

SUPPORTS AND SERVICES FOR ADULTS AND CHILDREN AGED 5–14 WITH DISABILITIES IN CANADA:

An analysis of data on needs and gaps

Commissioned by Federal-Provincial-Territorial
Ministers Responsible for Social Services

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By Gail Fawcett, Coryse Ciceri,
Spyridoula Tsoukalas, and Angela Gibson-Kierstead



Canadian Council on Social Development

Foreword by the Federal/Provincial/Territorial Working Group on Benefits and Services for Persons with Disabilities

Federal/Provincial/Territorial (FPT) Ministers Responsible for Social Services recognize the importance of access to disability supports as a key building block of the *In Unison: A Canadian Approach to Disability Issues*¹ policy framework for the full citizenship of persons with disabilities. Disability supports consist of the aids, devices, programs and services that help people living with a disability actively participate at home, at work, at school and in the community.

Following the release of *In Unison 2000*, a report outlining joint progress on disability issues, FPT Ministers Responsible for Social Services instructed the FPT Working Group on Benefits and Services for Persons with Disabilities to explore reform options designed to increase Canadians' access to disability supports programs and services. Ministers reinforced the need to take a comprehensive approach to this assessment by looking at a range of possible measures, including both tax changes and investments in programs and services.

In 2002, the FPT Working Group on Benefits and Services for Persons with Disabilities assessed the feasibility of a tax-based approach to better recognize the added costs incurred by persons with disabilities in their day-to-day living. Since then, at the federal level, the list of disability-related eligible items under the medical expense tax credit was expanded. In 2004 a disability supports tax deduction for learning and employment was introduced. At the provincial/ territorial level, there have also been several positive reforms to programs and services to help persons with disabilities with active living.

One of the primary conclusions of exploratory work on the optimal way to increase access to disability supports was a requirement to better understand the levels of need, both met and unmet, for disability supports. In 2003, the FPT Working Group on Benefits and Services for Persons with Disabilities commissioned the Canadian Council on Social Development to provide a national picture of the availability of disability supports in Canada using data from the Participation and Activity Limitation Survey (PALS) 2001². The resulting report, entitled *Supports and Services for Adults and Children (Age 5-14) with Disabilities in Canada: An Analysis of Data on Needs and Gaps*, furthers knowledge in Canada on disability issues. The report is in two parts: one section covering seniors and adults and a second section covering children between the ages of five to fourteen to match the PALS survey groups.

This report responds to a request by Ministers and Deputy Ministers Responsible for Social Services for more information on whether persons with disabilities in Canada have adequate access to the supports and services they require for full inclusion. The types of supports examined include aids and devices, assistance with everyday tasks, supports within school, supports within the workplace, and household accommodations. The report provides a basic profile of those with requirements and unmet needs for disability supports.³

¹ Quebec shares the concerns raised in the *In Unison* report. However, the Government of Quebec did not take part in the development of this document because it wishes to assume control over programs for persons with disabilities for Quebec. Consequently, any references in this document to joint federal/provincial/territorial positions do not include Quebec.

² The Participation and Activity Limitation Survey did not include persons living in the territories, in institutions and on Indian reserves.

³ Not covered in this analysis are supports related to transportation, leisure activities, public infrastructure, and medication.

On a cautionary note, PALS does not capture the full range of supports and services needed for inclusive living. A high proportion of persons chose a generic “other” category to describe both the type of aids/devices required and the reason for not accessing them. This has an impact on the report’s findings.⁴

The FPT Working Group on Benefits and Services for Persons with Disabilities sincerely thanks the Canadian Council on Social Development for its professional and dedicated assistance with this report. The data presented in the report make a significant contribution to policy work in support of persons with disabilities.

⁴ As well, it should be noted that the total requirement for ‘hearing aids’ derived from the 2001 PALS tends to underestimate the actual requirement for hearing aids in Canada.

EXECUTIVE SUMMARY

MAIN CONCLUSIONS FOR ADULTS:

- The report's **main conclusions** are in the following areas:
 - context around unmet need
 - cost concerns
 - lack of information on where to obtain supports
 - unmet need in relation to type of disability
 - support with activities of daily living
 - specialized features within the home
 - educational supports
 - supports in the workplace
- The report found that those most **likely to live with unmet needs** are:
 - people with severe disabilities;
 - those with low incomes;
 - those of working age;
 - those who require high cost items (e.g. electric wheelchairs, scooters and lifts).
- The likelihood of having your needs met also relates to the nature of the disability. With respect to numbers, close to half of those with unmet needs require an aid/device to assist with mobility (this is largely due to the high prevalence of this disability type) but the rate of unmet need is highest amongst those with speech and learning disabilities.
- Overall, two-thirds of adults who require some type of aid/device have their needs fully met; one quarter have their needs partially met; and close to 1 in 10 have none of their needs met.
- The rate of unmet need is higher among those with severe disabilities, especially those living below low income cut off levels (LICO).
- There are large areas of unmet need for those on welfare (e.g. 56% for aids and 45% for assistance with daily activities). Those who are employed are the least likely to report unmet need for aids, devices and support with daily activity.
- **Cost concerns** are the main reason for unmet need and this affects persons with severe disabilities the most.
- While cost is the greatest barrier listed with respect to the acquisition of required supports and services, a substantial proportion of individuals note that a **lack of information** about where to obtain supports and services plays a major role in their unmet needs. Seventeen percent of individuals report that they did not know where to obtain aids/devices.
- The report also finds that there is a very large requirement for **support with activities of daily living**. Currently, these supports are being provided primarily through informal sources such as families and friends. This suggests that the formal infrastructure for such supports, such as organizations and agencies, can adequately service only a small fraction of those in need.

