secondary consumers). In contrast, understanding and responding to legitimate concerns of all stakeholders – manufacturers, suppliers, service providers and end-users – should shape public policy. Pertaining to the use of public monies, return-on-investment determinations should encompass the costs and benefits to all stakeholders including the greater society rather than being narrowly limited to insurance companies' bottom line. Research projects could play a valuable role in providing evidence to support claims for advanced, higher-end equipment.

End users can provide valuable insights into the problems faced by wheelchair users. However, as discussed in the Supplier's Perspective chapter (Chapter 10), end users are not necessarily well versed in available technology and are generally not privy to upcoming technology developments that might take years to be integrated into products and arrive on store shelves.

This project confirmed the end user's lack of knowledge regarding available products in the wheelchair industry in two ways. First, a number of experts who participated in a structured interview stated that education of end users regarding products and proper fit was a critical need area. Second, when end users were asked to identify available technologies that could meet some of their otherwise unmet needs, they were at a loss. Very few actual technologies surfaced,

and responses typically avoided specific scenarios or a reliance on other people. The establishment of ongoing end user education programs could increase consumer advocacy for appropriate and available technology, thereby creating demand for such products and eventually stimulating new product developments.

In addition to the reimbursement and consumer education topics mentioned above, research is needed to show the benefits that could be achieved with the standardization of service delivery. Specifically, standard protocols are needed for the processes of assessment, product selection, fitting and monitoring. Standards in these areas are likely to result in cost savings, improved service delivery and improved understanding of product availability and application. Many other chapters in this Industry Profile explore issues related to policy and standards including: legislation (Chapter 3), industry standards (Chapter 4) and service delivery standards (Chapter 7). This pilot study (even with a small sample size) identified gaps between products available and products needed. However, the findings clearly indicate that additional primary market research is needed and justified. Results from such research would be very valuable to the stakeholder groups mentioned previously. As a suggested starting point, this study might be readily improved by using a larger, more diverse sample, stratifying participant responses (manufacturer, supplier, clinician, end user) and sampling other stakeholder groups (public policy, insurers). It is the hope of the T²RERC team that the preliminary information delivered in this chapter will encourage researchers and manufacturers to consider further exploration leading to improvements in the wheeled mobility industry.

Chapter 3

Legislation and Funding

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Contents

Section	Pg
3.1. Introduction	51
3.2. Legislation and Reimbursement	53
3.3. Medicare Coverage of Wheeled Mobility Devices	54
3.4. Wheeled Mobility Coverage Under Part B of Medicare	56
3.5. Covered and Non-Covered Products	57
3.6. ABN and ADMC Processes	58
3.7. Competitive Acquisition Policy and Impact	60
3.8. Impact of Medicare Policy on Consumers	62
3.9. Impact of Medicare Policy on Industry	62
3.10. Medicaid Coverage of Wheelchairs	63
3.11. U.S. Department of Veterans Affairs	67
3.12. Private Health Insurance	69
3.13. Assistive Technology Act Program and Coverage of Wheelchairs	71
3.14. Assistive Technology Loan Programs	72
3.15. Assistive Technology Recycling Programs	73
3.16. Lemon Laws and Product Warranties	74
3.17. Replacement Schedules For Wheelchairs	75
References	76

3.1. Introduction

Wheelchairs change the lives of millions of people who, due to some medical condition, either chronic or acute, have a decreased ability to walk. In some cases, large facilities purchase wheelchairs in volume to meet people's needs. This type of wheelchair is frequently seen at airports, hospitals and even amusement parks to facilitate the mobility of visitors or residents. These wheelchairs are typically referred to as either *transport* or *depot* wheelchairs.

Another large segment of the industry is composed of rental wheelchairs. Rental wheelchairs are typically owned by a rehabilitation technology supplier and rented to people who have short-term needs, such those that would stem from a fractured leg. Depot and rental wheelchairs are usually generic in size and configuration and not individually fitted to a particular person.

For many people with mobility limitations, a wheelchair is the primary means of mobility. The Center for Medicaid and Medicare Services (CMS) categorizes wheelchairs as durable medical equipment (DME). Customized wheeled mobility systems are extremely expensive. Approximately 70% of people with long-term disabilities who need the systems are unemployed, and many do not have the discretionary income necessary to afford these systems. Thus, many people who depend on wheelchairs for daily mobility do not pay for their own systems. A third-party payment system funds wheelchairs for many people who require, but cannot afford, them. Understanding the third-party payment system and the impact of government policy on the reimbursement of wheeled mobility devices is critical to understanding the industry.

Providing customized wheeled mobility systems to people who require them in a third-party payment system can be very difficult. Customers' seating and mobility needs must be met in a way that ensures effective mobility, comfort, and health for the user. Manufacturers and

suppliers try to meet the needs of both the customer who use the system and third-party payers who impose an increasingly restrictive funding process.

This chapter focuses on the third-party payment resources that may be available to people with mobility impairments to provide reimbursement for a wheeled mobility device. For a vast majority of persons with long-term mobility limitations, a government-sponsored program provides these benefits. The three major government programs that routinely cover DME are:

- Medicare Part B – This federal medical insurance program is for persons older than 65, persons under 65 years old who have contributed to Social Security and have been unable to work for at least two years due to injury or illness and persons with chronic kidney failure.
- Medicaid – This state-administered medical insurance program is for people or families who are determined to be indigent based on household income. Eligibility requirements vary by state. However, non-income-related variables factor in the decision to provide Medicaid. These variables include whether an individual is pregnant, disabled, blind or aged, for example.
- Veterans Administration (VA) – This is federal medical insurance funding for veterans.

Private medical insurance is also a significant source of payment for wheelchairs. Many employers offer private insurance as a benefit to their employees to cover the cost of medical care. Most employers who offer the benefit offer a variety of managed care plans. Many people who are self-employed, or who do not receive employer-provided plans, purchase private insurance out of pocket. These policies may or may not include a DME coverage option.

Private payment is always an option for people with mobility impairments who have sufficient discretionary income to pay for wheeled mobility systems. Too often, consumers'

choices are limited to items covered by a third-party payer; they have no exposure to, or knowledge of, the availability of other options. For many people, the internet can be a useful resource for information about available products, even if these products are not covered. A consumer with mobility needs should be shown a range of products by someone skilled in performing seating and mobility evaluations, as additional resources may be available for purchase beyond the third-party payment system. Once informed of available options, people in need may seek alternative resources. Without knowing the possibilities, people cannot make informed decisions about which devices may best meet their needs.

3.2. Legislation and Reimbursement

As previously stated, wheeled mobility devices are classified as durable medical equipment under Section 18 of the Social Security Act (SSA) of 1965 [1]; (P.L 74-271).42 CFR 414.202 of Center for Medicare and Medicaid Services regulations. Under these regulations, DME is defined as equipment which:

- a. can withstand repeated use;
- b. is primarily and customarily used to serve a medical purpose;
- c. generally is not useful to a person in the absence of an illness or injury; and
- d. Is appropriate for use in the home.

For items to be considered DME, all requirements of the definition must be met. As DME, wheeled mobility devices are funded through Part B of the Medicare benefit program. Similarly, wheeled mobility is also funded under Section 19 of the same SSA as a part of the Medicaid program.

Wheeled mobility devices, as one type of assistive technology, are also included or described in other legislation, including the Assistive Technology Act (Tech Act) of 2004 (P.L.

108-364) [2], the Individuals with Disabilities Education Act (IDEA) of 2004 (P.L. 108-446) [3], and the Workforce Investment Act of 1998 (P.L. 105-220) [4] among others. Most of these laws fund assistive devices, as needed for specific purposes, such as work-related activities or devices needed for appropriate access to education. These laws often provide mechanisms to fund wheeled mobility systems. However, these are less common funding sources for wheelchairs because wheelchairs typically fulfill the medical need for mobility across areas of life rather than meeting a specific work-related or school-related need.

3.3. Medicare Coverage of Wheeled Mobility Devices

Medicare, the nation's largest health insurance program was signed into law on July 30, 1965 in Section XVIII of the Social Security Act.[1] Medicare currently covers nearly 42 million Americans including 35 million seniors and six million people under the age of 65 who have permanent disabilities.

Medicare is a health insurance program for:

- a. people 65 or older,
- b. people younger than 65 who have certain disabilities, and
- c. People of all ages with end-stage renal disease (permanent kidney failure requiring dialysis or a kidney transplant).

Medicare has multiple coverage plans – Parts A, B C and D:

Part A: Hospital Insurance — Most people don't pay a premium for Part A (hospital insurance) because they are eligible for coverage, based on their workforce participation for the qualifying number of years (a total of approximately 10 years), or their having a parent or spouse who is eligible for coverage based on this requirement. While employed, working individuals and their employers pay into the system through payroll taxes. If a child is permanently

disabled, he or she will be eligible for coverage based on his or her parent or parents' earning history. The spouse of a qualified worker is eligible for coverage as well. Part A helps cover inpatient care in hospitals, including critical access hospitals and skilled nursing facilities (not custodial or long-term care). It also helps cover hospice care and some home healthcare services. Beneficiaries must meet certain conditions to be eligible for these benefits.

Part B: Medical Insurance — most people pay a monthly premium for Part B. Medicare Part B (medical insurance) helps cover doctors' services and outpatient care. It also covers medical services that Part A does not, including physical and occupational therapy and some home healthcare. Part B helps pay for these covered services, supplies and DME when they are medically necessary. [5]

Part C: Medicare Advantage Plan — formerly known as the Medicare + Choice plan, Part C is available in many areas. Medicare Advantage plans include health maintenance organizations (HMO), preferred provider organizations (PPO), private fee-for-services plans and Medicare special needs plans. Medicare approves these programs, but private companies administrate them and provide the hospital and medical coverage typically provided under Medicare Parts A and B. If the HMO or PPO plans are selected, Medicare Advantage recipients are required to use healthcare providers who participate in these plans.[6]

Part D: Medicare Prescription Drug Plans – Anyone who has Medicare hospital insurance (Part A), medical insurance (Part B) or a Medicare Advantage plan is eligible for prescription drug coverage (Part D). Joining a Medicare prescription drug plan is voluntary. The coverage requires an additional monthly premium.

3.4. Wheeled Mobility Coverage under Part B of Medicare

Medicare refers to all wheeled mobility devices as *mobility assistance equipment* (MAE). Coverage of MAE, including wheelchairs and scooters, is provided to Medicare beneficiaries under the voluntary, out-patient-based, Part B of the Medicare benefit.

The Center for Medicare and Medicaid Services (CMS) is a government agency under the Department of Health and Human Services (HHS), which develops coverage, payment and coding policies for the nationally administered Medicare program.

Once the CMS coverage and payment policies are adopted by the Secretary of Health and Human Services, contract health insurance carriers administer the policies. For durable medical equipment, these intermediaries were called *durable medical regional carriers*, or DMERCs, until December 2005. As of January 1, 2006, these intermediaries became known as *durable medical equipment-Medicare administrative contractors* or DME-MACs. Each new MAC assumes full responsibility for administering the DME benefit as of July 1, 2006. The goal of this reform was to improve service to beneficiaries and providers and to increase administrative efficiency in the process.

CMS contracts administration of coding policies through the *statistical analysis durable medical equipment regional carrier* (SADMERC). The SADMERC Reports and Analysis Unit provide statistical support to the four MACs. The SADMERC Healthcare Common Procedure Coding System (HCPCS) division is responsible for identifying and assigning codes to items of *durable medical equipment, prosthetics, orthotics and supplies* (DMEPOS) services for Medicare billing.

The SADMERC division that implements the Healthcare Common Procedure Coding System, the means by which DMEPOS services are identified for Medicare billing, is referred to as SADMERC HCPCS division.

Additionally, the SADMERC performs a variety of national pricing functions for DMEPOS services, assists CMS with the DMEPOS fee schedules, and analyzes DMEPOS fees to identify unreasonable or excessive reimbursement.

3.5. Covered and Non-Covered Products

In 2004, CMS issued a new coverage policy for wheeled mobility devices. Medicare coverage policy is codified in the National Coverage Determination (NCD). The NCD on Mobility Assistive Equipment (MAE) specifies coverage criteria for canes, walkers, crutches, manual wheelchairs, powered wheelchairs and power operated vehicles (POV), also known as scooters. This regulation covers wheeled mobility devices, once a device receives a HCPC code from the SADMERC.

The DME MACs draft and implement Local Coverage Determinations (LCDs) that are in harmony with the NCD and are applied regionally across the country. LCDs clearly define specific coverage and payment criteria for different types of wheelchairs and wheelchair-related accessories, in various geographic regions.

The 2004 MAE NCD specified a clinical decision-making algorithm that guides clinical decision making and helps determine the level of equipment that the beneficiary is eligible. This algorithm is based on a beneficiary's inability to safely and effectively perform what Medicare terms "mobility related activities of daily living (MRADL)." Examples of MRADL include bathing, dressing, toileting and feeding. The evaluation of the beneficiary's ability to perform MRADLs under the Medicare policy is restricted to those activities performed "in the home." [7] Medicare policy does not cover the beneficiary's mobility needs outside the home.

Once a beneficiary has an identified MRADL limitation caused by a medical condition, a stepwise decision making process determines the level of appropriate equipment. Consideration

must be made for the effectiveness of each type of equipment to assist the beneficiary to perform the affected MRADL. The equipment consideration includes (in order): canes, walkers or crutches, manual wheelchairs (properly configured), power-operated vehicles (scooters) and power wheelchairs. Beneficiaries must be willing to use the device within their homes and home environments must allow for use of the device. Using this process, covered items may include any listed devices, as long as the device is required for performing the MRADL in the home.

Coding groups and more specific product codes are assigned to each product brought to the SADMERC for coding. Each product is assigned a specific HCPCS code. The LCD coverage policy aligns closely with this equipment coding. In 2006, the SADMERC re-coded all powered mobility devices based on several criteria, including testing results of wheelchair performance characteristics and the payload capacity of the device. Wheeled mobility products with performance characteristics consistent with outdoor mobility needs, such as Group 3 POVs and Scooters and Group 4 powered wheelchairs, are considered non-covered items in the LCD because of their specific capabilities for outdoor mobility.

Devices can be deemed “convenience items,” particularly if they are not considered “primarily medical in nature.” An example of such a convenience item is a seat elevator or seat lift for a wheelchair. This wheelchair accessory is considered non-medical in nature and is currently excluded from Medicare coverage.

3.6. ABN and ADMC Processes

Two processes exist for enhancing the Medicare coverage system for durable medical equipment. These processes are:

- The Advanced Beneficiary Notification (ABN); and
- The Advanced Determination of Medical Coverage (ADMC).

These processes may help beneficiaries obtain wheelchairs when they may fail to meet *medical necessity* criteria or when the beneficiary wishes to upgrade or obtain equipment that may not be covered based on their medical needs.

Since June 2001, the *Advanced Beneficiary Notification* (ABN) process has been available for use by Part B suppliers when the provider suspects that specific services or devices may not be covered by Medicare. If a beneficiary wishes to upgrade to a higher-level device than what would be covered, or if the beneficiary doesn't meet the criteria for coverage, the supplier completes what is called the Advanced Beneficiary Notification (form CMS-R-131-G), and the beneficiary signs it. This form notifies beneficiaries that the items they seek may not meet eligibility rules. The ABN is most commonly used for DME when beneficiaries wish to upgrade their equipment beyond what Medicare considers medically necessary. When using the ABN, the beneficiary receives information about coverage, prior to receipt of any product, and agrees to accept responsibility for payment for items that Medicare does not cover.

The *Advanced Determination of Medical Coverage* (ADMC) process allows suppliers to submit medical documentation for a specific wheelchair. After Medicare receives the documentation, it has 30 days to provide the supplier with written notice of whether the device meets the medical coverage criteria. This process is restricted to highly customized items listed by the DME MACs Medicare Supplier Manual. As of January 2007, devices eligible for the ADCM process included ultra-lightweight manual wheelchairs (K0005), Group 2 power wheelchairs with single or multiple power seating options, Group 3 power wheelchairs, Group 4 power wheelchairs, and Group 5 (pediatric) power wheelchairs.

Medicare provides an affirmative or a negative decision based on the medical documentation that the supplier submits. If the decision is negative, Medicare must provide reasons for the denial. Following a denial, a supplier may re-apply for equipment once during

the six-month period following the original determination. If the ADMC determination is affirmative, it is valid for items delivered within six months of the decision. A positive determination on an ADMC submission reflects only that there is a medical need for the device. It does not guarantee payment. ADMC, therefore, is not a prior authorization. Payment can be denied after the device is delivered to the beneficiary if Medicare determines, for example, that the person received a similar device within the last several years. This device may have been received through another supplier and the beneficiary may have failed to report it when asked about previous equipment use.

Both the ABN and ADMC processes provide some flexibility to meet the unique needs of specific beneficiaries and should be explored if a person's functional needs are outside the strict coverage criteria.

3.7. Competitive Acquisition Policy and Impact

In 2003, Congress passed and the president signed the Medicare Prescription Drug, Improvement and Modernization Act of 2003 (P. L. 108–173). This law is referred to as both the “new” Medicare Prescription Drug law, Part D and the MMA or Medicare Modernization Act. The same law that created Part D for coverage of prescription drugs for Medicare beneficiaries also mandated CMS to develop and implement a Competitive Acquisition Program for *certain* DMEPOS items. The law instructed CMS to develop a program to:

- Identify “certain” DMEPOS items, which, if “put out for bid,” would result in significant savings to the agency, as compared to the purchase of those items through the current fee schedule.
- Determine a method by which suppliers in a given metropolitan statistical area (MSA) can submit bid prices for the selected items. Suppliers chosen as “winning

bidders” agree to supply the item at the “winning” price – a price based on submitted bids. Suppliers within that MSA who were not selected, or who did not submit a bid proposal, cannot supply that product to a Medicare beneficiary if Medicare is to be billed.

- Establish quality standards for all DMEPOS suppliers. All suppliers who bill Medicare for any Part B DMEPOS items must demonstrate compliance with the adopted quality standards through accreditation by a CMS qualified accreditor. This quality standard requirement applies to all DMEPOS suppliers, not just those involved in competitive bidding.
- Identify 10 of the largest MSAs in which to implement the competitive bidding program by 2007, and a further 80 MSAs in 2009.

The proposed rule for the implementation of competitive bidding, as proposed by CMS, was published in the Federal Register, May 1, 2006 (Part 2 – Department of Health and Human Services - 42 CFR Parts 411, 414, and 424)[5]. As this chapter goes to print in 2009, the competitive bidding program has yet to be implemented. The initial round began on July 1, 2009, but it was almost immediately suspended by Congress via a new bill — Medicare Improvements for Patients and Providers Act of 2008 (MIPPA). MIPAA instructed CMS to stop round one and to re-vamp key areas in the program with a mandate to re-initiate the bid program by 2009. CMS has a website that lists published information regarding the competitive bidding program at <http://www.cms.hhs.gov/CompetitiveAcqforDMEPOS/>. On this website, important documents are available in the Downloads section. Currently posted are the Quality standards for suppliers of durable medical equipment, prosthetics, orthotics and supplies (8-14-2006) and a list of accreditation organizations for DMEPOS suppliers.

3.8. Impact of Medicare Policy on Consumers

When considering Medicare policy regarding wheelchair coverage, even before the implementation of competitive bidding, a restriction negatively impacts consumers. This restriction is referred to as the *in-the-home rule*. Medicare determines whether a manual or power wheelchair is reasonable and necessary (i.e., whether it is covered) based on the person's need for the device inside his or her home. [7] This is commonly known as the in-the-home restriction and only applies to coverage of durable medical equipment. For a consumer to be eligible for a power wheelchair he or she not only must require this device for moving around within the home, but also be unable to propel a "properly configured" manual wheelchair, or negotiate inside his or her own home using a walker or cane. These policy interpretations significantly limit the ability of Medicare beneficiaries who require a specific device for community mobility to obtain an appropriate manual or power wheelchair. This restriction significantly limits beneficiaries who are active community wheelchair riders and use their wheelchairs to participate fully in community life.

3.9. Impact of Medicare Policy on Industry

As the largest funding source for wheelchairs, Medicare not only has a significant effect on consumers, it directly affects the wheelchair industry in many ways. A significant portion of industry sales relies on the ability of Medicare beneficiaries to obtain funding through this system. Without Medicare reimbursement, many of these wheelchairs would simply not be purchased because consumers would be unable to afford the entire burden of the cost on their own. This has both a positive and a negative impact on industry. As mentioned previously, CMS contracts with the SADMERC to provide coding and pricing determination for all items of durable medical equipment, including manual and power wheelchairs. The SADMERC

establishes the coding system and related requirements and all manufacturers of equipment must submit their devices for coding determination. In this way, Medicare determines the fee schedule for all wheelchairs. All items are assigned an HCPCS code which is then used across all medical insurance systems, as required by the Health Insurance and Portability Accountability Act of 1996 (P.L. 104-191) or HIPAA, for billing of wheelchairs. [9] While Medicaid and private health insurance companies develop their own reimbursement fee schedules, many of them rely on what Medicare will pay for an item to determine their own fee structure. Manufacturers of wheelchairs must constantly adapt to these changing fee schedules and must produce equipment that is able to compete in this marketplace. When equipment quality suffers because of cost containment, then consumer satisfaction will decline. When equipment choice is limited due to “code assignment,” the customer’s access to this equipment is undermined.

3.10. Medicaid Coverage of Wheelchairs

The Medicaid program was created as part of the same law that created Medicare. Medicaid is codified as Title XIX of the Social Security Act, 42 U.S.C. §1396 et seq., and was enacted to provide healthcare services to low-income persons in multiple groups, including individuals with disabilities. Medicaid now serves more than 50 million low-income families, elderly individuals, and persons with disabilities. [10] Many children and adults with severe disabilities rely on Medicaid for coverage of their health care, including coverage for durable medical equipment.[10] When individuals with disabilities have low incomes and also are Medicare eligible, they can be “dually eligible” for both Medicare and Medicaid.

Medicaid is a federally created program with a broad outline of coverage. This broad outline includes both who is eligible for coverage and what services are included. While the Medicaid program includes a clear statement of federal oversight, Medicaid gives each state

latitude to broaden the scope of people who are eligible beyond federally defined groups and to expand the scope of covered services beyond federally mandated care. The Social Security Act also delegates day-to-day administration of program to the states. Perhaps the most significant aspect of the Medicaid program is its financing scheme: the federal government assures each state at least 50 percent federal funding for all Medicaid covered health care the state provides, whether for mandatory coverage populations or services, or optional ones. As long as the state continues to meet its share of expenses and follows the requirements of the federal law, the federal government will continue providing its share of these expenses. [11]

There are three basic criteria for wheeled mobility device coverage under Medicaid:

1. The individual who needs the device must be eligible for Medicaid;
2. The device requested must meet the definition of one or more coverage categories;
and
3. The device requested must be medically necessary.[10]

Unlike Medicare, durable medical equipment is not specifically identified as a covered benefit category in the Medicaid Act. Instead, DME is covered by Medicaid in every state, for adults and children, under its Home Health Care benefit (42 C.F.R. § 440.70). Most states, however, copy the Medicare DME definition in whole or substantial part. For children, DME is covered in the Medicaid program under a benefit known as “early and periodic screening, diagnosis, and treatment services,” or EPSDT. For adults, home health services, and hence, DME, is mandatory for all individuals who are otherwise eligible for nursing facility care.

Medicaid does not have specific coverage guidelines such as the NCD for MAE, and instead allows states to write their own coverage criteria for these items. Federal Medicaid authorities, however, prohibit state programs from developing exclusive lists of covered items. Instead, according to the September 4, 1998 HCFA State Medicaid Director Letter, for any item

sought, there must be full and fair access to a procedure that allows the recipient to establish that the item fits the state definition of DME and is medically necessary. In addition, for any item of DME that is coverable, (i.e., fits the state's DME definition: is medically necessary and not experimental) Medicaid coverage is required. Failure or refusal to cover such an item is "per se unreasonable and inconsistent with the stated goals of Medicaid," according to *Lankford v. Sherman*. [12] These policies result in Medicaid coverage for all types of wheeled mobility devices, including pediatric products, bariatric products, standing, tilt-in-space, lightweight and other types of devices and all manner of seating and positioning accessories that can be established as medically necessary.

Federal law outlines Medicaid payment for DME items. Medicaid establishes no specific funding rate for any item, service or procedure. Instead, it requires state programs to establish rates that ensure equal access to covered health benefits that would be available to individuals with other types of third-party health care coverage. One caveat is that the amount Medicaid sets for a covered item must represent payment in full. Unlike Medicare, there is no authority for billing the client in addition to the payment received from Medicaid. Because Medicaid is a means-based program, co-payments for Medicaid services are rare. For these reasons, even though a Medicaid recipient may have insurance or Medicare as sources of partial payment, when those contributions are supplemented by a Medicaid payment up to the Medicaid payment limit, that amount must be payment in full for that item, service or procedure. This means that Medicaid programs cannot set arbitrary limits or payment rates for DME items, such as \$562.00, which Florida Medicaid once proposed as the mandatory payment it would provide for any type of wheelchair. [13] When Medicaid payments are too low, suppliers will refuse to provide products to Medicaid recipients who have been determined to have a medical need for the equipment. This is not permitted.

One of the statutory purposes of the Medicaid program is to assist the recipient to attain or retain the capability for independence and self care (42 U.S.C. § 1396(2)). This has been described as the “primary goal of Medicaid, according to *Meyers v. Reagan*. [14] This statutory purpose does not exist in the Medicare Act. This Medicaid statutory goal and others that are not copied in the Medicare statute make clear that Medicare and Medicaid, although enacted as part of the same legislation, and addressing the same general subject – healthcare – are distinct programs with distinct criteria. And, for these reasons, Medicaid programs are barred from borrowing Medicare criteria. One example is a Medicare Act requirement that limits access to home healthcare benefits to individuals who are homebound. No similar requirement exists in the Medicaid program, and federal Medicaid guidance expressly prohibits its application. Medicare also lists equipment that it considers convenience items and refuses to cover, or covers only under certain, listed circumstances. However, Medicaid guidance expressly prohibits exclusive lists and requires state programs to allow each recipient to show an item is medically necessary for that person and under that person’s unique circumstances.

For the same reason, Medicaid programs should not apply the Medicare in-the-home limitation. This Medicare Act provision is not stated in the SSA, suggesting that Congress’ intention was that it wouldn’t be applied to Medicaid recipients. In addition, Medicaid must establish “reasonable” standards related to services eligibility, and the touchstone for reasonableness is that access standards are consistent with current standards of medical practice.[15] Medicare does not claim the in-the-home limitation in the NCD for MAE is consistent with medical practice standards. Instead, Congress requires it. As noted, Congress did not require in-the-home for Medicaid. Finally, residents of nursing facilities are entitled to services that allow them to maintain or attain the highest practicable physical well-being (42 U.S.C. § 1396r(d)), including access to medical equipment, such as wheeled mobility devices to

meet mobility needs, including their needs to leave the facility to access community-based services (42 C.F.R. §§ 483.10; 483.15; 483.25). Medicaid application of the in-the-home standard violates the SSA as well as the Americans with Disabilities Act of 1990 (P.L. 101-336).

[16]

3.11. Department of Veterans Affairs (VA)

In addition to Medicare and Medicaid, the federal government also supports the purchase of wheelchairs through the Department of Veterans Affairs (VA). As the largest integrated healthcare system in the country, the VA is a significant consumer of wheelchairs and related products and services. The VA spends approximately \$100 million each year on power wheelchairs, manual wheelchairs and scooters.

Eligibility for most VA benefits is based upon honorable discharge from active military service. “Active service means full-time service, other than active duty for training, as a member of the Army, Navy, Air Force, Marine Corps, Coast Guard, or as a commissioned officer of the Public Health Service, Environmental Science Services Administration or National Oceanic and Atmospheric Administration (NOAA) or its predecessor, the Coast and Geodetic Survey.”[17]

The VA provides health services to individuals who became ill or injured “in the line of duty” while serving in the military (service connected or SC) and those who became ill or injured after an honorable discharge from the military (non-service connected or NSC). In addition to SC versus NSC conditions, the client’s financial data is also analyzed during the enrollment process. Veterans are assigned to one of eight numbered, priority groups with SC military given priority to 50% or more of the highest priority groups. Once enrolled, veterans can receive services at VA facilities anywhere in the country. For details on VHA eligibility visit the website at <http://www.va.gov/healtheligibility>.

The Prosthetics and Sensory Aids Service (PSAS) coordinates the provision and funding of all equipment and devices that are issued to veterans. The Veterans Health Administration (VHA) Handbook (2007b) section 1173.6 outlines eligibility, procedures, and guidelines for issuance of manual wheelchairs, motorized wheelchairs, scooters and sports wheelchairs.[18] Eligibility for a back-up manual wheelchair is also addressed, as is the process for maintenance and repairs.

A supplementary document, Clinical Practice Recommendations for Motorized Wheeled Mobility Devices: Scooters, Pushrim-Activated Power-Assist Wheelchairs, Power Wheelchairs and Power Wheelchairs with Enhanced Function was published in 2004 by the Prosthetics Clinical Management Program (PCMP) national Wheeled Mobility Integrated Product Team (IPT). This document further outlines specific clinical guidance in determining appropriateness for options in power mobility. The document defines each power mobility option, offers indications and contraindications for each device and demonstrates, using case examples, sound clinical decision-making. The IPT is currently compiling a similar comprehensive document to address clinical practice recommendations for the issuance of manual wheelchairs. A separate work group is actively addressing eligibility and processes for sports wheelchairs and recreational devices.

Wheelchair eligibility in the VA is different from other government agencies (i.e., Medicare and Medicaid) and most private insurance companies. Several examples demonstrate these significant differences. The VA “supports the dispensation of power mobility to allow the veteran to access medical care and to accomplish necessary tasks of daily living in ordinary home and community environments,” thus “in the home restrictions” do not apply. Individuals who use a manual wheelchair for primary mobility are eligible for a custom configured ultra-lightweight wheelchair with justified options/accessories and a second wheelchair of equal value

to serve as a back-up. Clients who use power wheelchairs are also provided with a back-up manual wheelchair. The VA is one of the only healthcare agencies in the country to provide sports/recreational wheelchairs and devices to beneficiaries who meet specific eligibility criteria and for whom the equipment will allow achievement of rehabilitation goals.

Actual processes for wheelchair evaluation, prescription, fitting and patient education vary between VA facilities. A client-focused team approach that fosters a supportive collaboration between interdisciplinary professionals is most effective in optimizing outcomes for veterans.

The VHA Handbook (2007b) section 1173.6 specifically states that “all wheelchairs for use by eligible beneficiaries will be purchased from current VA contracts using established procedures.”[18] There are processes for purchasing wheelchairs that are not “on contract” with specific justification. Manufacturers are encouraged to contact the National Acquisition Center (NAC) in Chicago for specific information about VA wheelchair contracts. The NAC establishes and administers the Federal Supply Schedule and national contracts for wheelchairs and other equipment provided by the VA. For more information, see <http://www1.va.gov/vastorenac/>.

3.12. Private Health Insurance

Over the past 25 years, employer-provided health insurance has changed. Before the 1980s many employers provided to employees a type of insurance referred to as indemnity plans. An indemnity plan reimburses the beneficiary’s medical expenses regardless of who provides the service. In the last two decades, in an effort to help contain costs associated with providing healthcare insurance, employers began to offer alternative insurance products, all referred to as managed care plans. There are three basic types of managed care plans: (1) Health Maintenance

Organizations (HMOs), (2) Preferred Provider Organizations (PPOs), and (3) Point of Service (POS) plans.

Although there are important differences between the different types of managed care plans, there are similarities as well. All managed care plans involve an arrangement between the insurer and a selected network of healthcare providers (doctors, hospitals, and DME Providers, in many cases). All offer policyholders significant financial incentives to use the providers in that network. There are usually specific standards for selecting providers and formal steps to ensure that quality care is delivered. [19]

Durable medical equipment (DME) is frequently, but not always, a covered benefit within a private insurance plan. To determine coverage, a careful review is needed for a specific policy. Depending on the policy and type of plan being offered, wheeled mobility products may only be available through a Preferred Provider Network, a DME supplier or group of suppliers who have a contractual agreement with the insurance carrier. Most private insurers have both co-pay and prior authorization requirements for purchasing specifically configured DME, referred to as rehabilitation technology, or complex rehab devices. Once a specific order configuration has been determined with a supplier, the request for authorization is submitted to the insurance company prior to ordering the product from the manufacturer. The insurer may decide to:

- Fully fund the requested item, minus a co-pay or deductible to be paid by the beneficiary;
- Fully reject the claim; or
- “Down code” – authorize a payment less than the submitted amount by the supplier.

The supplier must then make a business decision if the “allowed” price does not cover

the supplier's costs. The beneficiary can either self-fund through private payment or will need to make an alternate product choice.

It has been observed that private insurers have increasingly indicated the coverage policy used by their companies "follow the Medicare guidelines." As noted earlier, Medicare's Mobility Assistance Equipment (MAE) coverage policy outlines a clinical decision making algorithm, which guides one through the process of determining the appropriate assistive device for a person with a mobility impairment from ambulation aides (canes, walkers, etc.) and self-propelled manual wheelchairs through power mobility options including scooters and power wheelchairs. The concern does not arise from the application of this algorithm to a coverage policy; the greater concern comes with the application of the in-the-home restriction. Policyholders need to query the benefits coordinator and or insurance representative about the extent to which the mobility needs of the beneficiary will be met, in both in the home and in the community.

3.13. Assistive Technology Act Program and Coverage of Wheelchairs

Congress passed the Technology-Related Assistance for Individuals with Disabilities Act (Tech Act) of 1988 (P.L. 100-407) to increase access to, availability of, and funding for assistive technology through state efforts and national initiatives.[20] The Tech Act Amendments of 1994 (P.L. 103-218) reauthorized the Act through September 30, 1998.[21] In November 1998, the Assistive Technology Act (ATA) of 1998 (PL 105-394) was signed into law to re-authorize and extend funding for the programs originally established under the Tech Act.[22] This legislation was amended in 2004 (Assistive Technology Act of 1998, as amended (P.L. 108-364)) to improve access to assistive technology (AT) for individuals with disabilities. Under the current act, statewide AT programs must use the funds made available under their grant to provide and

or support state financing activities including alternative financing programs, device reuse, device loan programs and device demonstration programs. In addition, states are responsible for carrying out training and technical assistance, public awareness and coordination and collaboration activities. [23]

Since 1988, several major initiatives have come out of the Assistive Technology Act that relate to the wheeled mobility market, including device reuse programs and alternative financing programs. Additionally, many states have established Lemon Laws related to assistive technology devices that help protect consumers from faulty assistive technology devices – including wheelchairs. State-run programs also provide significant consumer education regarding all technologies, including wheelchairs and are active in many states in helping consumers obtain devices. The legislation also funds protection and advocacy services to help consumers obtain funding for and access to AT through public sources including education, vocational rehabilitation, Medicaid and Medicare as well as private insurance.

3.14. Assistive Technology Loan Programs

The alternative financing programs offered under the Assistive Technology Act of 2004 provide affordable, often low-interest rate loans to individuals to purchase AT. According to the law, states are required to provide programs that:

- i. support for the development of systems for the purchase, lease, or other acquisition of, or payment for, assistive technology devices and assistive technology services;
- ii. support for the development of State-financed or privately financed alternative financing systems of subsidies (which may include conducting an initial 1-year feasibility study of, improving, administering, operating, providing capital for, or

collaborating with an entity with respect to, such a system) for the provision of assistive technology devices, such as

- (I) a low-interest loan fund;
- (II) an interest buy-down program;
- (III) a revolving loan fund;
- (IV) a loan guarantee or insurance program;
- (V) a program providing for the purchase, lease, or other acquisition of assistive technology devices or assistive technology services; or
- (VI) Another mechanism that is approved by the Secretary (118 stat. 1720).

The primary technologies funded under this law and its reauthorizations primarily include adapted transportation and mobility equipment. Fifty-six U.S. states and territories have projects funded under the act. RESNA's website provides a complete listing of state-funded programs.

3.15. Assistive Technology Recycling Programs

Statewide Assistive Technology Act Projects have fostered the development of assistive technology device recycling programs. Such programs frequently include manual and powered wheelchairs, particularly those at the higher end of capabilities or more those that are more highly customized (for example ultra-lightweight manual wheelchairs, power scooters and power wheelchairs). The programs may accept and refurbish devices then re-sell them to consumers with disabilities at reduced or no cost. Many of the programs also warrantee the devices. The impetus for these programs involves enhancing savings in the area of assistive devices, satisfying unmet needs of consumers and providing value for devices that are functional but no longer in use. An estimated 20% to 40% of assistive technology goes unused. Reasons for that include that users medical needs change, users outgrow their equipment or the equipment may have

inappropriate to begin with. Unused equipment is potentially a resource that could meet the needs of many individuals. [24]

Recycling and exchange programs fill several needs. They provide assistive technology devices and equipment to individuals with disabilities at reduced cost or no cost. They supply needed equipment in a timely manner, and they make convenience and other items (such as backup devices and recreational technology) affordable to many consumers. The programs also leverage resources by reusing equipment that otherwise would be abandoned. [24]

While most third-party payers have yet to embrace equipment recycling, these programs meet the needs of consumers who are ineligible for wheelchair funding through traditional third-party payment programs.

3.16. Lemon Laws and Product Warranties

Assistive technology *lemon laws* have been established through multiple state AT programs. As of 2001, 38 states offered these protective laws to assistive technology consumers.[25] The laws vary by state and require assistive device warranties — most for one year — and other protections for consumers of assistive devices. These laws aim to protect consumers from being stuck with assistive devices that don't work properly or haven't been correctly repaired. A few lemon laws cover all AT, but most apply only to wheelchairs. [25]

Many manufacturers of wheelchairs, particularly power wheelchairs, provide warranties for part or the entire wheelchair. Manufacturers of ultra-lightweight manual wheelchairs commonly provide lifetime frame warranties and provide the parts to replace a broken frame based on this coverage. Powered wheelchair manufacturers frequently have limited warranties on electronic components or motors. They frequently provide lifetime warranties on the

wheelchair frames. These warranties typically cover parts; however, the services needed to replace them are frequently reimbursed by the third-party payer or by the consumer.

3.17. Replacement Schedules for Wheelchairs

There is no generally accepted replacement schedule for wheelchairs. However, most third-party payers limit how frequently they will fund new wheelchairs. This range can be anywhere from three to five years, depending on the type of wheelchair and the wheelchair user's activity level. Additionally, wheelchairs may be replaced with different levels of equipment if users' needs change. This may happen if the user has a progressive condition such as multiple sclerosis, for example.

Manufacturers of wheelchairs test the durability of their products in several ways, depending on whether the product is a manual wheelchair or a power wheelchair. Minimum testing requirements typically consider a two-year lifespan, however most wheelchairs exceed this basic requirement and can last well past the two-year warranty. This depends heavily on the wheelchair user's characteristics. Individual user characteristics, such as body weight or "riding style" can significantly affect the rate of wear and tear of a chair.

Replacement schedules also depend on the equipment itself. A highly adjustable wheelchair, or one with multiple moving parts, wears more quickly and requires replacement more often. Many wheelchairs, both manual and power, require regular maintenance and repairs. The third-party payer, who paid for the device in the first place, typically covers these repairs. The need for wheelchair replacement typically depends on the age of the wheelchair, the size and activity level of the wheelchair rider, repair history and the cost of needed repairs versus the costs of device replacement. All factors are presented to the third-party payers who determine whether to repair the existing wheelchair or replace it with a new one

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Chapter 4

Voluntary Industry Standards for Wheelchair Technology A Model for Successful Advancement of Assistive Technology

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	Contents Section	Pg
4.1. Introduction	81
4.1.1 Purpose and Rationale for Industry Standards	81
4.1.2 Historical Overview of United States Involvement in National and International Standards Development	83
4.1.3. Astounding Accomplishments to Date	85
4.2. Voluntary vs. Regulatory industry standards	86
4.3. Organization of national and international Industry standards	88
4.3.1 How Does a New Industry Standard Get Initiated?	89
4.3.2 Brief Description of the ISO Standards Development Process	90
4.3.3. Organization of Standards Development in the United States	93
4.3.4 Relationship Between National and International Efforts	94
4.4. Anatomy of a typical iso industry standard	95
4.4.1 Foreword	96
4.4.2 Introduction	97
4.4.3 Scope	98
4.4.4 Normative References	98
4.4.5 Terms and Definitions	99
4.4.6 Design Requirements	100
4.4.7 Identification, Information, and Instruction Requirements	100
4.4.8 Performance Requirements	101
4.4.9 Test Report	102
4.4.10 Information Disclosure	103
4.4.11 Test Methods	104
4.4.12 Bibliography	105
4.5. The standards model and its potential benefits for stakeholders	105

4.5.1 The Participant-Responsive Development Model	105
4.5.2 Impact/Benefits for Users, Clinicians, Industry and Healthcare Funding Agencies	106
4.5.3 The Unexpected Benefits of Voluntary Industry Standards Development	107
4.5.3.1 <i>A strange and amazing multidisciplinary model</i>	107
4.5.3.2 <i>The magnitude of the goal and potential impact of the final result</i>	108
4.5.3.3 <i>Consolidation of worldwide knowledge</i>	108
4.5.3.4 <i>Development of collegial networks</i>	109
4.5.3.5 <i>Clinical/user application of industry standards</i>	110
4.5.4 How to Get Involved	110
4.6. Barriers to standards development and implementation	111
4.7. Addressing the barriers and opportunities for future growth	112
4.7.1 Addressing the Barriers	112
4.7.2 Future Growth	117
4.7.3 Sustaining the RESNA Technical Standards Board Management Function	117
4.8. Summary	118
References	119
Annex a: listing of iso/tc 173 standards (10-07)	121

4.1. Introduction

4.1.1. Purpose and Rationale for Industry Standards

Products for persons with disabilities, especially those that users rely upon to carry out their daily activities, assume a high level of need and expectations in terms of design, technical performance, cost-benefit, reliability and safety. Prior to 1980, there was no systematic way for wheelchair users, product prescribers or healthcare insurers to determine, in advance of purchase, what products actually met these higher needs and expectations. Reports of poor reliability, user injuries and occasional fatalities were documented by the FDA and Ummat, S., & Kirby, L. [1] Large bulk purchasers, such as the Veterans Administration in the United States and national healthcare providers in Europe also needed objective information to guide decisions related to product choices for inclusion on their provider listings of approved products for government payment.

For example, despite many years of research on wheelchair seat cushions that incorporate design features intended to prevent the formation of pressure sores and maintain tissue integrity, there were no objective tests or established criteria that could help differentiate the efficacy of different products. Since pressure sores can be very debilitating, costly and in some cases life-threatening, the performance of these products takes on an important medical, as well as functional dimension. In the absence of industry standards that provide objective test information, any manufacturer can claim superior performance capabilities for their products. Objective presale information is critical for clinicians and users to aid in their product selection decision-making process. Also, healthcare insurers need objective test information upon which to base their payment codes that reflect a justifiable relationship between the quality of product performance and reimbursement level.

In 1978, working within the auspices of the International Standards Organization (ISO) and inspired by European countries with large national healthcare programs (Sweden, Netherlands and the United Kingdom), a Subcommittee on Wheelchairs (SC-1) was established within a Technical Committee (TC-173) to develop voluntary industry standards for wheelchair products.

In brief, the rationale for the development of voluntary industry standards may be summarized as follows:

- Provide a common minimum benchmark of product quality, safety and accessibility which all manufacturers must attain
- Promote improved safety for areas in which problems have arisen or may arise with existing products
- Provide standardized product information, based on objective test information, that can be used for decision-making by service providers, product users and insurance agencies,
- Facilitate barrier-free trade of assistive technology products on a the worldwide scale,
- Seek and document agreement on standardized terminology
- Provide standardized test procedures that will enable national funding agencies to use the results of the testing to code products into different performance categories for purposes of reimbursement,
- Consolidate technical, scientific and clinical knowledge so as to advance the quality, safety and accessibility of assistive technology products worldwide.

4.1.2. Historical Overview of United States Involvement in National and International Standards Development

In the late 1970s in the U.S., the Health Industry Manufacturers Association (HIMA) served as the Technical Assistance Group (TAG) for the American National Standards Institute (ANSI) in terms of representing the U.S. wheelchair manufacturer's interests within the newly formed ISO TC-173/SC-1 structure. Keith Rodaway, then head of engineering at Everest and Jennings Inc., attended the early ISO TC-173/SC-1 meetings as a representative of HIMA. HIMA was unable to provide resources for development of a multidisciplinary U.S. national working group on wheelchair standards, which is essential for meaningful involvement in ISO activities. About 1981, the lead author was approached by Rodaway and asked to set up a forum within the Rehabilitation Engineering and Assistive Technology Society of North America (RESNA) for developing voluntary industry performance standards for wheelchairs so that the U.S. wheelchair industry could officially participate in the standards activities that had begun in ISO TC-173/SC-1 in 1978. The RESNA Board approved the proposal. A few years later ANSI designated RESNA as the U.S. standards development body in the area of disability products. RESNA was designated by ANSI as the official U.S. (TAG) to participate in related ISO activities (TC-173/SC-1). Subsequently, RESNA became accredited as a standards organization by ANSI with its own set of operating procedures that are in compliance with ANSI's Essential Requirements for standards setting organizations.

Since then, many positive activities have occurred. We now have published, or are in the process of publishing, more than 40 voluntary industry standards for wheelchairs, wheelchair seating and wheelchair-transportation safety products. These standards cover a wide range of design and performance requirements, test methods, information disclosure requirements and standardized terminology. Most wheelchair-related products now being manufactured and

marketed in the U.S. conform to the majority of the requirements of the applicable RESNA and or ISO standards. The U.S. standards have, to a large extent, been harmonized with Canadian and ISO equivalent standards, so as to minimize barriers to import and export for both consumers and manufacturers. Much of the early standards development work was supported by the Veteran's Administration (VA), the Paralyzed Veterans of America (PVA), and indirect support via industry and federal funding to research institutions, mainly the National Institute on Disability and Rehabilitation Research (NIDRR) through its funding of RERC on Wheeled Mobility located at the Universities of Virginia and later at the University of Pittsburgh (see acknowledgement at end of chapter).

Occupied wheelchairs are often used as seats in transport motor vehicles. In partnership with the Society of Automotive Engineers (SAE) Adaptive Devices Committee, an SAE recommended practice document, SAE J2249-Wheelchair Tiedown and Occupant Restraint Systems (WTORS) was developed. [2] This document sets requirements for WTORS intended for use with occupied wheelchairs during transport in a motor vehicle. Virtually all WTORS marketed in North America now conform to the SAE J2249 recommended practice. Because of RESNA's prior work in wheelchair standards and its long-standing liaison with ANSI and ISO, this SAE work was formally transferred to RESNA in the late 90s and established as the Subcommittee on Wheelchairs and Transportation (SOWHAT), later named the Committee on Wheelchairs and Transportation (COWHAT).

In May 2000, the SOWHAT completed the first voluntary standard for wheelchairs that is intended as a seat in a motor vehicle (ANSI/RESNA WC-19) (ANSI/RESNA, 2000). This effort was made possible by combined private, wheelchair industry, school-bus associations and federal grant support, all managed and supported by a consortium of research institutions. The four-year effort to develop the WC-19 standard cost approximately \$350,000. The effort also

permitted active participation in ISO WG-6, in which an equivalent standard, ISO 7176-19 was completed in 2001. [3] More information on standards for transportation safety may be found in the article by Schneider et al. [4]

In June 1998, RESNA's Technical Standards Board authorized the formation of the Committee on Wheelchair Seating Standards. The committee and three interrelated working groups began work on voluntary wheelchair seating standards. A parallel effort in ISO WG-11 was established shortly thereafter. A fourth standard, which addresses wheelchair seats for use in motor vehicles, was assigned to ISO WG-6 (ISO 16840-4, [2004]). At present three of the four seating standards have been published (16840, parts 1-3), with the fourth nearing completion.

Following the development of a standard, a need exists to provide user-friendly guideline documents for its clinical or real world implementation. There have been sporadic efforts to accomplish this, but much more remains to be done, as will be discussed in a later section. Publications by McClaurin and Axelson (1990) and Axelson et al (1994) provide examples of these earlier efforts. [5][6][7] [8]

4.1.3. Astounding Accomplishments to Date

Annex 1 provides a listing of the ISO TC-173/SC-1 standards as of October 2007. This listing is largely mirrored by the work committees and the four-volume series being updated and expanded for publication in 2008 by the RESNA-TSB. The ISO work began in 1978 with a 16-part series on wheelchair standards. Examination of the current ISO listing in Annex A will reveal:

- Five active working groups, each focused on unique assistive technologies
- A total of 40 unique standards, many published, others in process
- 27 published International standards

- Two technical guidelines to facilitate the application of the standards.

Given the volunteer resources and very limited government contributions, in contrast to the magnitude of the total investment, this can only be characterized as an astounding accomplishment. Wheelchair-related products being used in more than 15 countries are being increasingly designed and tested for compliance with various aspects of these ISO standards or their national equivalents. Equally important, a mechanism is in place to systematically review every published standard. ISO and ANSI protocol requires a five-year review cycle in which one of the following actions must be taken on a standard:

1. Re-approve without revision for an additional five years
2. Review and revise via the 5-stage national voting process
3. Recommend termination.

A further section attempts to analyze the standards development process in an effort to recognize the array of benefits to a wide range of participants and consumers, as well as the hidden or unexpected motivators that seem to drive such an exceptional level of volunteer contributions and coordinated effort.

4.2. Voluntary vs. Regulatory Industry Standards

Unlike Federal Motor Vehicle Safety Standards (FMVSS) in the U.S., for example, that have mandatory compliance requirements, all the wheelchair and seating standards development efforts have been based on voluntary industry participation. The approach's main advantage is that it's easier to reach consensus on contentious issues (because compliance is optional). The disadvantages are that manufacturers can opt to comply with design and performance requirements of their choosing or disclose limited test information in their presale literature.

Depending upon the laws and regulations in each country, government agencies at various levels can decide to make compliance a requirement. In Europe, Japan and the United States wheelchairs are considered medical devices. In Europe, this subjects them to European Union (EU) laws requiring compliance to requirements that govern all medical devices, including CE (Communauté Européenne) marking. In most cases, the ISO voluntary industry standards are the basis for these requirements related to wheelchair related technology, thereby making compliance to the EU-selected parts of ISO mandatory by law. CEN standards reference the ISO test procedures and specify requirements for different classes of manual and powered wheelchairs.