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- If baby boomers adopt the same rate of requirements for aids/devices as today's **seniors**, the total need could more than double in the next 20 years. Given anticipated demographic changes, there should be tremendous concern about the lack of formal infrastructure available to provide support when the 'family' can no longer continue to do so for free.
 - The report also explored unmet needs for **specialized features within the home**. Those with greater levels of severity are more likely to have an unmet need for this type of support. However, unlike for other types of supports, economic situation is not as predictive of unmet need. Those living above LICO and those relying primarily on market income are actually more likely to have unmet needs with respect to specialized features within the home (perhaps because fewer people living below LICO are home owners and/or programs helping with home modifications are targeted to lower income levels).
 - With respect to **educational supports**, about 8% of the student population aged 15 and over (including students in secondary and post-secondary school within the last five years) require some type of modified building feature, and 14% require some type of aid/device in order to attend school. When we separate the analysis into secondary and post-secondary school experiences, we find that there is actually a higher requirement for aids/devices in secondary school than in post-secondary school. Since one would not expect requirements to decrease, this suggests that those who have a need for such aids/devices may be less likely to go on to post-secondary education. A lack of such aids/devices could well be a serious barrier for this group.
 - Regarding **supports in the workplace**, there was a fairly high level of need for those who were employed and even higher levels for those who were unemployed. The greater requirements among the unemployed suggest that their need for supports may make them more vulnerable to unemployment. The two specific types of supports most required (particularly by the unemployed) are: 'job redesign' and 'modified hours', both of which are primarily within the purview of the employer.

MAIN CONCLUSIONS FOR CHILDREN AGED 5 – 14⁵:

Aids and Devices

- Two thirds of Canadian children with a disability (105,000) require aids and devices related to their disability.
- Just under half of these children (48,500) have some level of unmet need for aids and devices. Among adults with disabilities, over two-thirds of those who require aids and devices have their needs fully met. This suggests that children may not be doing as well as their adult counterparts in accessing aids and devices for their disability.
- Severity of disability plays a key role in level of need and unmet need for aids and devices:

⁵ Our examination of supports for children with disabilities is limited to those aged 5 to 14 because most of the relevant information from PALS is available only for that age group. Most of the questions regarding supports and services were not asked of those under the age of 5.

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- Half of children with mild disabilities require some type of aid or device, compared with 90% of the severely disabled.
 - Only 3 in 10 children with very severe disabilities have their needs for aids and devices fully met.
 - The nature or type of disability is another key factor:
 - In terms of *numbers*, children with learning disabilities (42,050), chronic illnesses (35,470) and speech disabilities (28,420) have the greatest unmet need for aids and devices.
 - Children with psychological and developmental disabilities have high rates of unmet need (64% and 61% respectively).
 - While a number of people reported multiple reasons for unmet needs, financial-based reasons are the most prevalent.

Supports Needed at School

- Seven in ten children with disabilities (just over 100,000) require an aid, device or service at school to pursue their education. Nearly three-quarters of these children have their needs fully met.
- The most commonly required aids/devices/services are ‘tutors’ or ‘teacher’s aides’ (required by just over 90,000).
- The most prevalent reason identified for the unmet need is “school funding cutbacks” (listed by 80% of those with unmet need).
- Only 7% of children with disabilities (9,760) attending school report a need for modified building features at school.

Supports Needed at Home

- 34% of children with disabilities (52,000) have parents who report a need for household support due to their child’s disability, with two thirds having unmet needs.
- Support to ‘take time off for personal activities’ is required by 50,000 families of children with disabilities while many require time off to attend to other family responsibilities; and 13% require support with everyday housework. Among those who require support with housework, 80% have an unmet need.
- Only 4% of children with disabilities (6,600 children) require special features to go in and out of their home, and a similar number require special features for use inside their home. However, there is a high degree of unmet need for all of these requirements.
- About three in five children requiring some type of specialized feature to get in, around, or out of their home have an unmet need. Cost is the number one reason listed for these unmet needs.
- It is important to note, however, that over a third of these families report that they do not know where to look for help.

PART ONE:

SUPPORTS AND SERVICES FOR ADULTS WITH DISABILITIES IN CANADA: AN ANALYSIS OF NEEDS AND GAPS

Introduction

There are many different areas where persons with disabilities may require supports and services related to their disabilities. Supports and services can range from aids and devices to assistance with household tasks to work-related supports. In this analysis, we examine the PALS to provide a glimpse of the level of requirements and unmet needs for a variety of supports. Here we examine: aids and devices, assistance with everyday tasks, supports within school, supports within the workplace, and household accommodations.⁶ We examine the level of requirements, certain aspects of those requirements, the level of unmet need, and provide a very basic profile of those with requirements and unmet needs. In our final discussion, we examine the requirements and unmet needs within the context of some of the programs available to assist persons with disabilities.

⁶ Not covered in this analysis are supports related to transportation, leisure activities, public infrastructure, and medication.

Section I: Aids and Devices

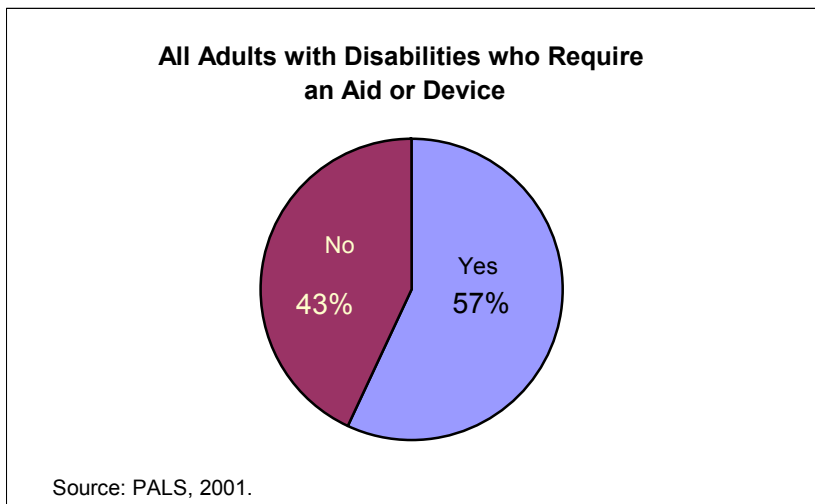
Persons with disabilities can utilize a wide range of aids and devices in their everyday life to facilitate in a variety of activities. In this section, we examine requirements for aids and devices as well as the level of unmet need.

Magnitude and Nature of the Requirements

Just Over Half of All Adults with Disabilities Require an Assistive Aid or Device

Of the 3.4 million adults with disabilities in Canada in 2001, over 2 million (2,008,460) require assistive aids or devices of some type. This represents just over half (57%) of all adults with disabilities.

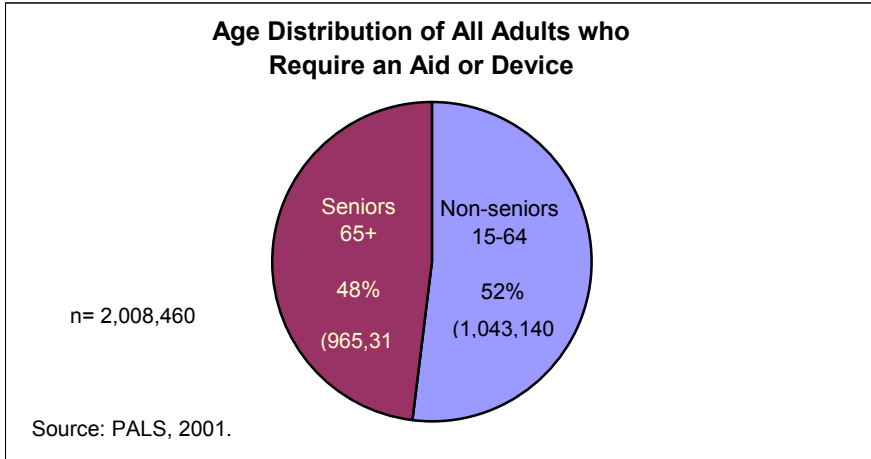
Chart 1.1



Of All Those Requiring an Aid/Device, Just Over Half (52%) Are Working Age Adults

Of the 2 million adults who require aids or devices, 1,043,140 are non-seniors (ages 15 to 64) and 965,310 are seniors (65+). This means that just over half, 52% of all those requiring an aid or device, are working age adults.

Chart 1.2



Seniors More Likely to Require Aids and Devices than Non-seniors

However, if we look at things a little differently, it is important to note that the *rate* at which seniors and non-seniors require aids or devices differs. In fact, seniors with disabilities have a *higher rate* of requiring aids or devices than do non-seniors – 66% versus 53%.

Chart 1.3

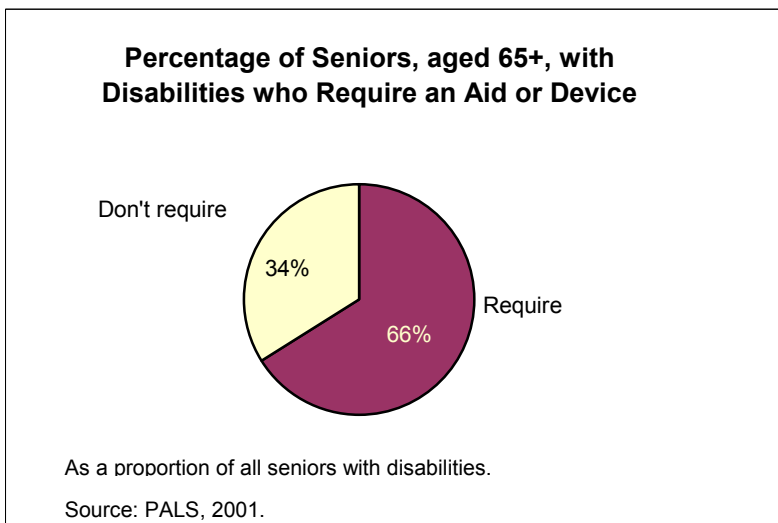
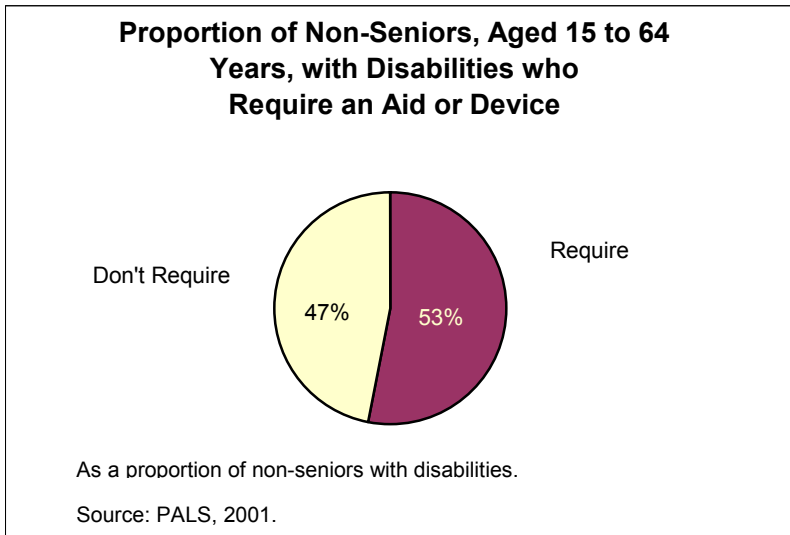
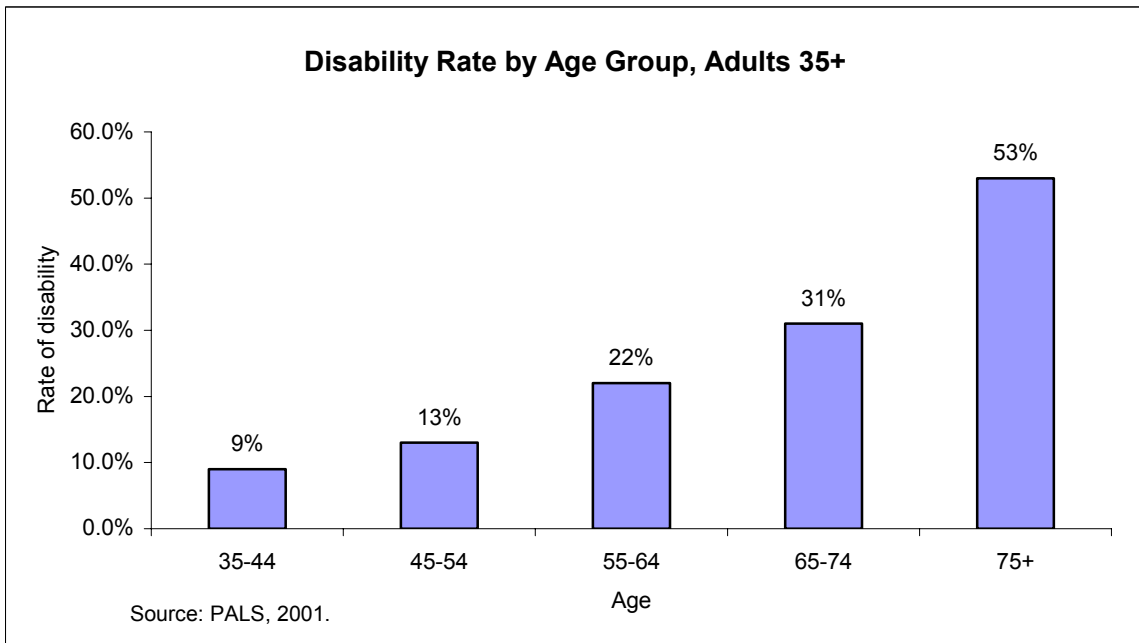