The irony is that if government agencies selectively use the standards to suit their needs for regulation or device classification and cost containment, it drives the payment system that can stifle future product development. It is imperative that agencies, such as Centers for Medicare and Medicaid Services (CMS) in the U.S., develop coding categories that cover the full spectrum of products from the lowest to the highest levels of performance. Failure to do so can lead to inferior clinical outcomes rather than an improvement. In an environment that depends on voluntary compliance by industry, such as in the U.S., standards and related test methods that have selectively been made mandatory test procedures for coding and payment purposes by a government payment agency like CMS, will become the de facto industry standard, with the real risk that the remainder of the national standards will be largely ignored.

More recently, CMS decided to selectively reference test methods to classify wheelchairs and seating products into categories to which funding codes for reimbursement are being assigned. This means that, to the extent that a manufacturer wishes to make a wheelchair or seating product eligible for reimbursement through the CMS system, compliance with those test methods referenced by CMS is mandatory. Although there is little experience to date with these

new policy decisions, potential problems loom. For example, in the case of wheelchair seat cushion products, CMS has published guidelines for classifying cushions into six billing code categories. The same document also specifies the eligibility of different groups of users for these billing codes. Although the introduction of the new codes is widely supported there is real concern with the manner in which CMS has elected to selectively use the draft standards and that the resulting clinical outcome (and future product development) will be driven by the funding formula (codes). [9] For example, CMS has elected to use relative peak pressure test data from variations of draft ISO test procedures as a means to classify seat cushions. In later versions of the draft standard tests were withdrawn due to difficulties in achieving repeatable results between laboratories and comparable results between different pressure-mapping systems. What is required is a balance across a wider range of cushion parameters that are applicable to a wider range of users. As intended by the standards, this approach will then provide the disclosure of the technical characteristics necessary to allow the judgment of skillful clinicians working with their client to arrive at the desired clinical outcome. [10]

In the U.S., the FDA has also selectively recognized the RESNA and or ISO standards as proof of safety compliance for 510k approvals on new wheelchair products.

4.3. Organization of National and International Industry Standards

Understanding the structure and processes involved in taking a new standard through the review and voting approval stages can be daunting. This section attempts to simplify that task. But first, remember that an overriding goal is to harmonize industry standards worldwide. The best way to achieve this is for each country to actively participate in the ISO arena during the development process, so that when the time comes for national adoption of the final ISO product there are, ideally, very few areas of incompatibility. Also, the ISO process creates a forum

where limited worldwide resources can be integrated and focused on creating a result that is much more robust than could be accomplished by any one country. The process used in RESNA is somewhat simpler since it's mostly a matter of formally adopting an ISO standard, often with only minimal changes. For these reasons, and since the ISO standards are the most universally applicable and referenced by most national standards bodies, the following discussion and examples will focus mainly on the larger international (ISO) picture.

4.3.1. How Does a New Industry Standard Get Initiated?

People commonly ask how a new standard is initiated. As with most new ideas, standards begin with an individual who recognizes a need then takes steps to convert the vision to reality, usually by convincing others of its importance and potential for success. In the case of standards, we can share a personal experience of how this happened with the ISO 16840 series on wheelchair seating.[11] In other cases, new standards are often a result of continuing work on related standards in which additional unresolved needs are identified by the work group and a new standard is proposed.

In the ISO process, formal proposals for new standards most often come from a participating country, in which the initiating expert(s) work(s) through their national ISO Technical Assistance Group (TAG). The RESNA-TSB (chaired by Peter Axelson) is probably unique as a national standards body in that it has a network of committees that mirror the ISO working groups. These committees are actively developing or revising standards appropriate to the U.S. market, as well as actively participating in the relevant ISO work groups. This close collaboration can often identify the need for a new or revised ISO standard that is then formally requested by the TSB.

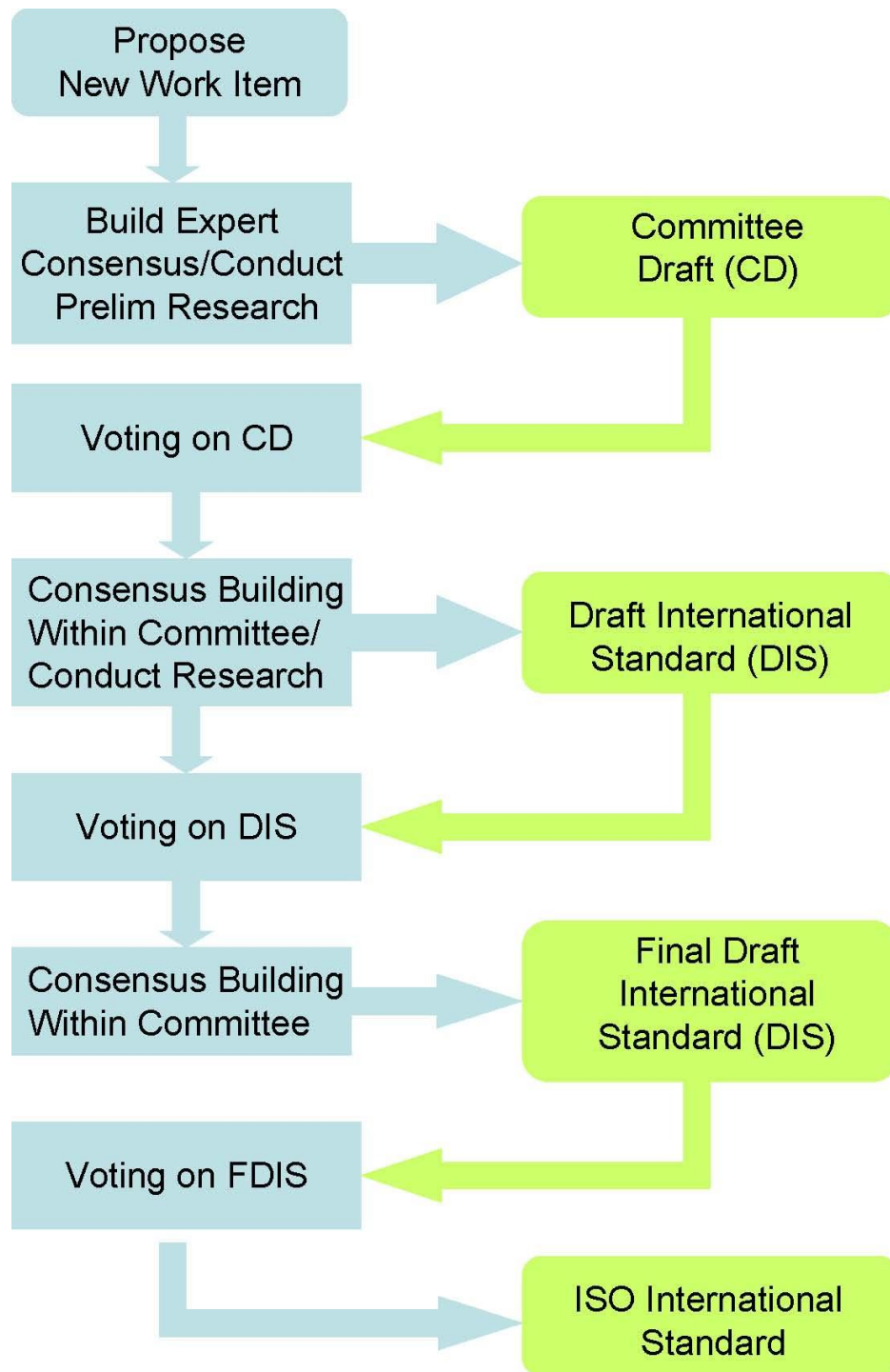
During the period of 1980-1997, the ISO and U.S. efforts focused primarily on wheelchair standards. Wheelchair seating was clearly an important aspect of wheelchair

technology that also required its unique set of industry standards. In 1998, a four-part proposal for seating standards was prepared by the lead author and submitted to the RESNA-TSB and ISO TC-173/SC-1 simultaneously. Both bodies accepted the proposals, established their respective working groups and formalized their programs of work. Now, almost 10 years later, three parts (ISO 16840, parts 1-3) are published ISO standards. The fourth part 4 is at the Draft International Standard (DIS) stage. The unique aspect of this series is that both bodies began with the identical proposals at roughly the same time, which led to a high level of collaboration of resources and harmonization between the U.S. and ISO efforts.

4.3.2. Brief Description of the ISO Standards Development Process

The following briefly outlines the six stages that each new ISO standard progresses through from a Preliminary new Work Item (PWI) to the end product, a published International Standard (IS). To progress from one stage to the next requires a 70% approval response by the national voting bodies that have elected to participate in a particular standard development process. Figure 4.1. and the following descriptions summarize the ISO process that typically takes four to five years to complete.

Figure 4.1. Flow process of typical ISO standard



(Graphic courtesy of Gina Bertocci, University of Louisville, RERC-WTS.)

1. Preliminary Work Item (PWI) (not on Figure 4.1.): The earliest stage in which a work group informally consolidates its ideas and prepares a working draft of a new standard.

A main goal at this time is to seek agreement on the scope (purpose) of the standard. To initiate this activity a proposal for a preliminary work item is made to the responsible sub-committee (SC) for approval.

2. **New Work Item (NWI):** This is the first formal stage in the process in which a proposal for a NWI is circulated to all participating member countries, complete with a working draft of the proposed standard for review and approval of the new work item to proceed. Upon approval, the ISO clock begins to run and timetables are established for each stage of advancement, with a completion target of 36-48 months for the Final Draft International Standard (FDIS level) vote. All levels of balloting are managed by the ISO central secretariat in Geneva, Switzerland.
3. **Committee Draft (CD):** Assuming voting approval as a NWI, the earnest work of the working group now begins. Test methods must be fully developed and validated, terms and definitions agree upon, a multitude of editorial revisions made, and graphics and text all formatted to strict ISO templates, in preparation for the CD review and vote by the national bodies within the participating countries. At this point, the standard takes its initial form. Test methods are often evaluated by multiple test laboratories. Once the working group members are satisfied that the test methods and requirements are reliable and reasonable, the CD is prepared for voting.
4. **Draft International Standard (DIS):** Assuming voting approval of the CD version, this stage usually results in many pages of suggested revisions that result from the comments associated with the CD voting process. The working group (WG) must act on each comment, and if rejected, explain the reason. Upon revision, the document is now sent out for national voting again either as a CD version for balloting again or as a proposed draft international standard.

At any stage to this point, if the voting comments are largely technical (as opposed to editorial), even though there are sufficient positive votes to warrant advancement to the next stage, a decision can be made to continue the development process at the same stage. If the timeline is not adhered to, the process may be cancelled and the draft standard is essentially suspended and a new work item must be initiated.

5. Final Draft International Standard (FDIS): Assuming a successful vote at the DIS level, the voting comments should be fewer and suggestions for change should be mostly editorial as the document has reached the penultimate stage of the process. National voting at this stage is only a 'yes' or 'no' vote as only editorial corrections are solicited. At this stage, assuming the FDIS passes, the work of the working group has been completed and it is removed from the list of work assignments.
6. International Standard (IS): This is the final stage in which approval is by an ISO internal ISO committee process. The standard is then finally edited into ISO format in Geneva, translated into French, published in both English and French as an international standard and posted on the ISO website. This final process typically adds six months to the FDIS-level process. The working group that prepared the standard never sees a copy of the final standard, unless it purchases it from ISO.

4.3.3. Organization of Standards Development in the U.S.

In the United States, standards for most assistive devices are under the umbrella of RESNA. RESNA is recognized as a standards development body by ANSI. The process of developing an ANSI/RESNA standard essentially mirrors that of ISO and most other countries. RESNA sponsors the Technical Standards Board (TSB). The TSB is made up of committee chairs, vice chairs and secretariats of the various standards committees and some at-large members. The TSB ensures that the standards development process is properly followed. It also

establishes priorities for new work items. The TSB creates and dissolves standards committees as needed. In reality, standards take years to develop and therefore committees typically have extended lives. Currently, the RESNA TSB has the following standards committees:

- RESNA Standards Committee on Wheelchairs (including Scooters) (WCS)
- RESNA Standards Committee on Wheelchairs & Transportation (WHAT)
- RESNA Standards Committee on Wheelchair & Related Seating (WRS)
- RESNA Standards Committee on Assistive Products for Persons with Vision Impairments & Persons with Vision and Hearing Impairments (VI)
- RESNA Standards Committee on Adaptive Sports Equipment (ASE)
- RESNA Standards Committee on Support Surfaces (SS)
- RESNA Standards Committee on Single Rider Golf Cars

Most committees are responsible for multiple standards. In order to have concentrated expertise on specific standards, the committees establish working groups. The working groups do much of the actual work in producing a standard. The working groups develop initial test methods, organize validation testing and draft the standard. Most RESNA working groups participate in equivalent ISO working groups in an effort to achieve as much harmonization as possible. Once an ISO standard has reached the FDIS stage it is typically considered by TSB for adoption and publishing as the RESNA national standard. This process typically results in only minor but sometimes technically significant differences between the U.S. and ISO standards.

4.3.4. Relationship between National and International Efforts

Many countries have bodies that develop standards for national usage. National standards bodies provide important sources of information and often can move more rapidly to address emerging issues related to standardization. However, the resources of national bodies

acting alone are more limited than when multiple countries work together. Also, international standards bodies bring a much wider range of experiences and may identify issues confronting some nations. By definition, the scope of national standards is limited to locally produced or distributed products. Imported products may be disadvantaged when national standards are not harmonized with international standards.

International standards development activities bring together the resources of multiple nations, global manufacturers and numbers of regulatory bodies. This has the advantage of gathering more broadly applicable data, and addressing potential international barriers in advance. A drawback of international standards is the potential that the standard is driven towards the lowest acceptable level of performance. An international standard may have been reached through broad consensus, but it may not be as stringent as a national standard in some countries. For example, some countries may wish to enter a particular market by driving down costs, while other countries with established markets may wish to reach higher standards. However, international standards create access to markets in multiple countries and benefit consumers by expanding choice. The international standards organization provides a rigorous and well-proven framework for the development of standards. The integrity of the ISO process makes their standards respected throughout the world and helps to provide at least a minimal level of assurance that the device is safe and effective.

4.4. Anatomy of a Typical ISO Industry Standard

As a standards-setting body, ISO follows very detailed formats for the preparation and publication of documents. Most people have no reason to review a typical ISO standard. Therefore, the following briefly illustrates the layout and content in each of the major sections of

a typical ISO standard related to wheelchair technology. Examples have been excerpted from draft versions of existing ISO 7176 and ISO 10254 series on wheelchair-related technology.

4.4.1. Foreword

The foreword provides mainly information about ISO, intellectual property, collaboration with other international standards bodies, ISO rules that have been applied, edition being replaced, TC and SC responsible for work, and a listing of all the other parts of the ISO 7176.

An example forward is presented below.

Foreword:

ISO (the International Organization for Standardization) is a worldwide federation of national standards bodies (ISO member bodies). The work of preparing International standards is normally carried out through ISO technical committees. Each member body interested in a subject for which a technical committee has been established has the right to be represented on that committee. International organizations, governmental and non-governmental, in liaison with ISO, also take part in the work. ISO collaborates closely with the International Electrotechnical Commission (IEC) on all matters of electrotechnical standardization. International standards are drafted in accordance with the rules given in the ISO/IEC Directives, Part 3. Draft International standards adopted by the technical committees are circulated to the member bodies for voting. Publication as an International Standard requires approval by at least 75% of the member bodies casting a vote. Attention is drawn to the possibility that some of the elements of this part of ISO 7176 may be the subject of patent rights. ISO shall not be held responsible for identifying any or all such patent rights. International Standard ISO 7176-2 was prepared by Technical Committee ISO/TC 173, *Technical systems and aids for disabled or handicapped persons*, Subcommittee SC 1, *Wheelchairs*.

This second edition cancels and replaces the first edition (ISO 7176-2:1990), which has been technically revised.

ISO 7176 consists of the following parts, under the general title Wheelchairs: (lists all other parts of 7176 series). (ISO, 2001)

(Source: ISO FDIS 7176-2 Determination of static stability for powered wheelchairs, 2001.)[10]

4.4.2. Introduction

The introduction provides an overview, less than a page, of problems in the field that the standard has been designed to address. It also provides a brief overview of the direction taken in the standard and what specific technology is covered by the standard.

Introduction:

The provision and selection of wheelchairs and associated seating supports relies on clear communication of information relating to these devices. Over time, many terms and definitions have evolved. Unfortunately, this process has resulted in a lack of clear meaning for some terms and duplication of other terms (sometimes with conflicting messages). For example, the terms tilt and recline are sometimes used interchangeably, but usually have quite distinct meanings. If used inappropriately, an entirely inappropriate wheelchair may be specified or purchased. The purpose of this part of ISO 7176 is to provide a nomenclature of terms and their definitions to form the basis of clear communication across the field of wheelchair and associated seating and to eliminate confusion from duplication or inappropriate use of terms. The nomenclature is drawn from surveys of the literature and language used by experts in this field. It excludes, however, terms which are adequately defined in the everyday language of English, medicine and technology. The standard recognizes that there are a number of terms in use, which, because of duplication in adequacies of meaning, should be replaced by terms from this nomenclature. To help people move towards a common vocabulary, these deprecated terms are included along with a reference to the preferred term from the nomenclature.

The development and application of wheelchair standards is particularly dependent upon clear and consistent terms and definitions. Hence, a major proportion of this part of ISO 7176 includes terms and definitions used in more than one of the ISO standards specifically related to ISO Wheelchair Standards. These include the ISO 7176, 10542, and 16840 series, and ISO 7193. In the future standards in these series will cite this document for definition of terms wherever possible, thus ensuring consistency of definitions.

This part of ISO 7176 is intended purely as a means of specifying terms and definitions. It does not attempt to classify wheelchairs and associated seating into any classification of device groupings as this is the purpose of ISO 9999. Annex A provides a standard set of descriptors for characterizing wheelchairs. (ISO, 2004)

(Source: ISO DIS 7176-26-Wheelchairs—Part 26: Vocabulary, 2004.)[12][13]

4.4.3. Scope

One of the most important sections in a standard is its scope. Its purpose is to specify concisely what the standard applies to, and in some cases to what it does not apply. An example scope is presented below.

Scope:

This international standard applies to all manual and powered wheelchairs, including scooters, which, in addition to their intended function as mobility devices, are also intended for use as forward-facing seating by adult occupants of motor vehicles. It also applies to wheelchairs with add-on components designed to meet one or more of the requirements of this standard.

This standard specifies wheelchair design and performance requirements and associated test methods, as well as requirements for wheelchair labeling, presale literature disclosure, user instructions, and user warnings. These requirements are applicable to wheelchairs that are designed to be secured by any type of wheelchair tiedown that complies with ISO 10542-1 and any other applicable parts of 10542. (ISO, 2000)

(Source: ISO FDIS 7176-19: Wheelchairs—7176-Part 19: Wheeled Mobility Devices for Use in Motor Vehicles, 2000.)(3)[12]

4.4.4. Normative References

This section references any other standards that need to be considered when applying the standard.

Normative References:

The following normative documents contain provisions, which, through reference in this text, constitute provisions of this part of ISO 7176. For dated references, subsequent amendments to, or revisions of, any of these publications do not apply. However, parties to agreements based on this part of ISO 7176 are encouraged to investigate the possibility of applying the most recent editions of the normative documents indicated below. For undated

references, the latest edition of the normative document referred to applies. Members of ISO and IEC maintain registers of currently valid International standards. (ISO, 2000)

(Source: ISO FDIS 7176-19: Wheelchairs—7176-Part 19:

Wheeled Mobility Devices for Use in Motor Vehicles, 2000.)

ISO 3795	Road vehicles, and tractors and machinery for agriculture and forestry - Determination of burning behavior of interior materials
ISO 6440	Nomenclature, terms and definitions
ISO 6487	Road vehicles - measurement techniques in impact test instrumentation
ISO 7176-15	Requirements for information disclosure, documentation and labeling
ISO 7176-22	Wheelchairs: Set up procedures

(Source: (ISO FDIS 7176-19: Wheelchairs—7176-Part 19: Wheeled Mobility Devices for Use in Motor Vehicles, 2000.) [3]

4.4.5. Terms and Definitions

The terms and definitions section provides definitions for any terms used in the standard that are not terms in common usage. A sample terms and definitions section is provided below.

Term and definitions:

For the purposes of this document, the terms and definitions given in ISO 6440 and the following apply.

3.1. *Running brake* means to stop or to slow the wheelchair

3.2. *Control device* means by which the user directs an electrically powered wheelchair to move at the desired speed and/or in the desired direction of travel

3.3. *Parking brake* means to keep the wheelchair stationary

(ISO, 2002)

(Source: ISO /FDIS 7176-3 Wheelchairs—Part 3: Determination of effectiveness of brakes, 2002.)[10]

4.4.6. Design Requirements

Design requirements are the minimum design features that must be exhibited by the product to be in compliance. These are used when the committee believes that safety or performance warrant specific requirements for the design of the device or potential product. Design requirements may restrict creativity and limit the ability of manufacturers in the design of devices, therefore, they must be specified requirements only when necessary.

Design requirements:

The wheelchair shall be designed to:

- Provide for forward-facing securement in a motor vehicle by one or more types of wheelchair tiedown systems that conform to ISO 10542.
- Have a minimum of four securement points, two at the front and two at the rear that conform to the specifications set forth in Annex B. (ISO,2001)

(Source—ISO 7176-19.) [10]

4.4.7. Identification, Information, and Instruction Requirements

Identification, information and instruction requirements must be provided by the manufacturer regarding permanent product labeling, user information, and, if applicable, installation instructions.

Identification and labeling:

WTORS and replacement parts shall be permanently and legibly marked with:

- a. manufacturer's name or trademark,
- b. month and year of manufacture, and any other identification necessary to clearly identify a WTORS in the event of a product recall, and
- c. A mark showing that the WTORS conforms to ISO 10542-1.

Instructions for installers:

Manufacturers of WTORS shall provide written instructions for the installer in the

principal (s) of the country in which it is marketed.

The instructions shall include statements that:

- a. The WTORS should be installed for forward-facing wheelchairs,
- b. Identify the number of separate packages containing WTORS components
- c. The WTORS conforms to ISO 10542-1...
- d. In order to fit low across the pelvis and/or over the upper thighs and thereby reduce the possibility of the belt loading the abdomen.

The instructions shall include diagrams and drawings that illustrate:

- a. Acceptable methods for fastening WTORS anchorages to the vehicle, along with minimum strength requirements for all WTORS anchor points
- b. An exploded-view drawing and a parts list for all components required in the installation
- c. The locations for anchor points of independent belt restraints relative to wheelchair tiedown anchor points, along with the information in Figure 5. (ISO 2000.)

(Source: ISO FDIS 10542-1: Wheelchair tiedown and occupant restraint systems — Part 1: Requirements and test methods for all systems-2000.)[10]

4.4.8. Performance Requirements

Performance requirements specify how the product must perform when tested in accordance with the methods contained in the standard. They are intended to set a minimum performance level to ensure the safety of the device user or to ensure adequate performance during normal usage.

Frontal impact test

The wheelchair shall be dynamically tested in accordance with Annex A using a four-

point strap-type tiedown that conforms to ISO 10542-2. It may also be dynamically tested using other methods of securement.

The following requirements shall be met during and after each test conducted. During the test:

- a. The horizontal excursions of the ATD and the wheelchair with respect to the impact sled shall not exceed the limits in Table 3.
- b. The knee excursion shall exceed the wheelchair Point P excursion as follows: $X_{knee} / X_{wc} > 1.1$

Note: Compliance with this requirement reduces the potential for the wheelchair to apply large horizontal loads to the wheelchair occupant.

- c. The rear-ward excursion of the head of the ATD shall not exceed the limits shown in table 3. (ISO, 2000)

(Source: ISO FDIS 7176-19: Wheelchairs—7176-Part 19: Wheeled Mobility Devices for Use in Motor Vehicles, 2000.)

Table 3
Horizontal Excursion Limits (mm)

Measurement Point	Excursion Variable	Excursion Limits
Wheelchair point P	X_{wc}	200
ATD Knee	X_{knee}	375
ATD front of head	X_{headF}	650
ATD rear of head	X_{headR}	400

4.4.9. Test Report

The test report section specifies what information must be contained in a test report and kept on file by the manufacturer. Only the information in the information disclosure section needs to be available to anyone upon request. However, regulatory bodies typically examine all aspects of testing conducted.

Test Report

The test report shall contain the following information:

- a. A reference to this part of ISO 7176
- b. The name and address of the testing institution
- c. The name and address of the manufacturer of the wheelchair
- d. The date of issue of the test report
- e. The wheelchair type and any serial and batch numbers
- f. The size of the dummy used or, if a person is used, the mass of the driver and weights
- g. Details of the set-up of the wheelchair as specified in ISO 7176-22, including equipping and adjustments
- h. A photograph of the wheelchair equipped as during the test
- i. Description of the parking brake(s) tested including method of operation such as finger/hand/foot control
- j. Manual, electrical, automatic, etc.
- k. If preparation of the wheelchair requires measurement of the brake operating force as specified in 6 b), the force, in Newton's, required to operate the brakes during the tests
 - l. The results of the parking brake tests as determined in 7.2; (ISO, 2002)

(Source: ISO /FDIS 7176-3 Wheelchairs—Part 3: Determination of effectiveness of brakes, 2002)[10]

4.4.10. Information Disclosure

The information disclosure sections specifies which test information must be disclosed in the manufacturers presale literature intended for use by clinicians and users.

Information Disclosure

In addition to the requirements in 7176, Part 15, the wheelchair manufacturer's presale literature shall include:

- a. A statement that the wheelchair is designed to be forward facing when used as a seat in a motor vehicle and that it complies with the requirements of ISO 7176/19-20XX
- b. A description of the types of tiedowns that are suitable for use with the wheelchair (i.e., four-point, strap-type, clamp systems, specific type of docking system, etc.)
- c. A statement that ease of access to, and maneuverability in, motor transit vehicles can be

significantly affected by wheelchair size and turning radius, and that smaller wheelchairs and/or wheelchairs with a shorter turning radius will generally provide greater ease of vehicle access and maneuverability to a forward-facing position

- d. A statement of whether the wheelchair provides for, and has been tested with, any wheelchair-anchored occupant restraint belts. (ISO, 2000)

(Source: ISO FDIS 7176-19: Wheelchairs—7176-Part 19: Wheeled Mobility Devices for Use in Motor Vehicles, 2000.)

4.4.11. Test Methods

Laboratory tests are used to verify that design and performance requirements have been met. A normative test means that it is required and must be followed to comply with the standard. An informative annex is for information or guidance only.

Annex A (normative): Method for determining brake lever operating force

A.1 Test method

- a. Select the part of the lever through which the force is to be applied from the following (see Figure A.1) with precedence for selection given to the earliest in the sequence below:
 1. If the lever is fitted with a generally spherical knob, apply the force through the centre of the knob
 2. If the lever is tapered, apply the force through the point where the largest cross section intersects the centerline of the lever;
 3. If the form of the lever is such that the lever is gripped by the whole hand, apply the force through the centerline of the lever, 15 mm from the end
 4. If the brake is operated by pushing or pulling a bar or pad, apply the force to the centroid of the bar or pad
 5. If the lever is parallel or any shape other than those above, apply the force through a point on the centerline of the lever, 15 mm

below the top

6. If the lever is telescoping or is supplied with an extension handle, apply the force 15 mm from the end when fully extended.
 - b. Set up a means to operate the brake by applying a force via the force measuring device specified in 5.8 and aligned as shown in Figure A.1.
 - c. Fully apply the brake via the force measuring device and record to the nearest Newton, the maximum operating force.
 - d. Perform step c. three times, rotating the relevant wheel between applications, and calculate, to the nearest Newton, the arithmetic mean value of the forces measured. (ISO, 2002)

(Source: ISO /FDIS 7176-3 Wheelchairs—Part 3: Determination of effectiveness of brakes, 2002)[10]

4.4.12. Bibliography

The bibliography provides references to research literature that were used in the standard.

4.5. The Standards Model and Its Potential Benefits for Stakeholders

4.5.1. The Participant-Responsive Development Model

In general, industry standards are developed for the benefit of manufacturers, regulatory bodies, purchasers, people with disabilities, and clinical professionals. The ANSI and ISO process is designed with the intent that these key constituents participate in the development of standards for assistive technology. Each participating country designates its official (voting) participant on the TC-173/SC-1. Subject experts from any country can attend work group (WG) meetings, where the work of each standard development takes place. This places the responsibility on the WG conveners for ensuring that the process is not biased towards the interests of any one constituent. Minutes are required to be recorded and filed for all work group

and sub-committee meetings. The minutes must include the names of all WG participants and their affiliations. There are at least four stages at which participating countries are required to cast single votes, as well as submit comments on the details of each standard, if they choose. When national voting comments are compiled, a 70% majority is required for the standard to progress to the next stage. All voting comments must be discussed by the working group and if a comment is rejected a written justification must be provided. This helps to ensure fair representation and transparency of the working group process. However, consumers and clinicians rarely have the financial means compared to, say manufacturers, to regularly attend meetings. Hence, the consumer voice is often under-represented at work group meetings.

4.5.2. Impacts and Benefits for Users, Clinicians, Industry and Healthcare Funding Agencies

Unquestionably, industry standards have improved quality, reliability and safety of wheelchair technology. People who use compliant wheelchair technologies gain access to safer, more reliable, and higher performing products. Also, standards help users and clinicians by providing a means of attaining more reliable information that is suitable for comparing and selecting products. The standards have helped all constituents by removing trade-barriers, opening wider markets and increasing access to competitive products.

Some may argue that standards increase the cost of developing a new device, but this argument gains little traction. Without the existence of standards, manufacturers must develop in-house test methods and performance criteria without the benefit of broadly based expertise and inter-laboratory testing validation offered by the standards forum.

Clinical professionals have consistently played critical roles in the development of wheelchair technology standards. A notable challenge for standards development is the usage of common terminology. This helps to improve the precision of the language of the technical standards and assists with clarifying product literature and clinical communications. Standard

terminology also helps to improve communication between professionals from different disciplines and with consumers.

Payers benefit in much the same way, plus the standards help to save costs through improvements in technology quality, safety, and reliability. In the U.S. Medicare program and in other countries with national healthcare services, decisions about what devices can be prescribed and paid for with public resources are more routinely becoming based on the results of the objective testing offered by voluntary industry standards.

Manufacturers receive numerous benefits from standards. As noted previously standards facilitate cross-border trade, reduce product liability, assist with regulatory approval, and provide design guidelines. Manufacturers actively participate in the development of national and international standards. Some do so from a defensive posture and others out of a sincere desire to ensure device safety, reliability, and appropriate performance. Most experienced manufacturers appreciate and recognize that safety and performance standards will weed out potentially competitive products that are not designed and built to meet industry standards.

4.5.3. The Unexpected Benefits of Voluntary Industry Standards Development

4.5.3.1 A strange and amazing multidisciplinary model.

The multi-disciplinary model that has evolved for voluntary standards development defies all logic. What other successful development model demands that the participants self-finance their participation for three to five years, meet rigorous deadlines at the threat of termination, travel far and wide in order to participate, volunteer their talents and knowledge, then relinquish ownership of the final product to the organizers so they can sell it at a profit? There must be hidden benefits that drive so many intelligent and talented people to act so illogically. This section explores these benefits.

4.5.3.2. The magnitude of the goal and potential impact of the final result.

It is proposed that those drawn to this activity (researchers, engineers, practitioners, consumers) are stimulated by the prospect of working as part of a collegial group that has set a goal for itself larger than that which could be accomplished by an one individual. The prospect that the realization of that goal, achieved within a stipulated time, can positively impact the quality and safety of the product of focus on a worldwide scale is highly appealing and motivating.

4.5.3.3 Consolidation of worldwide knowledge.

The research process, in theory, is a process in which new knowledge derived from rigorous scientific methodology is systematically added to prior knowledge, mainly through archived peer-reviewed publications. The fundamental assumption is that the initial questions or hypotheses being investigated are relevant to the void in knowledge being pursued. In reality, this process advances the field of rehabilitation technology rather slowly, since only rarely does new knowledge build on the known, because the system mainly rewards uniqueness. Another problem has been the randomness by which the investigators independently select their research questions and then acquire the limited research funding to pursue the answers, the usual end result being no more than an archived publication.

In the standards forum, researchers, clinicians, industry representatives and users combine their collective experiences to define the goals (scope) of a standard. This in turn defines (focuses) the research that must be done in order to provide the answers needed to advance the standard. This focus then tends to consolidate the leading minds internationally on the problem, who then agree to conduct collaborative investigations and subject the findings to critique by other researchers, clinicians and manufacturer's technical personnel. After validation, positive findings are then applied directly to the standards, usually in the form of a

design or performance requirement and a related test method. Somehow the intellectual property issues get sorted out as high quality peer-reviewed publications still result. It is proposed that this is a very cost effective model for focusing limited research resources on a worldwide scale, and that those participating in the process find it to be most professionally rewarding.

In the absence of standards development, an opportunity for a similar level of collaboration among leading researchers, clinicians and commercial developers would not naturally exist. A standards working group is an ideal environment in which to synthesize existing knowledge, focus future research initiatives and achieve positive outcomes in a time limited manner. Also, emerging researchers or assistive technology clinicians participating in standards development are provided access to a robust network of opinion leaders and new technical concepts. It is proposed that the participatory standards development model is much more effective at advancing assistive technology for persons with disabilities when compared to the traditional research and development mechanisms offered by isolated research studies, peer-reviewed publications and conference presentations.

4.5.3.4. Development of collegial networks.

In the scheme of medical technology, rehabilitation assistive technology is a small enterprise. Annual conferences provide opportunities for information sharing and meeting new and old colleagues. However, only rarely does this interchange translate into the building of any significant collegial relationships unless the parties are jointly engaged in a group activity that stimulates more extensive communication between annual meetings. Also, if one's research interests are narrowly focused it may be difficult to find like-minded colleagues with whom one can openly discuss ideas and concepts of common interest. It is proposed that the standards forum, especially the international arena, enhances the opportunity for these professional interchanges to take place as part of the collegial networks that seem to naturally form.

4.5.3.5 Clinical/user application of industry standards.

Another strong motivator, especially for clinicians and product users is the expectation that the application of the information generated by the test methods in the standards will improve the quality of clinical decision-making and client outcomes. Many leading wheelchair and wheelchair seating clinicians, (therapists, clinical rehabilitation engineers, and rehabilitation technology suppliers) have contributed countless volunteer hours preparing manuals and giving presentations to their colleagues on the application of the standards in clinical practice. It is proposed that their knowledge and understanding of this largely technical information places them in a leadership position in the eyes of their clinical colleagues. In turn, they find this and their obvious contribution to their chosen specialty a rewarding professional experience.

4.5.4. How to Get Involved

In most cases, it is very simple to get involved on standards working group. Simply contact the committee chair (convener) responsible for leading an area of your expertise, arrange to attend a meeting, decide if the activity and membership is appealing and arrange to get officially signed up as a working group member. In the U.S., there is an ANSI requirement that there be a multidisciplinary distribution involving researchers, clinicians, users and manufacturers as voting members on a committee. This means that you may not initially be a voting member. However, even if one is not immediately recognized as a voting member, attendance at meetings is always welcome and or remote electronic contributions are valued. Participation as a researcher or clinician on a RESNA standards committee costs \$30/yr for membership. Current information regarding participation in ISO working groups may be obtained from: http://www.iso.org/iso/joining_in_2007.pdf

4.6. Barriers to Standards Development and Implementation

In spite of the exceptional success of the industry standards effort it has not been without its struggles and times of precarious survival, particularly in the U.S. The RESNA TSB has become a victim of its own success. That is, given the exponential growth of the standards program, from 16 to 40 standards, each with a mandatory five-year review cycle and all with deadlines imposed by ISO, the administration of the TSB has become a colossal management undertaking, which now exceeds the abilities of its volunteer leadership. Efforts to train RESNA office staff has had very limited success. A long-term solution is urgently needed if the benefits of this program are to be sustained and expanded.

The quality of all standards is highly affected by the resources that can be mustered to address the issues in a timely manner. One essential resource is to have the right people at the discussion table, usually for a four- or five-year period. A second requirement is the laboratory research and experimentation necessary to support and validate the performance and test methods and requirements that are a critical part of most technical standards. Given that all participation is on a voluntary basis, lack of travel support or funding for research and communications that needs to occur between meetings can be a serious impediment to progress and quality of the final product.

In 2005, the RERC on Wheelchair Transportation Safety hosted its State of the Science Workshop. [14] One of four themes was “Barriers to the Development, Marketing, Purchase, and Proper Use of Transit-safety Technologies.”

The barriers agreed on upon by the expert panel include:

1. Concerns about product liability (i.e., desire to minimize lawsuits)

2. Lack of knowledge about standards, compliant products, and basic principles of safe transportation
3. Increased costs related to purchasing and using standard-compliant products,
4. The voluntary nature of the standards
5. The crashworthiness requirements of the standards being too severe for larger vehicles.

Although these barriers were specific to wheelchair transportation technologies and their related standards, the findings in many aspects can be generalized to all wheelchairs as discussed above.

The following section addresses these barriers to sustainability and future progress.

4.7. Addressing the Barriers and Opportunities for Future Growth

4.7.1. Addressing the Barriers

Sustaining research and development resources.

The majority of the research in support of assistive technology standards has come from government funds. In a few cases the support has come through competitive grants or contracts, while in others it has been through funds directly allocated to a government subsidized laboratory. Industry has provided the vast majority of the laboratory support. However, it is a constant struggle to find sustainable funding to develop valid and meaningful industry standards. A challenge is that research in support of standards does not fit into a traditional research model, and few funding agencies have the interest in supporting long-term work, especially the revision of an existing standard. Participation in the revision of standards is critical since technologies within each industry continue to evolve, usually becoming more sophisticated.

In addition, as the testing processes mature further specification of the procedures needs to be made to ensure greater comparability. Interpretation of how to conduct a test may seem clear to those involved in the writing the standard but laboratories reading the standards for the first time often interpret the standards incorrectly. Some manufacturers are not always diligent and look for ways to work around standards requirements by creating variations in their designs. As new failures turn up in the marketplace, new and revised test procedures also need to be developed to address these issues. However, as we now know, standards can have far-reaching positive effects for governments, consumers, and industry. Ideally, a private-public partnership should be developed to support the cost of developing standards. This is done in other industries where industrial consortia are effective in supporting standards work, and often partner with government agencies to share costs.

In the U.S., the designation by NIDRR of an RERC on Industry Standards could go a long way towards structuring the model for longer-term research partnerships that would provide the research and laboratory support structure to facilitate ongoing development and review of quality industry standards.

Resolving barriers to clinical and user application of standards.

There are two significant barriers to the application of assistive technology standards among clinicians and AT users. The first barrier is the lack of support to participate in the development of the standards themselves. In order to fully participate in the development of the standards, clinicians and consumers need to attend the working group meetings and participate in the electronic discussion groups. Greater participation by consumers and clinicians would help to improve the relevance of standards to meet their needs, and to make the language of the standards more accessible to clinicians and consumers. This is especially important for standards that focus on terms, definitions, and performance values.

The second barrier relates to dissemination. ISO and national standards are typically sold. Because the market for copies of the standards has been small, the cost for a single set of standards (e.g., RESNA wheelchair standards) can cost in excess of \$1000. The standards are also highly technical and require technical knowledge in order to be able to use them. Most clinicians and consumers do not need to actually read the standards, however, they need to be able to interpret and implement the results for their usage. This can be accomplished through incorporating information about the standards into textbooks, and by preparing many more guidance documents related to the usage and interpretation of the existing and future standards. Finally, lack of awareness of the existence of the industry standards is commonplace. Again, resolving these later barriers would be a worthy undertaking for an RERC on Rehabilitation Industry Standards.

Additional strategies may include:

- Encouraging manufacturers to inform clinicians and suppliers about standards applicable to their products
- Adding specific standards-related questions to the ATP/ATS/RET certification exams
- Educating users about the use of standards information before purchasing equipment
- Developing a standard message for manufacturers and suppliers relative to standards and best practices
- Educating rehabilitation clinicians on the importance of standards

Concerns about product liability.

It is unfortunate the U.S. is such a litigious society as it most certainly impedes innovation and the implementation of industry standards. Of the four strategies developed during the RERC-WTS, State of the Science workshop, educating corporate attorneys, risk managers and company policy holders, regarding the benefits of marketing products that are in

compliance with national voluntary industry standards is perhaps the most achievable. For example, one leading wheelchair manufacturer has consistently placed a label on their wheelchair product, even those crash-tested for use as a seat in a motor vehicle that in essence states that the wheelchair should not be used as a seat in a motor vehicle. This is truly a ridiculous position for any manufacturer since the use of a wheelchair product as a seat on a motor vehicle is clearly foreseeable, given the American with Disabilities Act (ADA) mandate that requires transport accommodation of persons with disabilities and the requirement in PL142, related to the transportation of children on school buses. Clearly, the lawyers of this company feel that the head-in-the-sand-approach will reduce their legal exposure in the marketplace. Most interestingly, the majority of their high-end wheelchair products are being produced and crash tested for compliance to the RESNA WC-19 transport standard, but they do not actively market the transport-safety features. [15] However, there are signs that as the manufacturers become more knowledgeable about the standards and that their products can pass the WC-19 testing, that contradictory labeling will become history.

Costs related to purchasing and using standard-compliant products.

Producing and testing products that meet higher standards of durability and safety generally cost more to produce. Unfortunately, the Centers for Medicare and Medicaid Services' (CMS) Healthcare Common Procedural Coding System (HCPCS) does not recognize these attributes in their pricing structure. Therefore, there is little or no financial incentive for industry to support the development and rapid implementation of industry standards.

As an example, let's look at the findings of the expert panel at the 2005 State of the Science workshop on Wheelchair Research and Clinical Practice.[13] The highest ranked strategy for addressing this barrier is that of providing key parties involved, including transit providers, third-party payers, and wheelchair users, with a cost-benefit analysis that shows the

potential tradeoffs of spending a few extra dollars to obtain products with the transit option versus the potentially high cost of injuries from motor vehicle crashes. The second highest ranked strategy is to develop a stakeholder's forum to apply pressure for granting HCPCS codes for transport safe technologies (TST). This may be one of the most important strategies as it is the key to third-party reimbursement for transit-option features on wheelchairs, and perhaps even the key to getting transit-option features to be standard or mandatory rather than optional. This leads directly to the third-highest strategy for addressing the economic barrier, which is to develop the concept that TST as an integral feature (of wheelchairs) and therefore should be included in the base price of transit wheelchairs, or in other words, in the base price of all wheelchairs. This seems justifiable in that even a wheelchair intended for use in the home will end up being used for transport to medical appointments. The fourth-ranked strategy for addressing this economic barrier is to provide funding to continue development of design tools (simulation, CAD, etc.). Presumably these tools would reduce the cost of design and testing wheelchairs to the requirements of the TST standards. The source or amount of this funding was, however, not identified.

The voluntary nature of the standards.

All standards discussed in this chapter, both RESNA and ISO, are voluntary industry standards. That is, unless some state or federal authority makes compliance a requirement, a manufacturer has the right to totally ignore the standard. The only real economic incentive for compliance is the fear of liability exposure if it can be shown that a user was injured as a direct result of non-compliance to a nationally recognized industry standard. The recognition of the standards by the FDA for 510k compliance documentation and partial requirements by CMS/HCPCS for product coding and reimbursement is beginning to add an indirect mandatory flare. Notwithstanding these limited federal initiatives, there is growing sentiment that an

across-the-board mandatory requirement, such as those for cars and school buses under FMVSS, would level the playing field for all manufacturers and foster an infusion of financial support and accelerated adoption of compliance throughout the marketplace. The big questions are which federal regulatory agency should this fall under, and who will lead the tremendous effort needed to get a congressional blessing?

4.7.2. Future Growth

Today, there are only standards in place or pending for a relatively small number of assistive technology devices. The Annex A list of existing international standards shows developed standards for wheelchair technologies, with more recent expansion to include bed support surfaces, recreation and low vision technologies. Separate from the RESNA and ISO initiatives, the RERC on Computer Access at the Trace Center has been successfully working with industry for many years towards fostering accessibility standards related to computer access, communication device access, as well as ATM and kiosk access for the visually impaired. Given that both models are now well established, the opportunity clearly exists to replicate the best practices in other areas of assistive technology. Again, this would be an excellent role for a NIDRR-sponsored RERC on Standards Development and Dissemination to systematically review the processes and prepare an integrated model for use in engaging new areas of assistive technologies in standards activities.

4.7.3. Sustaining the RESNA TSB Management Function

Finally, a critical need exists to evolve an enduring solution to the growing management demands of the RESNA-TSB. Initial steps were taken in 2006. A participation fee structure was proposed by the TSB that was Board-approved and implemented in 2007. This has allowed that contracting of Beneficial Designs, who exclusively have the professional expertise to provide the management services for the TSB. However, this should be considered as only the first step

towards an enduring management solution. Although several options exist, the elevation of TSB as a pseudo-independent entity (RESNA Technical Standards Association) with an arms-length association with RESNA, would separate liability from RESNA and permit the broadening of options to secure longer-term financial and management independence. Partnering of this entity with a NIDRR/RERC on Standards would provide the research and dissemination components that would permit consolidation of focus and expansion to include new untapped areas of assistive technology. This partnership would also allow expanded participation of clinicians and consumers, critical components that have been often missing from activities to date.

4.8. Summary

In this chapter, we have briefly outlined the rationale and benefits, both expected and unexpected, of voluntary industry standards, discussed the history of standards development in the U.S. and provided an overview of the basic ISO standard development process. We have not attempted to describe each of the standards in detail, as that would be impossible given the now forty standards listed in Annex A. For those with interest in the details of a standard they can be purchased from the ISO website, and on the RESNA website in the United States.

In the later sections the barriers to widespread implementation of industry standards were outlined, followed by possible directions that may be taken to resolve the barriers. Finally, the need for a sustainable management plan for the RESNA-TSB was discussed, followed by several suggestions as to how this may be accomplished.

Of critical importance is the continuing participation of expert volunteers. Especially those who share the vision that the potential for personal contribution towards the continual improvement of products for person with disabilities is maximized in the standards forum far beyond what one can accomplish on their own.

Finally, and perhaps most importantly, we have proposed that voluntary industry standards is a viable model and strategy for the effective advancement of assistive technology quality, safety and accessibility. The consolidation and expansion of this strategy should be strongly supported by worldwide government agencies that have a responsibility for the advancement or provision of assistive technologies services for persons with disabilities. The magnitude of structured volunteer effort, combined with industry contributions that can be leveraged with relatively modest government investment, is truly astounding.

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Annex A: Listing of ISO/TC 173 Standards (10-07)

ISO/TC 173 Assistive products for persons with disability			(as of 2007-10-18)	
Standard	Stage	Title	Voting Closing Date	Year Published
ISO/TC 173				
60601-2-52	DIS	Medical electrical equipment -- Part 2-52: Particular requirements for basic safety and essential performance of medical beds	2007-12-27	
ISO/TC 173/WG 7				
23599	CD	Assistive products for persons with vision impairment tactile walking surface indicators	2006-08-05	
23600	FDIS	Assistive products for persons with vision impairments and persons with vision and hearing impairments — Acoustic and tactile signals for pedestrian traffic lights	2007-10-09	

13570-1	TR	Guidelines for the application of the ISO 7176 series on wheelchairs		2005
13570-2		TR/NWI Technical Report: Wheelchairs - Typical values and recommended limits or dimensions, mass and maneuvering space as determined in ISO 7176-5	2004-10-02	
7176- 1	IS	Wheelchairs -- Part 1: Determination of static stability	2004-08-01	1999
7176- 2	IS	Wheelchairs -- Part 2: Determination of dynamic stability of electric wheelchairs	2006-05-13	2001
7176- 3	IS 2ed	Wheelchairs -- Part 3: Determination of effectiveness of brakes		2003
7176- 4	IS	Wheelchairs -- Part 4: Energy consumption of electric wheelchairs and scooters for determination of theoretical distance range	2002-09-15	1997
7176- 4	DIS	Wheelchairs -- Part 4: Energy consumption of electric wheelchairs and scooters for determination of theoretical distance range	2007-06-29	
7176- 5	IS	Wheelchairs -- Part 5: Determination of overall dimensions, mass and turning space	2001-08-16	1986
7176- 5	DIS	Wheelchairs -- Part 5: Determination of dimensions, mass and maneuvering space	2006-03-13	
7176- 6	IS	Wheelchairs -- Part 6: Determination of maximum speed, acceleration and deceleration of electric wheelchairs	2006-05-13	2001
7176- 7	IS	Wheelchairs -- Part 7: Measurement of seating and wheel dimensions	2003-10-01	1998
7176- 8	IS	Wheelchairs -- Part 8: Requirements and test methods for static, impact and fatigue strengths	2003-10-01	1998
7176- 9	IS	Wheelchairs -- Part 9: Climatic tests for electric wheelchairs	2006-05-13	2001
7176-10	IS	Wheelchairs -- Part 10: Determination of obstacle-climbing ability of electric wheelchairs	2003-10-01	1988
7176-10	DIS	Wheelchairs -- Part 10: Determination of obstacle-climbing ability of electric wheelchairs	2007-09-13	
7176-11	IS	Wheelchairs -- Part 11: Test dummies		1992
7176-11	NWI	Wheelchairs -- Part 11: Test dummies	2007-06-24	
7176-13	IS	Wheelchairs -- Part 13: Determination of coefficient of friction of test surfaces	2004-08-01	1989

7176-15	IS	Wheelchairs -- Part 15: Requirements for information disclosure, documentation and labeling	2001-08-16	1996
7176-16	IS	Wheelchairs -- Part 16: Resistance to ignition of upholstered parts - requirements and test methods	2002-09-15	1997
7176-16	NWI	Wheelchairs -- Part 16: Resistance to ignition of 2004-10-02 upholstered parts - Requirements and test methods	2004-10-02	
7176-20	CD	Wheelchairs -- Part 20: Determination of the performance of stand-up wheelchairs	2001-10-07	
7176-20	NWI	Wheelchairs -- Part 20: Determination of the performance of stand-up wheelchairs	2001-11-16	
7176-22	IS	Wheelchairs -- Part 22: Set-up procedures	2005-08-07	2000
7176-26	IS	Wheelchairs -- Part 26: Vocabulary		2007
7176-27	NWI	Requirements and test methods for pushrim activated power assisted wheelchairs (PAPAW)	2003-05-05	
7193	IS	Wheelchairs -- Maximum overall dimensions	2005-08-07	1985
ISO/TC 173/SC 1/WG 6				
10542- 1	IS	Technical systems and aids for disabled or handicapped persons -- Wheelchair tiedown and occupant-restraint systems -- Part 1: Requirements and test methods for all systems	2006-05-13	2001
10542- 2	IS	Technical systems and aids for disabled or handicapped persons -- Wheelchair tiedown and occupant-restraint systems -- Part 2: Four-point strap-type tiedown systems	2006-05-13	2001
10542- 3	DIS	Wheelchair tiedown and occupant restraint systems -- Part 3: Docking-type tiedown systems	2003-12-03	
10542- 4	IS	Wheelchair tiedown and occupant restraint systems -- Part 4: Clamp-type tiedown systems		2004
10542- 5	DIS	Wheelchair tiedown and occupant restraint systems -- Part 5: Systems for specific wheelchairs	2002-07-28	
10542-A	NWI CD	Wheelchair tiedown and occupant restraint systems for forward facing wheelchair-seated passengers -- Part A: Requirements and test methods – Frontal impact	2007-01-04	
10865- 1	CD	Wheelchair tiedown and occupant restraint systems for rearward facing wheelchair-seated passengers - Part 1: Systems for accessible transport vehicles designed for use by both seated and standing passengers	2007-08-10	

16840- 4	DIS	Wheelchair seating -- Part 4: Seating systems for use in motor vehicles	2006-11-02	
7176-19	NWI	Wheelchairs -- Part 19: Wheeled mobility devices for use in motor vehicles		2001
7176-19	DIS	Wheelchairs -- Part 19: Wheeled mobility devices for use in motor vehicles	2004-10-02	

ISO/TC 173/SC 1/WG 8

7176-23	IS	Wheelchairs -- Part 23: Requirements and test methods for attendant-operated stair-climbing devices	2007-12-17	2002
7176-24	IS	Wheelchairs -- Part 24: Requirements and test methods for user-operated stair-climbing devices		2004
7176-28	CD	Wheelchairs -- Part 28: Requirements and test methods for stair-climbing devices	2007-04-19	

ISO/TC 173/SC 1/WG 10

7176-14	IS	Wheelchairs -- Part 14: Power and control systems for electric wheelchairs -- Requirements and test methods		1997
7176-14	DIS	Wheelchairs -- Part 14: Power and control systems for electrically powered wheelchairs and scooters - Requirements and test methods	2006-02-09	
7176-21	IS	Wheelchairs -- Part 21: Requirements and test methods for electromagnetic compatibility of electrically powered wheelchairs and motorized scooters		2003
7176-21	CD	Wheelchairs -- Part 21: Requirements and test methods for electromagnetic compatibility of electrically powered wheelchairs and scooters, and battery chargers	2007-04-19	
7176-25	DIS	Wheelchairs -- Part 25: Requirements and test methods for batteries and their chargers for electrically powered wheelchairs and motorized scooters	2005-04-11	
7176-25	NWI	Wheelchairs -- Part 25: Batteries and chargers for powered wheelchairs and motorized scooters Requirements and test methods	2007-11-22	

ISO/TC 173/SC 1/WG 11

16840- 1	IS	Wheelchair seating -- Part 1: Vocabulary, reference axis convention and measures for body segments, posture and postural support surfaces		2006
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16840- 2	IS	Wheelchair seating -- Part 2: Determination of physical and mechanical characteristics of devices intended to manage tissue integrity -- Seat cushions	2007
16840- 3	IS	Wheelchair seating -- Part 3: Determination of static, impact and repetitive load strengths for postural support devices	2006
16840- 3	NWI	Wheelchair seating -- Part 3: Determination of static, impact and repetitive load strengths for postural support devices	
16840- 5	NWI	Wheelchair seating -- Test methods for determining the 2003-05-01 pressure relief characteristics of devices intended to manage tissue integrity - Seat cushions	

Chapter 5

Wheelchair Transportation Safety

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	Section	Pg
5.1. Need For Wheelchair Transportation Safety	127
5.2. Key Elements in Occupant Protection	128
5.3. Typical Role and Performance Requirements of a Wheelchair	129
5.4. The Wheelchair Transportation Safety System	130
5.5. Wheelchair Securement	131
5.5.1. An Overview	131
5.5.2. Wheelchair Securement Standards	131
5.5.3. Current Wheelchair Securement Technologies	132
5.5.3.1. Four-point strap-type tiedown systems	132
5.5.3.2. Automated docking systems	133
5.5.3.3. Other securement systems	134
5.6. Occupant Restraint Systems	135
5.6.1. Occupant Restraint System Standards	135
5.6.2. Current Wheelchair-Seated Passenger Occupant Restraint Technologies	136
5.7. WC19-Compliant Wheelchairs	138
5.7.1. Overview	138
5.7.2. Wheelchairs Used as Seats in Motor Vehicles: Standards	138
5.8. Important Remaining Challenges	141
5.8.1. General	141
5.8.2. Wheelchair Securement and Occupant Restraint	141
5.8.3. Wheelchair	142
5.9. New Strategies Being Considered	143
5.10. Summary	148
References	148

5.1. Need for Wheelchair Transportation Safety

In 1990, the U.S. Congress enacted the Americans with Disabilities Act (ADA) prohibiting discrimination against people with disabilities in employment, public accommodations and telecommunication services. [1] Under the public accommodations title, public and private transportation service providers must accommodate persons who wish to travel while seated in their wheelchairs.

More recently, the 2001 New Freedom Initiative cited integration of persons with disabilities in the workforce and the community as a priority, specifically noting “transportation” as a critical factor in meeting this priority. In support of the initiative, the director of Easter Seals Project Action reinforced this need, given that one-third of the 25 million transit-dependent people with disabilities reported inadequate transportation as a significant barrier to community integration.[2] Such governmental priorities are expected to continue supporting improved access for wheelchair users who seek transportation.

In addition to those who rely on public transportation (i.e., fixed-route, paratransit, over-the-road coach and school buses), many Americans seek the convenience and customization of personally owned adapted vehicles. For individuals who live in rural communities or away from transportation networks, a personally owned vehicle may be the only option for travel outside the home.

Wheelchair-seated travelers, who are unable to transfer to a crash-tested vehicle seat in public or private transportation, may be at increased risk for injury in the case of a motor vehicle crash. Industry standards aimed at creating an equivalent wheelchair transportation safety environment have been developed over the past decade. This chapter focuses on describing the

key elements in providing safe wheelchair transport. It also reviews the industry standards that have influenced wheelchair transportation and will continue to do so in the near future.

5.2. Key Elements in Occupant Protection

Motor vehicle accidents are the leading cause of death for Americans ages 3 through 33. [3] Research shows that using pelvic-shoulder safety belts reduces by 45% the risk of fatal injury to front-seat occupants of passenger cars (ages 5 and older); using safety belts reduces by 50% the risk of moderate-to-critical injury; and safety belts make an even more significant safety impact in light-duty trucks. [4]

Limiting the risk of death or injury in motor vehicle accidents requires a systems approach that takes into account the characteristics of the vehicle, the vehicle seat and its securement to the vehicle, occupant restraints (i.e., pelvic and shoulder belt, air bags) and occupant characteristics (i.e., size, weight, posture, position). The Federal Motor Vehicle Safety Standards (FMVSS) regulate the vehicle seat, its anchorage to the vehicle and occupant restraints for typical (non-wheelchair-seated) passengers. [5] However, no federally mandated FMVSS regulations apply to wheelchairs when they're used as seats in vehicles. In fact, the features that make a wheelchair a good mobility aid may make it a poor vehicle seat. A vehicle seat must provide a stable support surface for an occupant in case of a crash. This means that the vehicle seat must be securely anchored to the vehicle, and the seat structure must maintain its integrity. Maintaining the occupant's seated position via a stable support surface in a crash will allow properly positioned occupant restraints, like lap and shoulder belt restraints, to provide effective protection. In cases when the seat support surface fails, injury may occur through a phenomenon known as submarining. Submarining occurs when seat failure allows the pelvis to drop downward and the lap belt to ride upward over the iliac crests causing lap-belt restraint to load

the soft abdominal tissues.[6][7] Submarining can injure internal organs of the abdominal region.

Occupant restraints are critical to protecting an occupant in a crash. They are meant to prevent forward motion of an occupant during emergency driving maneuvers and crashes. Occupant restraints are designed to prevent occupant ejection from the vehicle and to prevent occupants from secondary collisions within the vehicle. They are designed to increase the amount of time over which a wheelchair rider comes to a stop, thereby reducing the deceleration experienced by the occupant. Proper belt fit and position – the belt should be over bony structures of the body – is key so that crash level forces are transmitted to structures capable of withstanding such forces.

5.3. Typical Role and Performance Requirements of a Wheelchair

Wheelchairs are valued because they provide mobility, are easily steered, are flexible and adaptable in many daily living environments and activities and are designed to accommodate individuals of all sizes and abilities.[8] Manual wheelchairs are intended to be lightweight and well balanced in relation to the user's center of mass to ensure optimal maneuverability. Power wheelchairs are expected to accommodate specialized seating and enable mobility for users with significant physical limitations. Because of the combined mass of batteries, seating system and structure, power wheelchairs typically weigh 200-plus pounds.

Because wheelchairs are primarily designed for mobility, the safest means of transport for any wheelchair-using passenger or driver is to be seated in an original equipment manufacturer's (OEM) occupant seat. [9] Motor vehicle seating is federally regulated, i.e., designed and tested to meet rigorous safety standards. However, sitting in an OEM is not viable for those who are unable to transfer to a vehicle seat due to weakness, paralysis or conditions that

make them vulnerable to falls and injury during transfer. This holds for individuals who use power wheelchairs as this form of mobility device is used when upper extremity weakness or a great level of impairment is present.

5.4. The Wheelchair Transportation Safety System

Committed experts in transportation safety have applied the principles of occupant crash protection to wheelchair-seated occupants and their transportation environments. Achieving safe motor vehicle transport while seated in a wheelchair requires a systems approach that includes the same components as for typical, non-wheelchair-seated passengers:

- A secured wheelchair that serves as a vehicle seat
- A stable seating support surface that serves as a seating surface
- An occupant-restraint system that includes a lap-and-shoulder-belt restraint.

A reasonable goal for wheelchair transportation is for all wheelchair users to be able to realize a level of safety equivalent to that afforded to passengers and drivers seated in OEM vehicle seats. To achieve this goal, wheelchairs must perform as a vehicle seat under all conditions; the wheelchairs must be secured to the vehicle; and the occupant must be restrained with a properly positioned, crashworthy occupant restraint. Accomplishing proper wheelchair securement and occupant restraint typically requires installation of after-market systems. Also, occupants must be forward-facing in the vehicle to assure occupant restraint effectiveness in a frontal impact. Because the focus of wheelchair transportation safety began by addressing wheelchair-securement and occupant-restraint components of the system, this chapter addresses these topics first followed by a discussion of the wheelchair as a motor vehicle seat.

5.5. Wheelchair Securement

5.5.1. An Overview

Efforts to increase safety for wheelchair-seated passengers began in the early 1990s with the work of an Adaptive Devices Subcommittee within the Society of Automotive Engineers. This resulted in SAE Recommended Practice J2249 Wheelchair Tiedowns and Occupant Restraints for Use in Motor Vehicles.[10]

Since frontal-impact collisions account for more than half of all serious injuries or fatalities, wheelchair-tiedown and occupant-restraint systems are designed for performance with the wheelchair-seated occupant facing forward.[11] Current safety standards for wheelchair-tiedown and occupant-restraint systems (WTORS) use the same 30mph/20g test pulse used in FMVSS testing to dynamically evaluate occupant protection in frontal impact. Comparable standards (e.g., SAE RP J2249) are used to design and test wheelchair-securement devices and occupant-restraint systems for wheelchair-seated travelers.

5.5.2. Wheelchair Securement Standards

Wheelchair-securement and occupant-restraint systems are addressed in the United States by the Society of Automotive Engineers (SAE) Recommended Practice J2249 Wheelchair Tiedown and Occupant Restraint Systems (WTORS) for Use in Motor Vehicles Standard. Internationally securement and restraint systems are addressed by the International Organization for Standardization (ISO) 10542 Wheelchair Tiedowns and Occupant Restraint Systems for Use in Motor Vehicles Standard. [10]

Both standards define design and performance requirements, instructions for users and test methods for WTORS. Compliance with these standards requires that WTORS be able to secure a 187-pound surrogate wheelchair and restrain a 50th percentile, 168-pound male

anthropomorphic test device (ATD) during a 20g/30mph dynamic frontal-impact test.

Performance criteria evaluate the strength and integrity of WTORS, along with wheelchair and occupant excursions during frontal impact.

5.5.3. Current Wheelchair Securement Technologies

Over the past decades, wheelchair securement has evolved. Past, and rather primitive, methods have included bungee-cording the wheelchair to the inside of vehicle and using wheel clamps, for example. Current securement systems are safer, but they have advantages and disadvantages, which are discussed below.

5.5.3.1. Four-point strap-type tiedown systems.

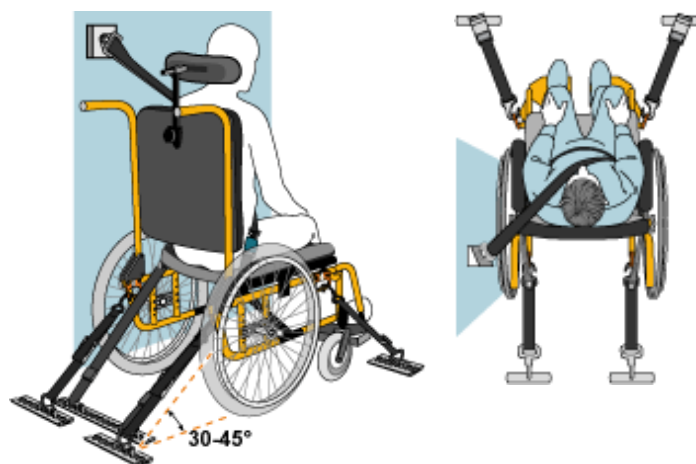
Four-point, strap-type tiedown systems are the most commonly used wheelchair-securement systems in public transportation because they accommodate a wide variety of wheelchairs. These systems consist of webbing straps with end fittings that anchor to the vehicle on one end and attach to the wheelchair on the other. Two straps are attached to the front of the wheelchair frame and two are attached to the rear of the wheelchair frame. A number of manufacturers provide four-point, strap-type tiedown systems that comply with SAE RPJ2249 (a standard listed at www.nercwtcs.org). Advantages and disadvantages of four-point, strap-type tiedowns are shown in Table 5.1.

Table 5.1. Advantages and Disadvantages of Four-Point Strap-Type Wheelchair Tiedown Systems

Securement System	Advantages	Disadvantages
<ul style="list-style-type: none"> · Four-point, strap-type tiedown systems 	<ul style="list-style-type: none"> · Can safely secure wheelchair in a 20g/30mph frontal impact when used properly · Capable of attaching to most wheelchair frames · Provides wheelchair stability under crash, emergency and 	<ul style="list-style-type: none"> · Time consuming to use · Wheelchair user must be dependent on others for securement · Often difficult to identify appropriate securement locations on wheelchairs

	<p>normal driving conditions given four points of attachment to wheelchair</p>	<p>with shrouds or housings encasing their frames</p> <ul style="list-style-type: none"> · Misuse and disuse are common in public transportation settings · Straps are subject to theft or being misplaced, leaving fewer than four straps for securement · Straps often become damaged or soiled, which can lead to malfunctions in use
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Figure 5.1. Four-point wheelchair tiedown system.



5.5.3.2. Automated docking systems.

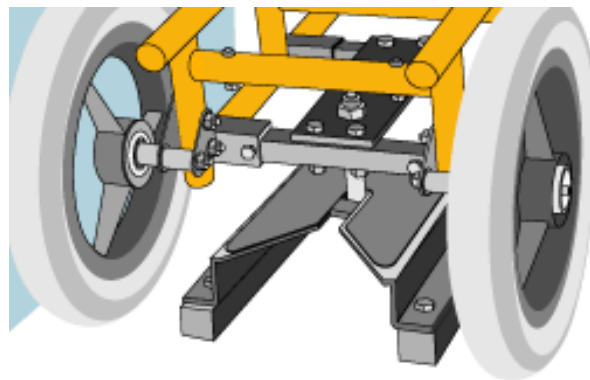
Automated docking systems are another type of commercially available wheelchair-securement system. These systems are primarily used in private transportation settings because a wheelchair must be modified with a custom hardware adaptor prior to using a docking system. Docking systems typically consist of a latch mechanism enclosed in a housing mounted on the vehicle floor or wall that interfaces with a hardware adaptor positioned on the wheelchair. Engagement between the wheelchair and the docking system is typically automated. It can occur at the rear or underside of the wheelchair. A number of commercially available docking systems

are compliant with SAE RPJ2249 listed at www.rercwts.org. Advantages and disadvantages of docking systems are shown in Table 5.2.

Table 5.2. *Advantages and Disadvantages of Docking Systems*

Securement System	Advantages	Disadvantages
· Docking systems	<ul style="list-style-type: none"> · Users can independently secure their wheelchair · Quick securement times · Human judgment of securement point selection on the wheelchair removed from securement process 	<ul style="list-style-type: none"> · Requires the use of interface hardware mounted on the wheelchair · Wheelchair interface hardware can increase weight of wheelchair · When mounted on the underside of the wheelchair, interface hardware can decrease ground clearance · When mounted to the rear of the wheelchair, wheelchair interface hardware can increase overall length of the wheelchair and turning radius · More costly than 4-point tiedown systems · Requires maintenance of mechanical components

5. 2. Wheelchair docking system and interface to wheelchair.



5.5.3.3. *Other securement systems.*

Other securement systems are also commercially available, such as rim pin systems and wheel clamp systems, but it is important to note that these systems fail to meet dynamic test requirements set forth by SAE RPJ2249 and are not crashworthy. Therefore, these systems should be avoided as they may lead to unsafe transport.

Disadvantages of these systems are shown in Table 5.3.

Table 5.3. *Advantages and Disadvantages of Other Wheelchair Securement Systems*

Securement System	Advantages	Disadvantages
· Other securement systems e.g., clamping and rim pin systems	· None. It is strongly suggested that these securement systems not be used.	· Systems are unsafe in vehicle crashes · Some systems require that the wheelchair be sideways-facing in the vehicle, which is unsafe

5.6. Occupant Restraint Systems

5.6.1. Occupant Restraint System Standards

The previously discussed standards developed by the Society of Automotive Engineers (SAE), Recommended Practice J2249 Wheelchair Tiedown and Occupant Restraint Systems (WTORS) for Use in Motor Vehicles, and internationally through the International Organization for Standardization (ISO) (ISO 10542 Wheelchair Tiedowns and Occupant Restraint Systems for Use in Motor Vehicles) also address the design, performance, testing and labeling of occupant restraint systems.

Occupant-restraint systems (ORS) that are a part of WTORS must also be tested under dynamic impact conditions while restraining a wheelchair-seated fiftieth percentile male anthropomorphic test device. Occupant restraints can be designed to anchor to the vehicle, the wheelchair tiedown or securement system or to the wheelchair (but only when designed for a

specific wheelchair, capable of withstanding such loading). Airbags should only be used as a supplemental restraint in conjunction with a belt-type restraint system.

5.6.2. Current Wheelchair-Seated Passenger Occupant Restraint-Technologies

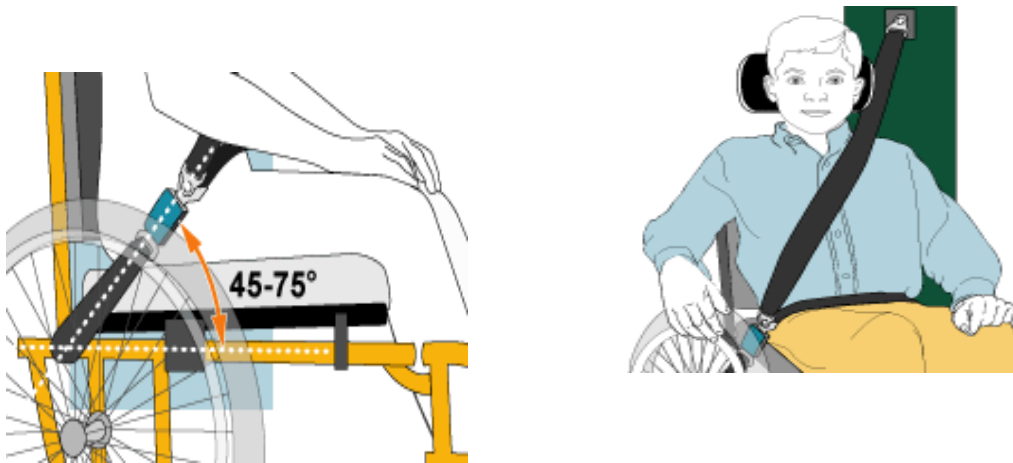
Occupant-restraint systems most often used in wheelchair transportation are similar to those found in personal vehicles; they include both a lap- and shoulder-belt restraint. Proper fit and positioning of the occupant restraint are key to adequately protecting occupants in a crash. A lap belt should be worn low across the pelvis near the thigh-pelvic junction. The shoulder belt should cross the torso at the sternum and mid-point of the clavicle. A lap belt that is held away from the pelvis by wheelchair armrests or a lateral trunk support may render the belt ineffective in a crash or even under emergency driving maneuvers. A lap belt that is not worn low and snug against the bony structure of the pelvis can become the cause of life threatening abdominal injuries. Technological advances in occupant restraint designs, such as retractors and pretensioners that can be found in recent model personal vehicles have not translated to occupant-restraint systems consistent, commercial availability for the wheelchair transportation environment. Because of poor postural stability, some wheelchair users require more than a lap- and shoulder-belt restraint. They may need the additional support of a four- or five-point harness to provide torso stability and occupant protection during transport. In many cases, these postural supports are not crashworthy. A common misconception among wheelchair users and transporters is that all lap belts mounted to wheelchairs are suitable for transport and provide occupant protection in the case of a crash. Unless these belts have been dynamically tested in accordance with the appropriate standard and are labeled as such, they are merely guides for pelvic placement and or postural stability. They are not designed to withstand the loads imposed by a crash.

Advantages and disadvantages of commonly used lap and shoulder belt restraints in wheelchair transportation are described in Table 5.4.

Table 5.4. *Advantages and Disadvantages of Lap and Shoulder Belt Restraints*

Occupant Restraint System	Advantages	Disadvantages
<ul style="list-style-type: none"> · Lap-belt and shoulder-belt restraints 	<ul style="list-style-type: none"> · Provides safe occupant-crash protection when fit properly to the occupant · Can accommodate a wide range of individuals 	<ul style="list-style-type: none"> · Time consuming to use · In many cases, wheelchair user must be dependent upon others to deploy restraint system · Proper fit may be compromised due to interference with wheelchair or seating components · In some cases, wheelchair users may not have dexterity to engage ORS buckles · Confusion may exist regarding postural belts that are not crashworthy

Figure 5.3. Proper lap (left) and shoulder (right) belt restraint position.



5.7. WC19-Compliant Wheelchairs

5.7.1. Overview

As stated previously, the wheelchair plays a critical role in safe wheelchair transportation when used as a motor vehicle seat. The wheelchair must have structural integrity sufficient to withstand crash-level forces and provide a stable support surface. It should be able to be secured to the vehicle and allow for accommodation of proper occupant restraint belt fit.

5.7.2. Wheelchairs Used as Seats in Motor Vehicles: Standards

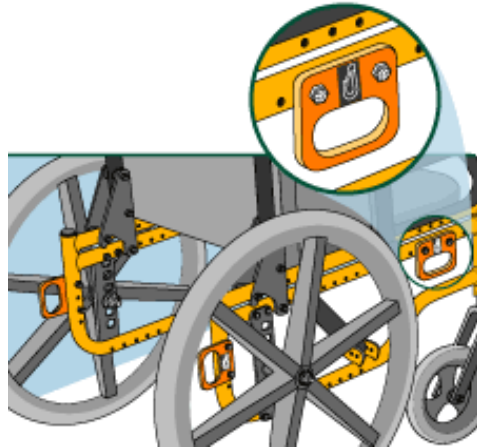
The second category of wheelchair transportation standards deals with wheelchair crashworthiness, and is addressed nationally through Volume 1, Section 19 of the ANSI/RESNA Wheelchair Standards (WC19), Wheelchairs Used as Seats in Motor Vehicles, and internationally through the ISO 7176/19, Wheeled Mobility Devices for Use as Seats in Motor Vehicles.[12][13] These standards, which focus on the use of a wheelchair as a motor vehicle seat, provide design requirements, instructions to users and test methods for transit wheelchairs.

The ultimate goals of the ANSI WC19 standard were to evaluate the crashworthiness of wheelchairs and to promote the design of wheelchairs that interface well with wheelchair-tiedown straps and occupant-restraint belts.

Frontal sled impact testing is perhaps the most stringent of tests to be conducted for compliance with ANSI/RESNA WC19 and ISO 7176/19. This dynamic testing subjects an appropriately sized wheelchair-seated anthropomorphic test device (ATD), or dummy, to a 20g/30mph frontal impact sled test. Size of the ATD is matched with the size of the expected wheelchair occupant. In the ANSI/RESNA WC19 dynamic test protocol, the wheelchair is secured and the occupant is restrained using a surrogate WTORS. (The ISO 7176/19 dynamic test protocol, which is primarily used internationally, permits wheelchair securement and occupant restraint, using a commercial WTORS.) ANSI/RESNA WC19 and ISO 7176/19 frontal impact test performance criteria assess wheelchair integrity, as well as occupant and wheelchair kinematics. This protocol uses the same test pulse as the one used for testing OEM motor vehicle seats and occupant-restraint systems used in passenger vehicles.

A key design requirement in the standard is the addition of four labeled and easily accessible securement points that are geometrically compatible with the end fittings of strap-type tiedown systems. This requirement was defined in response to difficulty in identifying where on the wheelchair to attach tiedowns. This design requirement, set forth by the standard, is intended to reduce the possibility of user error in securement. It increases the likelihood that a bus operator or parent will correctly attach wheelchair tiedowns straps. Ease of use was also a consideration in the implementation of the securement point requirement.

Figure 5.4. ANSI WC19 wheelchair securement point locations and geometry.



Additionally, ANSI WC19 requires that wheelchairs be evaluated and rated for their ability to accommodate vehicle-mounted occupant restraints. Wheelchair and seating components may prevent proper routing of occupant restraint belts. Since proper belt fit is critical to occupant protection, a rating of good, fair or poor is assigned to a wheelchair. The rating, which must be reported in product literature, describes how well the wheelchair accommodates vehicle-anchored occupant restraints. Although it is important for a wheelchair to accommodate a vehicle-anchored occupant restraint, compliance with ANSI WC19 requires a wheelchair to be dynamically sled impact tested with a wheelchair-anchored lap-belt restraint. The lap-belt restraint must be equipped with pin bushing to interface with a vehicle-anchored shoulder safety belt. Manufacturers must offer the wheelchair-anchored lap belt option to consumers. This option is meant to provide optimal belt fit, reduce invasion of personal space and reduce restraint time for vehicle operators

A number of commercially available wheelchairs that comply with ANSI/RESNA WC19 are listed at www.rercwts.org. Table 5.5. provides a summary of the advantages of a WC19 wheelchair and the challenges associated with provision of WC19 wheelchairs.

Table 5.5. *Advantages and Challenges of ANSI WC19 Wheelchairs*

Wheelchair	Advantages	Challenges
<ul style="list-style-type: none"> · WC19 wheelchair 	<ul style="list-style-type: none"> · Able to withstand crash-level forces, providing a stable support surface for the occupant · Increases ease of securement with four accessible securement points · Reduces human error in securement process · Incorporates wheelchair-anchored lap-belt restraint for improved belt fit · Promotes design that can accommodate vehicle-anchored occupant restraints 	<ul style="list-style-type: none"> · Medicare <i>in the home</i> restriction undermines the inclusion of features that make a wheelchair more suitable for use in the community such as the transit (WC19) option (approximately \$250) · Lack of knowledge regarding the existence of WC19 and its advantages for the end user results in fewer WC19 wheelchair prescriptions · Few adult WC19 wheelchairs are available because of funding restrictions and challenges of designing for larger adults · Some manufacturers not in full compliance with WC19 since wheelchair impact testing has been done without wheelchair-anchored lap safety belt · WC19 wheelchairs that do not accommodate vehicle-anchored occupant restraints

5.8. Important Remaining Challenges

A number of barriers slow safety advancements in wheelchair transportation. Some of those barriers are listed below.

5.8.1. General

1. Death and or injury to wheelchair-seated passengers or drivers is not captured in current injury statistics databases. Therefore, accurate incidence and prevalence data is unavailable.

2. There exist no federal or governmental mandates for compliance with voluntary industry wheelchair transportation standards (e.g., SAE RPJ2249, ANSI/RESNA WC19).
3. Standards developed to date have focused on improved safety in frontal motor vehicle impact. Wheelchair standards for rear and side impact performance are in the early stages of development. Design features that improve wheelchair performance in frontal impact may be inadequate for a wheelchair to withstand impact from other directions.

5.8.2. Wheelchair Securement and Occupant Restraint

1. Lack of independent usage of the most commonly used wheelchair securement system, four-point strap-type tiedowns, in public transit.
2. Lack of independent usage of occupant restraint belt systems.
3. Questions regarding usability of WTORS. There is prevalent misuse and disuse of WTORS in the public transportation sector.
4. Insufficient training of transportation providers (i.e., vehicle operators), which often leads to misuse and disuse of WTORS.
5. Inability of transit providers to apply occupant protection principles in non-standard situations, for example, when using specialized seating system, or a non-WC19 wheelchair.
6. Difficulty in obtaining effective occupant restraint belt fit given interferences of belt path with wheelchair and seating components. Also, belt fit may be compromised in cases where fixed vehicle mounted anchorages are unable to adjust to varying occupant sizes.

7. Driving from a wheelchair presents unique challenges in terms of use of occupant restraint belt fit and application given the environment with which the wheelchair and passenger must interface (e.g., steering column).

5.8.3. *The wheelchair*

1. Reticence of wheelchair manufacturers to commit to wheelchair transportation safety due to legal concerns. Some wheelchair manufacturers prefer to label their products “not suitable for use as a motor vehicle seat,” believing that it will alleviate liability if the wheelchair is involved in a crash.
2. Reluctance of insurers or third-party payers to cover the additional cost – about \$250 – of the transportation option for a wheelchair. The reimbursement allowable for wheelchairs has become so restrictive (with a 9.5% reduction in wheelchair manufacturer profits as of January 2009) that manufacturers are now forced to convert a transportation safety feature into a consumer option. Some manufacturers have even dynamically tested their wheelchair models for compliance with the ANSI WC19 standard. But they offer the same wheelchair model as WC19 compliant or WC19 non-compliant, depending on which options the consumer pays for.
3. The in the home restriction imposed by current Medicare reimbursement curtails payment for wheelchair features essential for community mobility such as transportation safety. Regrettably, the highly influential role of CMS in categorizing, coding and paying for Medicare-sponsored wheelchairs is expected to trickle down and reshape third-party payment for wheelchairs as well.
4. Obtaining proper occupant restraint belt fit is often a function of wheelchair and wheelchair seating design. Wheelchairs and seating must be designed to accommodate vehicle-anchored occupant restraints to assure effective occupant protection.

5.9. New Strategies Being Considered

1. *Rear-facing wheelchair passenger stations in large mass or low g vehicles:* In Europe and Canada it is common for ambulatory and wheelchair-seated passengers to travel facing rearward. Wheelchair-seated passengers can enter a rear-facing compartment or passenger station designed to contain the wheelchair and occupant when traveling on large buses. The basis of this concept, which retains the wheelchair in a designated space in lieu of securing the wheelchair, is built upon the lower incidence and severity of crashes in large transit buses. [14] When using a wheelchair passenger station, the wheelchair user backs against a back restraint that is anchored to the vehicle so that it is positioned between the rear wheels of the wheelchair. It provides head, neck and torso protection in the event of sudden stop or frontal crash. A stanchion or flip-down barrier prevents the wheelchair from moving into the aisle. A supplemental belt may aid in wheelchair retention. This practice is being evaluated in some large U.S. cities although American passengers are unaccustomed to riding facing rearward.

An ISO Standard is currently being developed to provide design and testing requirements for rear facing wheelchair passenger stations. The standard is ISO 10865-1: Wheelchair Tiedown and Occupant Restraint Systems for Rearward Facing Wheelchair-Seated Passengers – Part 1 Systems for Accessible Transport Vehicles Designed for Use by Both Seated and Standing Passengers.

2. *Universal Docking Interface Geometry (UDIG) and docking technologies:* Given the reliance of wheelchair-seated passengers on others for securement of their wheelchairs when using four-point strap-type tiedown systems, there have been efforts to develop a standard that describes a Universal Docking Interface Geometry

(UDIG). It would be used with interface hardware that would be attached to a wheelchair for mating with a vehicle-mounted docking system. Similar to the concept of a tractor and eighteen-wheel trailer interface, the UDIG describes the geometry, dimensions and position, relative to the wheelchair of this interface hardware. The system would require either that wheelchair users operating in this environment equip their wheelchairs with a UDIG hardware adaptor or that the UDIG be integrated as a design feature on the wheelchair frame. The UDIG will be incorporated into an informative Annex of ANSI WC18, which will become the revised version of SAE RP J2249. To date no commercial products have been developed in compliance with the UDIG interface hardware. But the University of Pittsburgh has demonstrated the feasibility of a docking system that relies on the UDIG.[15]

3. *Integrated occupant restraints*: The importance of proper belt fit and the diversity of body size and impairments of wheelchair-seated passengers has led to exploration of crash-tested occupant restraints that are integral to the wheelchair frame. While this would allow optimal fit and excellent compliance in the use of occupant restraints, the additional dynamic forces exerted on wheelchair frames in a crash create new performance and design challenges.
4. *Rotary occupant restraint buckles*: Reduced fine motor skills are often seen in passengers who are unable to transfer to vehicle seats. A rotary buckle that is easier to manipulate has been explored. The increased usability would enable many wheelchair-seated passengers to independently manage and deploy their own occupant restraint belt buckles.

5. *Passive occupant restraints for private vehicle drivers with significant impairment:*
Many wheelchair-seated drivers have significant fine motor limitations. They drive adapted vehicles using technologies that allow reduced-effort steering and adaptive control among other features. It is common for these drivers to use vehicle-anchored-occupant restraint systems that have been modified so that drivers can pull forward into the driver station and docks their wheelchairs with the expectation that the occupant restraint belt will passively position itself low and snug across the pelvis and across the bony regions of the torso. However, it has been determined that wheelchair armrests interfere with belt fit often. Many wheelchair-seated drivers are unaware of the risks posed by poor belt position or incorrectly installed occupant-restraint systems. A need exists to address occupant-restraint systems in the wheelchair-seated driving environment.
6. *Training materials:* In the 2005 State of the Science Conference held by the Rehabilitation Engineering Research Center (RERC) on Wheelchair Transportation Safety (WTS), lack of knowledge was cited as the primary barrier to the development, marketing, purchase and proper use of transit safety technologies.[16]
The staff of the RERC on Wheelchair Transportation Safety have developed extensive educational resources and reached out to communities of interest to promote education on proper wheelchair securement and occupant restraint. However, studies and anecdotal information show that education of transportation service providers is needed desperately, given the misuse and disuse of WTORS in the field.[17][18]
7. *Ongoing standards development:* Standards development has been the cornerstone of advancing wheelchair transportation safety technologies. These efforts continue. The

development of standards began with a focus on transit situations with the highest incidence and greatest risk of injury and fatality: frontal impact. Progress is motivated by considerations of risks associated with other directions of impact and an improved understanding of the various modes of transportation.

A summary of ongoing standards efforts follows.

- *ANSI WC20: Seating Systems for Use in Motor Vehicles*: This standard, which is nearing completion, will evaluate wheelchair seating systems under frontal impact conditions. (A parallel ISO standard, ISO 16840-4, is under vote to become a finalized international standard.) This standard will allow the independent testing of wheelchair seating systems that are often used in combination with wheelchair frames that have been manufactured by another company. The mating of a WC19 wheelchair frame and a WC20 seating system should increase confidence in the total wheelchair system.[19]
- *Secondary postural supports*: Other typical components of a wheelchair seating system that may be used for individuals with more significant impairments include lateral supports, hip guides, head rests, anterior trunk supports. These enable optimal alignment or provide external postural support. Although headrests are required by many school transporters, no standards for designing or dynamically testing headrests exist to date.[20] (ANSI WC20 will provide a protocol for evaluating headrests in frontal impact, but no test protocol has been established yet for rear impact conditions where headrests provide the greatest potential benefit.) Guidelines for the use of secondary postural supports in combination with crash-tested occupant restraint systems have been developed.[21] In general, the recommendation is to use secondary postural supports to support the postural needs to gain optimal value from

occupant restraints. Additional efforts are needed to provide crashworthy secondary postural supports that are suitable for use with wheelchairs used as seats in motor vehicles.

- *Rear impact:* The RERC on WTS is investigating the performance of wheelchairs and WTORS systems in rear impact crashes.[22][23] The development of design and testing requirements for WTORS and wheelchairs under rear impact conditions are underway.
- *Side impact:* Performance of wheelchair transportation safety technologies in side impact is largely unknown at this time. Anecdotal and preliminary crash testing data have shown that both wheelchair and WTORS performance are altered substantially in side impact crashes. In addition, effectiveness of the shoulder-belt restraint component of the occupant restraint system varies greatly depending on the whether the impact forces are introduced from the near or far side of the vehicle for a forward-facing wheelchair seated passenger. Development of transit safety technologies that are suitable for side impact in wheelchair transportation is greatly needed.

5.10. Summary

Technology development and implementation in the area of wheelchair transportation face challenges, ranging from wheelchair manufacturers' reluctance to market the "transit-option" feature of their products to the lack of federal safety policy regulating technology for persons traveling seated in wheelchairs. Continued priority and funding from the National Institute on Disability and Rehabilitation Research (NIDRR), the National Institutes of Health (NIH) and private foundations, such as the Paralyzed Veterans of America (PVA) in support of

research, development, knowledge translation and technology transfer in wheelchair transportation, will be key to advancing this industry.

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Chapter 6

Accessible Public Transportation

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Contents

	Section	Pg
6.1.	Scope	153
6.2.	Industry Drivers – Social Change	155
6.3.	Primer on Accessible Transportation Systems	155
6.4.	Transport System	156
6.4.1.	Infrastructure	156
6.4.2.	Categories of Accessible Transportation Systems	157
6.4.2.1.	Vehicle Accommodations Across All Modes	158
6.4.2.2.	Urban Public Transportation Modes	160
6.4.2.3.	Rubber-Tired Vehicles	160
6.4.2.4.	Demand-Responsive Public Transportation	162
6.4.2.5.	Steel-Tired Vehicles	164
6.4.2.6.	Passenger Ferry Service	166
6.4.3.	Intercity Public Transportation Modes	166
6.4.3.1.	Surface Modes	166
6.4.3.2.	Passenger rail	167
6.4.3.2.1.	Vehicles	168
6.4.3.2.2.	Bridging the gap-transition zones passenger rail	169
6.4.3.2.3.	Platforms	169
6.4.3.3.	Over-the-Road Buses	170
6.4.3.4.	Passenger Ferry	171
6.5.	Air Transport	171
6.6.	Transport Amenities	174
6.6.1.	Passenger information Systems	174
6.6.2.	E-kiosks	175
6.6.3.	Illumination	176
6.6.4.	Travel training	176
6.6.5.	Service Animals	177
6.7.	Market Needs Met	177
6.8.	Market Needs Unmet	178
6.9.	Market Trends	180
6.9.1.	Local travel	180
6.9.2.	Long distance travel	181
6.10.	Emergent Products and Technologies	181
6.11.	Barriers to Adoption	182
	References	182

6.1. Scope

People with disabilities require accessible transportation in order to pursue education, to find and maintain employment, and to live independently. Accessible transportation is a fundamental human right and is defined in U.S. Federal Civil Rights Legislation called the Americans with Disabilities Act of 1990 (ADA), Titles II and III.[1] The spectrum of human abilities is very large and this is the fundamental challenge in the planning, design and operation of accessible transportation services and systems.

Public transportation is defined, for the purpose of this chapter, as a derived activity that is undertaken to move people from one location to another where they undertake an activity. A sightseeing drive is not a derived activity; it is undertaken for its own sake. The entity that provides transportation service to the public may be publicly or privately owned or funded. Public transportation in this context does not include cruise ships, charter buses, excursion trains or school buses. Public transportation does include air, rail, over-the-road bus, transit bus, demand-responsive and paratransit, accessible taxis, and passenger ferries. Public transportation is commonly provided in two settings: urban, or intercity, and long distance. There are important differences in the transport technologies that are used in an urban environment and those used for long distance service. Therefore, they will be discussed separately.

It is important to identify and understand the users and beneficiaries of accessible transportation services. The short answer is that accessible transportation benefits all travelers, whether they're young, old or in between. The National Center for Accessible Transportation (NCAT) is working on a number of research and development projects that will change the current thinking about accessible transportation. Firstly, instead of defining stakeholders by their

disabilities, NCAT defines them by their abilities. In design solutions, NCAT does not look at the most common approach to design by merely satisfying the customer requirements; instead NCAT looks at inclusive design. Inclusive design includes a broad range of stakeholders and their characteristics. It also takes into account emotional aspects of design. This chapter will detail the holistic and broad approach to accessible transportation that is central to NCAT's mission, which is to make public transportation safe, seamless, and dignified for all.

Accessible transportation services and systems have traditionally been most concerned with providing transportation to individuals with obvious disabilities such as people who use crutches, canes, and wheeled mobility aids like wheelchairs and scooters. However, people with hidden disabilities also depend on public transportation. Hidden disabilities include epilepsy, traumatic brain injury and chronic fatigue syndrome. People who cannot drive vehicles because of sensory impairments, like low vision or blindness, are also considered to have hidden disabilities. Likewise, individuals who are hard of hearing or deaf are considered to have hidden disabilities; these individuals may require travel information to be presented in visual rather than audible modes. In addition, people with certain disabilities travel with service animals. These essential partners contribute significantly to enabling passengers with disabilities ability to travel independently. Service animal accommodation is a key element of accessible transportation.

All people are beneficiaries of accessible transportation. Anyone who has traveled with a child in a stroller or rolling luggage appreciates curb cuts, level boarding, and elevators. Absent-minded or distracted travelers benefit when essential travel information is presented in both audible and visual formats. Visual paging systems, which were designed to assist travelers with hearing impairments, are used in many transportation terminals. However, all travelers benefit from visual paging systems.

6.2. Industry Drivers – Social Change

Several factors are transforming public transportation. In North America, Japan, and Europe, an increasingly larger percentage of people are older than 60. This means that public transportation must service a growing number of senior citizens. The general population is also increasing. Meanwhile morbid obesity is a national health crisis in the United States.

The aging population and the increase in obesity significantly influence all aspects of public transportation. National legislation that promotes universal accessibility started in the developed world more than 25 years ago. It has recently spread to many nations in the developing world. In each nation, the legislation reflects a growing sensitivity to the needs of travelers with disabilities.

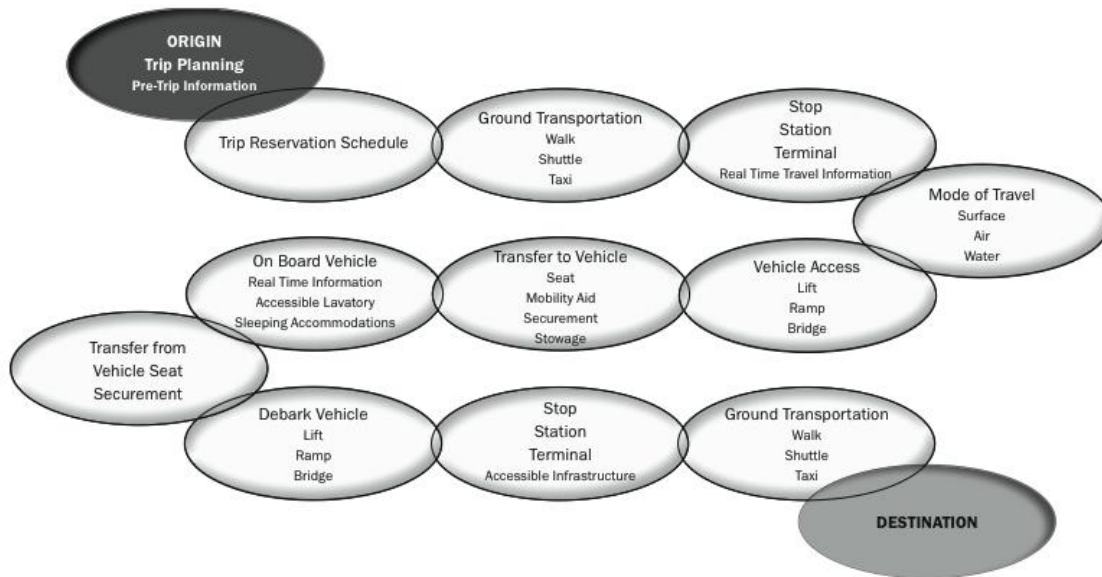
Geopolitical factors also impact public transport. Such factors include the declining availability of fossil fuels, the increasing cost of a barrel of oil, and the growing debate about how to deal with climate change. It remains to be seen how these will impact public transportation in the next 25 years, but most factors indicate increased demand for public transportation. The discussion in this chapter will focus on short-term industry impacts that are just starting to be influenced by world conditions.

6.3. Primer on Accessible Transportation Systems

A trip chain is generally defined as a series of stops at multiple locations during a single venture outside the home. However, in this context trip chain refers to the sub-activities involved in a single trip for a person with mobility limitations. Stops typically last no longer than 30 minutes and may be at any type of destination.[2] A trip is only accessible if all the links on

the trip chain are accessible. If any link is missing or broken, it is unlikely that a trip can be successfully completed. Figure 6.1. shows the links of the Trip Chain.

Figure 6.1. Trip chain concept.



6.4. Transport System

6.4.1. Infrastructure

The basic requirement of an accessible transportation system is that all civil and mechanical infrastructures be free of barriers. Ensuring the accessibility of civil infrastructure is often beyond the reach of the public transportation provider given that agencies such as the public works department, airport authority, or operating railroad typically control civil infrastructure. Civil infrastructure includes interfaces like terminals, stops, stations, and the area

around these facilities. On the other hand, public transportation agencies are responsible for the design, procurement and operation of the accessible vehicles that must interface with the civil infrastructure and facilities. In fact, one challenge of providing accessible transportation is creating and maintaining a smooth transition between the civil infrastructure and the accessible vehicles. The transition is also the interface between the vehicle and terminal. This transition, in particular, is often the broken link on the trip chain. One of the challenges in accessible transportation is that the terminal designs must meet the requirements of the ADA for buildings, and many of the vehicles must meet similar guidelines for vehicles. [3][4] Gaps in the interface between the vehicle and terminal are often problematic. The gaps are bridged by lifts, ramps, bridging plates, kneeling vehicles, gangways, or devices specifically designed to bridge the gap. The Americans with Disabilities Act Accessibility Guidelines (ADAAG) for Transportation Vehicles provides a number of specifications for this equipment. The reality is that the operating environment of public transportation is very harsh; thus, bridging devices require regular and on-going maintenance. In public transportation systems used by large numbers of people with disabilities, this equipment must include regular and intensive maintenance. As a result, many of these transit agencies also have excellent operations, and performance and reliability records.

A detailed discussion on bridging the gap follows in the section on intercity passenger rail, an environment in which bridging can be an acute problem. A discussion of transport and passenger amenities follows the discussion of air transport.

6.4.2. Categories of Accessible Transportation Systems

There are two basic categories of public transportation systems: surface transport and air transport. Surface transport is comprised of a number of modes, including: urban public transportation that is provided by rubber-tired, steel-tired, or passenger ferry vehicles. Intercity public transportation modes include over-the-road bus, passenger rail, such as Amtrak, and

passenger ferry. Air transportation is often categorized by the size of aircraft, the route or segment length, domestic or international services or the size of airport. Vehicle accommodations are specific design elements that pertain to the safety of all passengers and cross all surface public transportation systems and modes. These are introduced prior to a discussion of specific modes. The chart below shows categories of accessible transportation systems.

Surface		Air
<i>Urban</i>	<i>Intercity</i>	<i>Domestic</i>
Steel-Tired Rubber-Tired Water	Over-the-Road Bus Passenger Train Ferry	International Commuter Long Haul

6.4.2.1. Vehicle Accommodations Across All Modes

Vehicle accommodations include design elements on the vehicle that ensure the safety of all passengers. Elements that are key to safety include amply sized stairs and contrasting stair nosing, strategically placed stanchions, hand rails, and grab bars. Good illumination at stairways and doors is also important.

Vehicles with level boarding should include wide aisles that permit transportable mobility aids to easily enter the vehicle and navigate the aisle to the securement location. Details in vehicle design may increase the risks for semi-ambulatory passengers. For example, on transit buses, the side-facing priority seats near the driver can pose dangers to elderly passengers; there are no stanchions for people to hold on to. Often seats are upholstered in vinyl, which is easy to maintain though it can be slippery (especially if something has been spilled on it). The nearness of the seat to the vehicle operator is also an important aspect of accessibility. Specifically, elderly passengers or those with disabilities may feel more secure sitting in close proximity to the vehicle operator.

On rubber-tired vehicles, interiors must be configured with hand holds and stanchions, which passengers can use to steady themselves in case of sudden changes in speed or direction. The texture of the floor can also impact a vehicle's ease of access. Hard, slip-resistant surfaces are recommended while carpet is strongly discouraged.