Chart 1.4



The reason we see non-seniors presently comprising a slightly higher proportion of all those requiring an aid or device (see previous sub-section), is that the baby boom generation comprises such a large proportion of the population itself. And this generation is now just on the brink of entering their senior years. We also know that the rate of disability increases with age.

Chart 1.5



This means that, as the baby boom generation enters their senior years, they will begin to comprise an even higher proportion of all persons with disabilities than they do now. If they also adopt the same rate

of requiring an aid or device as today's seniors, the requirements for aids and devices in the total population could more than double in the next 20 years.⁷

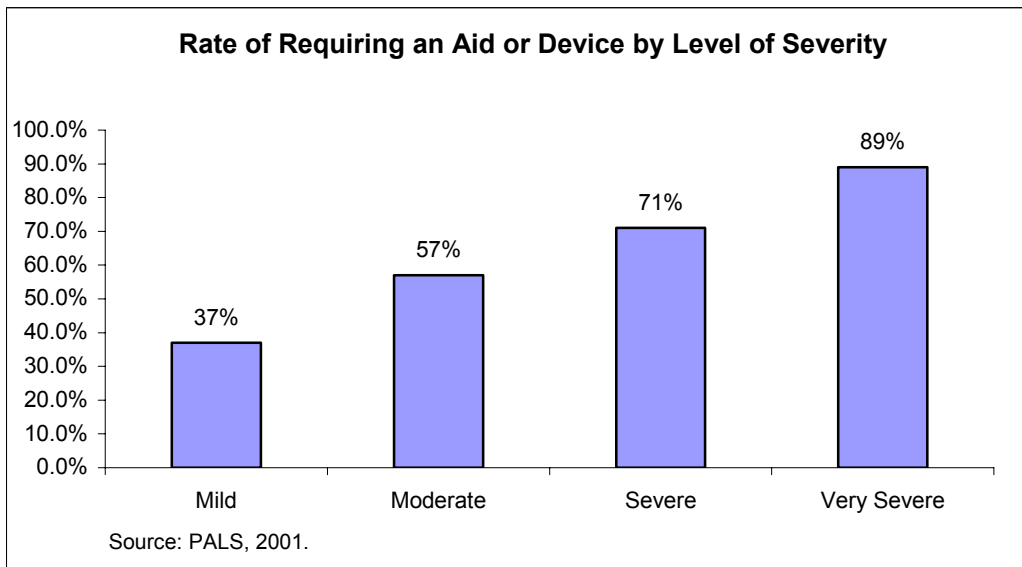
Women and Men Are Almost Equally Likely to Require an Aid or Device

About three out of five men (58%) and women (59%) with disabilities require an aid or device for their disability. However, because there are more women than men with disabilities (this is in part due to gender differences in life expectancy) we see a higher total number of women (1,118,890) requiring aids or devices than men (889,560).

Likelihood of Requiring an Aid or Device Increases with Severity of Disability

The likelihood of requiring an aid or device increases with the severity of the disability--ranging from 37% of persons with mild disabilities up to 89% of persons with very severe disabilities requiring an assistive device or aid.

Chart 1.6

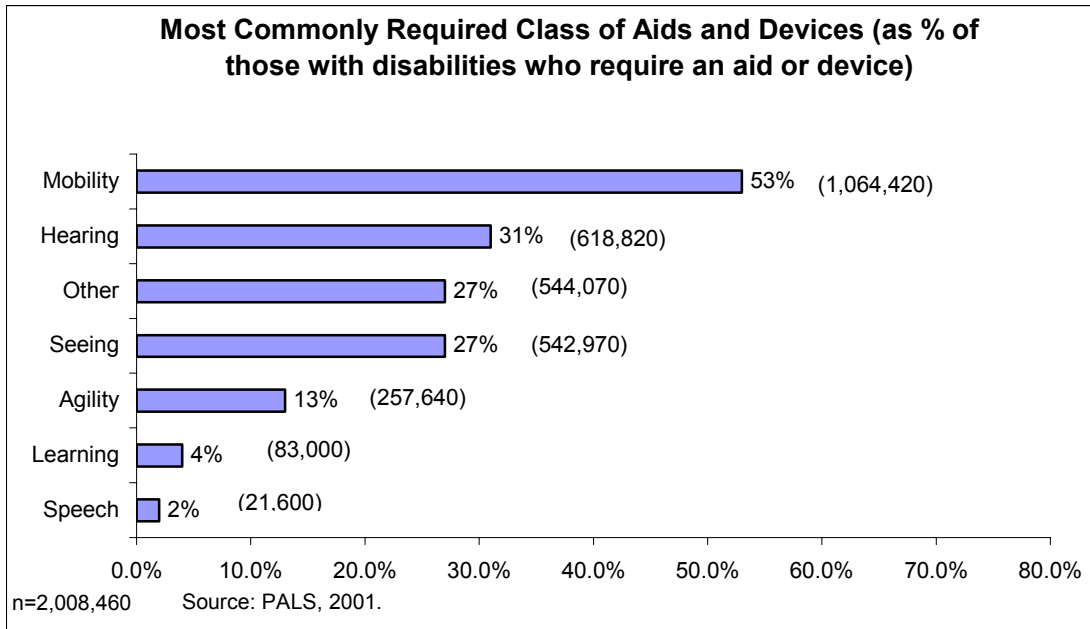


The Most Commonly Required Aids and Devices are Related to Mobility, Hearing, Agility and Seeing Disabilities

Assistive aids and devices can be classified into 7 broad types (using PALS data) based upon the nature of the disability typically leading to such a requirement. By far, the most commonly required aids and devices are those designed for mobility disabilities (Chart 1.7). Of those who have some requirement for an assistive aid or device, 53% (1,064,420 adults with disabilities out of 2,008,460) report a requirement for a mobility-related aid or device.

⁷ In addition to the impact of the baby boom generation, evidence also suggests that increases in life expectancy for Canadians will likely exacerbate this situation.

Chart 1.7



Note: These categories are not mutually exclusive, since some individuals require an aid or device for more than one type of disability.

Aids and devices related to hearing disabilities are the second most commonly required group of aids and devices with 31% (618,820 adults with disabilities out of 2,008,460) of those reporting some requirement for an assistive aid or device needing them.⁸

“Other” aids/devices represent the third most commonly required group with about 27% (544,070 out of 2,008,460) of those reporting some requirement for an assistive aid or device needing something from this category. This “other” category includes aids/devices that were not classified under a specific disability type such as respiratory aids/devices and devices for pain control such as T.E.N.S.⁹ Almost tied for third place, are seeing-related aids and devices that are also required by about 27% of those reporting some need for an aid or device (542,970 adults with disabilities out of 2,008,460).¹⁰

The fifth most commonly required aids and devices are related to agility disabilities with 13% (257,640 adults with disabilities out of 2,008,460) reporting a need.

Aids and devices related to learning disabilities and to speech disabilities are the least commonly required among those who require some aid or device.

⁸ Included in this count are some 67,590 individuals who use hearing aids (which is only one of the aids/devices related to hearing disabilities) that completely correct their hearing disability.

⁹ Unlike the categories of aids/devices based upon disability type, the “other” category was asked of all respondents in PALS (for the other six categories, the pertinent questions were only asked of those with that particular disability type). It was intended to pick up aids/devices not tied to a specific disability type. It might be thought of as a ‘catch all’ category.

¹⁰ Excluded from this count are those who use eyeglasses or contact lenses that completely correct their vision problem. However, those who use eyeglasses or contact lenses that do not completely correct their vision problem are included.

Those with a Seeing Disability Actually Most Likely to Require an Aid or Device Related to Their Disability

The number of persons requiring a type of aid or device related to a specific disability is a function of both the number of persons with that disability type and the rate at which persons with that type of disability require a related aid or device.

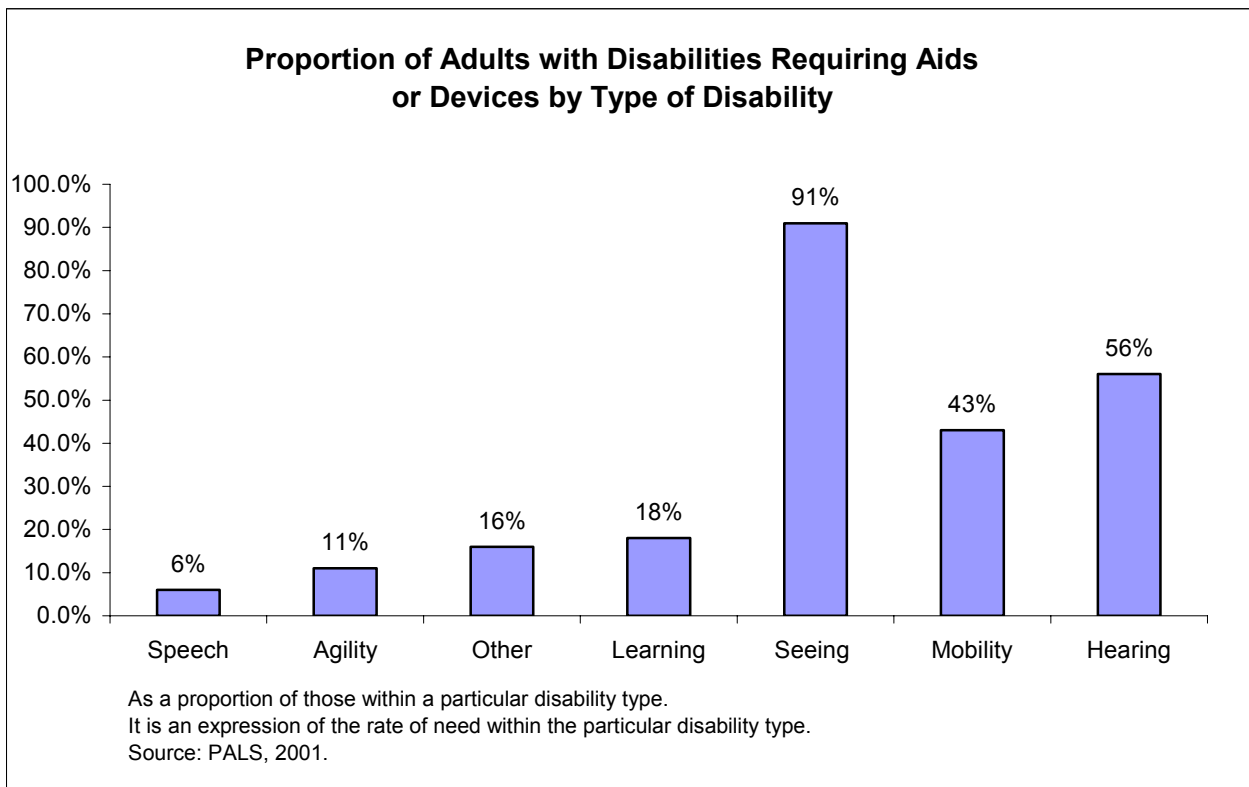
As just noted, aids and devices related to mobility disabilities are the most commonly required type of aid or device among all persons with disabilities who require any type of aid or device. However, this is, in part, due to the fact that the most prevalent type of disability is a mobility disability affecting about 72% of all adults with disabilities aged 15 and over.