Safe securement of wheeled mobility aids is more dependent on the type and mode of operation of the transport vehicle than on the style of mobility aid (i.e., crutches, canes, walkers, wheelchairs, or motorized scooters). The type and level of securement is dependent on the size or mass of the transport vehicle and the vehicle's operating environment. Smaller vehicles require more robust securement systems than large vehicles. Large urban rail systems operating on isolated guideways, for example, require no securement.

Mobility aid securement systems should be designed to accommodate a vast range of mobility aids while meshing with the vehicle's design and taking into account its operating environment. Restraint systems for mobility aid passengers should be provided on smaller vehicles, specifically any vehicle with a gross vehicle weight of less than 15,000 pounds. It should be noted that although personal restraints are strongly recommended, some physical conditions dictate that no personal restraint systems be used.

Also certain mobility aids can not be safely secured by any commonly available securement systems. Most of these mobility aids can, however, be accommodated by docking securement systems. These require additional interface hardware that is permanently attached to the frame of the mobility aid. The docking systems are common among mobility aid users who drive a vehicle while seated in a mobility aid. Anchorage, AK is the only American public transit system that uses docking securement systems in regular fixed route operations. Anchorage has been using the system for longer than 10 years. Rear-facing containment shows significant promise for independent securement on large transport vehicles.

6.4.2.2. *Urban Public Transportation Modes*

Urban public transportation can be divided into two basic types of service: those that operate on fixed routes and or schedules and those that are demand-responsive. Fixed-route service can be provided by rubber-tired vehicles, such as buses or steel-tired vehicles, such as metro rail, light rail, or commuter rail. Demand-responsive service is usually provided by rubber-tired vehicles that range in size from personal automobiles, accessible taxis, and vans, to small and large buses. Also, several cities in the world integrate passenger ferry service into urban public transportation systems. In many regions, long distance commutes blur the line between urban public transportation and intercity public transportation.

Urban Public Transportation Modes			
Fixed-Route		Demand-Responsive	Water
Rubber-Tired	Steel-Tired	Rubber-Tired	
Buses Small Large Articulated Double Deck Bus Rapid Transit	Street Car Light Rail Heavy Rail Commuter Regional Rail	Taxis Vans Shuttle Buses Small Buses	Passenger Ferry Primarily Pedestrian

6.4.2.3. *Rubber-Tired Vehicles*

Rubber-tired public transportation vehicles range from small sedans, providing demand-responsive service, to double-decked buses or articulated buses that can carry almost a hundred passengers.

Several key characteristics of rubber-tired vehicles pertain to accessible transportation. The mass of the vehicle directly impacts the type and level of mobility aid securement and occupant restraint. In general, smaller and lighter vehicles require more robust securement and

restraint systems in order to protect occupants. Smaller and lighter vehicles accelerate and decelerate more quickly than large, massive vehicles. Large massive transit buses by virtue of their mass and power transmission systems experience low acceleration forces.

The operating environment also influences the level of mobility aid securement and occupant restraint. The operating environments of vehicles that run on isolated guideways, or in exclusive bus lanes, such as the new Bus Rapid Transit (BRT) systems are more controlled than the environments of vehicles that operate on congested urban streets. Urban topography can also influence the options for mobility aid securement.

Rubber-tired vehicles are categorized as either high-floor or low-floor. Typically an accessible rubber-tired vehicle is equipped with a lift or a ramp. There are advantages and disadvantages to both high- and low-floor vehicles. In recent years, a trend has emerged toward the procurement of low-floor vehicles, which are easier for all passengers. The disadvantage of a low-floor vehicle is seen in cases where the ramp must deploy directly to the ground or road (lower than a sidewalk). Thus, the angle of the ramp can be too steep for mobility aid users to access the vehicle independently. Some low-floor vehicles are also unfit for travel on non-paved surfaces, rare though they are in most urban operating environments. Low-floor vehicles do not have steps, making boarding and de-boarding times much shorter than in high floor vehicles. Overall, these vehicles are easier for all passengers to board. Also, the ramps on low-floor vehicles usually accommodate larger mobility aids than many lifts. Still, many larger mobility aids are wider and longer than a “common wheelchair.” Many scooters are longer than four feet even without panniers or baskets. So even if these mobility aids scale the ramp, many won’t fit past the fare machine or maneuver to the securement station. In urban environments where vehicle fleets include both high- and low-floor vehicles, passengers with large mobility aids can

have difficulty reaching their destinations because the type of accessible vehicle can vary per trip segment.

The disadvantages of accessible high-floor vehicles are the stairs at boarding and the lift. Many buses have the lift at the front, negating the use of the stairs when the lift is deployed. The cycling of the lift and the time for securement and restraint add to the vehicle dwell time and detract from on-time performance. Most lifts also limit the size and weight of the mobility aid that can access the transit vehicle. Many high-floor vehicles are also kneeling buses, which reduces the height of the first step at boarding. But for many older passengers the stairs remain a barrier. High-floor vehicles are better equipped to operate in rural and unimproved areas where the lift may need to descend to the ground. The transit vehicle lift environment is harsh and regular maintenance is mandatory.

The type of operating environment also directly influences the type of access to vehicles. In many parts of the United States, Canada, and Sweden, access to demand-responsive vehicles is at the back of the vehicle. There are several drawbacks to this approach particularly in the U.S. Mobility aid passengers are usually relegated to the back of the bus where they ride behind the rear axle. The ride quality, particularly in smaller vehicles, is better near the front axle. In addition, mobility aid users are further from the driver.[5]

6.4.2.4. Demand-Responsive Public Transportation

Demand-responsive public transportation can serve the general public or eligible individuals. Federal regulations pertain to complementary paratransit service, but almost every agency has procedures for determining who is eligible. In many suburban and rural areas, demand-responsive service is available to all, and in a few rural regions, demand-responsive service is integrated with school bus service. Typically, demand-responsive public transportation requires the user to reserve a trip ahead of time. Many agencies still prioritize

trips according to trip purpose, although this is not permitted under the Americans with Disabilities Act, and consequently, information is mostly anecdotal. However, because many systems have major supply and demand problems, trip purpose is often used as a method to prioritize trips.

Vanpools and carpools provide ride-sharing options for commuters. In Washington and Oregon, accessible vehicles are provided by vanpool organizations when requested.

Accessible taxis are very popular for providing more spontaneous service particularly after hours or for visitors and tourists. In Portland, Oregon, accessible taxi service is regulated to ensure that service is available and affordable. In London England, there are purpose built vehicles that are low floor and have ramps, and securement systems. In the U.S., many large cities still do not provide accessible taxi service. Many advocacy organizations are working to promote accessible taxis, and a special-purpose, accessible taxi will be produced in the U.S. in 2008.

At the other end of the vehicle size and operating spectrum is Bus Rapid Transit (BRT). Bus Rapid Transit systems include rubber-tired vehicles, enhanced stations, limited-use guideways or exclusive bus lanes. BRT systems provide service with the amenities of light rail transit. A number of new vehicles are being designed for BRT service. The vehicles accommodate a variety of wheeled mobility aids, including Segway personal transporters, bikes and strollers. Most of these new vehicles are articulated, low-floor, and they can accommodate three or more mobility aids. Rear-facing securement systems are being designed and procured for many of these vehicles. Rear-facing securement includes a compartment that permits mobility aids users to travel facing the rear of the bus without being secured with belts or other devices. Rear-facing securement lets people travel independently and does not involve the

vehicle operator. Many of the new BRT vehicles include café-type seating so other passengers also travel in rear-facing seats.

6.4.2.5. Steel-Tired Vehicles

Steel-tired vehicles include streetcars, light rail, heavy rail, and commuter rail. Typically a street car is electric with power from an overhead wire or catenary and runs on rails in the street. Streetcars are usually single cars, but some can be hitched together in a “married” pair. Light rail transit (LRT) vehicles are usually larger than street cars, have electric power from overhead wires, and run on rails. However, one of the differences between street cars and light rail is that LRT systems almost always run two, four or six car train sets. Many of the newer LRT systems include low-floor vehicles, and many older systems run a mix of high and low floor vehicles. Both LRT and street cars have stations that are part of the sidewalk area. The floor level of the vehicles influences the design of these stations. Some stations include mini-high platforms or wayside lifts to accommodate high floor vehicles. The national trend is towards level boarding with low floor vehicles. Also LRT systems run a mix of isolated guideways and on street service. In general, LRT stations provide more amenities than street cars and nearly always include off vehicle fare payment mechanisms.

There is no clear distinction between light rail and heavy rail. Skytrain that operates in the Canadian city of Vancouver, British Columbia, uses light vehicles, but the system has all the features of a heavy rail system. The power is provided by a powered third rail, the guideway is completely isolated, the vehicle’s propulsion is provided by linear traction motors that permit the system to operate on steeper slopes than traditional propulsion systems where the friction between the steel tired and rail is the limiting factor. Linear traction motors work to pull the train along. Skytrain is like many systems in the world that are completely computer controlled. There are no drivers on the vehicle. This type of control is only possible on systems that run on

completely separated guideways. Computer controlled systems have the potential to operate with shorter headways and with more energy efficiency than operator controlled systems. There are always tradeoffs. Isolated guideway systems are more expensive to construct initially than in street systems, but they are more flexible and have fewer capacity constraints. There are tradeoffs between initial construction costs and long-term operational efficiencies. The heavy rail urban systems run independently of the street system. In cities with large underground networks, these systems also run in adverse weather or heavy traffic.

Both LRT and heavy rail fixed guideway systems also impact urban growth and development. Real estate values generally increase within a quarter mile of stations, and decrease as the distance from the station increases. In a number of cities, transit stations have become the catalyst for urban development and renewal. It is common for high density development to occur in the immediate vicinity of a station. Additionally, many of these developments are pedestrian-friendly.

Commuter rail systems operate with either electric or diesel engines and in general provide longer distance service than urban rail systems. Typically commuter rail systems operate multiple-car trains with stations spaced miles apart. In the U.S., these systems commonly share the rails with freight trains. Some of the vehicles are bi-level and provide “business” class service with many amenities. Many features of commuter rail are similar to intercity rail. They are discussed in detail in the passenger rail section. [6]

A key element of both urban and commuter rail service are stations that provide park and ride options for passengers. It is important that park-and-ride lots provide accessible parking and an accessible route from the lot to the station. The station itself needs to be accessible and the transition between the platform and the vehicles needs to be bridged by a ramp, lift or bridging plate. [7]

In addition to fixed infrastructure for accessible transportation, the public information system, fare machines and safety and security features need to be designed to accommodate passengers with a spectrum of physical, sensory and cognitive abilities, and these are discussed later in the chapter.

6.4.2.6. Passenger Ferry Service

Passenger ferry service is an integral component of many urban transportation systems. This is not surprising given that many of the world's oldest and largest cities are major ports, harbors. Many are located along waterways. Unfortunately, many ferry vessels and docks were designed and built without consideration for passengers who require wheeled mobility aids. As a result, these vessels and docks are not particularly accessible. On older vessels with raised doorsills, many of the restrooms are not accessible. However, newer systems are more accessible, and old systems are being retrofitted to become more accessible.

6.4.3. Intercity Public Transportation Modes

Intercity public transportation modes include over-the-road buses, passenger rail, ferry service, and air transportation. Typically intercity transport vehicles and vessels are larger than urban public transportation vehicles. Intercity vehicles stop less frequently, and the trip segments and trip lengths are much longer. Intercity public transportation includes amenities such as food service and lavatories. Long-distance rail service includes sleeping accommodation. Because air transport and surface mode differ significantly, they will be discussed separately.

6.4.3.1. Surface Modes

Surface modes include passenger rail, over-the-road buses and passenger ferry. The major accessibility issues on these surface vehicles include: ease of boarding and on-board

circulation, accessibility of lavatories and sleeping accommodations, access to amenities such as food service, availability of information on-board, and the effectiveness of communication systems and safety and security procedures.

6.4.3.2. *Passenger Rail*

Intercity passenger rail service in the U.S. is provided by both steel-tired vehicles and in many regions over-the-road buses that connect to mainline rail service. In the United States the accessibility of passenger rail is highly dependent on the rail vehicle or rolling stock, and these in turn are regional. Regional differences are reflected in the type of vehicles or rolling stock, the type of platform, the types of boarding devices used to bridge the gap



between the platform and the vehicle. The passenger rail vehicles that operate on the West coast are very different from those that operate in the Northeast corridor. [6]

6.4.3.2.1. Vehicles.

Amtrak uses two basic categories of passenger vehicles. These include single level or bi-level coaches. The newest systems are high-speed Acela and higher speed TALGO services that operate on the east and west coast respectively. The Cascadia service that operates between Eugene, OR and Vancouver, Canada uses the “Talgo” train technology developed in Spain. The train interiors were designed to be accessible, and for many people with disabilities the service works very well. This is daily service with no sleeping accommodations. On the East Coast the high-speed train called the Acela was derived from French technology. This train was also designed to be accessible. Despite improvements in vehicles, many stations remain inaccessible.

Long-distance trains that run west from Chicago and along the West Coast include bi-level coaches and sleeping accommodations. The West Coast Starlight is an example of this type of service. It operates daily between southern California and Seattle, Washington. The accessible accommodation is available only on the lower level. Passengers who require mobility aids cannot access the dining car, club car or viewing lounge. The accessible sleeping accommodation is limited to only one person with a disability per room since the berths are

Figure 6.2. (Above) An accessible lavatory on a bi-level commuter train vehicle.

Figure 6.3. (Below) Mini High Platform for Sound Transit in Seattle.



Figure 6.4. (Below) Bridge ramp between mini high platform and vehicle.



Figure 6.5. (Below) Wayside lift used to access high floor single level vehicle.



stacked. Travelers who use mobility aids are confined to their bedrooms for the trip, since they can not access the upper level or move between cars. They depend on the train conductor or traveling companions to bring them food from the dining cars. All accessible accommodation must be booked in advanced. Amtrak has a website for reservations; however it is only partially accessible.

6.4.3.2.2. Bridging the gap-transition zones passenger rail.

In the U.S., rail and some BRT platforms may be low, mini-high or high level. A mini-high platform is a raised section of platform that is typically located on a low level platform. It is used to provide a level transition to the vehicle. There is a transition zone between all vehicles and the platform and these are bridged by ramps or bridging plates, and lifts. The lifts are often called wayside lifts and are typically station-based while the ramps and bridging plates are most commonly vehicle-based. Vehicles are low-floor or high-floor.

6.4.3.2.3. Platforms.

Many accessibility challenges are associated with rail travel in North America. One is that many rail lines in North America are shared by passenger and freight trains. In Western Europe and Japan, passenger rail generally operates on its own rails or tracks. Sharing between passenger and freight operations creates problems for schedule adherence and platform integrity. Morlock (2003) states:

“This conflict emerges where high level platforms are used (at stations) on tracks that are also used by freight trains, because such platforms intrude into the normal clearance envelope of freight trains. High level platforms are now most commonly used in the Northeastern U.S., but more extensive use elsewhere is

contemplated because of various benefits for passenger service.”[8]

Higher speed rail vehicles and stations on the U.S. West Coast are comparatively new and most stations have low-level platforms. The boarding ramp is at the doors of the accessible coach and mounted to the interior of the train vehicle. Bi-level commuter coaches usually interface with mini-high platforms. Ramps stored on-board are used to bridge the gap. The train operator must align the accessible coach with the mini-high platform so that passengers in mobility aids can board or disembark. Wayside lifts are used at West Coast Amtrak stations to access the West Coast Starlight. Typically these lifts are stored at stations and used when requested.

6.4.3.3. Over-the-Road Buses

Over-the-road buses (OTRB) include intercity buses. Amtrak’s Thruway Bus, for example, services the country. Some of the service is provided under contract to Amtrak, and the contractors do not always operate lift-equipped vehicles. In Oregon and Washington, Amtrak operates a fleet of accessible coaches, or thruway buses. This fleet provides feeder service that interfaces directly with mainline rail operations. The OTRB industry has been slower in adopting accessibility than many other modes. An accessible vehicle provides a lift at the front, middle or rear of the bus. Mobility aid securement is also provided, although many passengers prefer to transfer from their mobility aid to regular seats if they are able. The mobility aid is then secured or stowed in the luggage compartment. Passengers also may choose to travel in their own mobility aid. A key issue with OTRB is the provisions for accessible lavatories on board the vehicle. The dynamics of an OTRB moving on a roadway are significantly different from those of a passenger rail system.

Moving about on a moving vehicle is much more of a challenge for all passengers, and using the on-board lavatory is a challenge for all. Many passengers prefer the option of using accessible restrooms at train stations or bus stops. [9]

6.4.3.4. Passenger Ferry

Intercity passenger ferries may or may not carry motor vehicles. It depends on the size of the vessel, the trip length, and the destination. Passenger ferries are essential for accessing coastal communities. For vessels that carry motor vehicles, where occupants are encouraged to leave their vehicles for the duration of the trip, it is important that provisions be made for drivers and passengers who use wheeled mobility aids. Specifically, accessible parking spaces should permit egress on either side of the vehicle and an path to the passenger amenities. Stairs and raised door sills are barriers for all not just people who use wheeled mobility aids. Many older vessels have retrofitted elevators, and many newer vessels have accessibility features designed and built in. On ships, raised door sills can be found not only between the exterior doors and interior space but also throughout the vessel. Raised door sills are being removed to make the interior circulation space more accessible to all. Passenger vessels are also being retrofitted or designed with accessible lavatories. New vessels often include accessible unisex lavatories that meet the needs of families and individuals. Regulations for accessible accommodations for cruise ships and passenger ferries are in development. Thus many vessels do not have ADA-compliant sleeping accommodations. Individual companies or agencies will try to accommodate passengers with special needs when adequate advance notice is provided.

6.5. Air Transport

Travel by air for many people is essential for employment and education, as well as for enjoyment. The U.S. the Air Carrier Access Act has provisions for improving access to aircraft.

However, a lack of enforcement together with significant challenges in the commercial air travel industry have made air travel for people with disabilities inconsistent. For example, some aircraft have lift-up armrests and others do not. Armrests that do not move can make access to aircraft seats very difficult. There are variations in policies and subsequent treatment of passengers with disabilities within airlines. The inconsistency in accessibility levels is one of the most frustrating aspects of air travel by people with disabilities. The National Center for Accessible Transportation recently completed a survey of all commercial service airports in the continental U.S., and the major airports in Alaska and Hawaii. The survey was completed by airport management and not by passengers. The general trend was that most airports are making significant progress in making improvements to meet the needs of travelers with physical disabilities. However, many survey respondents had never considered any modifications for travelers with sensory or cognitive disabilities. The survey results indicated that most airports had at least one individual whose job description involved accessibility. Almost universally, respondents indicated the need for additional technical and financial assistance and training to make improvements for travelers with disabilities. Although the survey posed no questions about boarding smaller aircraft, this emerged as a significant problem in the open comment section and by phone calls that were received.[10] The building accessibility requirements of airport terminals are covered by the ADA/ADAAG. Several aspects of air travel challenge travelers with disabilities. These aspects include security, aircraft boarding, on-board lavatories, and the dissemination of passenger information in real-time.

The Air Carrier Access Act (ACAA) covers airside or aircraft-related issues. The boarding bridge is located in the airside operational area, but neither ACAA nor ADA regulates it.

The Transportation Security Administration issues regulations for screening passengers with disabilities, however front-line staff does not always follow these regulations. Passengers who use supplemental oxygen or ventilators often encounter problems when traveling by air. These problems often include security screening of the equipment and the procurement of supplemental oxygen canisters during transfers between aircraft and at final destination. Passengers who use wheeled mobility aids encounter many challenges and these include: safe transport of their personal wheelchair, transfers to and from the boarding area to the aircraft, use of on-board chair and lavatory. Passengers with sensory and cognitive impairments often encounter difficulties at check-in, security screening, departure gates and while aboard the aircraft.[7][11]

Air travel is becoming more of a challenge for all travelers, but these challenges are increased for travelers with special needs, such as those who are obese, frail or have disabilities. Airport terminals and their operators are increasing accessibility in the infrastructure. The world's major aircraft manufacturers are actively developing new aircraft interiors that are more accommodating and accessible. Most airlines operate under challenging economic conditions, struggling to stay in business. One of the major challenges for improving accessibility of aircraft is the high value of aircraft real estate. Every seat generates significant annual revenue for the airline. Increases in seat pitch, aisle widths, seat widths and lavatories are very costly. Improvements for passengers with special needs will benefit all passengers and will contribute to overall passenger satisfaction, however the costs are very high. Some airlines make accommodations for travelers with disabilities, outfitting aircraft with interiors that more readily accommodate the special needs of travelers with disabilities.[12] Other improvements include specialized training and new positions for front-line staff who work directly with travelers with

disabilities. Often these people are customer service representatives at the end of the phone, or staff who help transfer passengers from their wheelchairs to boarding chairs and aircraft seats.

In the United States, air travel is an essential mode for travel due to the large size of the country. Advances in accessible air travel are occurring now, and the next decade will see the implementation of new technologies that make air travel more accessible and easier for all. These advances include on-board accessible lavatories, more dignified boarding equipment, in-flight entertainment systems that can be used by passengers with sensory and agility challenges.

6.6. Transport Amenities

6.6.1. Passenger Information Systems

Accessible public transportation systems must include accessible real-time passenger information and communication systems. Well designed information and communication systems benefit all users of the systems, not just those with visible disabilities. Tourists or infrequent users can be intimidated by the complexity of public transportation route and fare structure. All systems users require basic information on how to use public transportation. Pre-trip information on accessible web sites can help tourists, people with disabilities or infrequent users to familiarize themselves with a transit system. Many large transit systems are investing in trip planning systems that allow users to plan multimodal trip itineraries ahead of time. Trip planning gives all travelers' confidence in the likelihood of a successful trip. Once en route, travelers like to know where they are, and if they are on time. En route and real-time information are particularly important if there are detours, emergencies, or unforeseen events that disrupt a trip. For people with sensory and or cognitive disabilities, it is very important that real time information and communication systems provide the same information in multi-sensory modalities. All passengers benefit from captioning and visual and oral paging. All public

transportation providers should use technology to provide real-time emergency information in both oral and visual formats. Doing so would make it easier to meet the requirements of ADA, one of which is that major bus stops be announced. In many U.S. cities this is being automated with the application of intelligent transport system technologies. Many of the automated systems are available in both audio and visual formats.

Wireless personal communication devices are revolutionizing the dissemination of real time information. For example, in Japan, many blind pedestrians use cell phones equipped with GPS and cameras for orientation and mobility. The phones can help people in need of direction by transmitting GPS coordinates and receiving specific wayfinding and guidance information.

A weakness of many traveler information systems is that they fail to consider universal or inclusive design. The human-machine interface is fraught with problems. For example, text and font sizes can be too small, and keyboards and interfaces are designed to be used by very small fingers.[10] NCAT is collaborating with the National Center for Accessible Media and the RERC on Wireless Technologies as well as industrial partners to develop new technologies that meet the needs of a wide spectrum of users.

6.6.2. E-Kiosks

The travel industry is adopting the use of self-service automatic transaction machines for a number of services in terminals and stations. Federal regulations and standards for these devices exist, but the industry is reluctant to develop and deploy accessible machines. The machines are common in Europe, Asia and most of North America. Unfortunately, few ticket machines, ATM or travel kiosks are accessible to people with physical and or sensory impairments. Even some “accessible” machines are installed on pedestals that make them too high for use by a person in a wheelchair, and render them inaccessible.

Other methods of fare payment simplify travel for all. In many regions, a single smart card can be used to pay for parking, transit, and other consumer purchases. Off-vehicle fare collection speeds the boarding process, decreases dwell time, and improves overall performance. Pre-paid fares and monthly pass programs make public transportation easier for all.

6.6.3. Illumination

Illumination is a key but often-overlooked aspect of accessible public transportation. Light is important at all transition points, fare machines, and in waiting areas. Good lighting on stairs and ramps can reduce tripping and falls. Lighting is also essential for safety and security. In North America, the ADA guidelines for buildings and vehicles provide limited guidance on lighting and illumination. It is hoped that future research will support new guidelines.

6.6.4. Travel Training

The highest priority for most public transportation entities is the removal of visible and physical barriers. For many consumers of accessible transportation fear of the unknown is a barrier to travel. In recognition, progressive public transportation agencies offer programs that provide travel training, orientation, and practice opportunities for people transitioning from rehabilitation facilities and using public transportation for the first time. For surface transportation, travel buddy programs offer people with disabilities the opportunity to act as ambassadors and escorts to other travelers with disabilities. New friendships result from these opportunities.

Entities that provide public intercity travel often develop extensive training programs for front-line transport personnel. For the air travel industry this is required in the Air Carrier Access Act. NCAT has ongoing traveler assistance training for the air transport industry. A new program that focuses on passenger transfer techniques will be released in 2007. It is part of a

larger program by the NCAT which seeks to improve the traveler's safety and perception. It also aims to reduce the number of injuries to both air transport personnel and travelers.

6.6.5. Service Animals

All modes of travel follow procedures for accommodating, transporting and respecting service animals. For many individuals with disabilities service animals are essential for an independent lifestyle. Many airports and terminals designate space for service animal relief. These areas are often used by other dogs that work at the airport.

6.7. Market Needs Met

The Americans with Disabilities Act (ADA), a piece of civil rights legislation, has been the catalyst for significant progress in accessible urban public transportation in the U.S. There were transit systems that exceeded the transportation regulations of the ADA before the ADA was enacted. It is not surprising that these agencies still lead in innovation in accessible transportation services. Most new rubber-tired transit vehicle purchases are low-floor, and many urban rail light rail systems also have low-floor vehicles or level boarding systems. Newly purchased over-the-road buses include lifts and on-board accommodation for mobility aids.

Amtrak is replacing passenger rolling stock that does not include overnight accommodation with more accessible vehicles and amenities. Transportation stations and terminals are also being upgraded gradually to remove barriers and improve access for all passengers.

A special purpose-built accessible taxi has been recently unveiled in the U.S. market. Currently, most accessible taxi service is provided by lift-equipped vans. The level of safety and security on these vehicles has not been researched however.

Passenger communication systems show substantial technological advances that benefit all travelers by providing real-time information in visual and audible formats.

6.8. Market Needs Unmet

The ADA has helped make public transportation to be more accessible for all but some areas need more work. In the U.S., few regulations pertain to placement and luminosity of lighting at boarding areas and around the vicinity of boarding and exit areas. It is well known that as people age, they need more light. Anecdotal information indicates that transition areas and stairways are not well enough lit.

Problems remain with transition zones such as boarding bridges, ramps, and bridging plates. In the U.S., there are few vendors of boarding bridges. The National Center for Accessible Transportation facilitates the development of standards for accessibility of boarding bridges. The initial focus is at air terminals, but issues in air terminals are similar to those on passenger vessels. The increased interest and development of Bus Rapid Transit systems has also increased awareness of the challenges of bridging plates as well as the need for new technologies and design guidance materials.

Several industry needs for accessible transport vehicles remain unfulfilled. There is a need to improve accommodations for passengers who use wheelchairs on long-distance rail coaches. Currently, accessible sleeping accommodations confine passengers to their coaches and do not permit passengers to access all train amenities. Among rail terminals, the transitions between the vehicle and platform are inconsistent. In systems that do not have level boarding, there is a need for development of lifts that offer safety and dignity for all users.

The National Center for Accessible Transportation (NCAT) hosts the Rehabilitation Engineering Research Center for Accessible Public Transportation. NCAT is working on several

projects that will ultimately improve the accessibility of aircraft lavatories and other aircraft amenities. In over-the-road buses, the on-board lavatory is rarely accessible. Most people prefer to use station-based lavatories.

Several critical areas require industry attention, according to NCAT. NCAT currently hosts industry forums that address issues of safe stowage and transport of mobility aids in the cargo holds of aircraft. Other industry groups are examining problems associated with supplemental oxygen and ventilators. It is also anticipated that new regulatory guidelines for e-kiosks will be undertaken. These devices include self service check-in machines and automatic transaction machines.

The impact of an unmet need is similar to that of a broken link in the trip chain. NCAT is initiating a traveler survey aimed at discovering why people with disabilities do not travel, and for those who do, what problems they encounter. Preliminary information indicates that many people with disabilities don't travel because of one or more bad experiences. People with respiratory conditions and those who use supplemental oxygen and or ventilators tend not to travel by air. Frequent travelers with disabilities experience inconsistent service and accommodation in all links of the trip chain. For example, some airports have accessible ground transportation such as accessible taxis or public transportation while others lack even accessible buses to rental cars. The lack of standards for accessible lavatories on aircraft and airlines' inconsistent training of flight crews make access to on-board lavatories difficult for many travelers with disabilities.

6.9. Market Trends

The most significant impacts on accessible transportation are the changing demographics in terms of population age and obesity. Today's aging population is more mobile and travels more than previous generations. Medical and rehabilitation advances have increased the overall quality of life of the aging population. Discussion of market trends is divided into local travel and long distance travel.

6.9.1. Local Travel

The key issues with regard to local travel are mobility options associated with driving cessation. These include: accessible main line transportation, paratransit or demand-responsive transportation, and taxi programs. For many older Americans aging in place is very important. In order to accomplish this goal, mobility options must be available to permit people who stop driving to remain in their home while maintaining their quality of life. There are significant differences between urban and rural environments. Urban settings offer more transportation options than do rural environments where often there are no public transportation options.

A significant issue for seniors transitioning from driving to non-driving is travel training in a non-threatening environment to learn and use public transportation. Use of public transportation is threatening. There is a lack of training available to elders or seniors to prepare them to use that transportation.

For people who use mobility aids accessible public transportation options are very important. One of the major challenges is that wheelchairs or wheeled mobility aids are getting larger and do not fit on public transportation vehicles. Typically, the rehabilitation team, or the family purchasing mobility aids, does not consider transportation needs as one of the considerations in prescribing mobility aids. Durable medical equipment dealers do not consider

the transportation needs of the user when selling mobility aids. Often people end up with inappropriate mobility aids that do not permit them to access public transportation.

6.9.2. Long Distance Travel

In the post-ADA environment, new intercity public transportation vehicle designers are building vehicles that consider universal and inclusive design. Primarily this includes new passenger rail and passenger aircraft. The most significant issues include changes in population demographics and the increasing size of mobility aids. Progress is being made toward making intercity public transportation safer and more seamless for all passengers.

The aging Baby Boom population is gradually impacting the design of consumer products. Manufacturers of communication systems are beginning to realize the buying power of aging Baby Boomers.

The American with Disabilities Act is influencing the design of vehicles. The transportation industry is also realizing the importance of universal design and the power of the customer. New vehicle requests include amenities that improve the complete travel experience for all travelers. Level boarding, which is a benefit for all, reduces dwell time at stations and minimizes slipping and falling. Transport operators are slowly realizing that inclusive design can benefit the bottom line.

6.10. Emergent Products and Technologies

In the urban transport environment, rear-facing securement/containment is an emerging securement technology that permits mobility aid users to travel more independently. Low-floor vehicles and level boarding systems also simplify travel for all.

Lavatories that meet the new regulations for accessibility will make air travel more comfortable for all passengers. NCAT is developing new boarding technologies that will make access to aircraft safer and more dignified for all.

6.11. Barriers to Adoption

The public transportation industry is highly regulated and fiscally constrained. The attitude of agency administrations toward universal and inclusive transportation impacts the implementation and adoption of policies and products that promote accessibility and full inclusion. The most progressive transport agencies tend to be leaders in developing, promoting, and adopting products that increase accessibility and inclusion. Similarly, progressive manufacturers are developing vehicles that meet the needs of a changing demographic.

In the airline industry the lack of clarity of regulations, such as the ACAA, and the lack of enforcement have been the main barriers to adoption. While the transport industry is generally slow to adopt new technologies and systems, there are always exceptions! Industries and agencies that are customer-focused are more likely to adopt inclusive strategies. The same industries and agencies are the leaders in promoting access for all.

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Chapter 7

Interpretive Overview: Wheeled Mobility

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Contents

	Section	Pg
7.1. Introduction	186
7.2. Background	187
7.3. Provision of Wheeled Mobility Devices and Services	188
7.3.1. Education	188
7.3.1.1. Certification	189
7.3.1.2. Continuing education opportunities	189
7.3.2. Research and Development	192
7.3.3. Administration	195
7.3.3.1. Context	195
7.3.3.2. Performance indicators	196
7.3.3.3. Quality measures	198
7.3.4. Standards	202
7.3.4.1. Standards for devices	202
7.3.4.2. Standards for services	205
7.3.4.3. Classifications for AT	207
7.3.4.4. Terminology	208
7.3.5. Knowledge Translation	210
7.3.5.1. Conventional clinical terminology and interventions	211
7.3.5.2. Developing a plan of care	213
7.3.6. Medical Standards of Care	219
7.3.6.1. Standards of quality	220
7.3.6.2. Clinical practice guidelines	221
7.3.6.3. Medical review criteria	222
7.3.6.4. Performance measures	224
7.4. Summary	226
References	228

7.1. Introduction

Approximately four million wheelchair users of all ages in the United States use wheeled mobility devices daily to maintain their health and well-being and to participate in educational, vocational and community opportunities.[1] The enactment of disability legislation that recognizes the value of Assistive Technology (AT), combined with the production of innovative wheeled mobility devices, has facilitated the ability of individuals with impaired mobility to participate fully in their lives. These rapid advances have produced an era of tremendous possibility tempered by numerous challenges in providing the quality health care services necessary to obtain these devices.

Assistive technology services require multidisciplinary collaboration to assist individuals with disabilities in the selection, acquisition and use of wheeled mobility devices, specifically wheelchairs and the attached postural support devices also known as seating. Despite significant progress in providing mobility-related assistive technology devices and services to people with disabilities, there remains a profound need for research-generated data to flow to assistive technology providers and service delivery organizations so that they can improve their offerings.

Health services research has recognized the importance of quality management “to reduce variation in the production process [service performance] through work standardization and continuous improvements in outcomes...”[2] Toward this end, federally funded agencies continue to conduct research and development activities for AT technical standards, outcome measures to determine the effectiveness of these devices and “knowledge dissemination for practical utilization of research-related activities.”[3] Unfortunately, providers of wheelchair-related healthcare services, including physicians, occupational and physical therapy clinicians and suppliers of durable medical equipment/rehabilitation technology suppliers have an immediate need to demonstrate accountability and productivity.

The intent of this contribution to the Industry Profile on Wheeled Mobility is to provide an interpretive overview of services for the provision of wheeled mobility, quality measures relevant to these services and to propose a comprehensive framework to optimize clinical practice.

7.2. Background

Wheeled mobility devices are typically provided through a process that requires an extensive chain of providers, funding sources and manufacturers. The devices are then utilized by people with varying degrees of impairment, for participation in a multitude of activities, across complex physical, social and attitudinal environments.

Providers with diverse backgrounds and qualifications are involved in developing specifications for device prescription. However, clinicians typically have limited educational opportunities or experience in providing assistive technology to individuals with mobility impairments and whose personal definition of well-being may be in direct conflict with traditional healthcare values that focus on restoration of function according to a prescribed set of “normal” standards.

The devices specified must not only meet the person’s medical needs. They must also support their participation in life activities, including self-care, domestic life, education and work. Full participation requires that these devices operate in multiple environments, including tightly configured homes and community locations that are physically constrained if not completely inaccessible. A myriad of societal factors must be considered, including the availability of devices to meet these needs, the attitudes, support of and relationships to the people impacted, as well as the services, systems and policies that support wheeled mobility use.

Given these complexities, it becomes apparent that use of a standardized service delivery model is essential in defining provider roles, responsibilities and the knowledge necessary to support excellence in service. By using benchmarks for the provision of wheeled mobility services, providers will be able to more effectively assess their consumers' needs and discuss solutions. Using benchmarks will also help providers efficiently develop strategies and implement processes to obtain devices and identify outcomes that demonstrate the need for, and use of, AT to improve quality of life.

The following sections will: provide an overview of typical barriers to high quality service delivery, identify currently available resources and provide a rationale for their use in wheeled mobility AT services. The value of performance indicators, standards and quality measures for continuous quality improvement will be discussed. Stakeholder perspectives and other expert contributions will lend support to overview positions.

7.3. Provision of Wheeled Mobility Devices and Services

7.3.1. Education

Building an effective service delivery model requires a sound educational foundation. Education for health professionals typically provides minimal instruction on AT, particularly as it regards wheeled mobility. Therefore, clinicians who wish to pursue basic AT instruction must seek post-graduate education, typically via symposiums and seminars. These training programs tend to focus on entry-level clinical skills for assessing and developing specifications for prescriptions.

The American Medical Association (AMA), in its "Primary Care for Persons with Disabilities: Access to Assistive Technology: Guidelines for the Use of Assistive Technology Evaluation, Referral, Prescription," acknowledges that "General practitioners are the most

commonly reported source of information on disability services but have been shown to have minimal knowledge of assistive technology.”[4] This limitation in the educational foundation means clinicians must pursue other means of establishing professional competence, such as by certification and continuing education, for example.

7.3.1.1. Certification.

Professional organizations that recognize the need to maintain and assess continuing competence are turning to certification programs. These organizations have developed standards “that articulate a measurable degree of required performance.” The standards assume the need for clinicians to participate in “life-long-learning that includes development of knowledge, skills and abilities in order to meet current standards of practice.”[5] As such, many providers are now required to demonstrate this learning by accumulating continuing education credits and specialty certifications. “Certification of a service provider in any profession, in any field, is the process by which a non-governmental agency or association validates an individual’s qualifications and knowledge in a defined functional or clinical area.”[6]

7.3.1.2. Continuing education opportunities.

Continuing educational opportunities are available from local, national and international organizations. In the field of wheeled mobility, sources for professional development include:

The Rehabilitation Engineering and Assistive Technology Society of North America (RESNA) is an international organization whose mission states: “We are an interdisciplinary association of people with a common interest in technology and disability. Our purpose is to improve the potential of people with disabilities to achieve their goals through the use of technology. We serve that purpose by promoting research, development, education, advocacy and provision of technology; and by supporting the people engaged in these activities.”

RESNA holds annual conferences and provides professional development training with International Association for Continuing Education and Training (IACET) with approved continuing education credits (CEU). Special Interest Groups (SIGS) provide “a forum for exchanging information relating to its area of specialty” and Professional Specialty Groups (PSGS) provide a forum for members “with a common background to share information within their profession.” RESNA offers a certification program for the provision of AT that is undergoing designation and policy changes. [7] These changes will result in a designation of Assistive Technology Professional for both clinicians and suppliers that became effective January 1, 2009.

The International Seating Symposium (ISS) is sponsored by the University of Pittsburgh and held biannually in the U.S. The ISS syllabus states that presentations cover “evaluation, provision, research, and evidence-based practice issues in seating and mobility for people with physical disabilities.”[8] The symposium includes “scientific and clinical papers, in-depth workshops, special topic sessions, poster sessions and an extensive exhibit hall.” Program objectives are to “identify seating and mobility interventions for people with physical disabilities, discuss service delivery practices, explore current research, and understand the features and clinical impact of seating mobility technologies.” Instructional courses are provided with associated continuing education credits. [9]

Alternating years, the ISS is held in Canada and cosponsored with the University of British Columbia. Information regarding this conference can be found at. [10] This website was developed “to promote networking and information exchange amongst individuals and agencies with a shared interest in adaptive seating and mobility, by Sunny Hill Health Centre.” The site also contains information regarding clinical resources, literature review, best practice, pressure management, postural management, equipment, research and education.

At the University of Pittsburgh's School of Health and Rehabilitation Sciences, the Department of Rehabilitation Science and Technology provides continuing education web-seminars and resources for wheeled mobility at RSTce. [11]

The Center for Medicare and Medicaid Services (CMS) sponsors the Medicare Learning Network among its outreach and education online services for providers. The MLN Products Catalog, for example, offers a fact sheet for Medicare coverage of power mobility devices free of charge. [12]

The twice-yearly MedTrade exposition, considered the premier international home healthcare tradeshow, is held in the western U.S. in spring and in the eastern U.S. in fall. The show features the latest innovations in Durable Medical Equipment (DME), including wheeled mobility products. The expo's conference programs offer continuing education credit. Additional sources are contained in the appendices. [13]

A new opportunity for continuing education will occur at the Home Medical Equipment Exposition and Conference, which is concurrent with this year's Continuing Education and Legislative Advocacy Conference, CELA '09. The CELA seminar, called the Complex Rehab Education and Legislative Forum, will be presented by the National Registry of Rehab Technology Suppliers (NRRTS), in association with the National Coalition for Assistive and Rehab Technology (NCART) and the University of Pittsburgh's Department of Rehabilitation Science and Technology/Continuing Education (RSTce). The forums intend to provide "quality Complex Rehab clinical education and provide lobbying activities" for the home medical industry. CELA '09 corporate sponsors include leading wheeled mobility manufacturers, including: Invacare, Permobil, Quantum, Sunrise Medical, the MedGroup, the ROHO group, U.S. Rehab, United Seating and Mobility, ATG Rehab, Convaid, MK Battery, Ride Design/Aspen Medical and Motion Concepts. [14]

In spite of certification and post-graduate training opportunities, the educational foundation for service providers remains somewhat suspect. It is worthwhile to examine the research and development activities that are producing the new knowledge upon which education might be based.

7.3.2. Research and Development

The National Institute on Disability Rehabilitation and Research (NIDRR) is a federally funded agency that provides “leadership and support for a comprehensive program of research related to the rehabilitation of individuals with disabilities.” NIDRR’s extramural research is conducted through a network of research projects and centers of excellence located throughout the country. Most NIDRR grantees are university academics or providers of rehabilitation and related services. NIDRR’s largest funding programs are the Rehabilitation Research and Training Centers (RRTCs) and the Rehabilitation Engineering Research Centers (RERCs).” Several NIDRR-sponsored centers conduct basic and applied research pertaining to wheeled mobility and to the dissemination of research findings. [15]

The RERC on Wheeled Mobility is currently at Georgia Institute of Technology with the RERC on Accessible Public Transportation at Carnegie Mellon University and the RERC on Wheelchair Transportation Safety at the University of Michigan. These centers perform research, development, training, and outreach activities. [16] References to their research findings are provided in the expert contributions section.

The National Center for the Dissemination of Disability Research (NCDDR) “focuses on knowledge translation (KT) of NIDRR-sponsored research and development results into evidence-based instruments and systematic reviews. NCDDR is developing rigorous, evidence-based standards for describing, assessing and disseminating research and development outcomes.”[17]

The National Rehabilitation Information Center (NARIC), as a NIDRR contractor, offers online “disability and rehabilitation-oriented information organized in a variety of formats designed to make it easier for users to find and use.” Formats include semi-monthly publications of the RehabWire newsletter, brochures listing agencies, organizations and online resources. The NARIC website includes tabbed areas for public to access “resources for employment, advocacy, benefits and financial assistance, education, technology and more. NARIC enables the public to sign up for monthly email alerts for REHABDATA, an online database of electronically available documents containing results of government-funded research. NARIC also maintains a database of NIDRR projects which includes: the institute holding the project in any given fiscal year, an abstract of projected goals and activities, contact information and principle investigators. [18]

In principle, RERC, NCDDR and NARIC research outcomes should provide focus and direction to service providers. However, those who want to access intermediate research and final reports must often subscribe to expensive research journals or purchase reprints. In addition, at the end of RERC grant cycles, critical outcomes are not always archived or available for continued reference. Websites are often shut down without protocols to redirect visitors to archived information. In addition, highly jargonized research terminology can make the material difficult for average readers to decipher. “A basic problem is that historically, funded research projects were not required to translate and transfer their research outcomes to targeted stakeholders, nor were researchers expert in Knowledge Translation. [19]

Knowledge Translation (KT) is defined by the Canadian Institutes for Health Research (CIHR) as “The exchange, synthesis, and ethically sound application of knowledge within a complex set of interactions among researchers and users to accelerate the capture of the benefits of research for all; through improved health, more effective services and products, and a

strengthened health care system.” Quality research continues to be produced but knowledge translation “requires coordination and process movement amongst a complex system to influence behavior change and patient outcomes.”[20] “NIDRR has remarked that KT plays an important role in enhancing the lives of individuals with disabilities, as science-based knowledge, technologies, and applications must be translated in order to inform disability and rehabilitation policy and improve practice.”[21]

In recent years, NIDRR has established KT-related requirements for major grantees like the RERCs and RRTCs, for example. In particular, NIDRR solicitations ask grantees to document how their research will reach and be used by critical stakeholders. Starting in 2005, NIDRR funded the Research Utilization for Support and Help (RUSH) project at the South East Development Lab.[22] The purpose of RUSH is to “expand awareness, strategies, and evaluation of knowledge utilization outcomes among NIDRR-supported researchers in order to increase access and use of research results by those that can most benefit from them.” The RUSH project facilitates KT by offering competitive Research Utilization Awards (RUA) to NIDRR grantees. One such award, titled “Face-to-face and Online Workshop for Clinicians and Suppliers on Manual Wheelchair Research and Practice” was won by the RERC on Wheeled Mobility in Everyday Life. As a result of the project, the RERC offers a web-based training program, called “Evidence Based Manual Wheelchair Prescription and Practice.”[23]

Certain of these centers help with knowledge translation by offering practical guides to their research findings. RideSafe, for example, offers a very user-friendly brochure, with information about how to ride safely in a wheelchair while traveling in a van or bus. The RideSafe brochure was developed by the University of Michigan Transportation Institute supported by the RERC on Wheelchair Transportation Safety. The brochure can be downloaded free (and is thus distributable to the public) at <http://travelsafer.org>. This brochure provides a

perfect example of knowledge translation making research and development outcomes accessible to clinicians and end-users.

7.3.3. Administration

Today's rapidly changing health care environment dictates that providers be able to identify appropriate services, rapidly modify their service delivery and manage their practices according to the best available evidence. In the absence of formal standards and in a specialty not acknowledged by professional therapy organizations, providers typically employ highly individualized methods of service delivery. The principles of evidence-based management offer a practical approach to improve organizational performance.

Evidence-based management (EBMgt) involves decision-making with development of organization practices based on the best available information. This form of management has roots in evidence-based medicine. EBMgt "...is a simple idea. It just means finding the best evidence that you can, facing those facts, and acting on those facts – rather than doing what everyone else does, what you have always done, or what you thought was true." [24] This section will provide examples of evidence-based management. Meanwhile, many concepts in management literature can be applied to wheeled mobility service delivery.

7.3.3.1. Context.

Providers of wheeled mobility devices are not typically involved in the administrative management of the service delivery organization. Conversely, healthcare managers are generally unaware that AT has been identified as one of the "key interventional approaches used to optimize function of people with disabilities." [25] In order to provide optimal service delivery, these perceptual gaps must close. Healthcare criteria for "excellence in organizational management" require performance analysis to include outcomes measurement.

The development of AT outcomes to guide clinical practice requires that the services be set in context and that the stages through which services progress be identified. Toward that end, the Rehabilitation Research Design & Disability (R2D2) Center, UW-Milwaukee as part of its research on AT outcomes produced the IMPACT2 model. This model “delineates variables we must measure to understand outcomes of assistive technology interventions as they are practiced in the natural environment.”[25] These variables are set within the six stages of an outcomes-based model that includes: 1) Pre-Intervention: Health Promotion and Universal Design, 2) Context: Person, Task and Environment, 3) Baseline: Function (performance, quality of life, participation), 4) Intervention Approaches: Reduce the Impairment, Compensate for the Impairment, Use Assistive Technology Devices and Services, Redesign the Activity, Redesigning the Environment, 5) Outcome Covariates and 6) Outcomes.

“Models such as IMPACT2 help researchers and practitioners understand key variables, relationships, and systems that stimulate advancements in theory, research and development, policy, and practice.”[26] This model can assist providers in educating other stakeholders, including administrators, policy makers and reimbursement agencies on the role of assistive technology to improve functional performance. In the IMPACT2 model, assistive technology is identified as a distinctly separate, person-specific intervention that takes into account individuals’ tasks, the environment in which they undertake them, the variables that may influence the success or failure of the assistive technology and the anticipated outcomes.

7.3.3.2. Performance indicators.

Clinical services by definition focus on direct patient treatment with therapeutic objectives rather than the purchase and sale of goods. Technological advancements have enabled therapeutic interventions, including the provision of devices, to substitute for loss of function. Acquiring these devices requires a skill set which clinicians typically lack. Understanding the

provision of wheeled mobility as a commercial enterprise will enable clinicians to use well-established business standards to improve their service delivery outcomes. In particular, it is critical to identify Key Performance Indicators (KPIs) for clinical service delivery. KPI are quantifiable performance measurements used to define success factors and measure progress toward the achievement of clinical service goals. The following example from the Baldrige National Quality Program suggests the relevance of KPI to clinical service delivery. [27]

The Baldrige National Quality Program offers the Healthcare Criteria for Performance Excellence, which [27] defines seven categories of core values and concepts that are “embedded in the beliefs and behaviors of high-performing organizations.” The seven performance categories include: Leadership, Strategic planning, Focus on patients, other customers and markets, Measurement, Analysis and knowledge management, Workforce focus, Process management and Results.

Consider as an example how Strategic Planning can apply to clinical service delivery. Strategic Planning involves analyzing the organization’s environment, deciding what it wishes to accomplish and how it will do so. As part of strategic planning, the development of vision, mission and value statements clarify: why an AT clinic exists, the purpose that it serves, and the clinic’s core priorities as it regards stakeholder value. Easy-to-access information on this process can be found online at the Free Management Library. [29]

Once performance categories for the provision of Wheeled Mobility have been identified – and valid measures established for each category – an evaluation of the organization’s performance in each category can guide improvements on behalf of both the practitioner and the organization.

7.3.3.3. Quality measures.

A 2001 NIDRR research priority “expressed concerns that outcomes measurement in AT [lag behind] those [of] other fields, and that AT outcomes have not kept pace with the growth of the field of assistive technology.” NIDRR specifically requested that two assistive technology outcomes projects – CATOR, based at Duke University, and the ATOMS Project, based at the University of Wisconsin-Milwaukee — address three specific areas: 1) Perform a needs assessment about assistive technology outcomes; 2) develop and explore new measurement methodologies and 3) examine issues surrounding assistive technology device abandonment. The ATOMS and CATOR Projects were each funded in the fall of 2001 for five years.