We can look at the figures for requirements for aids and devices a bit differently if we compare individuals with different types of disabilities and the likelihood of each type requiring an aid or device related to that specific disability type (Chart 1.8). While mobility-related aids and devices are the most commonly required type of aid or device among all persons with disabilities, persons with mobility disabilities are not the most likely of all the disability types to require an aid or device related to that disability. Among those with a mobility disability, 43% report requiring some type of aid or device related to their mobility disability. However, it is actually those with a seeing disability who are the most likely to require an aid or device related to their seeing disability; 91% of those with a seeing disability require some type of seeing-related aid or device. It is important to remember, however, that more than half of those requiring a seeing-related aid or device are individuals who require only eyeglasses or contact lenses.

Those with hearing disabilities are the next most likely to require some type of aid or device related to their hearing disability with 56% reporting such a requirement. Third on this list (Chart 1.8), are those with mobility disabilities among whom 43% have a requirement for some type of mobility-related aid or device. Those with speech disabilities are the least likely to require a speech-related aid or device with only 6% of those with a speech disability reporting a requirement for a speech-related aid or device.

There are a variety of reasons why one disability type is more likely than another to lead to a requirement for aids and devices. One reason might lie with differences in technology. For some types of disabilities, there may simply not be a lot of aids or devices available that can enable function. This could be due to fewer research and development resources being applied to developing aids and devices related to a particular type of disability as well as to greater challenges involved in developing aids and devices aimed at some types of disabilities. It is also possible that the PALS questionnaire did not inquire specifically about a wide enough range of aids and devices.

Chart 1.8



Some Require an Aid or Device from More than One Grouping

Some individuals require aids and devices from more than one grouping since some individuals have more than one type of disability. If we add up the requirements listed for each of the 7 groupings, we find 3,132,500 reported requirements—this represents an average of 1.56 groupings per individual with any requirement for some type of aid or device.

Which Specific Aid or Device is Most Required?

Within each of the seven groupings of aids and devices are a number of sub-devices or specific aids or devices related to each type of disability. The most required specific aid/device listed in PALS is a *cane or walking stick*; this mobility-related aid is required by 679,560 people (Table 1.1). Over half a million (520,170) required *eyeglasses or contact lenses*.¹¹ And, a little over half a million (501,980) require another mobility-related type of aid--*grab bars or bathroom aids*. The prominence of mobility-related aids and devices on this list of required aids/devices is evident. However, the prominence of hearing-related devices is also evident. Unfortunately, we are unable to determine the true requirement for *hearing aids* from the PALS. We are able to determine that at least 397,970 people ‘use’ hearing aids; however, unlike with the other sub-devices, respondents were not asked if they ‘needed’ hearing aids that they did not have.¹² This oversight in the questionnaire results in an estimate of the requirement for hearing aids that is very low. It should be used with caution.

¹¹ This does not include those who wear eyeglasses or contact lenses that completely correct their vision.

¹² Unfortunately, respondents were asked which aids/devices they needed ‘other than hearing aids’. It is likely that those requiring hearing aids who either didn’t have them or didn’t have the proper ones would have answered this question by listing “other hearing-related devices” or by not providing a valid answer (there was no doubt a certain level of respondent confusion

Table 1.1**Requirements for Specific Devices by Disability Type**

	Disability Type	Total requiring
Cane or walking stick	mobility	679,560
Glasses	seeing	520,170
Grab bars or bathroom aids	mobility	501,980
Hearing aids	hearing	397,970*
Walker	mobility	294,410
Orthopaedic footwear	mobility	227,530
Braces or supportive devices	mobility	204,480
Volume control telephone	hearing	199,170
Respiratory aids (e.g. inhalers, puffers, oxygen)	other	183,100
Manual wheelchair	mobility	173,170
Magnifiers – seeing	seeing	167,920
Grasping tools or reach extenders	agility	135,200
Lifts or lift type devices	mobility	98,920
Scooter	mobility	90,560
Hand or arm brace	agility	85,440
Large print materials	seeing	69,190
Crutches	mobility	62,360
Closed caption T.V. or decoder	hearing	59,040
Pain management aids (e.g. TENS)	other	51,780
Home computer – learning disability	learning	49,660
Motorized wheelchair	mobility	47,080
Other phone related devices hearing	hearing	46,710
Computer to communicate - hearing	hearing	39,300
Amplifiers (e.g. FM, acoustic, infrared)	hearing	37,500
Spell/grammar checking software	learning	30,120
Talking books – seeing	seeing	26,460
Scanner or printer – learning disability	learning	25,960
Visual or vibrating alarms	hearing	24,340
White cane	seeing	22,640
TTY or TTD	hearing	19,120
Message relay service	hearing	18,380
Software organizational tools	learning	15,910
Pocket organizers	learning	14,790

for those who were waiting to be asked about unmet needs for hearing aids only to discover that there was no such category provided). The number of people who ultimately ended up in this ‘other hearing-related devices’ category is 152,570. There is no accurate method of determining, however, what proportion of the ‘other’ category is actually comprised of those needing hearing aids.