ATOMS (Assistive Technology Outcomes Measurement System) was housed in the Rehabilitation Research Design & Disability (R2D2) Center at the University of Wisconsin-Milwaukee. The project’s website was last updated in 2007 and still makes available a list of major grant accomplishments, including publications, presentations and links to additional sources of information. [30]

The stated mission of CATOR (The Consortium for Assistive Technology Outcomes Research) is to “conduct multiple research projects on AT outcomes and impacts to determine the effectiveness and usefulness of AT and the implications for use/discontinuance of AT devices.”[31] The CATOR research and development section lists current, funded research and states “This work is being conducted to address the three biggest needs facing AT outcomes researchers, namely: 1) efficient capture of data regarding the impact of AT on activity and participation, 2) efficient, comprehensive capture of data characterizing the nature of AT treatment interventions and 3) capture of data that reflects the impact of AT on caregivers for people with disabilities. It is anticipated that by achieving these specific aims, we will substantially improve the quality of AT outcomes research that can be conducted henceforth.”

Key findings from completed research include the importance of bringing conceptual clarity to the field of assistive technology outcomes measurement. The research also identifies barriers and factors contributing to assistive technology abandonment. The site also contains links relevant to the field of assistive technology and outcomes measurements.

A three-volume RESNA Resource Guide for Assistive Technology Outcomes was published in 1998. It “lays out the fundamentals of outcomes measures for assistive technology.” It is available through RESNA and at the Education Resources Information Center (ERIC), which is “an online digital library of education research and information. ERIC is sponsored by the Institute of Education Sciences (IES) of the U.S. Department of Education. ERIC provides ready access to education literature that supports the use of educational research and information to improve practice in learning, teaching, educational decision-making, and research.” Although the focus of the ERIC site is educational, technology-related, peer-reviewed articles can be accessed for information on process and outcome measures. [32]

Research continues on quality measures for outcomes specific to the provision of seating and wheeled mobility. These measures are “typically applied at the individual level rather than [being] global performance measures applied to the health care system.” A new conceptual model for AT outcomes research and practice has been proposed by Lenker et al that is user-centered and also predicts utilization patterns for AT to “frame research questions, interpret results and guide clinical practice.” “The goal of outcomes research is to identify generalizable truths that will improve practice.”[33]

Healthcare quality has historically been measured in a model with three separate domains: structure, process and outcome. [34] Current service delivery practices assume that good services will result in good outcomes. However this belief hinges on anecdotal evidence. It becomes obvious that all three domains must be recognized, assessed and improved upon.

Measures specific to service delivery of wheeled mobility have not been developed. To develop such measures, clinicians must understand the value of applying quality indicators, utilizing performance benchmarks and developing outcome measures to identify effective and efficient services. The following sections will introduce resources for identifying and applying such measures.

The National Quality Measures Clearinghouse™ (NQMC), sponsored by the Agency for Healthcare Research and Quality (AHRQ), U.S. Department of Health and Human Services, maintains a database and website that provide information on specific evidence-based health care quality measures and measure sets. AHRQ sponsors NQMC to “promote widespread access to quality measures by the health care community and other interested individuals.” The site contains scarce information specific to the provision of mobility AT but contains a vast data on quality measures for related clinical services and “examples of terms used to describe common properties of health care quality measures.”[35]

The AHRQ glossary provides information about the science of comparative effectiveness in “plain language” to be accessible to clinicians, consumers and others. Comparative effectiveness consists of a variety of health care outcomes research “that compares the results of one approach for managing a disease to the results of other approaches.”[36] Outcomes can “measure the effects a treatment has on people’s lives, such as changes in their ability to function or changes in their quality of life.”[37] Comparative effectiveness can help to determine which interventional approach provides the most effective, efficient, satisfactory and safe outcome.

Cost-benefit analysis, clinical performance measures and evidence-based practice are examples of other frameworks used to evaluate the effectiveness of healthcare delivery.

- *Cost-benefit analysis* is defined as a “form of economic analysis from a social perspective, in which the costs of medical care are compared with the economic

benefits of the care provided, with both the costs and benefits being expressed in monetary units; the benefits evaluated include projected decreases in future health care costs and increased earning as a result of the healthcare intervention of interest.[38]

- *A clinical performances measure* is a “subtype of quality measure that is a mechanism for assessing the degree to which a provider competently and safely delivers clinical services that are appropriate for the patient in the optimal time period.”[39]
- *Evidence-based practice* “includes the integration of best available research, clinical expertise, and patient values and circumstances related to patient/client management.”[40] “Development of evidence-based practice standards is crucial for developing outcomes that measure the impact of AT to facilitate decision making by practitioners, reimbursement agencies and consumers.”[33]

The above frameworks share similar concepts, but it is essential to develop a comprehensive framework with quality measures specific to wheeled mobility services. Clinicians must understand how the measures function as indicators of optimum performance in healthcare decision-making. The National Quality Measures Clearinghouse™ (NQMC), sponsored by the Agency for Healthcare Research and Quality (AHRQ), U.S. Department of Health and Human Services, provides information on how to select, apply and interpret a quality measure.[41] The following section will discuss the use of standards in relation to quality measures.

7.3.4. Standards

Standards include published documents developed to provide specifications for conformity in products, consistent terminology and broadly recognized measures of excellence for services.

7.3.4.1. Standards for devices.

RESNA is a standards-developing organization accredited by the American National Standards Institute (ANSI), which “is the official U.S. representative to the International Standards Organization (ISO).” “International standards are developed by ISO technical committees (TC) and subcommittees (SC) that adhere to a six-step process described in the Standards Chapter of this Industry Profile. A technical committee includes a working group (WG) of experts who prepare a working draft. Work being completed by ISO’s technical committees, including work on wheelchairs, wheelchairs and transportation and wheelchair seating, is listed on the RESNA website. The process by which members of the working groups are identified or how clinicians might participate in the standards development process is not clearly stated in the public domain.

A number of wheelchair standards exist already and others, as they relate to technical specifications, vocabulary and seated measures, are being developed. A clinician who must describe and quantify wheelchair seating solutions can consult measures contained in ISO 16840-1 Wheelchair seating Part: 1 Vocabulary. “The purpose of this part of 16840 is to specify standardized geometric terms and definitions for describing and quantifying a person’s anthropometric measures and seat posture, as well as the spatial orientation and dimensions of a person’s seating support surfaces. This also allows for the systematic monitoring of a person’s seated posture change over time.”[42] These standards enable providers to cross-reference wheelchair seating products and compatibility with cushion characteristics identified in funding

policy articles. The standards, however, have not been systematically translated into a format for clinical applications and are costly for the average clinician to purchase. Therefore, clinicians generally do not use these important standards to improve the quality of service delivery.

ISO 16840-1 vocabulary enables clinicians to measure body segments and posture in accordance with internationally recognized standards. Standardized measurements for postural support devices must then be linked to the terms “orthopedic deformities” and “postural asymmetries.” While these terms are meant to help define the medical necessity of funding coverage, no standard definition exists for either term. An overview of seating codes and determinations for medical necessity follows with concerns and inconsistencies highlighted.

“Standards” for funding through health insurance is provided by The Centers for Medicare & Medicaid Services (CMS). [43] CMS is a federal agency within the U.S. Department of Health and Human Services. One of its responsibilities is to administer funds allocated by Social Security law under Title XVIII Health Insurance for the Aged and Disabled. CMS, in turn, contracts with four regional Durable Medical Equipment Medicare Administrative Contractors (DME MACs). These DME MACS authorize funding for Durable Medical Equipment, Prosthetic, Orthotics and Supplies (DMEPOS), including wheelchairs and wheelchair seating by way of a number of supports including Local Coverage Determinations (LCDs). The LCDs contain Indications and Limitations of Coverage and or Medical Necessity sections and a Policy Article with definitions and guidelines for development of the numerical, Healthcare Common Procedure Coding System (HCPCS) codes mandated to be used for reimbursement. This standardized coding system is owned and maintained by the AMA. CMS deems it necessary to efficient claims-processing. For the purpose of this discussion, HCPCS Level I codes identify medical services and HCPCS Level II codes define durable medical equipment to include wheelchairs, seating and accessories.

There are numerous inconsistencies and insufficiencies within CMS's reimbursement system. For example: The LCD Indications and Limitations of Coverage and or Medical Necessity states, "A general use seat cushion (E2601,E2602) and a general use wheelchair back cushion (E2611-E2612) is covered for a patient who has a manual wheelchair or a power wheelchair with a sling/solid seat/back which meets Medicare coverage criteria." [44] In contrast, medical necessity is defined by CMS as "Services or supplies that are proper and needed for diagnosis or treatment of the patients' medical condition; furnished for the diagnosis, direct care, and treatment of the patient's medical condition; meet standards of good medical practice; and are not mainly for the convenience of the patient, provider, or supplier.[45] These contrasting definitions for medical necessity are both provided by CMS and yet the LCD does not reflect need relevant to secondary medical complications from sitting, only that the patient has a wheelchair.

Meanwhile, CMS criteria for provision of a skin protection cushion is divergent. The LCD Indication for Coverage and or Medical Necessity requires a present pressure ulcer or history of a pressure ulcer, impaired/absent sensation of the area in contact with the seating surface or inability to carry out a functional weight shift due to one of a listing of diagnoses. Conversely, within the CMS Manual System there are Guidelines to Surveyors for Long Term Care Facilities, henceforth referred to as "CMS Guidelines." These require facilities to focus on preventing pressure ulcer development. The CMS Guidelines also list indicators of residents who are at risk of developing pressure ulcers. These indicators include tissue changes "due to aging, for example: decreased subcutaneous tissue and lean muscle mass, decreased skin elasticity, and impaired circulation and or innervation." The guidelines also state that "Many studies and professional documents identify risk factors that increase a resident's susceptibility to develop or not heal pressure ulcers." [46] Examples of these risk factors include, but are not

limited to: exposure of skin to urinary and fecal incontinence, under-nutrition, malnutrition and hydration deficits. Clinicians are expected to recognize these risk factors and recommend appropriate interventions. The CMS Guidelines list research and resources to identify and support appropriate interventions for the prevention of pressure ulcers. But the LCDs set forth by CMS for funding these interventions only allow for treatment of a present pressure ulcer due to one risk factor: the resident's inability to carry out a functional weight shift. This does not support CMS mandates for a comprehensive quality care plan that includes preventative measures in response to the identification of multiple risk factors.

Obtaining CMS funding for wheelchair seating requires evidence-based prescription that can directly conflict with recognized standards of good medical practice. Despite these inconsistencies, clinicians are bound to recommend the interventions that are in the best interest of individuals with disabilities, based upon clinicians' skills and knowledge, rather than external standards whose principle purpose may be cost containment.

7.3.4.2. Standards for services.

Assistive technology service is defined as any service that directly assists an individual with a disability in the selection, acquisition or use of an assistive technology device.”[47] The rapid introduction of AT devices and a change in focus to the patient as a decision-making consumer has required clinicians to redefine their wheelchair clinic services. These changes focus on functional outcomes and performance in the community rather than traditional rehabilitation goals for increased functional capacity. By implementing the quality standards contained in the following resources, an AT service structure for today's health care environment can be defined.

The Baldrige “Health Care Criteria for Performance Excellence” are “designed to help organizations use an integrated approach to organizational performance management that results

in delivery of ever-improving value to patients and other customers, contributing to improved health care quality, improvement of overall organizational effectiveness and capabilities as a health care provider, organization and personal learning.”[29] The core values and concepts section “Management by Fact” asserts that “an effective health care service and administrative management system depends on the measurement and analysis of performance.” This measurement can, for example, be accomplished by completing a strategic analysis that identifies strengths, weaknesses, opportunities and threats (SWOT) for the provision of wheeled mobility. Such a strategic analysis could also set direction for service delivery systems. A basic SWOT analysis can be easily completed with the processes outlined on websites such as the Free Management Library. [48]

Quality standards for the provision of durable medical equipment prosthetic orthotic supplies (DMEPOS) have recently been developed by CMS.[49] The standards offer suppliers product standards that are specific to wheeled mobility and tools for business services including administration, financial management, human resource management, consumer services, performance management, product safety, and information management. These standards are intended for use by suppliers, but they offer guidance to clinicians on quality measures specific to wheeled mobility.

In RESNA’s “Guidelines for Knowledge and Skills for Provision of the Specialty Technology: Seating and Mobility” the authors acknowledge that “to provide the best possible services in the provision of Seating and Mobility, the knowledge and skills of several disciplines is required.” The clinician involved typically functions as the Seating and Mobility Assistive Technology Provider (SMATP). “A primary role of the SMAT Provider implicit in all the roles discussed is that of coordinating and managing the team effort in order for the consumer to achieve maximal functional seating and or mobility.”[50] These clinicians need a working

knowledge of the DMEPOS standards to assure that each team member is operating within good business and service practices. Additional information on these guidelines is contained in the section on medical standards of care.

Accreditation is defined as “a qualified endorsement that an organization provides services according to internationally recognized standards and demonstrates a commitment to continuous quality improvement with its focus on consumer satisfaction...”[51] Accreditation also provides a means of verifying service delivery quality. While these standards do not state how a service should be provided, they describe which services should be provided, and they explain why. A number of accreditation agencies providing direction to healthcare providers are context-specific (i.e., Rehabilitation centers, home and community-based centers, etc.). These agencies include: the Joint Commission on Accreditation of Healthcare Organizations (JACHO), the Community Health Accreditation Program (CHAP), the Accreditation Commission for Health Care (ACHC), the Compliance Team and others.

7.3.4.3. Classifications for AT.

The phrase classification rules imply a system of categorizing things according to their similarities. Classifications provide globally agreed upon definitions and descriptions to facilitate communication in a multitude of applications. An Assistive Technology device is defined in disability law as “any item, piece of equipment or product system, whether acquired commercially off the shelf, modified, or customized, that is used to increase, maintain, or improve functional capabilities of individuals with disabilities.”[47] Classifications for practical use of this definition can be found in The National Classification System for AT Devices and Services submitted to NIDRR in 2000 by the Research Triangle Institute.[52] The RTI classification system includes examples of architectural elements, sensory elements, computers,

controls, independent living, mobility, orthotics/prosthetics, recreation/leisure/sports, modified furniture/furnishing and services.

7.3.4.4. Terminology.

Each provider in the service delivery process brings a level of competence that is supported by knowledge gained from experience. The diversity of backgrounds and terminology — whose terms and definitions depend on the location and era in which they originated — negatively impacts the consistency required for effective knowledge translation. It is incumbent upon providers to extend themselves beyond the comfort of the familiar and recognize that continuous quality improvement requires learning and change to reflect the incorporation and application of new knowledge. Standardization of terminology is critical to improving communication between stakeholders and providing a basis to establish and assess health-related outcomes.

For example, if you seek information on “wheeled mobility,” a search of online dictionaries and encyclopedias returns no standard definition. The standardized terminology contained in the TRI classification and ISO terminology suggest that undefined terminology such as wheeled mobility might be replaced with Wheelchair Mobility Assistive Technology (WMAT) Devices and Services with support from the following standards:

- Wheelchair – a device to provide wheeled mobility with a seating support system for a person with impaired mobility in the ISO DIS 7176-26 standard.
- Mobility AT – an RTI classification that includes wheelchairs.
- Mobility Activity – moving around using equipment such as a wheelchair (or other mobility devices as defined in the WHO-ICF).

- Assistive Technology Devices and Services – defined in the Assistive Technology Act of 2004.

Consistent use of standardized terminology is also supported by the international standard “ISO 7176-26:2007 Wheelchairs. Part 26, which is titled “Vocabulary,” uses the term “postural supports” to expand upon the term wheelchair seating. Postural supports includes the entire body support system, including “those parts of the wheelchair which directly support or contain the body of the occupant including the seat, back support, arm support and foot support assembly.”[53] The clear definitions eliminate the confusing and inconsistent use of terms such as “seatback.” Other postural support devices are identified by which body part they support and by the direction of that support, whether anterior, posterior, medial, lateral, inferior or superior. One example is the term “medial upper leg support” to replace the terms abductor (typically used by medical professionals), medial thigh support (used by CMS in the LCD) and leg divider (used by manufacturers).

Terminology for health and health-related states developed due to an international recognition that a standard language and framework improves “communication between different users, such as health care workers, researchers, policy-makers and the public, including people with disabilities.”[54] In 2001, the World Health Organization (WHO) published the standard terminology in the International Classification of Functioning, Disability and Health. “The International Classification of Functioning, Disability and Health, known more commonly as the ICF is a classification of health and health-related domains. These domains are classified from body, individual and societal perspectives by means of two lists: a list of body functions and structure, and a list of domains of activity and participation. Since an individual’s functioning and disability occurs in a context, the ICF also includes a list of environmental factors.”[54]

ICF's stated aim was to provide a unified, standard language and framework for the description of health and health-related states in order to facilitate communication between medical and non-medical stakeholders. The standard language also appears to be capable of describing seating and wheeled mobility outcomes. [54]

“In June 2008, the American Physical Therapy Association (APTA) joined the World Health Organization (WHO), the World Confederation for Physical Therapy, the American Therapeutic Recreation Association and other international organizations in endorsing the International Classification of Functioning, Disability and Health. With this endorsement, ICF language will be incorporated into all relevant association publications, documents and communications through existing planned review and revision cycles.” To assure professional compliance, ICF terminology can be easily linked to individual states' rules, regulations and definitions for clinicians. [55]

7.3.5 Knowledge Translation

In the healthcare domain, *knowledge translation* (KT) has been defined as “The process whereby information is transferred to clinicians and applied in practice, a process that requires understanding of organizations, individual and team education and health services research, among others.[56] The central theme of this chapter is knowledge translation as a means to clarify communication between stakeholders and to facilitate the incorporation of processes for continuous quality improvement in the provision of WMAT services.

In an effort to advance KT, several academic programs and international organizations have established centers that conduct KT-related research, development, and dissemination activities, including the Knowledge Translation Program at the University of Toronto in Canada. There, a multidisciplinary academic program “was developed to address the gap between

research evidence and clinical practice and the need to focus on the processes through which knowledge is effectively translated into changed practices.”[56]

Previous sections of this chapter bridged the gap between research evidence and clinical practice by providing a framework for the description of health and health-related states, a classification for assistive technology and standardized terminology to describe wheelchair mobility assistive technology (WMAT) devices and services. This framework can now be extended to clinical practice.

The provision of WMAT requires inter-disciplinary participation and much of the previous information pertains to both clinicians and suppliers as providers of assistive technology. However, this author emphasizes that ultimately, business practices and professional conduct are defined by the rules and regulations to which each provider is legally bound. For example, physical therapy records are legally defined by state practice and professional conduct regulations. These regulations outline how to prepare and maintain documents, including: findings of examinations, evaluation conclusions, determination of the diagnosis and prognosis, referrals, a plan of care with measurable goals for the intervention, response to the intervention and current status, progress, changes, communication and a discharge summary. [59] The following sections demonstrate how clinical practice can apply the concepts introduced in this chapter.

7.3.5.1. Conventional clinical terminology and interventions.

The Centers for Medicare and Medicaid Services (CMS), Durable Medical Equipment Medicare Administrative Contractors (DME MAC), Local Coverage Determination (LCD) and Policy Articles use the conventional clinical terms of orthopedic deformities and postural asymmetries. Relevant glossaries and dictionaries offer either no reference or varying descriptions for these terms. The Merriam-Webster Medical Dictionary defines orthopedic as

“...marked by or affected with a deformity, disorder or injury of the skeleton and associated structures...” Stedman’s Medical Dictionary defines deformity as “a permanent structural deviation from the normal shape, size, or alignment...” Dorland’s defines posture as a position of the body “usually considered to be the natural and comfortable bearing of the body in normal, healthy persons” with Merriam-Webster defining asymmetry as a “lack of coordination of two parts acting in connection with one another.” In the general case, this conventional clinical terminology is compatible with descriptors for body structure and function found in The World Health Organization International Classification of Functioning, Disability and Health (WHO-ICF).

The WHO-ICF states as its intent to establish “a common language for describing health and health-related states in order to improve communications between different users, such as health care workers...” Part 1: Functioning and Disability contains two components: a) Body Functions and Structures and b) Activities and Participation. Body Functions are the physiological functions of body systems. For example, Chapter 7 of the WHO-ICF defines neuromusculoskeletal and movement-related functions (i.e., functions of the joints and bones, muscle and movement). Similarly, Body Structures are the anatomical parts of the body related to movement (i.e., the pelvic region, lower extremity and trunk). Under Activities and Participation, Chapter 4, Mobility, describes sitting as a component of changing and maintaining body position.

Combining standardized WHO-ICF terminology and conventional clinical terms to describe skeletal deformity and movement deviations enables the following working definitions. Orthopedic deformities are body structure deviations. Postural asymmetries are mobility impairments due to neuromusculoskeletal and movement-related function impairments. These

working definitions, and the use of ICF qualifiers indicating the severity of the associated impairment, can be used to describe a level of function.

A working definition for the term *intervention* can be found in Taber's Medical Dictionary. Here "neurophysiological treatment" (intervention) is defined as, "In occupational and physical therapy, various techniques used in sensorimotor rehabilitation that rely on voluntary and involuntary activation, facilitation, and inhibition of muscle action through the reflex arc."

7.3.5.2. Developing a plan of care.

Using these terminologies, a plan of care for the provision of wheelchair mobility assistive technology (WMAT) would include:

- a. The objective (for the intervention), which is the provision of WMAT (wheelchairs and seating systems)
- b. Managing the mobility impairment (defined disability/diagnosis of/prognosis for)
- c. Meeting the goal of increasing movement-related body function (or amelioration of movement-related functional limitation/medical necessity)
- d. Improving the activity of moving around using equipment (intervention intended to produce change in level of function)
- e. Pursuing a functional outcome (performance/quality of life/well-being) of increased participation in life situations (ICF) or CMS's mobility-related activities of daily living (MRADLs).

The following sections provide further detail to the outlined plan of care by using international terminology and integrating available evidence into clinical practice for recommending wheelchair seat cushions. The expectation is that the same conceptual

framework could be applied to the other postural supports and to wheelchairs in general. Giving further detail to the plan of care:

- a. The objective or purpose for the clinical service is the provision of durable medical equipment (DME) for WMAT. It is expected that the patient has received the defined clinical elements of management that lead to optimal outcomes. These elements are defined for physical therapists as: *examination, evaluation, diagnosis, prognosis, intervention and outcomes.*
- b. Effective patient management, including examinations and evaluations, has resulted in a diagnosis of defined neuromusculoskeletal and movement-related impairments to “help determine the prognosis (including the plan of care) and the most appropriate intervention strategies.”[58]
- c. These diagnosis-driven descriptors of body impairments can be linked to the conventional clinical terms, describing orthopedic deformities and postural asymmetries, necessary to meet funding criteria.
- d. Physical therapy prognosis “means the determination of the predicted level of optimal improvement that may be attained through the intervention...”[58] The subsequent descriptors for wheelchair seating interventions follow the algorithmic progression of need as outlined by CMS and adds the conventional clinical terms and principles of treatment previously defined.

The intervention of wheelchair seating is therefore recommended, due to a defined disability that results in body structure and or body function impairments, with the prognosis to:

1. Provide therapeutic benefits (by allowing buttock immersion) for sitting due to the individual’s inability to walk (ambulate effectively) for individuals who have been

- determined to require a wheelchair to move around their environment for participation in their life situations or mobility-related activities of daily living (MRADLs).
2. Decrease the potential for development of pressure ulcers associated with long-term sitting secondary to impaired body functions (neuromusculoskeletal and movement-related) by redistributing the pressure across the body structures related to movement and skin, or by addressing microclimate, shear, tissue deformation, etc. concerns secondary to identified risk factors.
 3. Support impaired muscle (power and endurance) functions (of the structures related to movement) that result in a (quantifiable) impaired ability to change and or maintain the sitting position necessary to participate in life situations/mobility-related activities of daily living (MRADLs).
 4. Decrease movement function impairments due to impaired muscle tone using neurophysiological techniques of placing the body segment in the degree of angle necessary to provide the sustained continuous mechanical stretch to reduce impaired motor reflex functions (i.e., spasticity that results in an impaired ability to maintain a sitting position) to participate in life situations/mobility-related activities of daily living (MRADLs).
 5. Provide the cushion characteristics necessary to support body structures (due to impaired motor reflex functions, i.e., startle syndrome and or involuntary movement reaction functions such as balance and or righting reactions) to participate...
 6. Provide the postural support necessary (due to ineffective control of the voluntary movement functions, i.e., coordination) necessary to participate...

7. Provide the postural support necessary (due to impaired involuntary movement functions, i.e., athetosis) to participate...
8. Provide the postural support, via custom fabricated seat and or back cushions, necessary (due to orthopedic deformities and or postural asymmetries that exceed the immersion levels, structural feature heights, and or posterior or lateral contours provided by pre-fabricated seating) to participate...

The rationale for the first, second and eighth descriptors are based on CMS's LCD for Wheelchair Seating. As discussed, certain CMS LCD criteria, like stating that a general-use seat cushion is covered for a patient who has a Medicare-covered wheelchair, has little relevance to clinicians who need to establish medical necessity. The following sections will demonstrate how available knowledge can be used to document medical need for the above interventions.

Steven Sprigle, Ph.D., PT director, Center of Assistive Technology & Environmental Access, Georgia Institute of Technology, Atlanta produced an article for Rehab Management with the intent "to help define common terms that can be used to describe cushions and the new manner in which many payers categorize cushions." [59] In this article, "Categorizing Cushions," Sprigle states that CMS coverage and coding "requirements suggest that to have therapeutic value, a cushion must allow the buttocks to immerse a minimum of 2.5 cm (~1")." Therefore, a general-use seat cushion could be considered medically indicated as therapeutic due to "loss of function." The Disability Evaluation under Social Security "Blue Book" defines loss of function as the inability to ambulate or perform fine or gross movements effectively and or limitations due to pain of people with disorders of the musculoskeletal system to include "the inability to walk effectively." [60] This document is discussed further in Section 3.6.3.

To receive a skin protection seat cushion, the CMS LCD indicates that a patient must currently have, or must have once had, pressure ulcers or absent or impaired sensation on the

area of contact with the seating surface or an inability to carry out a functional weight shift. Sprigle states, “In addition, to provide skin protection, a cushion must allow 4 cm” (~1 ½”) of immersion. This value [immersion depth] was chosen because it reflects the anatomical relationship between the inferior aspect of the ischial tuberosities and the trochanters. In short, a cushion is deemed to have skin protection characteristics if it permits enough immersion to involve the lateral aspect of the buttocks in load redistribution, thus rationalizing the second intervention above. If the medical necessity is to provide skin protection, this could perhaps be more accurately defined as a need to redistribute the pressure load in sitting and decrease the potential for development of pressure ulcers, due to an inability to carry out a functional weight shift.

A combination skin protection and or positioning seat cushion is covered if the patient has a Medicare-covered wheelchair, has met the stated coverage criteria for a skin protection cushion and or has any significant postural asymmetries included among a list of diagnoses. If the patient’s needs cannot be met by these previously described pre-fabricated cushions, the LCD states that a custom-fabricated cushion is covered if the patient “meets all of the criteria for a prefabricated skin protection seat cushion and positioning seat cushion” and “[t]here is a comprehensive written evaluation by a licensed/certified medical professional, such as a physical therapist (PT) or occupational therapist (OT), which clearly explains why a prefabricated seating system is not sufficient to meet the patient’s seating and positioning needs. The PT or OT may have no financial relationship with the supplier.” No indications for medical necessity are provided.

A biometric approach can establish medical necessity by documenting that the patient’s orthopedic deformities and or postural asymmetries (as measured according to international standards in the sagittal, frontal and transverse planes) exceed the LCD-described immersion

levels and structural feature heights provided by pre-fabricated seating dimensions. This provides an objectively quantified explanation for why a prefabricated cushion will fail to meet the patient's seating and positioning needs.

In summary, the above framework advances a therapeutic plan of care that defines a medically relevant intervention to achieve a functional outcome for WMAT, specifically seating, by stating that the recommended wheelchair seat or back cushion (as defined by funding criteria and codes) is indicated:

- Due to orthopedic deformities and or postural asymmetries (documented according to conventional clinical terms)
- To provide the therapeutic intervention necessary for people with body structure and or body function impairments (as identified by the ICF common language used to describe body systems)
- To achieve the goal of safely changing and or maintaining the sitting position (according to international standards for quantifying anthropometric measures)
- To occupy and or operate a wheelchair, to be moved or move around (using equipment)
- For the functional outcome of improving and or maintaining the capacity of an individual with disabilities to participate (performance) in life situations (mobility related activities of daily living).

This example shows that WMAT devices can be acquired through a demonstration of medical necessity using a common terminology and framework, and in accordance with funding requirements. This approach could be generalized to plans of care for: other classifications of WMAT specific to an individual's body structure and or function impairments, use of WMAT to

facilitate participation in varying life situation activities, and WMAT use within a task specific or general environment.

To conclude this example, use of a common terminology and framework to facilitate inter-disciplinary communication and practice can and must be addressed to improve the efficiency and effectiveness of service delivery. “Leaders or organizations must have the courage to act on the best facts they have right now, and the humility to change what they do as better information is found.”[61]

7.3.6. Medical Standards of Care

Development of internally driven standards enables clinicians to “maintain control over the definition and quality of medical care.” “Only by applying medical standards of care and evidence-based medicine can inappropriate care be identified in a manner that is credible...”[62] The failure of clinicians involved in WMAT service delivery to develop analogous standards has resulted in third-party payers stepping into this void and developing both national coverage policy and medical review criteria for its programs. These criteria, with a focus on cost-containment, portend significant ramifications for clinicians’ inability to address known risk factors and for their clients, who may develop secondary medical complications as a consequence. Incorporating medical standards of care into daily practice can ensure that acceptable levels of performance have been identified, guidelines will be used for decision making, services will be reviewed for appropriateness and measures for quality of performance will be applied.

In the absence of standards for WMAT services, related medical standards offer guidance in defining quality of clinical practice. Medical standards of care “have become an accepted and essential part of medical practice and health care delivery.” “The American health care sector

has indeed moved from a paradigm of autonomous professional decision making to one of collective decision making based on empirically derived standards of care.”[63]

For example, the Institute of Medicine (IOM) Roundtable Evidence-Based Medicine, Annual Report, Learning Healthcare System Concepts v. 2008 was convened “to help transform the way evidence on clinical effectiveness is generated and used to improve health and health care. “Activities include collaborative exploration of new and expedited approaches to assessing the effectiveness of diagnostic and treatment interventions, better use of the patient care experience to generate evidence on effectiveness, identification of assessment priorities, and communication strategies to enhance provider and patient understanding and support for interventions proven to work best and deliver value in health care.”[63] These activities expand upon a 1990 report on medical standards of care in which the IOM established a taxonomy of standards that remains relevant today. [62]

According to this taxonomy, the following types of medical standards are used in the United States: standards of quality, clinical practice guidelines, medical review criteria and performance measures. The following sections will use IOM standards as a framework to discuss quality measures from the perspective of WMAT service delivery and resources for quality measures.

7.3.6.1. Standards of quality.

According to the IOM, standards of quality are “statements of the minimum acceptable level of performance or results, what constitutes excellent performance or results, and the range in between.” The focus is process-oriented. For example, accreditation is defined as an endorsement that “the organization’s programs and services have met consumer-focused, state-of-the-art international standards of performance.”[64] The Commission on Accreditation of Rehabilitation Facilities (CARF) lists among its AT accreditation standards the basic principles

that should be demonstrated and include expectations regarding the organization, the services, outcomes, collaborations, time frames and identification of needs. This component of the IOM standards would include the development of vision, mission and value statements as previously recommended in section 3.3.2.

7.3.6.2. Clinical practice guidelines.

According to the IOM, clinical practice guidelines are “systematically developed statements to assist practitioners in their decision making in specific clinical settings.”

In 1997, the National Institute on Disability and Rehabilitation Research (NIDRR) of the U.S. Department of Education, awarded grant #133A300328, titled National Guidelines for Education of Providers and for Continuous Quality Improvement in Assistive Technology. This grant was awarded to RESNA with members of the Guidelines Development Committee of the RESNA Special Interest Group 9 (SIG09) Wheeled Mobility and Seating producing: Guidelines for Knowledge and Skills for Provision of the Specialty Technology: Seating and Mobility.[50] The document identifies the “particular skills and knowledge that are needed beyond the basic skills of an Assistive Technology Practitioner or Assistive Technology Supplier. Although certification for this Seating and Mobility Assistive Technology Provider (SMATP) does not yet exist, the document describes the roles providers fulfill to Inform, Assess, Strategize, Implement and Assure provision of seating and mobility. The SMATP guidelines can also provide a basis to: clarify clinician roles and responsibilities, establish a mentoring program to fill educational gaps, measure clinical performance and evaluate departmental policies, procedures and customer satisfaction.

Research into the development of clinical prediction rules suggests how clinical practice guidelines can improve the decision making process. *Clinical prediction rules* (CPRs) are defined as “decision-making tools for clinicians, containing variables from the history, physical

examination, or simple diagnostic tests.”[65] Development of these rules involves a review of methodological standards, synthesis of the evidentiary data, selection of predictive variables for the CPR, assessment of intended and unintended outcomes using the CPR and practical issues such as the acceptance, reproducibility and ease of use of the CPR in clinical settings.[65] Clinicians would necessarily need to be familiar with the evidence rating scales, scales for grading recommendations and their implications for practice.

The article, *Development and Application of Clinical Prediction Rules to Improve Decision Making in Physical Therapist Practice* in the *Journal of the APTA* provides an excellent overview of the rationale and process intended to improve clinical decision making. [65]

7.3.6.3. Medical review criteria.

Medical review criteria, according to the IOM, are “statements used to assess the appropriateness of specific decisions, services, and outcomes in the delivery of health care.”

Before target outcomes, like increased participation in life situations, can be stated, the individual’s activity limitation must be quantified, using disability criteria. The next section will discuss common language used to document impairment, via the WHO-ICF, which, when aligned with Social Security definitions for loss of function, supports eligibility for benefits such as wheelchairs and seating.

Although the WHO-ICF provides a framework for describing function and health, it does not identify a level of impairment that determines whether an individual is considered to be disabled and thus, qualified for medical assistance in the U.S. To fill this gap between the WHO ICF and the legal definition of disability, the Disability Evaluation under Social Security can be utilized.

Disability Evaluation under Social Security (also known as the Blue Book), “has been specially prepared to provide physicians and other health professionals with an understanding of the disability programs administered by the Social Security Administration. It explains how the programs and provides information a health professional can furnish to help ensure sound and prompt decisions on disability claims.” The Listing of Impairments categorizes system disorders and defines impairments to include loss of function and evidentiary requirements such as medical evidence and reports, consultative examinations and evidence relating to symptoms.[60]

The provision of WMAT to individuals with disabilities, to increase function, is now supported by the following logical progression:

1. Therapy interventions include the treatment of movement-related functional limitations, according to state licensure rules and regulations.
2. A wheelchair is defined by international standards as a device to provide wheeled mobility with a seating support system for a person with impaired mobility (ISO 7176-26).
3. The evidence, for body-system impairments that result in impaired mobility (loss of function) required to qualify for health insurance benefits, is described in the Disability Evaluation under Social Security.
4. Use of a wheelchair has been classified as a means to move the body from place to place (WHO-ICF Activities & Participation Component, Mobility Domain).
5. Medical need for a wheelchair and seating can be clinically supported by use of standard terminology to define impairment and activity limitations (WHO-
6. ICF, Body Function and Structure Component).
7. The selection of wheelchair seating products to provide “improved body support, movement control and injury prevention” can be quantified by standardized

- geometric terms and definitions for a person's anthropometric measures and seat posture (ISO 16840-1).
8. Funding requirements for wheelchairs and seating can be met through utilization of the above resources to describe indications for coverage/medical necessity (CMS LCDs).
 9. Outcomes resulting from the wheelchair intervention, i.e., increased participation in life situations, can be quantified according to situation-specific outcome measures.
 10. Provision of a wheelchair (a device to provide mobility to a person with impaired mobility to improve function) is thus a reasonable, medically necessary intervention.

This progression demonstrates the use and value of standards to define the provision of WMAT. This approach provides a solid foundation for establishing assistive technology outcomes.

7.3.6.4. Performance measures.

Performance measures, according to the IOM, are “specific measures of a quantitative nature that estimate or monitor compliance with medical quality standards, medical practice guidelines, and medical review criteria by health care professionals.”

Information on performance measures can be found at The National Quality Measures Clearinghouse (NQMC). NQMC is sponsored by the Agency for Healthcare Research and Quality (AHRQ), U.S. Department of Health and Human Services and “is a public repository for evidence-based quality measures and measure sets.” The clearinghouse contains “measures of access, process, outcome, and patient experience [to] assess the quality of care provided by health care professionals and organizations” with measures of structure [to] assess the capacity of health care professionals and organizations to provide high quality of care.”[66]

Despite the dearth of practice guidelines, best-practices standards that incorporate evidence-based data, clinical prediction rules or outcome measures for service delivery,

providers of WMAT devices and services are being scrutinized in their overall performance. Many clinicians have relied upon expert opinion to guide clinical performance with a focus on personal methodology and minimal consideration of process management. In sharp contrast, increased oversight and regulatory activities by funding agencies mandate that healthcare professionals demonstrate accountability through consumer responsiveness and provide accurate documentation of the plan of care. The agencies also mandate that these actions have value.

The current clinical “state of the practice” is unlikely to satisfy funding agency requirements. Escalating health care costs, resulting in measures to contain expenditures, have also created a demand for clinical productivity. One clear example is the delivery of WMAT services in timeframes that enable organizations to remain fiscally viable. Providers should not advocate an idealized service delivery model that cannot be supported. Instead, clinicians should advocate and develop evidence-based clinical performance measures that promote implementation of effective and cost-efficient services through continuous quality improvement (CQI).

CQI has its origins in the Japanese term “Kaizen,” a system of making small improvements on a regular basis. The concept involves moving beyond problem solving to an overall attention to detail with a constant search for opportunities to improve processes. The intent of this section on medical standards of care was to look beyond use of the simplistic term “best practice” with the implication that there is one static process that is more effective at delivering a particular outcome than any other. Perhaps “best practice” could better be defined as a dynamic process that uses “reasonable standards of effectiveness and efficiency, adopting widely accepted research and evaluation procedures, and pursuing continual, incremental improvement... while acknowledging the legitimate value of experience, observation, and judgment.”[67]

This interpretive overview has discussed external standards that influence medical practice and health care delivery. The development of internal standards to improve the quality of wheelchair mobility assistive technology services obliges providers to demonstrate professional competency and develop a strategy for the future. Review of national programs, projects and initiatives can facilitate the process to delineate a strategy, identify priorities for assistive technology services and enable integration of new findings into practice for continuous quality improvement.

7.4. Summary

RESNA states, “We are an interdisciplinary association of people with a common interest in technology and disability” and yet we are so much more. We are a united group of professionals who take profound interest in, and care deeply for, our fellow human. We use skills and knowledge to serve this expression of our deep belief in the inherent worth and dignity of all individuals.

We appreciate that, despite shortcomings and imperfections, wheelchair mobility assistive technology enables every member of this global community to participate in the life they choose.

Understanding and improving the service delivery model is a work in progress. This chapter is merely an overview of a small portion of available resources. It is by no means to be considered comprehensive. It is offered to demonstrate a response to an average clinician’s question, “How can I better serve my patients?”

How? I embrace the vision that wheelchair mobility assistive technology can optimize the health and well-being of individuals with disabilities and empower them to achieve personal goals.

My mission is to maintain a practice that is an excellent resource for information, with competent providers and quality services for the provision of wheelchair mobility assistive technology devices according to the following values:

- This practice adheres to professional Standards of Practice and Codes of Ethics, legal and regulatory mandates, and risk management strategies.
- This practice informs individuals and their representatives on Mobility Assistive Technology devices, the applications and related services.
- This practice conducts an assessment via recognized Seating and Mobility Assistive Technology provider roles, responsibilities and defined tasks supported by the necessary knowledge base.
- This practice defines a strategy with team members to develop an intervention supported by: the individual's desired outcomes, service delivery structure, funding and availability of community resources.
- This practice implements services according to accreditation standards as a qualified endorsement that providers conform to national and internationally recognized service standards.
- This practice collaborates with Healthcare and Assistive Technology Providers who demonstrate the qualifications, consumer-related service work experience and a dedication to the welfare of those served.
- This practice values certification as a means to validate a provider's qualifications and knowledge in a defined functional or clinical area.
- This practice utilizes national and international standards for clear communication and a unified framework for provision of assistive technology devices and services.

- The practice strives to assure provision of quality services through the use of evidence-based management and practice, identification of functional outcomes and affirming the need for continuous education and quality improvement.
- This practice affirms that quality of life is specific to and defined by each individual person receiving services.

Today's culture has come to recognize that health and well-being can truly only be defined by people with disabilities themselves. As providers, we are obliged to increase our expectations, expand our knowledge and deepen our understanding of how to best serve these individuals and society as a whole. The recommendations in this overview should not be seen as insurmountable hurdles but rather as stepping stones to elevate our professions above the mundane and be recognized for the worthy endeavor it is.

“The journey of a thousand miles begins with one step.” Lao Tzu.

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Chapter 8

Wheelchair Seating and Mobility Research

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Contents

	Section	Pg
8.1. Introduction		237
8.2. Establishing Seating and Wheeled Mobility Research Priorities		239
8.3. Research Priorities: Wheeled Mobility		244
8.4. Research Priorities: Seating and Positioning		253

8.1. Introduction

In 2006, the Mobility Rehabilitation Engineering Research Center (Mobility-RERC) at the Georgia Institute of Technology held its State of the Science Conference. The purpose of this Conference was to “address challenges in studying the health, activity and participation of wheelchair users.” One hundred and ten researchers, clinicians, policy-makers, manufacturers, methodologists, wheelchair users and representatives from federal research funding agencies were invited, ninety accepted and sixty-seven participated. Each invitee was asked to identify three “most important issues” in each of the two areas of wheeled mobility and seating/posture. Following a review process, seven highest ranked topic areas were each identified under mobility and under seating/posture.

Conference participants voted to select eight topic areas for discussion. The four topic areas selected for mobility were: Impact of long-term wheelchair use; Relating activity and participation to health outcomes; Translating research into design; and Impact of wheelchair design on function. The four topic areas selected for seating/posture were: Determining cushion adequacy; Positioning abilities of cushions; Long-term impact of sitting; and Impact of seating and mobility interventions. Conference attendees participated in breakout groups to discuss the eight topic areas. The charge to breakout groups was to: ‘Configure your research topic into a research project’. They were provided with general guidelines to identify research questions, specific aims or hypotheses, significance, study design possibilities, recruitment considerations, measurement variables and tools, analysis considerations and anticipated challenges.

Results from the SOS Conference were published in three papers in the *Journal on Disability and Rehabilitation: Assistive Technology*, May 2007; 2(3). The titles of these papers are: 1) Establishing Seating and Wheeled Mobility Research Priorities, 2) Research Priorities: Wheeled Mobility, and 3) Research Priorities: Seating and Positioning. With permission, these

papers have been reprinted and incorporated into the Industry Profile on Wheeled Mobility. We thank the Journal on Disability and Rehabilitation: Assistive Technology and Informa Healthcare for their generosity and assistance.

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Establishing seating and wheeled mobility research priorities

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Establishing seating and wheeled mobility research priorities

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Abstract

Purpose. The Mobility Rehabilitation Engineering Research Center at the Georgia Institute of Technology held its State of the Science Conference to address challenges in studying the health, activity and participation of wheelchair users. The purpose of this project was to collect and report seating and wheeled mobility research priorities.

Methods. Invitations were sent to researchers, clinicians, policy makers, manufacturers, methodologists, wheelchair users and federal funding agency scientists. Invitees submitted their three most important wheeled mobility and seating issues. Submissions were blinded and collated into distinct topic areas with the most oft-mentioned topics comprising seven priority topics within each of the mobility and seating areas. Conference attendees voted on these topic areas, narrowing the priorities into four mobility and four seating/posture topics.

Results. The Wheeled Mobility research priorities included: impact of long term wheelchair use, relating activity & participation to health outcomes, translating research into design, and impact of wheelchair design on function. The Seating/Posture research priorities included determining cushion adequacy, positioning abilities of cushions, long term impact of sitting, and impact of seating & mobility interventions.

Conclusion. Significant areas of study remain to fully associate AT interventions and the health and everyday functioning of wheelchair users.

Keywords: Assistive technology, wheelchairs, mobility, seating, research

Introduction

The rapid change in the healthcare system and the development of emerging assistive technology (AT) dictates that rehabilitation scientists and clinicians keep pace. The field of AT and particularly the subspecialty of seating and wheeled mobility have not yet developed a mature scientific body of evidence. To date, there has been remarkably little study of the association between AT interventions and the health and everyday functioning of wheelchair users. Stakeholders have an interest in learning about whether new technologies and treatments are effective in impacting a person's everyday life.

Increasingly, clinicians and scientists are called to provide more scientific evidence to support the success seen clinically. This is especially true with regard to coverage determination for seating and mobility products. Moreover, in the world of wheeled mobility, one has yet to prove the link between active living and medical health.

Research design in the area of seating and wheeled mobility presents unique challenges. The length of time needed for the service delivery component (evaluation, lag time between evaluation and provision of seating and mobility device and follow-up evaluation), scarcity of reliable objective measures and the number of potential confounding factors specific to the person, technology and environment increase the complexity of issues under study. Specifically, variants include patient comorbidities and differences in severity of illness; system level variables, such as policies and regulations influencing patient care practices and funding; clinician knowledge, skills and training; and variations in environments and technologies.

Challenges in designing methodologies that can control for these confounding variables are vast. For these reasons, scientists are often reluctant to study the effectiveness of AT interventions related to everyday function. The purpose of this paper is to report the seating and wheeled mobility research

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priorities as defined by a diverse group of seating and mobility professionals.

Methods

The Mobility Rehabilitation Engineering Research Center (mobilityRERC) held its State of the Science Conference on 17–18 September 2006. This was a consensus building forum to address the methodological challenges of studying the health, activity and participation of wheelchair users.

Invitations were sent to 110 researchers, clinicians, policy-makers, manufacturers, methodologists, wheelchair users and representatives from federal research funding agencies. Of those, 90 accepted and 67 attended the working group portion of the conference. As a part of the registration process, invitees were asked to identify the three most important issues in the two areas of wheeled mobility and seating. These submissions were blinded and separated into either seating or mobility categories. MobilityRERC staff reviewed all submissions and collated them into 15–20 topic areas. The topics with the greatest number of responses were identified, resulting in a list of seven priority topics within each of the mobility and seating categories.

At the conference, attendees were introduced to each topic area and voted on their priorities, narrowing the topics to four each for mobility and seating/posture (Table I).

Results

The priority topics identified are listed below, using the format of an introductory statement followed by the specific research question(s) to be addressed.

Priority topics: Wheeled mobility

- (1) *Impact of long-term wheelchair use.* Long-term (manual) wheelchair use can expose users to secondary physiological complications, whether related to propulsion, transfers or performing functional tasks from a seated

Table I. Topics voted as highest priorities by Conference attendees.

Mobility	Seating/posture
Impact of long-term wheelchair use	Determining cushion adequacy
Relating activity and participation to health outcomes	Positioning abilities of cushions
Translating research into design	Long-term impact of sitting
Impact of wheelchair design on function	Impact of seating and mobility interventions

position. These secondary effects are difficult to measure as they do not occur in isolation, but rather co-mingle. Furthermore, over a lifetime of wheelchair use, the impact of using varying equipment in differing environments must be considered.

- What is the best methodology for studying the long-term effects (health impacts) of wheelchair use over the lifetime of a wheelchair user?
- (2) *Relating activity and participation to health outcomes.* In the US, provision of wheeled mobility devices within the third party payment system is based on medical necessity. General consensus in the service delivery community is that greater emphasis should be placed on functional needs to maximize activity and participation. Within the International Classification of Function model, activity and participation are seen as indicators of health.
 - What methodology can be used to study the relationship between activity & participation and medical benefit?
 - What are the health impacts of community activity and participation?
 - (3) *Environmental influence on mobility.* Despite the Americans with Disabilities Act and advances in wheelchair technology to overcome physical barriers, the environment continues to present hurdles, whether real or perceived, to the activity and participation of wheelchair users.
 - What methods can be used to measure the influence of the environment on the activity and participation of wheelchair users (being mindful of minimizing subject burden)?
 - (4) *Wheeled mobility vs assisted ambulation.* Wheeled mobility tends to be viewed differently from other forms of assisted mobility, i.e., lower extremity prosthesis use, with respect to societal attitudes, public policy and funding. Why? How do equipment use, activity and participation differ in wheelchair users vs ambulators who require prostheses?
 - What type of useful information would this comparison generate and what is the best method to do a comparative study of the activity and participation of wheelchair users vs those who ambulate with the aid of a lower extremity prosthesis?
 - (5) *Impact of wheelchair evaluations.* The consensus of many rehabilitation clinicians is that a proper and thorough seating and mobility evaluation is necessary to insure the health

and function of a client. As with the provision of any service, the quality of a wheelchair evaluation outcome is related to the skill of the provider(s). Participants voiced a myriad of concerns regarding assuring quality evaluations to optimize outcomes both in regard to matching technology to user needs and assuring high end training on use of the recommended equipment.

- What is the best means to train service providers (clinicians and Rehab Technology Suppliers) and to measure the impact of training/skill level on wheelchair evaluation outcomes?
 - What approach can be used to answer the question: does a seating/mobility evaluation improve the health and function of a wheelchair user?
- (6) *Translating research into design.* Historically, there has not always been a direct link between academic research findings and the design of new mobility products.
- What is the best method to apply research results to the design of new mobility products?
- (7) *Impact of wheelchair design on function.* Many designs of wheelchairs are commercially available—a fact that offers the potential for choice, but also complicates the selection process.
- How does mobility equipment impact the medical and functional outcomes of wheelchair users?

Priority topics: Seating and posture

- (1) *Defining acceptable tissue loading.* Causation of pressure ulcers is a multi-factorial process, although, by definition, localized external pressure is the primary causative factor. Studies have shown that both magnitude and duration of pressure can be damaging. There is currently not a scientifically sound method of determining a 'safe' magnitude and duration of load, specific to the individual. These factors drive clinical interventions such as cushion selection and pressure relief schedules. The guideline most often referenced, the Reswick and Rogers Curve, lacks scientific rigor.
- How can acceptable pressure magnitude and duration be determined for an individual—in a lab environment and within a clinical situation?
- (2) *Determining cushion adequacy.* Each wheelchair user presents a unique profile, which impacts tissue tolerance, risk for pressure ulcers and equipment (support surface
- needs. Funding guidelines often dominate clinical decision-making regarding the type of cushion recommended (least costly) and the timing of cushion replacement. Short of obvious material failure or incidence of pressure ulcer, there is a dearth of clinical guidance to determine if a current cushion is still 'good enough'. Such clinical information could also guide whether initial cushion selection is good enough.
- What methods can be used to develop a systematic, clinical approach to answer the question: 'Is this cushion good enough?'
- (3) *Balancing postural support and function.* By nature, postural support devices can limit freedom of functional movement. Whether postural support devices are used to aid in balance, address orthopaedic deformity or both, there is generally a trade-off of restricted movement. Is the trade-off too great? Is there a way to achieve a better compromise?
- How can one study the compromise between postural support and functional movement to better address the tradeoffs between the two?
- (4) *Positioning abilities of cushions.* Current cushion categories include those which offer 'positioning'. Bench tests exist to determine whether a cushion fits into this category. However, correlation of these bench tests with actual clinical performance of positioning cushions is lacking. Furthermore, does a cushion which offers positioning also offer a better base of support from which to perform functional tasks?
- What are the best methods to objectively measure performance of functional activities across different wheelchair cushions *in situ*?
 - What is a clinically valid approach to study the postural and functional impacts of cushions and postural supports?
- (5) *Variable position seating.* Variable position seating systems, especially power seating functions (tilt, recline, seat elevation and standing), are under regular scrutiny by third party funding systems as lacking medical necessity.
- How does one best study the medical benefits of variable position seating?
- (6) *Impact of seating and mobility interventions.* In the seating (and mobility) profession, 'proof' of the benefits of seating (and mobility) interventions is largely anecdotal or based on single-subject case studies. The typical Randomized Clinical Trial (RCT) is not an appropriate methodology to study the effects

of a particular seating or mobility intervention.

- In lieu of the RCT, what is the best method to measure the effects of a particular seating or mobility intervention? Is there a way to effectively study the return on investment of a particular seating or mobility intervention?

(7) *Long-term impact of sitting.* The long-term use of wheelchairs can expose users to secondary postural/musculoskeletal complications. Understanding the impact of long-term wheelchair use may lead to prevention of these complications. A need exists to study how specific mobility and seating devices and interventions impact long-term conse-

quences of wheelchair use. For the purpose of this discussion, the following two questions are raised:

- How does one measure the long-term consequences of sitting with respect to spinal and pelvic deformities?
- How can one measure the ability of cushions and support surfaces to prevent musculoskeletal complications?

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Research priorities: Wheeled mobility

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Research priorities: Wheeled mobility

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Abstract

Propose. To bring together an interdisciplinary group of leaders in the field of seating and wheeled mobility to discuss and exchange information about the methodological challenges of studying health, activity and participation of wheelchair users. This article summarizes the discussions from the Wheeled Mobility breakout groups.

Methods. Conference attendees were provided with wheeled mobility priority topics determined by consensus. Groups were tasked with configuring a research topic into a research project. Each group was provided with a general framework to guide discussions: identify research questions, specific aims or hypotheses, study design possibilities, recruitment considerations, measurement variables and tools, analysis considerations and anticipated methodological challenges.

Results. The four priority research topics examined were: Impact of mobility equipment on health outcomes; Relating activity and participation to health outcomes; Impact of wheelchair design on function; and Health impacts of long-term wheelchair use.

Conclusions. Synopses were compiled from group notes and presented to all conference attendees. Groups identified several challenges that require consideration, a few examples include: recruitment of homogeneous samples, controlling for biases, sample sizes, complexities of multisite studies, intrusive monitoring and measures, validity and reliability of test environment.

Keywords: *Wheelchair, research, methodology, activity, participation, health, outcomes*

Introduction

The Wheeled Mobility State of the Science Conference, hosted by the mobilityRERC at the Georgia Institute of Technology, was a forum to identify and discuss important research topics. The Conference was configured around Breakout Groups which were assigned specific research topics. These topics were selected via dot-voting by Conference attendees.

The charge to the Breakout Groups was simple, yet unattainable: 'Configure your research topic into a research project'. They were provided with general guidelines to identify research questions, specific aims or hypotheses, significance, study design possibilities, recruitment considerations, measurement variables and tools, analysis considerations and anticipated challenges.

This article summarizes the discussions from the Wheeled Mobility Breakout Groups. The four research topics selected for discussion were: Impact of mobility equipment on health outcomes; Relating activity and participation to health outcomes; Impact

of wheelchair design on function; and Health impacts of long-term wheelchair use. One member of each Group documented the discussion and a summary presentation was made to all Conference attendees. The following synopses were compiled from the Group notes and presentation. They are presented in sequence and reflect variability in discussion, presentation and content. Some research topics were more amenable to the suggested guidelines than others.

Impact of mobility equipment on health outcomes

Research questions

- What is the effect of powered vs manual mobility on secondary conditions (arthritis, obesity, etc.) over time?
- What is the effect of several, optimal mobility devices vs a single, general purpose device on access to daily activities?

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Hypotheses

- H1: Users of powered mobility devices (and/or their caregivers), when compared to manual mobility users, will have a decreased incidence of shoulder pain and fatigue, but may show an increase in obesity and other health issues.
- H2: Compared to single device users, individuals with multiple devices will have fewer incidences where loss of equipment limits activity, more social participation, fewer falls, and more independent activities of daily living (ADLs).

Significance

It is generally agreed that research examining the impact of mobility equipment on health outcomes can influence public policy and clinical practice. Depending on the results, there can be a positive or negative effect. Public and private policy dictates reimbursement practices for most mobility equipment. Today, available evidence is largely anecdotal. Empirical evidence is needed in order to influence funders and policy makers, effect change and improve clinical practice.

As an example, in the US, funding policy mandates the use of a manual wheelchair for as long as possible. Only when a person can no longer functionally use a manual wheelchair are they eligible to move to a power wheelchair. By that time, frequently, the individual has developed co-morbidities that are not only limiting their ability to manage a manual wheelchair but also affect their ability to perform ADLs. Studies examining equipment distribution practices (devices, timing and health outcomes) will provide empirical evidence that is needed to influence and transform reimbursement practices.

Another important policy trend is the provision of only one mobility device which is meant to address all of an individual's mobility needs for all environments. However, one device for multiple functions may result in the device becoming sub-optimal for everything. This group suggests conducting a multiple device study which can have important public policy implications. Why not have multiple devices specifically targeted for certain activities? What happens when something breaks? Clearly people with multiple devices will have less down time as they have an alternative option. Does having multiple devices affect social participation? Long-term costs of equipment vs healthcare utilization costs? Reduction in secondary complications due to having more than one way to do things? These are some of the questions identified.

It is not unusual that professionals responsible for making mobility equipment decisions are unfamiliar with contemporary evidence. There is a significant gap in what is known in research and what is known in the clinic. For instance, it is sometimes argued that a manual wheelchair provides cardiovascular

exercise that limits obesity and maintains fitness. Consequently, professionals and funders are sometimes hesitant to recommend power mobility due to the detrimental effects. Yet, evidence supporting this claim is not compelling. More is needed to facilitate efficient knowledge translation and impact the clinical practice of front line professionals responsible for these types of decisions.

Design possibilities

Four design possibilities were discussed.

- (1) Multiple device study using ABAB single case design;
- (2) Longitudinal cohort study examining manual vs power mobility;
- (3) Multiple case control study using subject pools from Veterans Administration (VA) and Centers for Medicare and Medicaid Services (CMS) with adjustments for population differences; and
- (4) Multiple device study using ABAB single case design using real life situations (shopping mall, street crossing, daycare, etc.).

Recruitment considerations

Many of the workgroups at this State of the Science conference have recommended using the VA as an experimental variable. This group discussed the idea of comparing other healthcare systems internationally (across the border, north or south, across the ocean). However, these types of international collaborative studies can be difficult to coordinate and involve multiple confounders that can be hard to control.

Also, due to the diversity of disability populations, identifying homogeneous samples is challenging. Using the prior example of a VA population, it is known that Veterans have more comorbidities at any given age than other people. Therefore, a VA population is different from civilian populations and, although inferences can be made, the ability to generalize to other populations is limited.

Measurement considerations

Finally, the group discussed difficulties with measurement. Some measures available for use may be accurate and reliable yet can present aesthetic issues or complexity impacting subject compliance. For example, the Dynaport Activity of Daily Living (ADL) monitor is worn as inter-connected waist and thigh straps. This device is designed to detect a person's body position (orientation in space) and time (duration) in a position. Although this device may be useful for detecting movement, difficulty with donning and doffing the device can influence

the thoroughness and quality of the data. Subject burden must be considered when selecting measurement tools, as devices or measures that are viewed as invasive will certainly influence subject willingness to participate in both short-term and longitudinal studies.

Variables and measurement approaches

A number of variables and methods for measuring medical and functional outcomes are listed in Table I. This table is not intended to be a comprehensive list of variables and is offered only for consideration. A variety of measurement tools and instrumentation devices are available today. Others are continually becoming available for general use. The groups' discussion centred only on general approaches and methods but did not go further to detail specific measures.

Analysis considerations

The Group agreed that estimating power calculations is problematic due to the lack of prior research. Pilot studies and resultant preliminary findings are needed to establish appropriate sample and effect sizes for larger studies. Furthermore, care is needed when examining the impact of mobility equipment on outcomes as it is not possible to blind the subject or researcher from the intervention introducing potential bias. Also there is a potential for selective

perception—the newer different technology is better. Finally, each subject will naturally vary in their day-to-day activity level, attitudes and perceptions. This variability will undoubtedly have an effect on the outcomes of interest. It is important that these variables are considered and controlled for as much as possible in the design of the study.

Anticipated challenges

In summary, the group has identified several challenges that require consideration when embarking on this line of research. A few examples are described here.

- Recruitment of homogeneous samples of subjects is unattainable; therefore in the study design, consideration of methods that can control for confounders is needed.
- Multi-site collaborative projects involving multiple facilities, healthcare systems or organizations can encounter obstacles (i.e., recruitment issues, facility operating procedures, documentation and Institutional Review Board requirements). Anticipate delays.
- Intrusive monitoring and measures that jeopardize subject privacy is yet another challenge that can adversely affect subject compliance especially for longitudinal studies.
- Using a geriatric population presents unique challenges such as experimental mortality, attrition, loss to follow-up, etc. Therefore, larger sample sizes may be required to account for this problem.
- The test environment (laboratory vs field) contributes to the validity and reliability of the findings. Yet, both approaches are vital to advancing science. Examining the strength of the correlation (positive or negative) between controlled standardized trials and real life environments is needed.
- There is a cost associated with the equipment needed for trials that involve the use of technology. Partnering with manufacturers is essential to leverage resources to enable advancement of this line of research.

Relating activity and participation to health outcomes

Research questions

- What methodologies can be used to study the relationship between activity and participation and health benefit (medical, psychosocial, communication, mental health, employment)?
- What are the health impacts of community activity and participation?

Table I. Variables and methods for measuring medical and functional outcomes.

	Descriptors
Independent variables	
Healthcare system	VA, Medicare/Medicaid, Workers' compensation, Vocational Rehabilitation, Private Insurance, International healthcare systems, etc.
Device(s)	Type or number of mobility device(s)
Environment	Controlled test laboratory, real world environment
Dependent variables	
Pain	Pain scales
Fatigue	Survey instruments
Metabolic consumption	Wearable metabolic energy monitors, instrumented devices (GPS, data loggers)
Joint integrity	X-rays, Ultrasound, palpation, examination
Productivity	Efficiency, time, success rate
Social perception	Social interactions, attitudes
Satisfaction	Survey instruments and scales
Behavioural monitoring	Observation, video, self report survey, diary
Assistance required	Observation, self report survey, video

Need

The need to study the link between activity and participation (A&P) and health benefit was unanimously agreed upon by this group. Evidence is needed to assist practitioners as to how to best prescribe mobility devices to those with mobility impairments and to inform public policy regarding the impact of proper equipment. The lack of objective evidence regarding the true impact of mobility devices on users' health, activity and participation, as well as on caregivers and society at large, leaves policy-makers to make decisions based solely on the initial costs of the devices themselves. With such limited information it is not surprising that policy would be driven more to restrict the purchase of items than to enable those with mobility limitations.

In addition to impacting public policy, this area of investigation can provide important feedback to manufacturers. Identifying specific problems experienced by wheelers during daily activities can drive innovation and improve devices.

With a greater understanding of the activities and participation of individual users, one can begin to develop patterns and eventually predictor variables that are strongly correlated with health. Furthermore, understanding health benefits related to activity and participation will enable clinicians to improve the quality of their wheelchair assessment and prescription skills by making better matches between the person and the technology.

Discussion Question 1: What are the methodological challenges to studying health, activity and participation of wheelchair users?

In discussing methodological challenges the group identified several issues surrounding the International Classification of Functioning, Disability and Health (ICF) categories. The group agreed additional work is needed to operationalize terms and concepts.

Precise operational definitions can afford straightforward measurement and at the same time enable different research groups to study health benefit, activity and participation in ways that can be compared. Operational definitions will drive the selection, use and development of specific measurement tools. For this topic, multiple terms and questions were identified that require operational definitions. A greater understanding of these issues is the first step towards identifying an appropriate research design.

While discussing the ICF category *Functioning and Disability*, the group discussed the sub-category of *body structure and function*. It was agreed that *health benefit* is closely tied to the concept of *medical*

necessity. For instance, if a mobility device does not have a health benefit it is not considered medically necessary and therefore not funded by traditional third party payors. Therefore, linking health benefit to mobility device use has important implications in influencing access to mobility devices. The group questioned if medical necessity should include categories beyond body structure and function (i.e., activity and participation, environmental factors, personal factors)?

In discussing activity and participation the group established that it was non-sensical to separate these two categories. In practicality it is less important to differentiate these categories than it is to agree upon sub-categories that can be clearly defined and applied to studies in a uniform way.

The group unanimously agreed that the concept of *medical necessity* needs to be operationally defined. Medical necessity was a controversial topic of discussion with differing opinions depending on a group member's position and perspective. There are numerous definitions of medical necessity used today, even within the same federal agencies. There is no doubt a range of interpretations, some more restrictive than others, underlining the complexity of the subject. A discussion ensued comparing and contrasting other concepts of necessity: *functional necessity* and *health necessity*. Are these concepts related? Is there overlap? How are these concepts related? More work is called for defining medical necessity.

Next, the group discussed how clinical interventions (seating and positioning and mobility) can be linked to outcomes (i.e., health benefit). The value of this link is undisputed but making the link is complex since withholding an intervention is unrealistic and possibly unethical. This discussion transitioned into why the link between clinical interventions and outcomes is important. Clinicians desire outcomes so they can utilize evidence-based practice (EBP) to improve clinical care. Researchers and clinicians want to prove effectiveness and efficacy of interventions. Manufacturers want to design useful, desirable and fundable products.

In summary, three primary aims were identified.

- (1) Define medical necessity in terms that reflect the real day-to-day activities of wheelers.
- (2) Define activity and participation incorporating sub-categories to lead to specific measures that afford greater precision and agreement.
- (3) Determine the cost/benefit of provision of proper mobility and assistive technology equipment.

Question 2: What methodologies are appropriate to study activity and participation and health benefits?

There are many study design possibilities to tackle this research topic. This group discussed the need for concurrent projects to address the complex and pressing issues associated with activity and participation, health benefits and public policy. Various samples were discussed. Cohort studies comparing veterans and civilians are one way to examine differences in healthcare systems within the US. Also, matched cohort studies were identified as another method to enable specific comparisons.

In no particular order, five topics emerged. Yet, detailed methodologies require further development.

- (1) Develop a computer model of different concepts of medical necessity specifying levels of qualification (lesser to greater limits). Using a model, examine the relationship of levels of qualification to health benefit and health costs to the individual, family and society. Does dispensing less equipment result in greater costs down the line (lost work hours, secondary complications, etc.)?
- (2) Conduct a matched cohort study to compare outcomes of veterans and civilians with similar injuries/disabilities. Determine if there is a relationship between funding source and the equipment provided, activity and participation and health outcomes based on the equipment provided.
- (3) Conduct an exploratory study examining expert clinician conduct for mobility prescription. How do specific variables (diagnosis, functional ability, coverage) impact prescription? Determine the levels of agreement and discord.
- (4) Conduct a study randomizing persons with disabilities to physical activity interventions (exercise related activities and participation) vs non-exercise related activities and participation (i.e., art classes, social activities, support groups). Determine if there is a relationship between group and health outcomes.
- (5) Compare the use of different devices (power assist vs traditional manual or powered mobility) and the impact the device has on activity, participation and health outcomes.

Recruitment considerations

Study of activity and participation and health outcomes is complicated. Identifying a sample of homogeneous recruits is particularly challenging. It was generally agreed that focused research is needed, resulting in typically smaller sample sizes. For estimate purposes and due to the lack of precedent studies, it was agreed that a sample of 30 is a good starting point, adding 10 subjects per

variable, depending on the desired effect size. Therefore, with seven variables, 90 subjects are needed. Overall it was agreed that in order to obtain large enough sample sizes, multi-centre studies are needed.

Variables

Study of activity and participation and health outcomes is challenged by identifying variables that are quantifiable and sensitive to change. The group discussed variables of interest. Clearly the number of variables studied needs to be carefully considered as more variables dictate larger sample sizes which can be difficult to obtain.

There are a number of valid and reliable measures for the variables listed in Table II. A few specific examples are in Table III. For other variables, new measures will need to be developed and psychometrically tested.

Anticipated challenges

Standardized use of terminology (activity and participation, health benefit, medical necessity) emerged as a surmountable challenge. The group believed that adoption of common operational definitions will improve the ability to compare and repeat study results.

Identifying the variables to be studied and the measurement tools used presents both methodological and logistical challenges. The burden of data collection (subject burden, caregiver burden, clinician burden) clearly impacts the feasibility of conducting this type of clinical research. Researchers are challenged to purposefully design studies that can allow data collection to be as unobtrusive as possible. New psychometrically developed measurement tools are also needed for this line of investigation.

Overall, there was agreement that significant impact on public policy can be achieved with credible empirical evidence. A need exists and it is a priority to produce this type of evidence.

Impact of wheelchair design on function

Research question

- How can evidence-based practice guidelines drive the design and dissemination of knowledge regarding mobility devices?

Need

The group collectively agreed on the importance of educating all stakeholders who make product decisions (product design, manufacturing, prescription,

Table II. Domains and variables of interest to the study of activity and participation and health outcomes.

Domain	Potential variables
Health body function and structure	Personality profile (hardiness, temperament) Psychological (depression, affect, well-being, Positive Affect Negative Affect Scale (PANAS) [1]) Physiological perceptions (pain, fatigue) Wheelchair Users' Shoulder Pain Index [2] Health/fitness measures (body mass index, cardiac output, pulmonary function, wheelchair performance, lipid profiles, etc.) Physical measures (ROM, strength, joint integrity)
Activity and participation	Functional status (ADLs, IADLs) Level of activity and participation (Participation Survey/Mobility - PARTS-M, Physical Activity Scale for Persons with Physical Disabilities (PAS-PD) [3], Daily Life Events inventory (DLE) [4], survey, interview, prompted recall) Instrumentation of wheelchair or person (cameras, distance, speed, global positioning devices, etc.)
Environmental factors	Home and community accessibility Community Perceived Participation Receptivity Survey (CPPRS) Home and Community Environment Instrument (HACE) Levels of support within the community (personal assistance, accessible transportation, employment, etc.)
Economic measures	Cost of device Cost of not getting equipment (personal assistance required, pressure sores, lost productivity, hospital stays), etc. Healthcare utilization (clinic visits, hospitalizations) Impact on family (caregiver burden)

Table III. Measurement variables.

Dependent variables via Physical examination	Independent variables	Covariates
Pain (e.g., Wheelchair User's Shoulder Pain Index)	Duration of manual wheelchair use	Other health conditions—complete medical screen
Musculoskeletal Overuse Syndrome—upper extremity nerve entrapment syndrome, rotator cuff tendonitis, bicipital tendonitis and/or subacromial bursitis	Level and completeness of SCI	History of wheelchair type (i.e., type/make and model, seating system)
Strength and ROM: shoulder and wrist		Age
Skeletal deformities: pelvic alignment, spine deformities		Age at injury
		% time wheelchair used during day
		Environmental factors (i.e., surfaces and inclines)

fitting and training) in order to ensure that individuals with mobility impairments obtain access to the most appropriate technologies. Viable research evidence is needed to drive this process. In order to provide greater clarity and specificity, the group chose to substitute *evidence-based practice* (EBP) for *research results*.

How do you go about establishing EBP guidelines that can drive product design and knowledge dissemination? And how do you close the loop communicating information from the field back to manufacturers so that new features or fixes can be incorporated into new product designs?

One answer is to ensure that all stakeholders take part in the research process. Utilizing participatory design enables manufacturers to identify real life needs and create solutions to address those specific needs. Rather than utilizing custom fixes to recurrent problems the group saw the need to influence innovation and development. A systematic process is needed for establishing a research agenda that can have the greatest influence on

product design and product function. Then the process can be generalized for other technologies.

Discussion Question 1: What challenges are there in establishing EBP guidelines to drive mobility product design and dissemination of knowledge about mobility products?

The group agreed that manufacturers and clinicians need to collaborate in developing a research agenda that can validate the effectiveness and efficacy of mobility products. Due to the rapid manufacturing cycle (concept to design to manufacturing to marketplace) it is important that EBP research be embedded in this research process. Once optional laboratory standards' testing (ISO, ANSI/RESNA) are becoming more commonly required for certain mobility products due to federal demands and regulations. Future research needs to link standards testing to product performance in everyday life. In addition, stakeholders need to develop reliable and

valid measures of product performance that can be used in the field.

Similarly, clinicians are under pressure to provide evidence supporting the claims espoused in marketing materials. Currently, position papers frequently published by clinicians are comprised solely of 'expert opinion', the least rigorous form of evidence and most vulnerable to bias.

Working together, manufacturers and clinicians can provide evidence that demonstrates what works and for whom it works best. EBP means integrating individual clinical expertise with the best available external clinical evidence from systematic research. A systematic and collaborative effort between these groups will provide the most rigorous and useful research data. Once a claim has been empirically proven, researchers can disseminate and publish this information. Then, a purposeful plan of knowledge translation and utilization can be devised which will influence front line clinicians and manufacturers, impact patient outcomes and, thus, close the research loop.

Specific aims

- (1) Develop EBP guidelines for matching the person to the technology or product;
- (2) Use evidence to drive the design process;
- (3) Implement a knowledge translation programme for those who make product decisions;
- (4) Validate standards (ISO/ANSI/RESNA) testing in everyday life;
- (5) Develop new valid and reliable functional metrics of mobility device performance that can be used in the field,
 - (a) Determine priority performance variables,
 - (b) Develop a means of measuring knowledge utilization (decision-making using EBP);
- (6) Validate current *expert opinion*; and
- (7) Accumulate and use evidence to influence public policy

Discussion Question 2: How are EBP guidelines established to drive the design and dissemination of knowledge about mobility products?

The group discussed a progressive process to establish EBP guidelines as follows. First the group suggested creating a logic model (identifying short-, medium- and long-term impacts) as a means to create a theoretical model. Data mining and consensus building to facilitate this process were established as potential approaches to accomplish this task. Secondly, the group proposed identifying

tentative or formative guidelines for decision-making about mobility products. Next, a pilot study was proposed to evaluate initial guidelines and identify specific areas to measure. Later on, more complex cost effectiveness studies can be conducted to establish the return on investment for mobility products.

Discussion Question 3: What measurement considerations are needed?

A mixed methods approach with both quantitative and qualitative data was determined to be optimal for this area of investigation. Methods may include a range of approaches including video, case analysis, literature review, data logging/instrumentation and data mining of medical charts and repair history. Objective evidence is needed to quantify product performance and function. Self-report, interviews and surveys are methods that can be employed for obtaining user perception and quality of life measures.

Recommendations

In closing, the group suggested some recommended rules for approaching this topic of investigation.

- Stay focused on task;
- Keep the project small and manageable;
- Seek and obtain collective administrative buy-in and prioritization; and
- Gain support from others involved (line workers, sales force, funders, therapists, physicians, etc.).

Health impacts of long-term wheelchair use

Research question

What are the effects of long-term manual wheelchair use on musculo-skeletal status and function among people with SCI?

Hypotheses

- H1: Impacts on the musculo-skeletal system are a monotonic function of duration of manual wheelchair use.
- H2: Musculo-skeletal effects are a function of level and completeness of injury.

This Breakout group focused the research question on a specific diagnosis. This was a prudent decision given the complexity of the question. The variability in health and function of wheelchair users is enormous and a more homogeneous

subject cohort will increase power to discern differences. However, as the Group's discussions reveal, even a cohort of only wheelchair users with SCI has a lot of variability and poses many research challenges.

Need

Understanding the long-term impact of wheelchair use has a very high level of importance as it can contribute to the development of multi-faceted interventions, including lifestyle changes, equipment and education.

Study design considerations

The group identified a descriptive cross-sectional study as the most appropriate. Within this design, people differing in length of wheelchair use (hypothesis 1) and completeness of SCI (hypothesis 2) will be recruited and evaluated for musculoskeletal impairment. This cross-sectional design can suggest associations between exposure (e.g., wheelchair use) and impairment, but cannot prove causality.

Recruitment considerations

As mentioned, the decision was made to specifically define the subject cohort as persons with spinal cord injury. Inclusion criteria would include manual wheelchair users (minimum of 1 year) who have different levels and completeness of SCI. Subjects should be without concomitant disabling conditions such as a traumatic brain injury. Bias would be controlled, in part, by recruiting subjects from different geographic regions which would require a multi-site study. Focused outreach efforts would be used to insure inclusion of underserved populations. Providing transportation and offering appropriate honoraria would also help control for recruitment bias. Sample size was discussed and appears very dependent on available funding.

Two potential sources of subjects and data are the SCI Model Systems and the VA SCI Registry. Both include information on medical conditions and extend across geographical boundaries.

Measurement variables

Consistent with the two stated hypotheses, the independent variables reflect manual wheelchair usage and level and completeness of SCI. Impairment will be determined via physical examination and concentrate on skeletal alignment, pain and muscular functioning. The list of covariates under-

scores the reasoning behind narrowing inclusion to a single diagnosis. Despite a focus on a single disability, the number of confounding variables is long and will pose a measurement problem. The differences in equipment and equipment usage (in both time and environment) may have a great influence on long-term effects. Subject variability may also confound those variables due to differences in age and age at the time of injury.

Analysis considerations

These variables lend themselves to a multivariate analysis. MANCOVA is a special type of multivariate analysis of variance in which dependent variables are adjusted for differences in the covariates. Secondary analysis may include log-linear regression, a type of regression that seeks the best fit of data within a log-linear model. It can work well with categorical data such as included in this study.

Anticipated challenges

The anticipated challenges for such a cross-sectional study are many. Recruiting a large enough subject pool over different areas is a paramount challenge. As with any multi-site study, attention must be paid to standardizing data collection and developing a centralized database. In essence, this research project will require many people to come together for the greater good.

Acknowledgement

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Research priorities: Seating and positioning

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Research priorities: Seating and positioning

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Abstract

The Mobility Rehabilitation Engineering Research Center at the Georgia Institute of Technology held its State of the Science Conference to address challenges in studying the health, activity and participation of wheelchair users. This article summarizes the discussions of four seating and positioning research topics.

Attendees were divided into Breakout Groups and assigned specific research topics that were deemed priorities by the attendees. Breakout Groups were charged with configuring the research topic into a research project and were asked to identify research questions, specific aims or hypotheses, significance, study design possibilities, recruitment considerations, measurement variables and tools, analysis considerations, and anticipated challenges.

The four research topics selected for discussion were: Impact of a seating and mobility intervention, Defining a systematic clinical approach to cushion selection, Functional impact of wheelchair cushions, and Long term impact of sitting.

Group synopses presented in this paper were compiled from Group notes and presentation. They are presented in sequence and reflect variability in discussion, presentation and content. Some research topics were more amenable to the suggested guidelines than others.

Keywords: *Wheelchair, seating, wheelchair cushion, pressure ulcer, posture*

Introduction

The Wheeled Mobility State of the Science Conference, hosted by the mobilityRERC at the Georgia Institute of Technology, was a forum to identify and discuss important research topics. The Conference was configured around Breakout Groups which were assigned specific research topics. These topics were selected via dot-voting by Conference attendees.

The charge to the Breakout Groups was simple, yet unattainable: 'Configure your research topic into a research project'. They were provided with general guidelines to identify research questions, specific aims or hypotheses, significance, study design possibilities, recruitment considerations, measurement variables and tools, analysis considerations and anticipated challenges.

This article summarizes the discussions from the Seating and Positioning Breakout Groups. The four research topics selected for discussion were: Impact of a seating and mobility intervention; Defining a systematic clinical approach to cushion selection; Functional impact of wheelchair cushions; and Long-term impact of sitting. One member of each

Group documented the discussion and a summary presentation was made to all Conference attendees. The following synopses were compiled from the Group notes and presentation. They are presented in sequence and reflect variability in discussion, presentation and content. Some research topics were more amenable to the suggested guidelines than others.

Impact of a seating and mobility intervention

Research questions

- What methodologies are appropriate to measure the effect of a particular seating and mobility intervention?
- When is the randomized control trial (RCT) appropriate for seating and mobility research?
- What approach can effectively study the return on investment of an intervention?

These research questions developed via discussion about the overall goal: linking 'benefit' to an intervention or to a product. The group chose to

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discuss different methodologies that may meet this overall goal, with a specific discussion on one methodology, the RCT. This endeavour was meant to promote clinical research using all appropriate methodologies. The aims of such discussion would be to develop a protocol to select a level of research methodology to better measure the outcomes of seating and mobility interventions and to standardize the types of data collected across types of studies.

Significance

The need to study seating and mobility interventions was met by strong consensus of the group. Evidence-based practice is needed by wheelchair users, clinicians, funding agencies and industry. Practitioners and students (e.g., Physical and occupational therapy students) were identified as key to performing this type of research since they can address one important barrier, the lack of research capacity. Their involvement requires methods that are accessible and amenable to clinical research.

Question 1: What methodologies are appropriate to measure the effect of a particular seating and mobility intervention?

As a part of the methodology discussion the group reviewed a recent article by Guyatt et al. [1] which presented a hierarchy of strength of evidence for treatment decisions (Table I). The $n=1$ methodology fostered significant discussion. On one hand, an $n=1$ methodology may be accessible to practicing clinicians and can inform treatment decisions. A possibility exists to compile and aggregate $n=1$ data into a database of clinical evidence. On the other hand, the $n=1$ methods have well-documented validity risks that must be addressed via sound methodological approaches.

Other design possibilities were also discussed, many of which included correlational or quasi-experimental designs. For instance, a standardized seating evaluation could generate consistent clinical data across facilities. Aggregated data would increase statistical power and may permit an epidemiological-

Table I. Hierarchy of strength of evidence for treatment decisions.

n of 1 randomized trial
Systematic review of randomized trials (meta analysis)
Single randomized trials (classic RCT)
Systematic review of observational studies addressing patient-important outcomes
Single observational study addressing patient-important outcomes
Physiologic studies
Unsystematic clinical observation

type investigation. The greatest challenge lies in establishing a standardized assessment to permit such investigation.

Question 2: When is the RCT appropriate for seating and mobility research?

The group readily acknowledged that the randomized control trial is firmly entrenched in medical research. However, investigating the effect of a seating and mobility intervention does not fit nicely into a RCT methodology. The group identified and discussed 28 challenges in using a traditional RCT within seating and mobility research, including the following:

- Subject pool is small and non-homogeneous;
- Interventions cannot be withheld on ethical and legal grounds;
- RCTs work best with a single outcome, yet seating and mobility interventions are multi-variate;
- What is the standard of comparison? There is no 'gold standard' to compare a new product to because the outcomes vary for different people;
- Intervention outcomes have too many confounding factors: Is the product successful because of the product or because of the service delivery team or because of the client's social support or ...?
- Seating and mobility products come in too many permutations, hindering the definition of the experimental variables;
- Product field trials do not have a standardized testing protocol;
- Funding of interventions: Clinicians cannot provide multiple interventions. Seating and mobility devices are covered only once every 5 years;
- Funding of research: Since there is no mandate to prove effectiveness of a product, manufacturers have no incentive to support an expensive methodology. In addition, the short lifespan of certain technologies lessen manufacturer interest in longer trials; and
- Service delivery is a complex process.

Measurement variables

Any study into the effectiveness of seating interventions will be challenged by the identification of variables. The group discussed both outcome or dependent variables (Table II) and the descriptive variables needed to reflect client characteristics (Table III).

Clearly, not all of these outcome or descriptive variables can be collected and tracked. Therefore,

researchers must clearly define their constructs and only collect variables that validly reflect them.

Anticipated challenges

Standardization of data emerged as a challenge in measuring effectiveness of an intervention. This conclusion resulted from the belief that multiple facilities will be needed to collect an adequate amount of data. Defining the variables collected during an evaluation and the outcome variables presents both logistical and methodological challenges. A multi-facility approach will also complicate data analysis as potentially disparate data sets will emerge since facilities may see different types of people and prescribe different types of equipment. Finally, the group was not confident that funding could be attracted for such a study. Members from the US felt that the types of projects funded were different than those needed by the funding agencies.

Question 3: What is an effective way to study the return on investment?

To facilitate a discussion of return on investment, the group selected a specific intervention scenario, provision of a tilt-in-space wheelchair. Through discussion of the scenario, it became apparent that the barriers to using RCT methodologies would also be inherent to investigating return on investment. Outcome and descriptive variables would need to be defined and would be applicable specifically to the

Table II. Seating intervention outcome variables.

Function; ability to perform ADL	Posture
Ability to transfer	No skin redness
Hours of sitting	Skin temperature
Comfort	Occurrence of pressure ulcers
Pain	Size and severity of pressure ulcer
Range of motion for balance	Pressure distribution; contact area

Table III. Seating intervention descriptive variables.

Co-morbid conditions	Diagnosis and function within diagnosis
Tissue type and age	Length of diagnosis
Fat percentages	Support system for the individual
Activity level	Environments of use
Lifestyle choices	Climate of use
Medication	Sweat level
Dietary nutrition	Permutations of interventions
Body type	heat and humidity
Pre-existing conditions affecting posture	Smoking
Seating history: prior pressure ulcers or interventions	Continence and management

technology provided and desired result. For example, the return on investment for a tilt-in-space wheelchair may be different if the desire was to reduce pressure sores than if it was to improve functional posture and balance.

Since return on investment evaluates the costs and benefits of an assistive technology intervention, comparison of the cost for provision of healthcare prior to and following the intervention is a possible methodology for study. The group recognized that a limitation to this approach is that some of the benefits are not easily expressed in monetary terms. Provision of a lightweight, more maneuverable wheelchair may cause reduced need for attendant care, but may also allow for more participation in the community, thereby improving quality of life.

Systematic clinical approach to cushion selection

Research Question: Can a systematic clinical approach be defined to answer the question: 'Is this cushion adequate for my client?'

Specific aims

- To define a standardized seating assessment;
- To identify which standard cushion tests reflect clinically relevant product characteristics;
- To determine if the results of a clinical evaluation and standardized cushion tests drive cushion selection; and
- To determine whether clinical measures confirm a safe seating environment?

As evidenced by the research questions, this Break-out group had many topics to address. The group defined a four-step clinical approach to acquire and evaluate cushions (Figure 1). From a research perspective, each step must be studied as one



Figure 1. Stepwise clinical approach.

optimizes the approach. This Breakout group presented three of the four steps for discussion.

Client *assessment* begins the process and provides a baseline for the provision of services, including cushion provision. Different clinicians and clinician groups have advocated for a thorough seating evaluation but have never been explicit about what measures must be made. Therefore, a standardized seating assessment represents one challenge of this project. Because specific types of information are needed to drive cushion selection, a common evaluation approach is needed to insure the accuracy and validity of this information. Four areas were defined by the Breakout group: history, diagnosis, functionality and special needs.

Cushion *selection* uses the results of the assessment to define client needs and these needs are matched to cushion performance. Standardized test methods are needed to provide qualitative and quantitative measurements of relevant cushion performance. Therein lies the second research challenge. Members of this Breakout group have been involved with the development of wheelchair cushion test methods by the International Standards Organization (ISO). The clinical relevance of such standards is a common topic for discussion by this ISO Working Group.

The *validation* aspect of the process is used to answer the defining question: 'Is this cushion adequate for my client?' Seven variables were defined, five of which were quantitative assessments at the human-cushion interface and the remaining two variables include some qualitative inputs (Table IV). The third research challenge lies in development of ways to measure these variables in clinically-viable manners. Since determining the adequacy of a cushion must be done *in situ*, measures must be compatible with a clinical environment and its time constraints. Some of the measurement options and issues are listed in the second column of Table IV. Certainly, the development of clinically-friendly point-of-care devices represents a high research need.

Information obtained from the client and clinician poses a different set of challenges. Group consensus confirmed the importance of this information, but questions remain about how to input this information into the cushion selection process. The final variable concerns the physical properties of a used cushion. Clinicians and users are often faced with the question of whether a cushion has ceased being an effective supporting surface. Currently, the most typical approach is to visually inspect the cushion. A need exists to develop more reliable tools to identify when a cushion needs to be replaced.

A second line of research involves the identification of the important variables to include in any validation. Of these seven listed here, perhaps only a sub-set is needed to determine cushion adequacy.

Table IV. Variables used to validate cushion performance.

Validation variable	Comments and issues
Microclimate	Temperature measurements FSA temperature mat Hand held thermocouple meters Humidity measurements with Handheld RH sensor Hand check
Tissue deformation	Visual examination Palpation Bend sensors Open MRI
Shear measurement	Pressure gradients at interface Molten handheld sensor VERG shear sensor Goossens sensor
Pressure mapping	Well received and intuitive Inherent limitations Unverified reliability of parameters and clinical significance
Direct measurement of tissue status	TCPO ₂ , TCP CO ₂ Laser Doppler flowmetry Near infrared, tissue reflectance and Raman Spectrophotometer Micro dialysis Sweat analysis
Clinician and patient experience/input	Clinician Experience and reasoning Visual observation of skin condition Palpation Client Pain/discomfort Functionality Product appeal
Cushion physical properties	Initial performance Aged/used performance Leaks Hardening Degradation Microbial UV Laundering

Functional impact of wheelchair cushions

Research questions

- What are the best methods to objectively measure performance of functional activities across different wheelchair cushions *in situ*?
- What is a clinically valid approach to study the postural and functional impacts of cushions and postural supports?

To answer these research questions, three specific aims were proposed:

- Define quantifiable functional activities of a seated posture;

Chapter 9

The Clinician's Perspective

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Contents

	Section	Pg
9.1. Individuals Evaluated by Clinicians	259
9.1.1. Children as Clients	261
9.2. An Overview of Client Needs	262
9.2.1. Evaluation for Seating and Manual and Powered Mobility	263
9.2.2. Physical Considerations	265
9.2.3. Cognitive and Perceptual-Motor Considerations	267
9.3. Activities of Daily Living and Functional Skills	268
9.3.1. Environment and Transportation	268
9.3.2. Lifestyle Concerns	269
9.3.3. Technology Tolerance	270
9.3.4. Trial Equipment and Measurement	270
9.4. Types of Mobility Technologies Prescribed	271
9.4.1. Seating	271
9.4.2. Wheelchair Bases	273
9.4.3. Dependent Manual Frames	274
9.4.4. Independent Adult Manual Frames	277
9.4.5. Independent Pediatric Manual Frames	278
9.4.6. Adult Powered Mobility Bases	279
9.4.7. Pediatric Powered Mobility Bases	280
9.5. Problems Therapists Encounter	280
9.6. Technology Solutions Envisioned by Therapists	282
9.6.1. Smart Wheelchairs	282
9.6.2. Other Approaches	284
9.7. Conclusion	284
References	285

9.1. Individuals Evaluated by Clinicians

Clinicians who perform wheeled mobility and seating evaluations and training see individuals who need augmentation or replacement of their means to walk to accomplish activities of daily living (ADL) in a safe, efficient manner. The evaluation process involves a team of professionals, including the client and family. The client, family and caregivers must be interviewed extensively in order to recommend a mobility system that is user-friendly and functional for the client.

In some cases, this individual is suddenly completely dependent, unable to walk or to self propel a manual wheelchair. Or the individual may be cognitively unable to control a power wheelchair. The goal, in this case, is to enable a caregiver to position and move the person to facilitate care giving with a dependent manual wheelchair. The evaluation of a client's needs by an occupational or physical therapist is an important opportunity to educate and discuss functional potential. It's also an opportunity to ease the individual's transition into an appropriate wheeled mobility device while ensuring the individual's safe, functional use and optimal posture.

Usually, evaluations for the seating and mobility devices occur at the same time. Seating is addressed first to maximize postural stability, upper extremity function and or head control. These factors can impact the individual's ability to control or propel a mobility device. The population of clients who use wheeled mobility devices includes individuals with neurological, musculoskeletal and cardiac and or respiratory diagnoses. Some clinicians specialize in one diagnosis or age group. The Census Bureau estimates the population of wheelchair users in the non-institutionalized U.S. to be 2.2 million. [1] Cooper and Cooper state that approximately 70%

of all wheelchair users have manual chairs. [2] The remaining 30% is split evenly between power wheelchair and scooter users. [2]

Mobility is the ability to move oneself from point A to point B. For those who walk without impairment, the ability to move at will is as basic as breathing. When a person has a disability that impairs or prevents walking, a variety of mobility aids can be used to augment or facilitate mobility, including orthotics, walkers and crutches. But when these mobility aids do not enable the person to accomplish all of their mobility-related activities, wheelchairs are considered. Mobility-related activities are aspects of daily living at home and participation in the community, school or work.

Wheelchair users include:

- Individuals who are able to walk only very short distances due to pain or (high) level of exertion
- Those whose ability to walk fluctuates from day to day or week to week
- Those who are unable to walk at all.

Individuals in the first two categories pose the greatest challenge when attempting to determine the most appropriate type of wheelchair system or whether one is needed. It must be remembered that the purpose of mobility is to move from one place to another in the most efficient manner possible. Mobility is not the same as exercise. If walking or self-propelling a manual wheelchair from point A to B is too demanding or challenging, then that action becomes exercise and is no longer considered mobility per se. People with mobility impairments should be able to move about efficiently at will and still have the energy to accomplish tasks once they arrive at their destinations. Using a wheelchair augments, and is consistent with, aided or unaided walking. The mobility method should fit the activity. [3] For example, walking around

the house or classroom may be functional, but grocery shopping or playing on the playground might require a wheeled mobility device.

9.1.1. Children as Clients

Children with disabilities have needs that are significantly different from adults with disabilities. Their seating and mobility systems must adapt or adjust to them as they grow physically and mature cognitively. Parents must be educated as to the importance of psycho-social development in children with independent wheeled mobility and not view them as “a failure” if walking is inefficient. The approach to successful intervention involves asking clients – and their families, siblings or other caregivers – for input about activities and interests, such as dressing, eating, chores and hobbies, environments of use (i.e., home or school) and transportation needs. Parents are typically an integral part of meeting the child’s needs. They are primary advocates for their children’s needs. And, as primary caregivers, they must express their own needs for their children’s wheeled mobility devices.

Seating and mobility systems function to facilitate or support physical, cognitive and social development. Self-initiated movement is crucial for the development of a young child’s cognitive, emotional and psycho-social development.[4][5] For children who are unable to move about independently, assistive devices such as walkers, wheelchairs and or powered mobility devices offer a means of independent exploration, locomotion and play. Independent mobility has been related to improvements in a host of skills, including spatial awareness skills, hand-eye motor coordination, visual perceptual skills, spontaneous vocalizations, improved sleep habits, disposition, initiation of contact with others, motivation to explore and an increased ability to interact meaningfully with peers.[6][7][8][9] Unfortunately, many children with disabilities are

not given the opportunity to acquire independent mobility, especially at a young age when the stimulus of mobility is so critical in influencing development.

9.2. An Overview of Client Needs

People who require seating and mobility evaluations have a wide variety of needs. However, some generalizations can be made. Individuals, no matter their age, want to be comfortable. Pain and discomfort, which can range from distracting to intolerable, are often motivators for seeking professional help. People must be able to maximize their function in valued activities of daily living (ADL). Independent control of their environment through mobility is especially important to the development of young children. Interacting with their indoor and outdoor environments, reaching, touching and exploring spontaneously to quench their curiosity enables them to grow developmentally and psycho-socially. In summary, the motivators for seeking intervention are comfort, independence and the ability to be mobile.

Thirty years ago, there were few wheelchair and seating technologies available to assist persons with physical disabilities. Today, a plethora of powered and manual wheelchair and seating technologies available exists. The challenge is to match client needs to specific wheelchair technologies and components. This requires knowledge of the client's diagnoses and potential risks such as pressure sores from sitting, and the implications of the diagnoses for a client's present and future functional needs and their present and future mobility environments. Clinicians, in partnership with rehabilitation technology suppliers, who are familiar with product features and the compatibility of components, recommend mobility and seating solutions to meet client needs.

Three main services are provided within a wheeled mobility evaluation. These may be performed by up to three different service providers, or they may be combined – as is often the case in a wheelchair clinic setting.

First, an OT or PT performs a basic evaluation in response to a physician’s referral for service. Any OT or PT may do this evaluation, or it may be the first part of an evaluation performed by a seating specialist.

Second, a more specialized assistive technology assessment is performed by a therapist with advanced training and experience in the area of wheelchair seating and mobility. This therapist has often earned RESNA specialty certification as an assistive technology professional (ATP). This more targeted evaluation is specific to mobility and seating technologies and may include a mat evaluation to determine the impact of spasticity, fixed deformity or limitations in range of motion on seated posture, simulation of one or more pieces of equipment, pressure mapping and evaluation of a best control method in powered mobility. From this evaluation, a list of desired features of the technology will be generated, and client goals relevant to the use of the technology are formed.

The third part of the evaluation is performed in partnership with the rehabilitation technology supplier or RTS. The RTS works with the therapist in equipment trials, simulation and selection of products or product features that will best meet the client’s needs and the therapist’s treatment goals.

In addition to assisting the therapist during the technology assessment process, the supplier often performs a follow-up visit with the client in his or her home and will trial possible equipment selections and assess the home accessibility and transportation issues.

9.2.1. Evaluation for Seating and Manual and Powered Mobility

While seating and manual and powered wheelchair technologies have advanced rapidly, the primary focus must remain on the consumer's needs and abilities. A poor match between consumer and technology can lead to abandonment of even the best technology. At worst, a poor match can cause harm. For example, poorly selected seating could actually cause a pressure sore or worsen a developing deformity. A scooter that is too large for the interior space of a small apartment, or a powered wheelchair prescribed for someone who is unable to safely operate it, can cause injury and diminish the effectiveness of the wheelchair. As with any other clinical intervention, prescription of seating, or a powered or manual wheelchair, begins with an evaluation.

The evaluation generally begins with a physical assessment on a mat table to determine the client's neuromuscular capacity and postural needs. Transferring the client to the mat table enables the therapist to see how the individual sits without postural support. Moving the client between seated and supine postures allows the therapist to determine the presence of fixed or flexible deformities in the spine and pelvis.

In general, a fixed deformity must be accommodated and a flexible deformity should be corrected to prevent worsening. In the second situation, the seating system functions like an orthotic to support stabilize or correct a pelvic or spinal deformity. Sitting reduces movement for the spine so the mat assessment provides information the therapist needs to make informed recommendations for seating as well as for mobility base components. For example, based on mat examinations a clinician may recommend a power tilt-in-space component, a more open seat-to-back angle or a custom-molded system to accommodate a fixed deformity.

The accepted clinical team for a manual or powered seating and mobility evaluation is generally composed of a therapist and a rehabilitation technology supplier (RTS). As of January 2009, both therapists and suppliers who have passed the RESNA certification exam are identified

with the ATP or AT Professional credential. (Currently, RESNA is developing an advanced certification in wheelchair seating and mobility practice with roll-out expected in 2009.) In fact, Medicare requires this credential for RTSs in order to provide certain categories of wheelchairs. The optimal RTS is also a member of the National Registry of Rehabilitation Technology Suppliers (NRRTS). The ATP credential plus NRRTS certification, continuing education and adherence to a code of ethics enables the RTS to use the credential Certified Rehabilitation Technology Supplier (CRTS) after their name.[10] Though many rehabilitation technology suppliers sell wheelchairs to consumers directly, those with the CRTS credential provided by NRRTS have the knowledge and professionalism to refer their clients with complex needs to be evaluated by therapists. They recognize the significance of the needs and want the additional skills that therapists bring to assessment.

It is the responsibility of the evaluators to obtain information from and coordinate with any medical, therapeutic or other information relevant to the client's needs and abilities. It is taken for granted that the mobility evaluation will be performed once a seating evaluation has been completed. It is only after the client's seated positioning, pressure management and postural support needs are understood that an evaluation for a wheeled mobility device takes place. This is true whether the evaluation is for dependent or independent mobility.

Dependent mobility involves caregivers moving the client in the wheelchair, while independent mobility means that clients move themselves. Overall, the seating and wheelchair mobility evaluation process is comprised of evaluation, trial of equipment, specific recommendations, funding, fitting and or training. The areas that are evaluated and taken into account include: physical considerations, cognitive and perceptual motor considerations, ADL and functional skills, environmental and transportation needs and "technology tolerance."

9.2.2. Physical Considerations

The first thing to consider is the client's diagnosis – its characteristics and ramifications. Is the diagnosis progressive? If so, in what stage is the individual? What are the characteristics of the disease or condition? Weakness or spasticity, for example? To illustrate this point, a clinician seeing a client with multiple sclerosis would need to know-how quickly the disease is progressing. A more aggressive form of the disease may lead to recommending a mobility device that is modular, flexible and easily modified. Clients with no sensation or ability to lift themselves off the seat cushion (known as a wheelchair push-up) to get pressure relief should be considered for technology that provides the ability to unweight the pelvis, using a mechanical pressure relief system through tilt or recline. A child with cerebral palsy should have spasticity and reflexes considered in their positioning.