Table 1.1 – continued

Computer with braille, large print or speech access	seeing	13,650
Recording equipment	learning	13,590
Recording equipment or portable note takers	seeing	12,410
Talking books – learning	learning	12,010
Voice recognition software	learning	11,770
Computer or keyboard device to communicate	speech	11,740
Closed circuit devices (e.g. CCTV's)	seeing	11,210
Portable spell checker	learning	10,880
Voice amplifier	speech	3,700
Communications board (e.g. Bliss)	speech	3,070

Source: PALS, 2001.

* **Caution:** This estimate for the requirement for hearing aids is incomplete. This includes only the portion of individuals who actually have hearing aids. We are unable to determine the unmet requirement. See footnote 8.

While this list of specific devices and the number of persons requiring them is most useful, it is important to note that a substantial number of individuals reported a requirement for an aid or device not specified in the PALS questionnaire. For example, 378,220 adults with disabilities reported a requirement for “other aids or devices” related to unspecified disability types; while 145,630 reported a requirement for “other mobility-related” aids or devices (Table 1.2). Similarly, 152,570 fall into this “other” category in hearing-related aids and devices (see footnote 8 for more explanation). This suggests that there are aids and devices that were not included in the PALS questionnaire that are required by a considerable number of individuals. In other words, there are a lot of aids and devices missing from this analysis.

Table 1.2

Requirements for Specific Devices - Other Sub Categories

Other Category	Disability Type	Total requiring
Other aids/devices for other disability types	other	378,220
Other mobility related devices	mobility	145,630
Other Agility related devices	agility	91,310
Other learning related devices	learning	39,810
Other hearing related devices	hearing	152,570
Other sight related devices	seeing	22,980
Other speech related devices	speech	8,350

Source: PALS, 2001.

Multiple Aid/Device Requirements Most Likely Among Mobility-related Aids/Devices

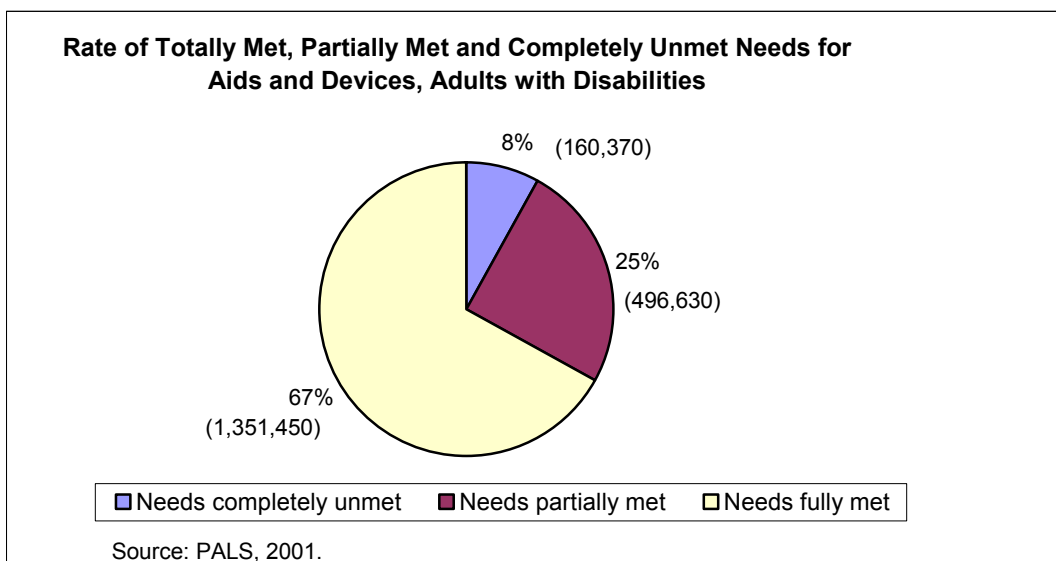
While some individuals require aids/devices from more than one grouping (based on disability type), similarly some individuals require more than one aid/device within a grouping. Those with a requirement for some type of aid/device related to *mobility* disabilities are the most likely to report multiple aids/devices within that grouping; on average, these individuals require 2.9 aids/devices. The comparable figures for those requiring aids/devices related to other types of disabilities are: *sight* with an average of 2.2 aids/devices; *learning* with an average of 2.1 aids/devices; *hearing* with an average of 1.7; *speech* with an average of 1.3; *agility* with an average of 1.2; and “*other*” with an average of 1.1.

What is the Gap between Requirements and Reality— What is the Unmet Need for Aids and Devices?

One-Third of Those Requiring Some Type of Aid/Device Have Unmet Need

Of the 2,008,460 individuals who have some requirement for an aid or device, 1,351,450 or 67% report that their needs are fully met. This means that another 657,000 (or 33%) have some level of unmet need for an aid or device. Of these 657,000 people with an unmet need, nearly a quarter of them (160,370)¹³ have none of the aids/devices that they need at all and about three quarters of them (496,630)¹⁴ have some aids/devices, but still need more.