When performing an independent mobility evaluation, the clinician determines whether the client has the range of motion, strength and coordination necessary for propelling a manual wheelchair or accessing the controls of a powered wheelchair. Movements necessary for propelling a manual wheelchair include one of the following combinations: use of upper extremities, one upper and one lower extremity or lower extremities. The individual should be able to perform these movements with sufficient strength and coordination to enable access to their functional environments without a deleterious effect on the client's posture or stability. For example, a client with spastic quadriplegic cerebral palsy may have a kyphotic posture (excessive curving of the upper spine) that is worsened by the motion of propelling with the upper extremities. A client with weak upper extremities, such as a client with C5/6 tetraplegia or Muscular Dystrophy, may have to over-use available musculature, resulting in compensatory movements and repetitive stress injuries. The clinician and client need to balance the need to be independent with the long-term effects of propelling a wheelchair full-time.

Movements needed to operate a powered chair are quite varied due to the wide array of available technology and access methods. If an individual cannot use the typical interface – a proportional hand joystick – other options are available. Other options include: head arrays, micro joysticks, sip and puff switches, or using multiple single switches (each switch dedicated to a direction of movement) that are placed near the head, imbedded in a wheelchair tray or distributed among body segments. The client's movements need to be reliable, for consistency and safety in operation of the powered wheelchair.

9.2.3. Cognitive and Perceptual-Motor Considerations

In general, the assessment determines if the client will safely use the chosen method of wheelchair mobility. Does the client demonstrate the ability to recognize a dangerous situation such as a curb or a stairwell? Can the client problem-solve and make appropriate decisions in the environments in which he or she functions?

Even clients with cognitive limitation may be able to have independent manual or powered mobility in limited environments. For example, a client with a consistent caregiver who can provide structure and supervision within limited environments could be considered a candidate. There is no substitute for actually observing the client using a wheelchair in his or her natural environments. Ensuring that the client is safe in the wheeled mobility system prescribed is of primary importance.

When conducting wheeled mobility evaluations with children, the wheelchair mobility evaluation is performed with the child's developmental level in mind. Children require supervision and instruction commensurate with their age and developmental level, no matter what their method of mobility. Mobility goals must include the current cognitive status and developmental age with the goal to improve or enhance cognitive skills and potential abilities. The evaluation of the cognitive or developmental level (rather than chronological age) is

important, as it is typical for an able-bodied child's cognitive skills to vary from their actual age (whether ahead or behind) by three to six months.

For children with impairment in both cognitive and motor skills, the discrepancy may be larger. Additionally, assessment for powered mobility in young children should include not only their cognitive developmental level, but also the motor aspects of interacting with the drive controller, their perceptual motor and dynamic sensory-motor processing (i.e., visual or motor planning) and awareness of their environment. These factors can significantly impact the child's ability to drive successfully and their mobility goals. It will also affect the type of equipment that is appropriate for the child.

For adults, neurological diagnoses such as stroke, multiple sclerosis or cerebral palsy can result in visual field disturbances, such as limited peripheral vision or difficulty in judging distances. Some clients may be able to compensate for these perceptual-motor problems. Evaluating clients while they drive a wheelchair is necessary in order to observe their cognitive and physical responses to moving through the environment.

9.3. Activities of Daily Living and Functional Skills

The clinician must be aware of the ADL and functional skills that the individual performs while seated in their wheelchair. This helps to ensure that structural stability, dimensions and wheelchair components will enable the client to perform these tasks successfully. For example, the client may be marginally able to transfer between the wheelchair and varying heights of a bed, commode or car seat, based on the single height of the wheelchair seat. Incorporating a powered seat elevator may overcome this limitation. Another client may dress while seated in the wheelchair. This task will require reinforced back posts to prevent damage to the chair over time. A child may require a lower seat height in order to stand and transfer safely. Components

such as oxygen containers, feeding bags and ventilators must be safely incorporated on to the wheelchair base.

9.3.1. Environment and Transportation

When evaluating a client who is new to wheeled mobility or considering a different wheelchair, therapists play a key role in determining whether the mobility device will fit in typical settings. The client's home and vehicle should be measured for allowable widths, lengths and turning radii. If environmental modifications to home or vehicle are needed, they should be considered and discussed during the assessment. Strollers with adapted seating for young children must be easy to fold and transport in the family car.

Transportation is an important consideration for people using wheeled mobility systems. When using a personal vehicle or public transportation, the recommended practice is to transfer from a wheelchair into the manufacturer-installed vehicle seating and use the vehicle's occupant-restraint system. However, for many people this may not be feasible. People who experience weakness, instability or low endurance are at risk of falling during transfer. There is also a high energy cost for making repeated transfers. A progressive impairment, or increasing age, indicates an inability to transfer safely.

Any wheelchair that will be used as a seat in a motor vehicle should meet the voluntary industry standard for crashworthiness (see Chapter 4: Voluntary Industry Standards for Wheelchair Technology) and include both crash-tested tie-down points and a wheelchair-anchored pelvic safety belt to be used during transport. Individuals who only use personal transportation may also consider using a crash-tested docking system that will be installed in their vehicle.

9.3.2. Lifestyle Concerns

Aesthetics are important in wheelchair or adapted stroller designs for adults, children and their families. A wheelchair becomes part of an individual's appearance and the way they present themselves to the world. Parents, siblings and peers are more accepting of the child's disability if the equipment is child-friendly, colorful like a "toy" and the children appear more approachable. Ease of cleaning and maintenance are also important, especially for children's seating systems.

When possible, it is highly recommended that the prescribed wheelchair be tried in the client's home, vehicle, workplace, school and any other environments in which it will be used. Wheelchair types and component selections are made according to how the wheelchair will be used. For example, a client who only wants to use the wheelchair in an indoor environment will not need a wheelchair base designed to handle rough terrain.

9.3.3. Technology Tolerance

Seating, powered and manual mobility technologies can be complex. An important factor in recommending seating and powered and manual mobility is whether the client and or caregiver are capable of using, adjusting and maintaining the system properly. Complex powered wheelchair systems can be difficult to maintain and not all people want to assume the responsibility. When using complex systems, clients and caregivers must be motivated enough to follow through with training, maintenance and other follow-up activities. When the wheelchair is not properly maintained, it is likely to break down, requiring frequent repairs or resulting in technology abandonment.[11]

9.3.4. Trial Equipment and Measurement

Once all the information is collected and the client's physical skills assessed, trial equipment should be used to validate the prescription of the clinical team. This is particularly

important in evaluating the effectiveness of seating components, as there is no substitute for observing the effects of these seating components on the client's posture and ability to function.

Once the final equipment is determined, the clinician and supplier must match client goals to specific pieces of equipment or features in order to justify any possible additional costs. It is beneficial for the wheelchair seating and mobility specialist to have first-hand experience with the chairs they recommend. This experience facilitates the subjective analysis of perceptual, cognitive and physical demands of the chair.

Once final equipment decisions are made, the clinician must document medical necessity. Most manual and powered wheelchairs are considered durable medical equipment (DME) and are often paid for by third-party payers that include Medicaid, Medicare, private health insurers and veteran health insurers. Each payer has different criteria for what is considered medically necessary and what equipment will be approved for payment as a covered benefit.

The supplier pairs the therapist's evaluation and documentation of medical necessity with quotes, appropriate coding and other paperwork. Then the supplier sends this package of information to the third-party payer. Once the technology is approved for payment and the chair is delivered, the client makes an appointment to be fitted for the equipment and trained to use it. A series of follow-up visits should be scheduled, especially with children or those with changing or complex conditions.

9.4. Types of Mobility Technologies Prescribed

It is essential to understand seating systems, manual and powered wheelchairs, and the types of control technologies and their function. This understanding enables the therapist to successfully match client abilities and skills to the variety of mobility technologies that are available.

9.4.1. Seating

There are general categories and considerations for seating components, the determination of which is based on the findings in the mat evaluation described earlier. Seating components include primary and secondary postural supports. Primary supports provide support under the pelvis and legs, and behind the pelvis and trunk. Secondary supports provide lateral trunk supports, anterior support through lap belts or chest harnesses and distal support through headrests and foot straps.

The primary supports must be considered first; they are key for comfort, pressure distribution and postural support. Seating can consist of off-the-shelf components, custom-contoured systems or a combination of the two. There are many materials used in seating and positioning. Each material used in a cushion has characteristics of stiffness, resilience, insulation and breathability. These characteristics must be understood and selected to support the optimal clinical outcome. The ability of a cushion or seating surface to serve a desired purpose depends on the types of materials used and how those materials are combined, as well as the shape of the cushion or seat. The following factors are considered when selecting cushions and seats and backs:

- Pressure-relieving qualities of the cushion, which depend on the child's or adult's protective sensation and ability to weight-shift
- The ability of the cushion or seat to support or accommodate to body shapes and postural control needs
- The ability of the client to balance and function on a particular surface. For example, a more conformable or contoured surface may be more difficult to use for sliding transfers or for someone who is only marginally able to transfer

- The ability of the cushion or seat to allow the addition of secondary supports, such as lateral pelvic supports.
- The ease of care and the ability of the client or caregiver to maintain the cushion or seat.
- The weight of the cushion or seat for transferring it between surfaces, or if additional weight will affect a client who self propels. This is especially important for children. A seating system could easily be half of a child's weight, which would negatively impact the child's ability to functionally self-propel
- The durability and reliability of the cushion or seat
- The seating systems ability to grow with the user. This feature usually requires either adjustment of hardware or the acquisition of additional parts.
- When assessing back supports, the following factors are considered:
 - The adjustability of the back-support hardware for seat depth and angle adjustability
 - The capacity to add secondary supports such as lateral trunk supports or headrests
 - Whether the shape of an off-the-shelf back matches the shape of the client
 - The capacity to change the shape easily for a back that includes shape adjustability.
 One would also consider what components are necessary to make that shape adjustment.

9.4.2. Wheelchair Bases

Manual mobility technology can be broadly divided into two categories: wheelchairs intended for dependent mobility and those designed for independent mobility.

Dependent wheelchairs include upright wheelchairs, tilt and or recline wheelchairs, transport wheelchairs and stroller-style bases.

Independent manual wheelchairs can be divided into semi-adjustable and fully adjustable. Independent mobility wheelchairs include both manual and powered wheelchairs and are selected based on specific mobility goals and typical environments where the wheelchair will be used. The adjustments for independent manual wheelchairs relate to setting up the wheelchair to meet the individual's postural stability, comfort and pressure management needs. It is also necessary to ensure that the location of the axle is adjusted so that it is directly below the user's shoulder, which enables better biomechanics when using the rear wheels for propulsion.

9.4.3. Dependent Manual Frames

Dependent wheelchairs are primarily meant for caregiver propulsion. Most accept a wide array of seating components. Very young children and adults with significant disabilities are often positioned and transported in dependent mobility systems (DMS). These are often stroller systems. Some DMS have virtually no seating beyond a sling seat and back. Other systems offer solid linear seats and backs and a variety of components, including hip guides, lateral chest pads, anterior trunk supports, seat belts, headrests, armrests, footplates or platforms and ankle straps. Typically, these components are mounted to a shell, rather than a wheelchair frame. Some people who use DMS require tilt or recline features. It is important to note that DMS with tilt and or recline bases tend to be very heavy and not easily transportable in a car.

Characteristics of DMS, which are available in adult and child sizes, are as follows:

- Growth and weight limits –DMS vary tremendously in seat width and depth, back height, and lower-leg length. Some systems offer very small starting dimensions for the neonate. Others offer limited growth. DMS have occupant weight limits that may restrict how long a child can continue to use the system.
- Weight of DMS – The weight of the base and seating system also varies with the DMS and its particular configuration. A DMS is usually a child's first base. The

- family's home and vehicle are often inaccessible. This system is often lifted in and out of vehicles and carried up steps, so the weight of the base is critical.
- **Foldability** – Some DMS fold only with the seating system removed, which creates another step for the caregivers. By removing the seat, however, one can greatly reduce the weight of the system: the caregiver is now lifting two lighter pieces. Some DMS are difficult to fold.
 - **Tilt and recline** – The DMS may offer tilt, recline or both. Many DMS have a fixed tilt built into the system. This can be problematic for clients who do not tolerate being seated in a tilt or who have reflex activity in response to being tilted (i.e., symmetrical tonic neck reflex). Systems that offer an adjustable tilt and or recline vary in the degree of adjustment. The tilt is usually a component of the base, while recline is usually built into the seating system. Many clients require a tilt and or recline to assist in feeding, respiration or control of specific medical conditions (i.e., blood pressure issues or seizures). Very young children are not yet able to sit upright and so require a tilt or recline to compensate. Adjustable tilts and or reclines are generally available only on pediatric DMS.
 - **Rear-facing** – Some pediatric DMS are available with a rear-facing seat. This is usually accomplished with either a stroller handle that can be moved from front to back. Or the entire seating system can be removed and reattached to face the opposite direction. This feature can be critical for infants or young children with medical issues that require close monitoring by the caregiver.
 - **IV pole** – Many DMS offer an IV pole. These poles are ideal for infants and children who are fed through gastrostomy tubes.

- Oxygen tank holder – Many clients who require a DMS have medical issues that require oxygen. The DMS must be able to support the weight of the tank. If the client uses a non-standard tank style, the supplier may need to fashion a custom holder. Tanks should be stored in the base of the chair as hanging them from the push handles can interfere with pushing or cause the base to tip. This is especially unsafe if an infant is in the rear-facing position. Regardless of how the tank is attached, it should be considered in the weight limit of the base.
- Ventilator base – The ventilators used by some clients to facilitate or enable breathing come in a variety of sizes and weights, however they have recently become much smaller. The platform that holds the ventilator is generally placed low and toward the center of the DMS to prevent tipping. Clients who require a ventilator often need oxygen. In this case, it is often beneficial to use a rear-facing seating system (so that the caregiver can monitor the child) and a tilt/recline to accommodate respiratory needs. The ventilator often affects the weight limit of the base and sometimes is available only on a larger model base.
- Tray – Some DMS offer a tray that can be adjusted to remain parallel to the floor if the seat is tilted, which prevents the contents of the tray from spilling into the client’s lap. A tray can provide a play surface for a child, hold food or allow the DMS to function as a high chair. Many children using DMS are unable to sit in a standard high chair due to insufficient postural support. Trays are important in pediatric systems because the seat to floor height of many DMS prevents children from sitting in the base with their knees under a table, which are often very low in preschool settings. Finally, a tray can provide support to the upper extremities, as many DMS have no armrests.

- Crash-tested – Dependent mobility bases are available in models that have been crash-tested for use in vehicles and have tie-down attachment points on the base. This allows the client to ride in the base, rather than in a standard child car seat or standard vehicle passenger seat. This is usually required for children who ride a school bus. Several DMS seating systems are actually removable adaptive car seats. At this time, more DMS are crash-tested than typical wheelchairs, perhaps because only one type of seating system is generally available on each DMS (though with different components). Typical manual and power wheelchairs can be used with a wide variety of seating systems. Currently, the base and seat must be crash-tested together, so testing a wheelchair with every possible seating system is not cost-effective. This situation will change with the finalization of standards currently in development for independently testing wheelchair seating systems and wheelchair bases, which will allow the mating of two independently tested products.

9.4.4. Independent Adult Manual Frames

A standard manual wheelchair with large rear wheels appears suitable for self-propulsion. However, its heavy weight, limited size options, sling upholstery and nonadjustable axle position make it a poor choice for self-propulsion. The axle adjustability found in ultra light wheelchairs is a valuable feature. Alignment of the rear axle directly below the shoulder improves access to the pushrims throughout the push stroke and balances the muscle groups that are used in propulsion. [12] This increased efficiency results in fewer strokes per distance traveled, which reduces the likelihood of repetitive strain injuries.

Appropriate axle position makes turning easier but can also cause the wheelchair to tip backwards. To combat this problem, the therapist must offer skills training and provide rear anti-tippers until the client becomes a skilled user. Axle adjustability is essential for long-term

users, but due to reimbursement restrictions, careful documentation of client needs is required to help a client secure reimbursement.

Ultra lightweight wheelchairs are available in rigid frames and folding frames. Rigid frames provide durability and efficiency because none of the force of propulsion is lost in flexing of the frame. Folding frames are more easily stored in vehicles. They can also be easier to expand because of their cross-frame design.

The body of scientific evidence that favors light, adjustable-axle manual wheelchairs is growing. Boninger et al found that rear axle placement relative to shoulder position is correlated with median nerve injury. [12] The study also showed that proper rear axle position reduced forces and improved propulsion biomechanics.

Manual wheelchair users experience a 49% to 73% incidence of carpal tunnel syndrome. [12][13] Because manual wheelchair users also depend on their upper extremities for transfers and ADLs, shoulder preservation is important. Carpal tunnel syndrome in wheelchair users leads to costly surgery, loss of productivity and usually to powered mobility and all its requisite changes in daily environments and lifestyle.

9.4.5 Independent Pediatric Manual Frames

Manual wheelchair bases designed to give children independent mobility can be configured with either front or rear wheel placement. Front-wheel drive (FWD) wheelchairs are unique in that the larger wheels are mounted in the front portion of the frame with the casters in the rear. This wheelchair can be recommended for children as young as 10 to 12 months. Front-wheel configuration creates propulsion that is more efficient for children. The child is closer to the tire and more pushrim surface area is within reach of the child's shorter arms. The frames that allow front-wheel drive configuration also permit lower seat-to-floor height to promote

independent transfers in and out of the wheelchair. These wheelchairs can be converted to a standard rear-wheel configuration as the child grows.

A rear-wheel drive (RWD) wheelchair can be appropriate for children generally at 4 to 5 years and older. RWD consists of a seating system on a mobility base (frame). The frame may be foldable, semi-rigid, or rigid, resulting in various configurations to assist with transportation of the wheelchair. The seating can vary from a simple sling to more sophisticated contour models. Seating systems may be removed to fold the wheelchair. Both the frame and seating system can be ordered in various sizes to allow for growth, or they may be fixed for an older child. A standard RWD wheelchair is the most common type of mobility device.

9.4.6. Adult Powered Mobility Bases

Powered wheelchair bases vary widely in their uses and characteristics. Powered wheelchair bases are sold in rear wheel, mid/center wheel and front-wheel drives. Each drive-wheel configuration offers different performance characteristics, so it is important for the therapist to have a clear idea about the physical environments (whether hilly, flat, uneven terrain, etc.) in which the wheelchair will be used in order to advise well. The placement of the drive wheel also affects turning radius and therefore how it will perform in small spaces and when turning corners. Therapists find it is difficult for long-term users who are familiar with rear-wheel drive to make a change to mid-wheel drive even when it offers a much smaller turning radius.

Power wheelchairs are grouped in performance categories according to their ability to climb obstacles of varying height, to offer programmable electronics or to accept powered seating components. Most “consumer,” non-adjustable powered wheelchair bases are meant for indoor use and light outdoor use. Meanwhile “rehab-type” power wheelchairs are designed for active, full-time extensive community mobility in all conditions. Using a power wheelchair in a

setting or in a way for which it is not designed will cause the wheelchair to break down or wear out quickly. Clear documentation of need is essential to match the consumer with the mobility product they need.

Following the selection of the power base, seating components must be selected and matched with the client's need for pressure management, postural support and or comfort. In addition to cushion and seatback, the client with more significant impairment may also need powered seating functions such as powered tilt-in-space, recline, seat elevation or elevating leg rests to address prevention of pressure sores or to allow bladder management.

Though the standard interface for driving a wheelchair is a joystick, clients with more significant impairment may need specialized controls that use switches, head movement, sip-and-puff or other forms of digital control. When power seating functions are added to a wheelchair, clients must use the control interface to independently manage power seating functions.

9.4.7. Pediatric Powered Mobility Bases

A pediatric power wheelchair base may include a manual or power tilt and or recline. The manual tilt/recline requires an adult's assistance. A child may operate a power wheelchair through a variety of controls such as a proportional joystick or switches in a head array or positioned where they can be activated using other body parts, such as hand, feet or chin. Dynamic seating such as seat elevation or sit-to-stand are options on some power wheelchair bases. These features allow the seat to go to the ground for floor access for play and interaction with peers and then back and up to a standing position. As with other wheelchair bases, a power base can accommodate most seating systems or a ventilator. It can be manufactured in compliance with the WC19 standard so that it is crash-tested with a tie-down system for securement in transportation.

9.5. Problems Therapists Encounter

One of the biggest problems in securing wheeled mobility products is funding. Evaluations for seating and mobility goals are unique to each client. These goals are then matched to suitable seating systems or wheeled mobility technology. Ideally, a third-party payer or other funding source will pay for the needed technology. However, third-party payers vary greatly in what they cover. Some are very restrictive. Medicare, for example, will not cover a powered seat elevator on a powered wheelchair for any reason, even though it can mean the difference between independent or dependent transfers from the wheelchair. Medicare will also only cover manual or powered mobility if it is primarily needed in the home. In other words, people who require mobility systems only for long-distance travel will not qualify for coverage.

Some private insurers place a \$1,000 limit on durable medical equipment, which is far less than the actual cost of obtaining a wheelchair and seating system. Some private insurers and some state Medicaid systems limit the age at which they will pay for powered mobility for children. The rules often state that the child must be old enough to be responsible. This creates a difficult position because a child must be provided with freedom within developmental limits in order to learn responsibility.

Another barrier to successfully funding wheeled mobility technology is that some private insurers have sole provider contracts with rehabilitation technology suppliers. This complicates the process of determining which supplier can be used to supply wheeled mobility technology for specific clients. Sometimes, this issue can completely eliminate client choice. It can also result in a clinician working with a supplier who is unfamiliar with high-end rehabilitation equipment required by a particular client.

Unrealistic client expectations of equipment can pose a challenge with seating and mobility evaluations and provisions. Occasionally, clients will request powered mobility systems that they have seen advertised on television. For example, one client brought a list of wheelchair features to an evaluation that included a powered chair whose parts, when disassembled, all weighed five pounds or less. However, the client had not considered the consequence of disassembling and reassembling the chair on a regular basis. In some instances, clients who require postural supports will reject them for aesthetic reasons. As one can imagine, layering funding restrictions on top of unrealistic client expectations can result in a frustrating evaluation experience.

9.6. Technology Solutions Envisioned by Therapists

Probably, many technologies could benefit wheeled mobility clients. This might mean, for example, having access to wheelchair components that allow client movement within a limited area or range. It could also mean a wheeled mobility solution that allows the client to use features on demand. It may be beneficial to incorporate ideas like “intelligent” seating or computer assisted driving to some clients based on their needs.

9.6.1. *Smart Wheelchairs*

Independent mobility is crucial for childhood development. But many children who have severe orthopedic disabilities, and cognitive impairment and or physical control problems, do not learn to use powered wheelchairs. This usually stems from limited access to training programs and loaner power wheelchairs, or limited therapy staff or time. Children with sensory-motor integration issues or other factors that influence the progression of learning such as distractibility and frustration tolerance require a longer training period to learn skills. Thorpe & Valvano found that children with cerebral palsy could benefit from increased practice with motor tasks.

[14] Thus, especially for this group, it is important to have a trial or loaner powered wheelchair available for an extended dynamic practice period. Researchers have been exploring “smart wheelchair technologies” that steer the wheelchair along a line using a tracking algorithm. A robotic joystick can physically guide the child’s hand during training. And an adaptive steering assistance algorithm gradually and automatically gives the child more control over the chair, based on measurements of steering ability.

There has been a surge of interest in developing technology to aid in wheelchair navigation with more than a dozen independent, research initiatives aimed at the development of navigation aids. [15] As motivation for this work, Fehr, Langbein, & Skarr cite the results of a survey of 200 clinicians, that indicated that 40% of the clinician’s patients or clients who use powered wheelchair have difficulty with steering tasks. Up to 9% could not steer without assistance. [15] The authors estimate that up to 50% of wheelchair users could benefit from “smart wheelchairs” that assist with navigation.[15]

The general approach in developing smart wheelchairs is to incorporate sensors and a controller onto a powered wheelchair in order to allow people with severe disabilities to drive safely for long periods with reduced cognitive and motor burdens. For more information see review of various projects in Simpson, LoPresti, Hayashi, Nourbakhsh, & Miller.[16] The device could automatically avoid obstacles, move along straight lines without continual input and follow other moving objects, receiving input from sonar sensors, bumper switches and infrared proximity sensors.[17] Other more recent examples include the Navchair, which uses a ring of sonar sensors mounted on the wheelchair.[16] The device makes vehicle-control decisions with the user for tasks such as obstacle avoidance, door passage and maintenance of a straight path. People who were unable to drive a standard powered wheelchair have used this system successfully. The Wheelesley chair allows the user to give higher-level commands such

as “forward” or “right,” and then implements the commands, automatically avoiding obstacles and keeping the chair centered in the hallway using a sensor-based approach. [18]

The Call Centre Smart Wheelchair allows the user to select from a variety of input devices, incorporates bumpers and sensors that avoid and minimize collisions. It can also use a line follower when a child has difficulty controlling the wheelchair. [19] The Smart Wheelchair provides a platform for gradually teaching a user to control a powered wheelchair. Smart Wheelchairs can allow potential users to safely control their wheelchairs as they learn, or the Smart electronics enable safe mobility by compensating for mild motor and or cognitive deficits. The training effect decreases time spent in loaner power wheelchairs that are difficult to obtain.

9.6.2. Other Approaches

Segway Personal Transporters are also used with persons with physical disabilities, who have no impairments of balance and equilibrium reactions, and have the ability to stand and shift their weight. It seems to be a viable option when the demands of walking are too great. Persons with disabilities such as arthritis, amputations and multiple sclerosis would benefit when walking causes too much pain or fatigue or requires great exertion. Segway’s SMART Motion Technology integrates controls engineering, advanced energy systems and sensor technologies. This technology could be deployed to an entirely new population of people with disabilities that limit community mobility.

9.7. Conclusion

Therapists envision mobility technologies that seamlessly integrate into a society, in which persons with disabilities are able to go to school, work or socialize. This return to participating in everyday life activities is the successful end-point of a rehabilitation process that can begin with a traumatic accident, or the onset of a neuromuscular disease, that radically

changes a person's life. Life participation continues and changes. It includes activities of a curious child, a teenager striving for independence, parenting, sustaining employment, coaching or teaching. Life participation requires the ability to go into any terrain or building – be it a grocery store, a public restroom at work or in a restaurant, church, little league games or beach volleyball. Mobility technology enables users to be as independent as possible and gives them the opportunity to live life fully.

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Chapter 10

Supplier Perspectives

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Contents

	Section	Pg
10.1.	Introduction	289
10.2.	Where to Obtain DME Products and Services	291
10.2.1.	HME and or Rehab Suppliers	294
10.2.2.	Manufacturers That Sell Direct	296
10.2.3.	Telemarketers	296
10.2.4.	Nursing Homes or Other Residential Programs	297
10.2.5.	Medical Equipment Catalog Suppliers and Internet- Based Companies	298
10.2.6.	Pharmacies and “Big Box” Retailers	299
10.2.7.	Directly from the Veterans Administration for Disabled Veterans Who Qualify	299
10.2.8.	Non-Profit Community Agencies (i.e., ALS Association, MD Association, MS Society, UCP, etc.)	300
10.3.	Who Pays for the Equipment?	300
10.3.1.	Private or Commercial Insurance	301
10.3.2.	Medicare	304
10.3.2.1.	Medicare policy	305
10.3.2.2.	Medicare coding	307
10.3.2.3.	Medicare allowables or fee schedules	308
10.3.3.	Medicaid	310
10.3.4.	State-Supported Workers Compensation or Vocational Rehabilitation Services	311
10.4.	Summary	311

10.1. Introduction

Most people who need wheeled mobility or adaptive seating systems are unfamiliar with the range of available products, where to obtain them, how much they cost and how they can be paid for. Unlike many other consumer healthcare goods, mobility and seating equipment are rarely products that you will find in the local neighborhood retail store. Although some retailers may carry one or two wheelchairs and three or four wheelchair seat cushions, these products only meet the medical needs of people who have very mild or temporary mobility impairment.

Wheeled mobility and seating systems (wheelchairs, cushions, special positioning devices and products, etc.) are part of a larger category of equipment commonly referred to as durable medical equipment (DME). Some types of DME require no special sizing or have limited, if any, special features or components. For example, crutches and canes, which are considered DME, offer simple length adjustments, and these products can usually be obtained many places and will fit almost anybody.

On the other hand, adaptive seating systems are rarely obtainable from sources other than specialized DME suppliers. In almost all cases, these products require a physician's prescription at a minimum. In many cases, much more documentation is needed. It is important to realize that most physicians do not have a working knowledge of the variety and types of wheeled mobility or adaptive seating products that are on the market today. Physicians are far more knowledgeable with medications, diagnostic tests, lab procedures, surgical techniques and other medical treatment approaches than they are with wheelchairs and seating systems. So it is not unusual for a physician to refer a person in need of this kind of technology to a physical or occupational therapist for more in depth evaluation and specific product recommendations.

Not all physical or occupational therapists have a detailed working knowledge of the variety of mobility and seating either. But most therapists are able to work with a competent and qualified equipment supplier to arrive at a desirable solution to a person's needs. This team approach often provides the best outcomes results. The combination of a therapist (who has the medical background and can evaluate a person's functional needs), and a qualified supplier (who can take that information and match the person's needs with an appropriate product) is the best approach. So, if your doctor can't offer specific advice about which mobility or seating product is best, ask the doctor to refer you to a therapist and a qualified supplier who can help in this process.

In the last several years, more and more emphasis has been placed on the use or the need for mobility equipment within the person's home. Public policy and private insurances are restricting access to many forms of advanced mobility products – limiting reimbursement only to products that allow a person to perform basic daily tasks in the limited environment of the person's home. Many people are able to get around inside their home without using a wheelchair, but they need the assistance of a mobility device to get around in their communities. Unfortunately, more and more funding sources consider mobility equipment for use primarily outside the home to be a 'convenience' and not a medical necessity.

This is a great concern to people with mobility impairments because it often directly impacts their quality of life, their independence and the kind of mobility equipment (if any) that their insurance will pay for. This limited focus of use only within the home contradicts the way many people with disabilities live, to federal mandates like the Americans with Disability Act (ADA), and the way many engineers and manufacturers design and make their products. People with disabilities are more active than ever before. Because of advances in mobility and adaptive seating products, they participate regularly in activities outside the home.

10.2. Where to Obtain DME Products and Services

Wheeled mobility and adaptive seating and positioning systems are available from a wide variety of sources. The most common sources of this equipment include:

- Home medical equipment (HME) suppliers
- Rehabilitation (i.e., rehab) equipment suppliers
- Hospital-owned HME or rehab equipment suppliers
- Manufacturers that sell directly to the public
- Telemarketers that advertise on TV but offer very limited services to target groups
- Nursing home or similar residential programs
- Medical equipment catalog suppliers
- Internet-based companies
- Pharmacies
- “Big box” retailers
- Directly from the Veterans’ Administration for disabled veterans who qualify
- Non-profit community agencies (i.e., ALS Association, MD Association, MS Society, UCP, etc.)

Choosing a DME supplier can be daunting, and each type of provider has strengths and weaknesses. But in many cases, the funding source dictates the choice. For example, some insurance companies have developed specific contractual relationships with a limited number of DME suppliers. These suppliers are often referred to as preferred providers. Using a preferred provider within a specific network usually means that the out-of-pocket expense to the consumer may be significantly less than if they obtained the product or service from a non-network

supplier. In some cases, using a DME supplier that is out of network could mean that the consumer pays the entire cost of the equipment.

Unfortunately, the use of preferred providers by insurances, and other funding sources, is usually based more on economics than on a given DME supplier's level of expertise or service quality. It is possible that a preferred provider of wheeled mobility and seating systems is competent and skilled, but it is even more likely that they were the lowest bidder. In order to be profitable, the supplier is likely to limit the range of products or services made available to the consumer based on the cost of the product.

The choice of DME suppliers may also be strongly influenced by the physician or clinician (physical or occupational therapist, discharge planner, case manager, etc.) based on their past experiences. The physician or clinician is more likely to recommend a supplier based on the supplier's reputation and skills.

The Medicare Modernization Act of 2003 is well known for its sweeping changes in policy regarding prescription drugs, but many people do not realize there was also a major policy shift, regarding DME provision. Because of this legislation, the Center for Medicare and Medicaid Services (CMS) developed a 'competitive acquisition' program for certain categories of Durable Medical Equipment Prosthetic and Orthotic Suppliers (DMEPOS) in 10 regions of the country. Included in the DMEPOS categories are all power wheelchairs and wheelchair accessories, including seating and positioning systems.

The details of the program go beyond the scope and available space in this chapter, but the first phase of this program went into effect in the spring of 2008. Five to seven winning providers (meaning suppliers that submit the lowest bid) in each region are the only approved suppliers for a category of DMEPOS for Medicare beneficiaries. In other words, people who are insured under the Medicare program were only able to obtain needed DMEPOS equipment from

a very limited number of suppliers. If a Medicare beneficiary were to obtain mobility or seating equipment from a supplier that was not a winning bidder in the region, Medicare would not cover that equipment even though the equipment was recommended by a physician and would otherwise be considered medically necessary.

Shortly after implementing this program, Congress passed legislation to postpone the implementation until further studying the merits of the program. There was a substantial outcry from consumer groups, suppliers and manufacturers that the bidding process was flawed and would mean significant hardship to people who depend on this equipment. But it is important to remember that the competitive acquisition program was not eliminated; it was simply postponed.

It is also important to point out that the product that the consumer actually needs is a small part of obtaining appropriate wheeled mobility and adaptive seating and or positioning system. Extensive service and knowledge, and a certain level of expertise, is associated with many types of mobility and seating equipment. Unlike a dishwasher or a piece of furniture, most mobility and positioning equipment must be adjusted or adapted to the individual. This is particularly true for people with significant mobility and postural impairments. In most cases, mobility and adaptive seating products require adjustments, adaptation or training before usage.

It is common for products from several different manufacturers to be combined and adapted to suit the unique needs of some individuals. This requires knowledge, skill and, more importantly, time. Some suppliers are set up to provide this kind of expertise, but many are not.

Obtaining the lowest price may not be best if the equipment is set up improperly or fails to meet the consumer's individual needs. In fact, there are many reports of people who suffered severe complications after being provided with low-cost seating or mobility equipment. In some instances, the costs of treating the medical complications far exceed the cost of a more appropriate mobility or seating system. Not only that, but it may be necessary to obtain a second

mobility or seating system to replace the low-cost and ineffective products that were provided originally. Remember, it is always more expensive doing it twice no matter the bargain obtained the first time.

For example, a person may be provided with a low-cost power wheelchair that has a very simple automotive or van-style seat (often referred to as a captain's seat). But this person should have been provided a more expensive power chair with a power-operated seat that allows them to shift position and a special seat cushion that distributes pressure points over a larger area. Because of the low cost and inappropriate equipment that was provided, this person develops a severe pressure sore where their skin has an open wound that requires hospitalization and surgery. Costs of hospitalization and surgery for a single pressure sore range from \$30 to \$60,000 or more. This cost often far exceeds what it would have cost to provide the person with the more expensive and necessary mobility and seating equipment the first time around. Not only that, but a lower cost power chair may not have the adjustability in the electronics that control the movement of the chair. This can significantly impact the person's ability to safely operate the equipment. So if the person gets a power chair that he or she cannot safely operate, and that equipment causes injury requiring additional medical treatment, there was no bargain to be had by the equipment's initial low cost.

10.2.1. HME and Rehab Suppliers

HME and rehab equipment suppliers, and for the most part, hospital-owned HME and rehab equipment suppliers are the most common source for wheeled mobility and seating products. HME suppliers are likely to focus on basic and (relatively) inexpensive types of mobility and seating. They generally stock a very limited number of models and sizes. Their sales staffs may have basic training, but their knowledge is often limited to manufacturers' trainings. Rehab equipment suppliers generally offer the consumer the highest level of expertise,

product availability and reliability. They generally employ more experienced sales staff with extensive training in anatomy, physiology and rehabilitation principles. Rehab equipment suppliers typically offer a wide range of products and can let consumers try different types of equipment before a final prescription is made. This is often vitally important as no single make or model of mobility or adaptive seating product can meet everyone's needs. It is often necessary to try different combinations of products prior to determining the final and best solution. HME companies and rehab equipment suppliers may be small and locally owned or they may be larger chains with multiple locations across the country.

Reputable HME or rehab equipment suppliers are often involved early in people's rehabilitation programs. They are often directly involved with a physical or occupational therapist in evaluating the person's needs to obtain the best solution. Good rehab suppliers deliver, set up, adjust, modify and or provide detailed instructions regarding the proper use of the equipment. This may cost more, but the saying "you get what you pay for" is true in this case.

HME and rehab suppliers are usually accredited, meaning they have established procedures and protocols to insure the health and safety of their customers. Many have specialized or certified staff that can work with the consumer, the physician and or the clinician to obtain the most appropriate product (or combination of products) to meet the persons' needs. This is particularly important for people with significant impairments or progressive conditions.

Two voluntary credentialing programs exist for individuals who work for HME and rehab suppliers that are designed to protect the consumer's needs and interests. RESNA (Rehabilitation and Assistive Technology Society of North America) offers the Assistive Technology Professional credential. And NRRTS (National Registry of Rehabilitation Technology Suppliers) offers the RRTS (Registered Rehab Technology Supplier) and the CRTS™ (Certified Rehab Technology Supplier). For more information on these credentialing

programs, or to find individuals in your area that hold these credentials, visit www.resna.org or www.nrrts.org.

10.2.2. Manufacturers That Sell Direct

A small number of manufacturers have designed products that they believe are unique and who sell their products directly to consumers. When their products meet the consumers' needs, it may be an acceptable way to obtain wheeled mobility and adaptive seating and or positioning products. But it is equally important to realize that if the manufacturer's product is not appropriate, or if a better product is available from a different manufacturer, the manufacturer may gloss over or minimize the information in an effort to close a sale rather than meet the consumers' unique needs.

Consumers should be very careful when working directly with a manufacturer that carries a very limited range of products. They should ask detailed questions, they should seek opinions from their physician or from a qualified physical or occupational therapist, and they should explore other equipment options before making a final decision. In other words, consumers should do their homework and make comparisons among different products that may meet their unique needs.

10.2.3. Telemarketers

Although advertising can raise consumers' awareness of existing products, consumers should be extremely cautious of national or even local chains that promote their products heavily on TV or in other media. Another old saying, "if it sounds too good to be true, it probably is," applies. It is possible to get an appropriate wheeled mobility device from these kinds of suppliers, but it is highly unlikely that this equipment will be individualized or that it will include specialized adaptive seating. Many of these companies have warehouses full of a narrow range of products and they tend to focus more on determining the customers' eligibility for mobility

equipment rather than on understanding their specific needs. There is often a “one-size-fits-all” type of mentality. If you happen to be that size or shape, then the equipment may be acceptable. But if you have unique needs, you may be very disappointed.

Media campaigns typically present a highly positive spin and often oversimplify what can be very complex equipment. In many cases, the consumer never sees a sales person or never has an opportunity to try the mobility or adaptive seating equipment before it arrives at their home. The representative they speak to on the phone is often in another state, and may have very little medical or product knowledge. These individuals may sound very caring. But they are often more motivated to make hefty commissions than they are to meet customers’ unique needs. Consumers have reported that these companies are more than happy to provide them a wheelchair but once the product arrives and there are problems, the companies act like there is nothing they can do. A common excuse is that the physician ordered the equipment and the claim has already been processed, so there is nothing that can be done.

10.2.4. Nursing Homes or Other Residential Programs

Residents of nursing or other long-term care facilities often obtain their wheeled mobility or adaptive seating equipment directly from the program that operates the facility. This is often due to the way these facilities are funded. For the most part, if a person needs a wheelchair or special positioning system, the facility is required to provide it using its basic operating budget. Medicare and most Medicaid programs, for example, do not pay separately for routine or basic DME. It is typically part of the facility’s per-diem cost.

Because DME is part of the residential facility’s budget, the equipment provided by the facility can vary widely. Many people report that only the least expensive options are provided in some residential facilities. They report that there is often a take-it-or-leave-it attitude, or they are told no other solutions are available. Therapists who have contracts in some facilities have

reported that they are pressured by their administration not to recommend expensive mobility equipment, no matter the person's needs. They are often encouraged to provide low-cost solutions to very complex challenges that could be remedied by a commercial product.

Unfortunately, it is common to see residents sitting in ill-fitting wheelchairs that are in poor condition or are even unsafe. Many are missing parts, or have badly worn upholstery. Some families report that nursing home administrators have told them that they are only required to provide a wheelchair, not provide an optimal wheelchair or seating system.

Some residential programs do make a genuine effort to provide high quality mobility and seating equipment. In many instances, they call on reputable HME or rehab product suppliers to supplement their own services. They value the recommendations of mobility specialists, therapists and others and institute a team approach. In some cases, it may even be possible to have insurance or other funding sources cover highly specialized seating and or mobility system, but this can vary by region of the country or state in which the person resides. If you or a family member have a mobility impairment that requires a wheelchair or seating system and residential care, it is important to ask questions and advocate for the highest quality services and products that meet the need.

10.2.5. Medical Equipment Catalog Suppliers and Internet-Based Companies

Catalog and internet suppliers can often be an excellent source of information, especially if you want to compare a wide range of products. Unfortunately, neither of these sources offers individualized and specific assistance that can be essential for many people. Unlike HME and rehab suppliers, internet- or catalog-based suppliers operate on a what-you-see-is-what-you-get approach. If a mobility product does not meet a particular person's need, internet- and catalog-based suppliers cannot offer alternative approaches or adapt their offerings to meet the person's needs. These types of suppliers do not personally deliver products or adjust them or provide the

consumer with instruction or other vital information. Some may bill insurances, but most require the consumer to pay for the equipment up front before shipping, and if the insurance does not cover the claim, they have no interest helping the customer get reimbursed.

If people know exactly what they need and they can pay cash for the mobility or seating products they choose, a catalog or internet supplier may offer the cheapest price. This lowest price is available because the additional and often critical services are not part of the cost of providing the product. The consumer places an order and the catalog or internet supplier ships it to the consumer's doorstep. There is little overhead and almost no individualized service component.

10.2.6. Pharmacies and "Big Box" Retailers

These types of suppliers can also offer very low pricing, but it is because they purchase their mobility and seating products in large volumes from a limited number of manufacturers. Just like catalog or internet suppliers, these types of suppliers rarely provide complex rehab mobility or adaptive seating systems, but they may offer more simple assistive devices or mobility devices (for example, a three-wheeled scooter). They can be more convenient because they allow people to see a product in person before taking it home with them.

10.2.7. Directly from the Veterans Administration for Disabled Veterans Who Qualify

The Veterans Administration provides a wide range of medical services to injured or disabled veterans. But this system operates much differently than those offered to the general public. So, unless you are a veteran with no other healthcare coverage, this is not a common source for obtaining mobility or seating equipment.

10.2.8. Non-Profit Community Agencies (i.e., ALS Association, MD Association, MS Society, UCP, etc.)

Some non-profit agencies have limited resources to provide mobility and seating equipment or services to people with disabilities. These services are often specific to the impairment or diagnosis of the person needing the equipment. For example, programs like the MS Society or the ALS Association may have loan closets or equipment recycling programs, but the equipment may only be available to people with these specific conditions. The equipment is often available as a first-come-first-served basis, but if available, the equipment is usually provided for little or no fee. These programs may have access to professionals who may be able to adjust the equipment to a persons needs.

Other non-profit agencies may not make equipment available, but they may provide information and referral services. They may even have funds to help pay for things that are not typically covered by the person's insurance plan.

10.3. Who Pays For the Equipment?

Funding for wheeled mobility and adaptive seating and positioning systems is significantly different from consumer goods and other types of medical equipment or supplies. People in need of a mobility or seating system rarely pay for the equipment themselves. Most of the time, some type of insurance program covers it.

The most common funding sources are:

- Private or commercial healthcare insurance
- Medicare
- Medicaid
- State-supported workers compensation or vocational rehabilitation services

10.3.1. Private or Commercial Insurance

There are literally thousands of different insurance carriers across the country. Each of these companies may offer several different types of healthcare plans to their subscribers. So, it is impossible to identify all of the coverage options that may be available to a person. It is therefore important for people with insurance benefits to contact their employer and to study their specific coverage benefits in order to understand what their insurance does and does not cover.

Most insurance plans cover the majority of DME costs, but there may be specific limitations or requirements that you obtain the products from a network provider. For example, if you obtain a wheelchair or adaptive seating system from an in-network provider, your insurance may cover 90% or 100% of the cost. But if you go out-of-network, the insurance may pay substantially less, or nothing, of the cost.

As mentioned earlier, in-network providers may limit the products that they are willing to provide because of cost - in spite of what your medical needs or personal preferences may be. Preferred providers (i.e., DME suppliers) often agree to accept a lower payment amount from the insurance company in exchange for more referrals or business. To offset this lower payment, a supplier is likely to offer only the lowest cost options available and will not allow the person to obtain higher cost products, even if the higher cost item has significant benefits to the person with insurance.

Even if your insurance reportedly covers 100% of the cost, it does not mean that you can get any type of wheelchair or adaptive seating system. When an insurance company says it will pay at 100%, it generally means they pay 100% of the 'usual and customary' cost of the product. So, what is a 'usual and customary' cost? Often it is based on a discount from the list price or a

formula based on what is typically covered by the Medicare program. (More about Medicare's coverage plans follow.)

More insurance companies place a maximum cap on DME benefits that may seem adequate to a healthy person but which are inadequate for a person with a serious injury or complex medical condition. For example, if your policy caps DME expenses at \$4,000 a year, and you are in good health, you will probably never make use of that benefit. But if you are in a serious auto accident and become paralyzed such that you need a \$10,000 power wheelchair, you will probably have to pay several thousand dollars out-of-pocket for that equipment. Some insurance plans do not even cover DME benefits, so if you are injured and need a wheelchair, you may have to pay the entire cost. Other insurances will only pay for one wheelchair per lifetime. Unfortunately, most people do not pay much attention to what their DME benefit is until it is too late. Thus, when they need this kind of equipment, they may be shocked to find how limited their coverage may be.

Insurance companies also have very specific eligibility policies regarding what type of mobility or adaptive seating systems they cover. These policies are often based on the policies established by the Medicare program. When a person needs more advanced or expensive mobility or adaptive seating equipment, it is common for a supplier to submit a written request to the insurance company to determine if the claim for the equipment will be covered before the equipment is actually provided. This pre-determination process often takes several weeks or more and usually involves submitting detailed information from medical records to justify the need for the equipment. If an insurance company deems the equipment to be "medically necessary," they will usually provide an approval or authorization to the supplier, but this authorization is seldom a guarantee of payment. This authorization also only addresses medical needs and rarely indicates how much of the claim the insurance company will actually pay. The

actual payment amount is usually based on various contractual rates after the equipment is supplied. In other words, a specialized wheelchair with a custom seating system costing over \$10,000 may be deemed “medically necessary” but when the claim is paid, the insurance may only cover \$4,000 of that cost, leaving the bulk of the cost to the person who needs the equipment.

Insurances often make liberal use of the term “medically necessary.” Unfortunately, the term is not always clearly defined and is open to interpretation. So even though your physician or physical or occupational therapist has done a very detailed evaluation and has recommended a specific wheelchair or seating system that includes features that promote a maximum level of independence, it does not mean that the insurance will consider it to be a medical need and cover the cost.

For example, more and more research suggests that people who push heavy manual wheelchairs will develop wrist or shoulder injuries after several years of use. But a lighter wheelchair is far more expensive than a heavy wheelchair. So many insurance companies, in an effort cut costs, deny the lightest models of manual wheelchairs, indicating that they are not “medically necessary” and are instead simply a convenience. The same goes for many types of wheelchair accessories such as standing components, powered seat elevating mechanisms or other expensive components. Insurances will often deny these items as not “medically necessary” even though they were prescribed based on a physician’s assessment of someone’s medical condition.

It is also important for people to realize that to obtain the mobility equipment or adaptive seating systems they need for maximal function and independence, they must often actively deal with their insurance. This can be very frustrating as anyone who has tried to get through to a claims person to obtain specific information will tell you. Even if an insurance company denies

a request for DME, it is important for people to challenge that denial. Almost all insurance companies have appeals processes for denied claims.

10.3.2. Medicare

Medicare is a federal healthcare program administered by the Centers for Medicare and Medicaid Services (CMS). It has become the model for many other private healthcare insurance programs. Although Medicare covers some permanently disabled individuals younger than, the vast majority of the policies developed by CMS are based on the needs of senior citizens.

There have been substantial changes in Medicare's coverage policies and rates of reimbursement in recent years. Some of these changes stem from fraudulent behavior by a very limited number of dishonest suppliers. Unfortunately, these policy changes have resulted in significant confusion and substantially more work for suppliers, physicians and other healthcare providers.

One of the most important aspects of Medicare program is that it is a fee-for-service-based system. CMS develops specific policies and procedures for products and services and pays for those services and products only after they have been provided. For the most part, there is no pre-determination process. Authorized Medicare suppliers are expected to know and follow the rules and regulations and only submit appropriate claims for equipment and services. If a supplier has all necessary information, supporting the medical need for a wheelchair or seating system that meets the Medicare policies, the claim will be approved and paid. If suppliers do not have sufficient medical documentation, or they know that the Medicare beneficiary does not qualify and they still submit a claim for payment, they can be found guilty of fraud and be subject to substantial penalties.

CMS may audit a claim several years after the product or service is rendered to guarantee that the claim was correct and proper. If it is determined that the claim does not have all the

required elements, it is possible for CMS to require the supplier to refund payment for that claim and pay interest and or penalties. In other words, reputable Medicare suppliers follow the Medicare rules and regulations very carefully so as not to risk substantial penalties. But some unethical suppliers take advantage of the Medicare program and submit fraudulent claims in an effort to get as much money as possible. These suppliers have little regard for rules and regulations and are bent on making a fast buck. So, it is critical that Medicare beneficiaries use good judgment and seek reputable suppliers that adhere to the strict Medicare regulations. The old saying “if it sounds too good to be true, it probably is” applies to Medicare suppliers that are out for a fast buck.

Medicare is not like having a credit card that allows people to get whatever they want or whatever they can afford. Many different and complex aspects of Medicare’s rules regarding wheelchairs and adaptive seating systems must be followed. The three most important components regarding wheeled mobility and seating products under the Medicare program are:

1. Policy – The criteria required to determine whether a person qualifies for a product
2. Coding – The types of similar products that are grouped together and available to a person who qualifies
3. “Allowables” or fee schedules – the amount paid for a given category of product.

All three of these components must be understood in order to comprehend the complexity of what is involved.

10.3.2.1. Medicare policy.

Medicare has extensive policies regarding who qualifies for wheeled mobility and seating systems. These policies are too detailed to discuss in this document, but some key issues are worth noting:

- Any type of mobility assistive equipment (also known as MAE) must be needed for a person to be able to perform basic mobility-related activities of daily living (called MRADLs) within the person's home
- MAEs range from a simple cane to advanced power wheelchair with highly customized components
- MRADLs do not include activity outside the home, so things like grocery shopping, banking, going to the doctor's office or pharmacy are not considered "medically necessary"
- People who perform MRADLs in their home using a cane or walker, they are not eligible for a manual wheelchair
- People who can get around inside their homes using a manual wheelchair are not eligible for a three-wheeled scooter or power wheelchair
- A lightweight wheelchair is only relevant to the person's ability to move that chair by themselves. A caregiver's needs are not taken into consideration for a lighter weight wheelchair
- Only one wheelchair at any given time is allowed, Medicare will not pay for a second or back-up wheelchair no matter the reason
- A physician's prescription and additional medical documentation from the medical records are required for Medicare to determine eligibility, but a physician's prescription for a wheelchair does not mean that the person qualifies for it nor that Medicare will pay for it

Medicare also has extensive policy regarding adaptive seating systems. Highlights include:

- A person must qualify for and have a wheelchair in order to be eligible for a special seat or back cushion to go into the wheelchair. These products may not be used for things like lift chairs, commodes or shower seats or for use in the car
- If a person has, or is at risk for, a pressure sore (i.e., decubitus ulcer), they may qualify for specific pressure distributing seat or back cushions
- A person must have substantial postural deficits or deformities to qualify for a positioning seat or back cushion
- Documentation from the medical records and specific medical diagnoses are required to qualify for certain types of seating systems

There are pages and pages of specific Medicare policy regarding mobility equipment and adaptive seating systems. For more information, it is best to contact your local supplier and or therapist.

10.3.2.2. Medicare coding.

Medicare does not pay for specific brands or models of mobility or seating products individually. They pay for these products based on a billing code. These codes are designed for billing and reimbursement efficiency and are called Healthcare Common Procedure Coding System codes (HCPCS).

All insurance providers and all state-funded Medicaid programs use HCPCS codes that Medicare develops. But Medicare does not pay for all its HCPCS codes. Sometimes CMS has developed a HCPCS code so that other funding sources may cover them. For example, CMS recently developed HCPCS codes for pediatric power wheelchairs, but because Medicare is almost exclusively for adults, these codes are rarely used. Some HCPCS codes are judged to be “not medically necessary” and are therefore not covered by Medicare. For example, a seat-elevating mechanism on a power wheelchair has a HCPCS code, but it is not a covered item.

Essentially, similar kinds of products are grouped together into different HCPCS. For the most part, products are grouped by performance characteristics or standards, rather than cost. Although products with similar characteristics may have similar costs, they may also have quite a range in cost. It is not unusual for suppliers to pay close attention to the various costs of equipment within a given HCPCS code and only offer those products that are on the lower end of the range because they do not get paid a higher amount for higher cost products. Suppliers may make exceptions to satisfy unique needs but this is often done on an individual basis. In other words, you may want to get a specific brand or model of wheelchair or seating system, but if the cost of that item is significantly higher than other products within that HCPCS code, or if the cost is more than what Medicare will pay, a supplier may be unwilling to accept Medicare as a payment source.

Some HCPCS codes are reimbursed only on a monthly rental basis. Some items (i.e., HCPCS) may have a monthly rental rate with a maximum cap of duration after which the rental is converted to ownership. Other items may be rented or purchased and are more commonly purchased than rented. For example, a standard weight manual wheelchair (HCPCS K0001) is a rental item that is capped after 13 months. A Medicare beneficiary cannot buy this product but must rent it under the Medicare program. It becomes theirs once the rental has capped. Power wheelchairs may be rented, but because most people need this kind of equipment for many years, most suppliers will typically sell rather than rent them.

10.3.2.3. Medicare allowables or fee schedules.

Products within a given HCPCS have an established reimbursement amount that Medicare pays. This amount is called an ‘allowable’ or part of a ‘fee schedule.’ Determining the allowable of a given HCPCS usually requires a complex formula. No matter how much a given product costs within a HCPCS code, Medicare pays only a set amount for that item. But

Medicare only pays 80 % of that allowable. The remaining 20%, or the co-pay, is to be paid by the Medicare beneficiary or by their supplemental insurance if applicable.

In unique circumstances, a supplier may charge a Medicare beneficiary for something that is beyond the Medicare allowable. To do this, a supplier must submit an 'Advanced Beneficiary Notice' (i.e., ABN) that has been signed by the beneficiary. The ABN is a specific form that explains why an item is being provided at a higher cost to the beneficiary and exactly how much the beneficiary is agreeing to pay. For example, if a Medicare beneficiary wants a powered seat lift mechanism on a power wheelchair (something that is considered a non-covered service), and they are willing to pay out-of-pocket, the supplier may charge for this item only if they have a signed ABN from the beneficiary. If the supplier does not have a signed ABN on file and they charge the beneficiary, Medicare could require the supplier to refund that amount to the beneficiary (who, by the way, gets to keep the seat elevator).

Suppliers are expected to accept that allowable and, under most circumstances, are not permitted to charge the Medicare beneficiary an additional amount. Suppliers are also required by Medicare regulation to make a genuine effort to collect the 20% co-pay from the beneficiaries insurance or from the person themselves. This co-pay may be waived under certain financial hardship situations, but suppliers are forbidden from waiving the co-payment as an inducement to solicit business.

Suppliers must be intimately aware of Medicare's rules and regulations and must gather all information that Medicare requires in order to submit a claim for reimbursement. If that information is unavailable, neither the physician, the therapist nor the Medicare beneficiary are at risk of claims denial. Only the supplier is at risk. Remember, in order to submit a claim for payment, a supplier must provide that equipment to the Medicare beneficiary. So, if a supplier does not follow the regulations, or does not obtain the documentation required to demonstrate a

persons' eligibility for mobility or seating equipment, the claim can be denied and the supplier is not reimbursed.

10.3.3. Medicaid

Medicaid is a program that is largely funded by the federal government, but it is administered by each state. Generally, Medicaid is state-administered insurance for poor people and those lacking health insurance. States are required to make Medicaid services available to eligible recipients under age 21. Many also offer this program for adults as well. States must match the funds provided to them by the federal government to administer their programs, and this can be a very substantial portion to their budgets.

Each state has different policies and procedures for coverage of wheeled mobility and adaptive seating products, so it is impossible to discuss all options. There are some commonalities however, and these are usually quite different from Medicare.

For example, most Medicaid systems either require or provide prior authorization for wheelchairs or adaptive seating systems. Some state Medicaid systems consider people's needs inside and outside their home environments. Medicaid fee schedules are usually very similar to Medicare's but can be lower or higher.

Many states also have special Medicaid waiver programs that pay for equipment that may not be covered by the regular Medicaid program. These programs are primarily designed to help people live in their own homes and avoid having to live in a more costly nursing home. Each program has its own procedures and regulations.

For more information about the specifics in your state, it is best to consult with a therapist, social worker or a reputable supplier.

10.3.4. State-Supported Workers Compensation or Vocational Rehabilitation Services

Workers compensation programs and vocational rehabilitation service programs are administered by the state. Like Medicaid, most have some type of federal matching funds.

But unlike Medicaid or Medicare, these programs are specifically geared toward people who were injured while working (workers compensation), or they are designed to help a disabled person obtain education, training or technology that would permit them to become employed (vocational rehabilitation).

Workers compensation or vocational rehabilitation programs may pay for mobility or seating systems that would not otherwise be covered by other funding sources.

10.4. Summary

Over the past several years, there have been many changes in policy, procedures and reimbursement for suppliers of wheeled mobility and seating systems. Some new regulations were necessary to better reflect the broadening range of products available in the market. Some of these policies and procedures were crafted in response to a very small number of dishonest suppliers who committed fraud because the previous policies were too vague and because oversight was minimal. But with all the additional regulations, there has been a major reduction in reimbursement. As a result, suppliers are required to do more while being paid less.

There have been reports of reputable and well established HME and rehab equipment supply companies that have gone out of business thanks to these added pressures. And the companies that have remained in business have drastically altered their business models to remain viable. Consumer groups have made some impact on a few of these restrictive policies, but they have had no impact on reimbursement levels. In fact, it is safe to say that most believe that the cost of mobility and seating equipment is far too high. All but a few people outside the

industry realize how the 'hidden' costs associated with providing this type of equipment impact companies' bottom lines. Accreditation, certification, staff training and benefits fuel costs.

Major increases in documentation collection and complex claims processes are examples of these additional costs. These costs are unlikely to decline in the future, and reimbursement levels are not likely to improve anytime soon.

This is not a very optimistic view, but barring major changes to healthcare policy and practice, it is likely that more suppliers of wheeled mobility and of seating and positioning products will close their businesses. The survivors will cut costs by limiting product availability and services.

Chapter 11

Parents' Perspectives of Assistive Technology

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Contents

	Section	Pg
11.1. Introduction	314
11.2. Current Products and Technologies	315
11.3. Unmet Needs	317
11.4. Contributing Factors	319
11.5. Reliability of Performance	320
11.6. Consequences	321
11.7. Proposed Solutions: A Commentary	321
11.8. Needed Products and Solutions	323
11.9. Conclusion	324
References	325

11.1. Introduction

Assistive technology plays an important role in helping children compensate for disability and is the key to unlocking children's potential. Assistive technology empowers children with disabilities to be heard and recognized as individuals of value and to build the self-confidence necessary to interact positively with the world at large. Self-initiated mobility powerfully impacts a child's development, self-confidence and social acceptance. A child's inability to move independently leads to a self-perception of incompetence and a sense of learned helplessness that can be instilled by 4 years of age. The challenge then is to provide age-appropriate technology to enable the child to become an independent being. Assistive technology devices augment children's functional capacity and facilitate their independence and psycho-social development. [1] Parents are left to perceive and respond to the needs of a growing child rather than the consequences and necessities of their child's disability.

Berry, et al interviewed 35 caregivers of children with powered wheelchairs. [2] They reported that consequences of wheelchair provision extended far beyond independent mobility to increased independence in other many domains. In addition, the children's increased independence and "freedom" with powered mobility also "freed up" time for the caregiver.

Quibble interviewed five adults with cerebral palsy who used power wheelchairs. [3] These adults reported that their most memorable therapy intervention was playing and experiencing movement in wheelchairs, tricycles and go-karts. In contrast to this positive intervention, they reported a repeated sense of failure tied to their inability to walk.

A 2004 study examined the perceptions of five mothers of children who used powered mobility. [4] These mothers were initially reticent when powered mobility was recommended for their children. After acquiring the power wheelchair, however, these mothers reported improvement in their children's life experiences; the children had a means to move

independently from their parents to play and interact with peers. The independence, which was afforded by powered mobility, increased acceptance by peers and general society. [4]

One of the obvious but important qualities that distinguish children from adults is growth, both physical and psychosocial. Pediatric seating systems and wheelchairs can be adjusted to accommodate for growth but should accommodate cognitive development and emotional and social maturation. The pediatric wheelchair must actually promote social development in order to truly minimize disability and maximize acceptance. In particular, it is important to be able to aesthetically customize their mobility system to be “cool” (in the parlance of teen-agers) and age-appropriate.

11.2. Current Products and Technologies

Pediatric mobility is obtained through a wide variety of products and accessories. A representative listing of these devices establishes a baseline for what technology is available and provides a perspective on where technology needs to go. Dependent strollers now come with seating, which can be customized with tilt-in-space and recline functions for changing position. Tilt allows a position change with a fixed seat-to-back angle whereas a back recline function allows opening the hip to back angle (e.g., allowing for a diaper change in the stroller or for respiratory management). Adapted seating in strollers allows adjustment of the postural components on a lighter weight, foldable frame. The stroller bases have become more streamlined and have colorful choices from which to choose. Overall, these bases may be perceived as child-friendly.

Adapted tricycles: Tricycles can have trunk support and pedals with straps that secure the rider’s feet. They can also be hand pedaled to assist leg-based propulsion. Adapted tricycles allow kids with disabilities to participate in age-appropriate mobility. Front-wheel drive manual

wheelchairs have the drive wheel positioned in front to allow better wheel propulsion for the very tiny or young child. Young children ages 12 months to about 4 years old, depending on their disabilities, may have shorter arms, which limit the range of a propulsive stroke. They may also have limited strength with which to propel a wheelchair in a standard rear wheel configuration.

Rear-wheel or center-drive manual wheelchairs: Folding frames are growth-adjustable, but few companies make truly pediatric rigid sports wheelchair frames. Moving the larger rear wheels to a forward or center placed position (a more efficient wheel placement for propulsion) may interfere with front caster placement in frames. The center drive wheel requires a rear extended caster for stability, which then compromises the ability to tip the chair back to negotiate curbs. Custom adapted high mount foot platforms are needed for the child's shorter leg length.

Dependent tilt-in-space wheelchair frames provide tilt, and some frames offer a separate back recline. The tilt-in-space wheelchair frame is a more heavy-duty frame for transportation of the larger and older children who require dependent positional changes in the chair. The wheelchair frames can accommodate a ventilator tray or an oxygen tank that cannot always be carried on a stroller.

Self-propelled standers enable children to stand and propel. Children bear weight on their legs while developing upper extremity strength and trunk control as they move and explore their environment. Standing facilitates the development of spatial awareness, allows eye-to-eye interaction with peers, and stretches muscles that become tight from sitting. It is, however, difficult to reach forward to interact with objects on standing frames.

Powered, off-the-shelf mobility toys suit children who have sufficient trunk control to sit unsupported and coordinate use of both hands. Depending on a child's motor control, most

power toys are unsuitable for the types of access or support that children with severe disabilities require. Power toys are loud and usually designed for outdoor mobility.

Power scooters are appropriate for children who have function in both arms and trunk balance sufficient sit upright without support. Children's balance, control and equilibrium must be sufficient to enable them shift their weight (to the opposite side) as they turn. These abilities prevent tipping a three-wheeled scooter.

Go-Bot was "a powered cart designed to be an electric toy vehicle for children with poor dexterity and motor ability." Originally designed as a transitional powered mobility device to provide indoor, exploratory mobility to preschoolers, using either switches or joystick controllers. [5]

Pediatric power wheelchairs use smaller bases but, they are still heavy with high seating. These chairs range from standard seating with proportional joystick controllers to chairs with custom seating and sophisticated control options for the head, hands or feet. Power seating functions, which are important to the child's sensory, motor and social development, include sit-to-floor, seat elevation, sit-to-stand, tilt-in-space and power recline.

11.3. Unmet Needs

Custom seating is needed for infants and the population of children that weighs less than 25 pounds. (These children are usually aged 0-3 years.) The infant and smaller children could benefit from smaller flexible supports. The parents of small infants and children want comfort, with the least amount of restraints or supports. Seating needs the softness of pillows or blankets along with the adjustability of firmer structures and support within. The material must be easily washable. [6]

Dynamic changing position in space is advantageous for all wheelchair seating regardless of wheelchair type. Seats that elevate for reaching or transferring to lower levels – like sit-to-stand, floor-to-seat – create functional mobility opportunities. The tilt-in-space option, for example, provides pressure relief while maintaining the same seat-to-back angle. Reclining opens the seat-to-back angle for both rest and bladder management. Dynamic positional changes are an important source of vestibular feedback for all children who may lack this due to mobility impairment and thus may crave the input.

Dependent strollers are most easily used if they are spring-loaded to enable opening and folding with one hand. They are most useful if they are lightweight and compact enough to be loaded in the trunk of the family vehicle. Adapted seating components are needed on the strollers to support smaller bodies. [6]

Recreation/Play: Children grow cognitively by interacting with their environments. Play is one form of an interaction that facilitates cognitive (and physical, social, etc.) growth. Children with disabilities must have a means to manipulate toys, explore surroundings and play with peers or siblings.

Universally adaptable toys or playgrounds for able-bodied and disabled kids are needed to allow children to play together. Adaptations such as optional supports would allow children with less physical control to be able to participate. For example, the Chailey School in England uses an assisted adventure power train concept, which lets able-bodied and disabled students to play together on the playgrounds. The power train was meant to provide dynamic driving to enable children with complex needs to control movement. The train was intended as a fun object to follow the same track, or line, that assisted power wheelchair users follow. The conductor (a child with or without a disability) allowed the driver a sense of control as he or she drove with passengers. The train was controlled by single switch for starting and stopping. Directional

control was through a “junction” of right or left switches. Children of different cognitive and physical abilities could operate the train. Children with and without disabilities could play together, taking responsibility, sharing control, taking turns and working as a group.[7]

11.4. Contributing Factors

Environmental limitations were cited as critical in Berry’s study. [2] Caregivers reported that more than 90% of children want to use power wheelchairs inside and outside of home. In reality, only half of these children were able to use power wheelchairs in their homes. Barriers to using power wheelchairs include difficulty negotiating doorways and hallways. Power wheelchairs can also make it difficult for users to get near enough to tables. Lack of accessibility in the community diminished the usefulness of mobility devices. For example, encountering a drop-off at the end of a sidewalk frustrated wheelchair users.

Size was a reason caregivers did not use power wheelchairs in their homes or in the friends’ homes. Sometimes the wheelchair was too large to fit between pieces of furniture or through doorways. Most caregivers had to ensure ahead of time that their intended destination could accommodate power wheelchairs. Before going to a movie theater for example, caregivers called to determine whether the wheelchair would fit in the aisles. [8]

Comfort is essential in seating and positioning for children and adults. Comfort includes well-supported, optimal postural alignment to facilitate head control or to prevent sliding and the need for frequent repositioning. Primary considerations for comfort seem to be both softness and supports that do not interfere with purposeful movement.

Aesthetic significantly influences the approachability of a child with a disability. A wheelchair can be a stigma that hinders socialization and isolates young children from their peers. Acceptance is important to inclusion by parents, siblings and friends. The mobility

system, like clothing, is an extension of the user's body and personality. Colors and designs should draw attention to or complement the child. The stroller should look colorful, playful, not bulky. Frame options and accessories should make the child or teenager feel good about themselves. [8]

11.5. Reliability of Performance

Parents and children rely on mobility technology for sitting upright and for being able to eat, breath, attend school, interact with peers and their surroundings. Considering their importance, power wheelchairs should have a low incidence of technical problems. [9]

Any necessary servicing or repair work must be prompt as the child's mobility is so limited without the device. A non-working mobility device can bring a child's life to a grinding halt, affecting their participation or attendance at as well as their participation in other daily activities. It also puts those children at risk for pressure sores, respiratory complications and depression. [9]

Ease of transportation is essential to facilitate the child's participation in the community. Folding and loading a mobility bases is difficult and time consuming. It requires an adequately sized vehicle trunk and a strong caregiver (preferably without back problems). Foldable power wheelchairs exist, but they are difficult to lift and load on a daily basis. Caregivers that had foldable power wheelchairs reported the wheelchair felt less stable. In the same study of 35 caregivers, only 57% had a van for transportation. Therefore using the power wheelchair in the community was difficult. Mobility bases that meet ISO or ANSI crash testing standards are essential if the child will ride seated in the mobility base while being transported to early childhood intervention or public school.

11.6. Consequences

Lack of control or independence perpetuates learned helplessness, lack of motivation, further cognitive and psychosocial delays. Mobility and inclusion are critically important at every stage of development: from ages 0 to 3 years, pre-school, grammar school, middle and high school. Children need the spontaneity afforded by control of mobility while playing and interacting.

Medical-looking devices deter acceptance by a child's parents, their peers and by society. Mobility devices that are child-friendly, colorful, playful and fun make children with mobility impairments more approachable and accepted as playmates. An inappropriate mobility device may prevent children with mobility impairments from being included and participating in age appropriate activities such as circle time, recess, games and sports.

Poor reliability of a mobility device contributes to a child's inconsistent attendance at school and parental stress. Children can become depressed if they are immobile or constrained to bed.

11.7. Proposed Solutions: Ruth Everard's Commentary

Below is a list of thoughts on consumers' needs based on some of the requests and needs of people that I (Ruth Everard, power wheelchair user) have met and some of the principles and ideals that Dragonmobility has tried to meet at users' requests. What I find is missing in the general market is the philosophy, not the clever features. A wheelchair should not be thought of or designed as a vehicle in the mainstream sense. It is mobility not transport (i.e., an alternative to walking, not to a car), so it should tap into natural instincts and understanding of the physical world rather than involve a conscious learning process. This opens up its use to people with cognitive limitation.

- The mobility system should be usable by a child of nine months of age (i.e., when crawling and walking might be expected).
- It should allow access to the environment, not enclose the user or place barriers between the user and other things and, most importantly, people. Trays, communication aids, straps on the power wheelchair should be kept to a minimum and be removable.
- It should provide feedback to all the senses about the environment (floor surface, up/downhill etc), a capability that would also enable use by the visually impaired.
- Its electronics should be capable of interpreting tremor or other unintentional movement of the user. It should be as compact as possible.
- It should provide access to the floor and to a height at which the user can look people in the eye. This helps the child physically reach a greater number of people and objects. It also augments social and developmental purposes.
- It should move in three dimensions at once. The configuration should not limit performance. If possible, it should enable the user to stand.
- Its battery life should exceed the stamina of its user and should re-charge in the time the user sleeps.
- It should be possible for a skilled bicycle mechanic to service and make basic repairs to the wheelchair (and the manufacturer's service operation should allow for this).
- The mobility system should be agile enough to "dance" and powerful enough for hiking.
- Its design should draw the eye to the face of the user and not draw attention to the seat or machine.

- It should be custom-built because nobody who uses a wheelchair has standard needs.
- It should be easy to transport in “normal” transport (including air transport) even if it is designed for adapted transport as the ideal. While stair-climbing is attractive, it is a low priority compared to other needs of safety, size and agility as ramps and elevators are easy to incorporate into the physical environment.[10]
- Ruth Everard is a customer support manager at Dragonmobility. Her contact information is listed in the References at the end of this chapter.

11.8. Needed Products and Solutions

Taking into account Ruth Everard’s guiding principles, the following products and technologies are needed or if nominally available, must be improved.

Universally adapted power toys or group activity playgrounds are needed that can be adapted easily for children with physical limitations to allow interaction with their able-bodied peers on the playground or in a recreational type environment.

Safe outdoor and indoor mobility – Device must be capable of safe, unsupervised self-initiated movement, semi-controlled as used in line-following and obstacle-avoidance technology for children who are still learning power mobility skills. They would greatly benefit from spontaneous movement in the environment as long as they could safely interact with other children.

Lightweight power-assisted wheels or gear-assisted wheels on all children’s wheelchairs – Children’s arms and are not long or strong enough to get leverage to propel wheelchairs. They would benefit from some type of assisted wheel propulsion. Power- and gear-assisted 24-inch wheels can be used on some pediatric wheelchairs. However not all children use 24-inch wheels.

Hover-type powered mobility – A particular (possible) power base that has been discussed would float over environmental barriers on an air cushion. A cushion of air will absorb shock and provide a smooth ride.

Robotics, i.e., guided and assisted mobility systems – These allow safe self-initiated mobility for those with cognitive or visual impairment.[11] They would help marginal drivers or young children just learning power wheelchair skills. And these systems would be useful in environments like small homes that demand tight maneuverability. Examples of guided and assisted systems include line-following, object-avoidance, corridor-guidance, doorway-guidance systems for power wheelchairs. Assisted or guided mobility would allow spontaneous mobility in the home where young children spend most of their time. Guided mobility could also allow safe mobility in a classroom where it is difficult to supervise many children at the same time.

Lighter weight, easily adjustable, smaller mobility systems would assist with transportation and improve accessibility in the home and classroom. Smaller children do not need heavy durable hardware sometimes seen on seating systems, which makes them hard to adjust and difficult to lift. Bendable, pliable seating supports that would stay in place are needed. [12]

11.9. Conclusion

The availability and use of pediatric mobility devices is essential to the physical, cognitive, sensory and social development of children with mobility impairments. Such devices allow children with mobility impairments to be... just children. Finally, such devices allow the parents of these children to concentrate on parenting, rather than on care-giving and overcoming barriers that block or slow their children's paths to their fullest potential.

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Appendix A – Wheeled Mobility Consumer Needs

The following information was gathered from end user focus groups, which are described in the Comparative Analysis chapter. Statements are prioritized by frequency of response and provide an outline of unmet needs related to manual wheelchairs, power wheelchairs, seating and positioning, wheelchair transportation safety, and public transportation.

A.I. Manual Wheelchairs Needs

- A. Adjustable push bars (rims) that can offer a better stride ratio, to prevent carpal tunnel and will provide a better grip.
- B. A safer and easier way to collapse (fold and unfold) the wheelchair.
- C. A cleaner propulsion system, preventing calluses, prevents hands from freezing, and in bad weather offers hand protection when propelling, preventing hands from getting dirty.
- D. A one-handed manual propulsion system.
- E. A lightweight manual wheelchair.
- F. There is a need for manual wheelchairs to have an adjustable, reclining back seat.
- G. All season, all-terrain tread, winter tires, Tires that are easy to clean and maintain. Self-cleaning tires.
- H. A seatbelt that can be easily accessed and will not fall out of reach from the user.
- I. Screws not to fall out.
- J. Front casters/wheels need to be more durable and provide more stability when propelling over lumps and bumps.
- K. Easily removable armrest and seat backs.
- L. Firm holding wheel locks (brakes) so the wheelchair doesn't slide when transferring.
- M. Standardize parts between wheelchairs.
- N. A better propulsion system so you can push another item (shopping cart).
- O. The ability to carry items, so they don't get caught in wheels.
- P. Be able to push the wheelchair more easily through various terrain.

A.II. Power Wheelchair

- A. Better weatherproofing on batteries, hand controls and wires.
- B. Way to see behind and around you.
- C. Longer lasting batteries.
- D. Reflectors and lights.
- E. Smart-wheelchair that has:
 - 1. Safety sensors to avoid collisions, knows when to slow down and speed up, automatic speed adjustment in tight situations.
 - 2. Voice activation (the chair will come toward you upon command).
 - 3. The capacity to inform you when things aren't operating correctly.
- F. Standardized parts between power wheelchairs.
- G. Interchanging controller (able to control the wheelchair from the left or right side).
- H. More storage space and storage ability (to carry items with you).

- I. Tighter turning radius (more maneuverability).
- J. Easier and faster charging of batteries.
- K. Sun and rain protection for driver. Retractable/convertible hood or umbrella-awning.
- L. Child safety strap (in order for the child to ride with the parent).
- M. Footrests that can be electronically adjusted for both the size and elevation of the person's feet.
- N. The ability to individually customize the location of the features.
- O. Controls that have the ability to be easily seen at night.
- P. Lightweight batteries for travel.
- Q. Power chairs that have a narrower width (i.e., aisles in airplanes and buses).
- R. Controllers (steering) that are larger and can be manipulated by a person's palm.
- S. A visual and or audible power-level (gauge) for the whole life of the batteries.
- T. An accessible location for the switch to disengage motors, by the user.
- U. Drink-cup holder.
- V. The ability for the user to disengage one motor if the other one dies.

A.III. Seating and Positioning

- A. The ability to adjust the customization of seating and the back, without specialized tools.
- B. Durable material armrests prevent cracking.
- C. Easily usable and safe footrests to stabilize the feet (prevent feet from kicking out without permanently securing the foot).
- D. The ability for the user to adjust the size and elevation of the foot and leg rests.
- E. More durable seat cushions for both power and manual chairs.
- F. Seating to maintain the user's position all day (prevent the person from slouching).
- G. The ability to adjust the length (depth) of the seat.
- H. The ability for the user to be able to replace gelatin pack in cushions.
- I. Arm rests with an adjustable length.
- J. User ability to adjust pre-set customized seating positions.

A.IV. Wheelchair Transportation Safety

- A. Lift that provides a greater sense of security for rider.
- B. A quicker, more efficient lockdown system (to eliminate the non-wheelchair user from climbing all over the wheelchair user).
- C. Power lift manual back-up control, which should be easier to activate by user and others.
- D. Manual and power chairs should have Q-strait holders.
- E. Tracks for lockdowns should be weatherproofed.
- F. The ability to reduce slack in Q-strait tightening.
- G. Child safety strap so the wheelchair user can carry a child.
- H. The hoist that takes a wheelchair into vehicles needs to be easier to manage (hook needs to be lightweight).
- I. Ability to extricate yourself from Q-strait (emergency release).
- J. Lockdowns that don't allow the wheelchair movement when they are engaged.

A.V. *Public Transportation*

- A. More accessible locations (wheelchair spaces) on busses, trains and planes.
- B. Public vehicles that allow the wheelchair user to get on and off at all locations using any door.
- C. Wheelchair accessible bathrooms on planes and buses, and in more locations.
- D. Wider airplane aisles.
- E. The ability for a wheelchair to maneuver between train cars.

Appendix B – National Organizations and Associations

1. ABLEDATA, www.abledata.com
2. ADAPT, <http://www.adapt.org/>
3. Advanced Medical Technology Association (AdvaMed), <http://www.advamed.org/MemberPortal/>
4. Agency for Healthcare Research and Quality (AHRQ), <http://effectivehealthcare.ahrq.gov/index.cfm>
5. Alliance for Technology Access (ATA), www.ataccess.org
6. American Academy of Physical Medicine & Rehabilitation (AAPMR), www.aapmr.org
7. American Association for Homecare (AAH), <http://www.aahomecare.org/>
8. American Association of Homes & Services for the Aging (AAHSA), www.aahsa.org
9. American Association of People with Disabilities (AAPD), <http://www.aapd-dc.org./index.php>
10. American Association of Spinal Cord Injury Nurses (AASCIN), www.aascin.org/
11. American Congress of Rehabilitation Medicine (ACRM), www.acrm.org
12. American National Standards Institute (ANSI), <http://www.ansi.org/>
13. American Occupational Therapy Association (AOTA), <http://www.aota.org>
14. American Paraplegia Society (APS), <http://www.apssci.org/>
15. American Physical Therapy Association (APTA), <http://www.apta.org/>
16. American Rehabilitation Association (ARA), <http://www.amrpa.org/>
17. American Spinal Injury Association (ASIA), <http://www.asia-spinalinjury.org/>
18. Asia-Pacific Risk and Insurance Association (APRIA), <http://www.apria.org/>
19. Assistive Technology Industry Association (ATIA), <http://www.atia.org/i4a/pages/index.cfm?pageid=1>
20. Association of Rehabilitation Nurses (ARN), www.rehabnurse.org
21. Baldrige National Quality Program (BNQP), National Institute on Standards and Technology (NIST), <http://www.baldrige.nist.gov/index.html>
22. Bloorview McMillan Centre, <http://www.bloorview.ca/>
23. Canadian Institutes of Health Research (CIHR), <http://www.cihr-irsc.gc.ca/>
24. Canadian Wheelchair Sports Association (CWSA), <http://www.cwsa.ca>
25. Carecure, <http://sci.rutgers.edu/>
26. Centers for Medicare and Medicaid Services (CMS), <http://www.cms.hhs.gov/>
27. Centre for Evidence-Based Medicine (CEBM), <http://www.cebm.net/>
28. Christopher and Dana Reeve Foundation, www.christopherreeve.org
29. Commission on Accreditation of Rehabilitation Facilities (CARF), <http://www.carf.org/>
30. Consortium of Assistive Technology Outcomes Research (CATOR) <http://www.atoutcomes.com/>
31. Department of Rehabilitation Science and Technology, <http://www.shrs.pitt.edu/CMS/Departments/RST.asp>
32. Disability Data, <http://www.infouse.com/disabilitydata/home/index.php>
33. Foundation for Spinal Cord Injury Prevention, Care, and Cure (FSCIPCC), <http://fscip.org>
34. Health Industry Distributors Association (HIDA), www.hida.org
35. Health Industry Representatives Association (HIRA), <http://www.hira.org/>

36. Human Engineering Research Laboratories, <http://www.herlpitt.org/>
37. Institute of Medicine of the National Academies, <http://www.iom.edu/>
38. International Association of Rehabilitation Professionals (IARP), www.rehabpro.org
39. International Organization of Standards (ISO), <http://www.iso.org/iso/home.htm>
40. National Association for Home Care (NAHC), www.nahc.org
41. National Registry of Rehabilitation Technology Suppliers (NRRTS),
<http://www.nrrts.org/>
42. National Center for Health Statistics (NCHS), <http://www.cdc.gov/nchs/>
43. National Center for the Dissemination of Disability Research (NCDDR),
<http://www.ncddr.org/>
44. National Institute on Disability and Rehabilitation Research (NIDRR),
<http://www.ed.gov/about/offices/list/osers/nidrr/about.html>
45. National Organization on Disability (NOD), www.nod.org
46. National Quality Measures Clearinghouse (NQMC), <http://qualitymeasures.ahrq.gov/>
47. National Rehabilitation Association (NRA), www.nationalrehab.org
48. National Rehabilitation Information Center (NARIC), <http://www.naric.com/>
49. National Spinal Cord Injury Association (NSCIA), <http://www.spinalcord.org/index.php>
50. [Ontario Rehabilitation Technology Consortium](http://www.ontariorehab.org/)
51. Paralyzed Veterans of America (PVA),
<http://www.pva.org/site/PageServer?pagename=homepage>
52. Rehabilitation Engineering and Assistive Technology Society of North America (RESNA), www.resna.org
53. Rehabilitation Engineering Research Center (RERC), on Wheeled Mobility, Center of Assistive Technology and Environmental Access <http://mobilityrerc.catea.org/>
54. Rehabilitation Engineering Research Center RERC on Accessible Public Transportation, <http://www.ap.buffalo.edu/idea/Projects/index.asp#apt>, <http://www.rercapt.org/>
55. Rehabilitation Engineering Research Center (RERC) on Spinal Cord Injuries,
<http://www.rercsci.pitt.edu/>
56. Rehabilitation Engineering Research Center (RERC) on Wheelchair Transportation Safety, <http://www.rercwts.org/index.html>
57. Social Security Administration (“Blue Book”),
<http://www.ssa.gov/disability/professionals/bluebook/>
58. The Rehabilitation Engineering Program Rancho Los Amigos National Rehabilitation Center, <http://www.ranchorep.org/>
59. U.S. Access Board, www.access-board.gov
60. US Census Bureau, www.census.gov
61. US Department of Transportation (DOT), <http://www.dot.gov/new/index.htm>
62. U.S. Department of Veterans Affairs (VA), <http://www.va.gov/>
63. United Spinal Association, <http://www.unitedspinal.org/>
64. Wheelchair Foundation, <http://www.wheelchairfoundation.org/>
65. Wheelchair Standards Information, <http://www.wheelchairstandards.pitt.edu/>
66. World Health Organization (International classification of functioning, disability and health) (WHO), <http://www.who.int/classifications/icf/en/>

Appendix C – Wheeled Mobility Conferences and Tradeshow

1. Abilities Expo, <http://www.abilitiesexpo.com/>
2. American Occupational Therapy Association Conference and Expo(AOTA), <http://www.aota.org/ConfandEvents/Conf.aspx>
3. American Physical Therapy Association Annual Conference and Exposition (APTA), <http://www.apta.org/>
4. Asia-Pacific Risk and Insurance Association (APRIA), <http://www.ccissr.org/APRIA2009.htm>
5. Canadian Seating and Mobility Conference (CSMC), <http://www.csmc.ca/>
6. Center on Disabilities at the California State University, Northridge (CSUN), <http://www.csun.edu/cod/>
7. Contemporary Forums – Spinal Cord Injury Show, <http://www.contemporaryforums.com/>
8. Home Medical Equipment Annual Conference (HME), <http://www.hmeexpo.com/>
9. International Conference on Mobility and Transport for Elderly and Disabled Persons (TRANSED), <http://www.tc.gc.ca/pol/en/transed2007/home.htm>
10. International Home Care and Rehabilitation Conference (HCR), <http://www.hcrjapan.org/english/index.html>
11. International Seating Symposium (ISS), www.iss.pitt.edu/index.html
12. Medtrade, <http://www.medtrade.com/>
13. National Mobility Equipment Dealers Association Annual Conference (NMEDA), <http://www.nmeda.org/conference/index.html>
14. Rehabilitation Engineering and Assistive Technology of North America Annual Conference (RESNA), <http://www.resna.org/Conference/Conference.php>
15. RehaCare Trade Fair and Congress, <http://www.rehacare.de/>
16. World Conference on Disability, <http://www.wcdexpo.com/index.cfm>

Appendix D – Manufacturers

1. 21st Century Scientific, Inc., <http://www.wheelchairs.com/>
2. Accessible Designs Inc, <http://accessibledesigns.com>
3. Action Products, <http://www.actionproducts.com>
4. ActiveAid, <http://www.activeaid.com>
5. Adaptive Engineering Lab, <http://www.aelseating.com>
6. Adaptive Equipment Systems, <http://www.aesys.com/>
7. Adaptive Switch Labs, <http://www.asl-inc.com>
8. Advanced Mobility Systems, <http://www.amstilt.com>
9. AdaptaChair, <http://www.adaptachair.co.uk/>
10. Alber, <http://www.ulrich-alber.de/en/index.php>
11. ALC, Inc (Action-Lift Chairs), www.actionliftchair.com
12. Allman Products, <http://allmanproducts.com>
13. Altimate Medical, Inc, <http://www.easystand.com/>
14. American Bantex Corporation, <http://www.americanbantex.com/aboutus.htm>
15. American Health Systems, <http://www.4ultraform.com>
16. Amigo Mobility International, <http://www.myamigo.com>
17. Amysystems, <http://www.amysystems.com>
18. Anna-Dote Inc, <http://www.anna-dote.com/>
19. Anthros Medical Group, <http://www.anthrosmedical.com>
20. *Apria Healthcare, <http://www.apria.com/home/>
21. Aquila Corp., <http://www.aquilacorp.com>
22. ARTSCO, Inc., <http://www.artscoinc.com/>
23. Aspen Seating, <http://www.aspenseating.com/>
24. Assembled Products Corporation, <http://www.martcart.com/>
25. *Atec, <http://www.swisstrac.ch>
26. Baby Jogger, <http://www.babyjogger.com>
27. Basic Medical Industries, Inc., http://www.basicmedical.com/access/index_new.asp
28. BG Industries, <http://www.bgind.com>
29. Blue Chip Medical, <http://www.bluechipmedical.com>
30. Body Point, <http://www.bodypoint.com/>
31. Bodyline Comfort System, <http://www.bodyline.com>
32. Body Tech NW, www.bodytechnw.com
33. *Broda Seating, <http://www.brodaseating.com>
34. Bromac Assistive Technology, <http://fp1.antelecom.net/bromac/index.html>
35. Bruce Medical Supply, <http://www.brucemedical.com/>
36. Bruno Scooters, <http://www.bruno.com/index.html>
37. Burke Corporate - General Inquiries, www.burke.com
38. BXL International Sales, <http://www.bxlintl.com/default.aspx>
39. *Chunc, <http://www.chunc.com/>
40. Clarke Health Care Products, Inc, <http://www.clarkehealthcare.com/index.html>
41. Cliplight, <http://www.cliplight.com>
42. Colours in Motion, <http://www.colourswheelchair.com/>
43. Columbia Medical, <http://www.columbiamedical.com/>

44. Companion Walker, <http://www.companionwalker.com/>
45. Comfort Company, The, <http://www.comfortcompany.com/cart/home.php>
46. Convaid, http://www.convaid.com/aa_homepage.php
47. ConvaQuip, <http://www.convaquip.com>
48. Core Products, <http://www.coreproducts.com>
49. Cover Connection, Inc., <http://coverconnection.org/>
50. Crest Healthcare Supply, <http://www.cresthealthcare.com>
51. CTM, <http://www.ctmhomecare.com/>
52. *Daher Manufacturing Inc., <http://www.daherproducts.com/content.htm>
53. Danmar Products Inc, <http://www.danmarproducts.com/>
54. *Daka, <http://www.daka.com.hk>
55. Dalton Medical, <http://www.daltonmedical.com>
56. Shoprider Mobility Products, Inc., <http://www.shoprider.com/>
57. Degage, <http://www.degage.us>
58. Deming Designs, Inc., <http://www.beachwheelchair.com/>
59. Drive Medical Design, <http://www.drivemedicaldesign.com>
60. Duro-Med Industries, Inc.,
<http://www.evertize.com/msdc/Durable/WHEEL%20CHAIR%20ACCESSORIES-DURO.htm>
61. Dynamic Controls, <http://www.dynamiccontrols.com>
62. Dynamic Systems, <http://www.sunmatecushions.com>
63. *Elmedex Ltd, <http://elmedex.com/body.html>
64. *ETAC, <http://www.etac.com/>
65. Eagle, <http://www.eaglesportschairs.com>
66. EASE Cushion, <http://www.easecushion.com/>
67. East Penn-Deka, <http://www.eastpenn-deka.com/>
68. Electric Mobility Corporation, <http://www.rascalscooters.com/>
69. Enduro Wheelchair Co.
http://hartford.citysearch.com/profile/35913737/east_hartford_ct/enduro_wheelchair_co.html
70. Ergo Air Inc.<http://www.ergoair.com/>
71. EVAC+CHAIR,<http://www.evac-chair.com/>
72. Evacu-Trac, <http://www.evacutrac.com/>
73. Everest & Jennings, <http://www.grahamfield.com>
74. Exide Technologies, <http://www.exide.com/>
75. ExoMotion, http://www.exomotion.com/th_exomotion/
76. EZ International, <http://www.ez-international.com>
77. Falcon Rehab Products, <http://www.falconrehab.com>
78. FLA Orthopedics, Inc., <http://www.flaothopedics.com/default.asp>
79. Frank Mobility Systems, <http://www.frankmobility.com/>
80. *Freedom Concepts Inc., <http://www.freedomconcepts.com>
81. *Future Mobility Healthcare, <http://www.future-mobility.com>
82. *Giraldin, <http://www.giraldin.it>
83. *GOVAN+, <http://www.mobilitymanagementdirectory.com/>
84. *Gowrings Mobility Ltd, <http://www.gowringsmobility.co.uk>
85. *Kuschall AG, <http://www.kuschall.ch>
86. *Levo, <http://www.levo.ch/>

87. *Liber-T Medtech, <http://www.libertmedtech.com>
88. Falcon Rehab Products, <http://www.falconrehab.com>
89. FLA Orthopedics, Inc., <http://www.flaorthopedics.com/default.asp>
90. Frank Mobility Systems, <http://www.frankmobility.com/>
91. Freedom Designs, <http://www.freedomdesigns.com>
92. Frog Legs, <http://www.froglegsinc.com>
93. Gaymar Industries, <http://www.gaymar.com>
94. Gelco Products, [http://www.gelcoproducts.com./](http://www.gelcoproducts.com/)
95. Gendron Inc, <http://www.gendroninc.com/>
96. Global Power Systems Inc.,
<http://www.macraesbluebook.com/search/company.cfm?company=739687>
97. Golden Technologies, <http://www.goldentech.com/>
98. Graham Field, <http://www.grahamfield.com>
99. Grover Gear, <http://www.grovergear.com/>
100. Gunnell, <http://www.gunnell-inc.com>
101. Harvy Surgical Supply Corp., <http://www.harvycanes.com/>
102. Healthwares, <http://www.healthwares.com>
103. Hermell, www.hermell.com/
104. Hitec Group International, Inc., <http://www.hitec.com/>
105. Hotshot Products, <http://www.hotshotproducts.org>
106. Hoveround Corporation, <http://www.hoveround.com>
107. Hudson Medical Products, <http://www.hudsonmedicalproducts.com>
108. Independence Technology, <http://www.ibotnow.com/ibot/>
109. Innovation in Motion, <http://www.mobility-usa.com/>
110. Innovative Products Inc., <http://www.iphope.com/>
111. Interstate Batteries, <http://www.interstatebatteries.com>
112. Invacare, <http://www.invacare.com>
113. Japlar Schauer, <http://www.battery-chargers.com/>
114. Jason Marine Enterprises, <http://www.jmeseeker.com/>
115. JT Posey, <http://www.posey.com>
116. Kareco International, Inc., <http://www.homecarebuyersguide.com/Kareco-International-Inc-cp198067.htm>
117. Karman Healthcare, Inc, <http://www.karmanhealthcare.com/>
118. Keen Mobility Company, <http://www.keenmobility.com/index.php>
119. KEMPF, <http://www.katalavox.com/>
120. KENDA AMERICAN AIRLESS, <http://www.americanairless.com/index.htm>
121. Ki Mobility, <http://www.kimobility.com>
122. Kik Technology, Inc,
<http://www.macraesbluebook.com/search/company.cfm?company=652159>
123. LaBac Systems, <http://www.falconrehab.com/LaBac.aspx>
124. Lawrence Nelson, <http://www.lawrence-nelson.com/>
125. Lester Electrical, <http://www.lesterelectrical.com>
126. Lewin Medical Supply, <http://www.lewinmedical.com/>
127. Lifestand, <http://www.lifestandusa.com>
128. Lifestyle Mobility, <http://www.lifestylemobilityaids.com>
129. LiftVest USA, <http://liftvest.com/index.html>
130. Liquicell Technologies, <http://www.liquicell.com>

131. LivingEaZy Inc, <http://www.merchantcircle.com/business/LivingEaZy.Inc.804-360-5600>
132. *Magic Mobility, <http://www.magicmobility.com.au/>
133. *MBL, <http://www.mbl.dk/>
134. *Meyra, <http://www.meyra.com/>
135. *Mobility Vision, <http://www.mobility-vision.com>
136. Magic Wheels Inc, <http://www.magicwheels.com>
137. Magitek, <http://www.magitek.com/>
138. Marinco, <http://www.guestco.com>
139. Mason Medical Products, <http://www.masonmedical.com>
140. McCarty's Inc, <http://www.mccartys.com>
141. Med-Lift & Mobility, Inc, <http://www.medlift.com/>
142. Merits Health Products, <http://www.meritshealth.com>
143. Merlexi Craft, <http://www.merlexi.com/>
144. Metalcraft Industries, <http://www.metalcraft-industries.com>
145. Miller's Adaptive Technologies, <http://www.millersadaptive.com>
146. MK Battery, <http://www.mkbattery.com>
147. MOBILITY 4 KIDS, <http://mobility4kids.com>
148. Mobility Engineering, <http://www.mobilityeng.com/>
149. Mobility Express, <http://www.mobilityexpress.com/index.htm>
150. Mobility Management, <http://www.mobilitymgmt.com/index.aspx>
151. Mogo, <http://www.mogowheelchairs.com.au/>
152. Motion Concepts, <http://www.motionconcepts.com>
153. Mulholland, <http://www.mulhollandinc.com/>
154. National Power Chair, <http://www.npcinc.com/index.html>
155. National Registry of Rehabilitation Technology Suppliers, <http://www.nrrts.org/menuFlash.asp>
156. Natural Access, <http://www.natural-access.com/>
157. New Abilities Systems, <http://www.newabilities.com/>
158. New Hall's Wheels, <http://www.newhalls.com>.
159. Nova Ortho-Med, Inc, <http://www.novaortho-med.com/wheelchairs.htm>
160. Nuprodx, Inc, <http://www.nuprodx.com/index.htm>
161. *Obus Forme, <http://www.obusforme.com>
162. *Ontario Rehabilitation Technology Consortium
<http://www.accessibilitydirectory.ca/English/default.asp>
163. Otto Bock, www.ottobock.com
164. PaceSaver Mobility, <http://www.pacesaver.com/>
165. Palmer Industries, Inc, http://palmerind.com/index_02.php
166. *Parsons ADL, <http://www.parsonsadl.com>
167. PDG Mobility, <http://www.pdgmobility.com/>
168. Permobil Inc., <http://www.permobilusa.com/>
169. PG Drives Technology Inc, <http://www.pgdt.com>
170. Prairie Seating Corporation, <http://www.prairieseating.com>
171. Pressure profile systems, <http://www.pressureprofile.com/>
172. Pride Mobility, <http://www.pridemobility.com>
173. Prime Engineering, <http://www.primeengineering.com/index.php?n=1&id=1>
174. PRM Rehab Inc, <http://www.signature2000.net>

175. Profex Medical Products, <http://www.profexmed.com>
176. Q'Straint, <http://www.qstraint.com>
177. Quantum Rehab A Division of Pride Mobility Products Corp.,
<http://www.pridemobility.com/index.asp>
178. *R82, <http://www.r82.com>
179. *Raz Design Inc,
http://www.razdesigninc.com/index.php?option=com_content&task=view&id=17&Itemid=83
180. Rand-Scot Inc., <http://www.randscot.com/bbd/>
181. Ranger, <http://www.rangerallseason.com/>
182. Rascal, <http://www.rascalscooters.com>
183. Redman, <http://www.redmanpowerchair.com>
184. *RGK, <http://www.rgklife.com/>
185. Richardson Products, <http://www.richardsonproducts.com>
186. Ride Designs, <http://www.ridedesigns.com>
187. Rifton Equipment, <http://www.rifton.com/contactus.html>
188. ROHO Group, <http://www.therohogroup.com>
189. *Rollability, <http://www.roll.co.za/>
190. Rosstron Inc, <http://www.rosstron.com>
191. *RVS Eurovema, <http://www.rvseurovema.se/>
192. Sammons Preston, <http://www.sammonspreston.com>
193. Scandinavian Medical, <http://www.scandinavianmedical.com/contact.html>
194. Seatcase, Inc, <http://www.seatcase.com/index.htm>
195. Skil-Care, <http://www.skil-care.com>
196. Skyway Machine, Inc., <http://www.skywaywheels.com/>
197. SMT Health Systems, Inc., <http://www.smthealthsystems.com/>
198. Snug Seat, Inc., <http://www.snugseat.com/>
199. SoloRider, <http://www.solorider.com/>
200. Soneil, <http://soneil.com>
201. *SOS Rehab Products, <http://www.sosrehab.com>
202. Southwest Assistive Technology Inc., <http://swattech.com/TurtleTrainerFlyer1.html>
203. Southwest Technologies, <http://swtechinc.com>
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