Chart 1.9



Note: Total Unmet Need=8% + 25%=33%

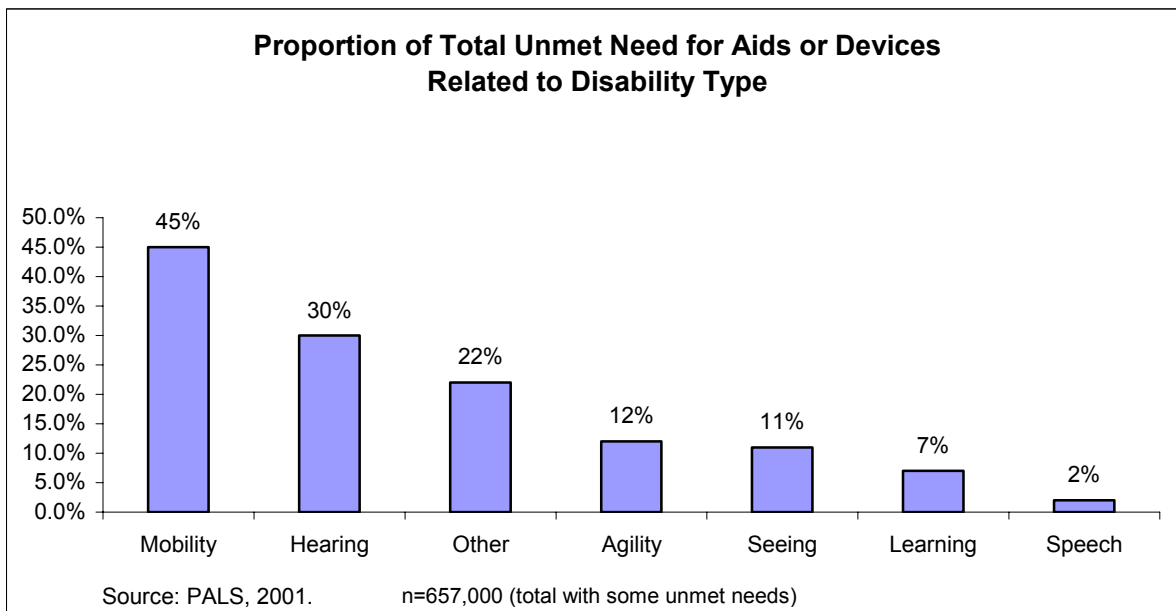
¹³ Put another way, this also represents 8% of the total number requiring an aid or device.

¹⁴ Put another way, this also represents 25% of the total number requiring an aid or device.

Mobility-related Aids/Devices, Then Hearing-related Aids/Devices Contribute Most to Overall Unmet Needs

Given the fact that mobility-related aids/devices are the most commonly required aids/devices, it is not surprising that mobility-related aids/devices are also the most likely to be connected with an unmet need. Of the 657,000 people with an unmet need, 297,400 (45%) have an unmet need for a mobility-related aid or device. Those with an unmet need for hearing rank next with 199,590 or 30% of the 657,000 with an unmet need.¹⁵

Chart 1.10



Rate of Unmet Need Actually Greatest Among Those Requiring Learning-related Aids/Devices and Speech-related Aids/Devices

If we examine these data a bit differently, we get quite a different perspective on the nature of unmet needs for aids and devices related to specific disability types. If we look at requirements for aids and devices related to specific disabilities, we find that the *rate* of total unmet need (partially met/partially unmet + completely unmet) is actually greatest among those who require learning-related aids and devices (14% + 43% = 57%) and speech-related aids and devices (8% + 46% = 54%). The *rate* of unmet need is lowest among those requiring seeing-related aids and devices (13%).¹⁶

The rate of unmet need for the remaining categories hovers between 27% and 32%. Although the unmet need for mobility-related aids and devices contributes most to overall unmet need (due to the very high number of people who require mobility-related devices to begin with), the *rate* of unmet need among those requiring mobility-related aids and devices is actually somewhere in the middle (28%). In fact, a

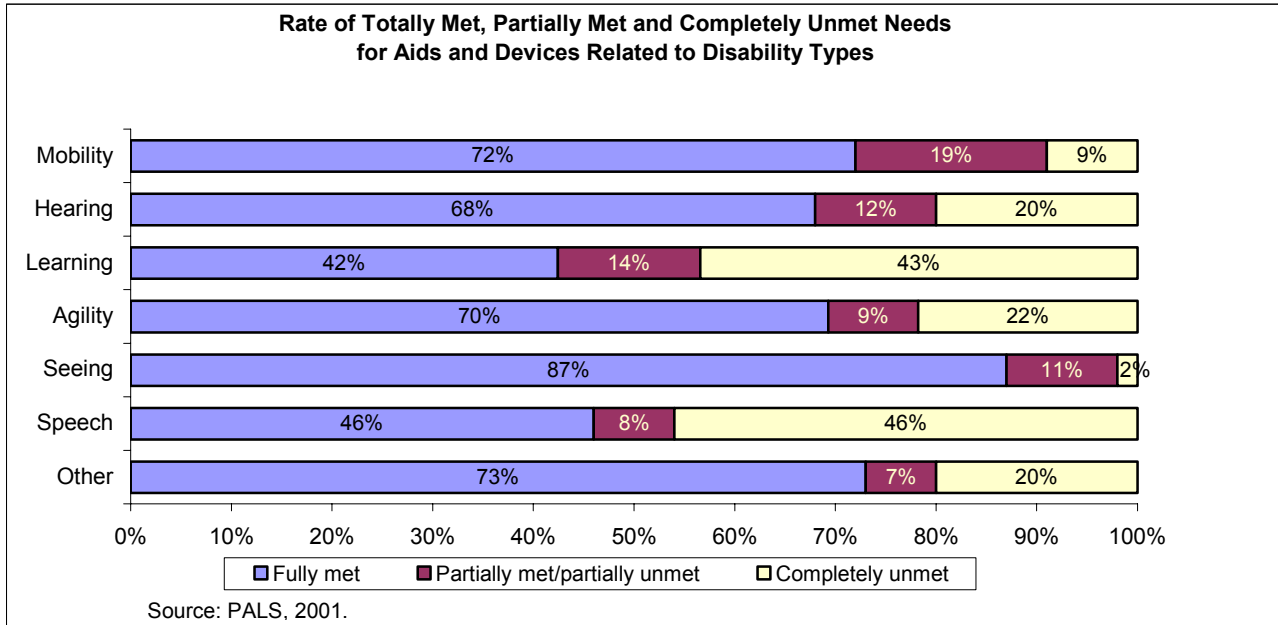
¹⁵ Note that some people will be counted under more than one category since some people have an unmet need from more than one category. Because these categories are not mutually exclusive, therefore, the percentages in Chart 10 exceed 100%.

¹⁶ This low percentage is largely due to the inclusion of those who wear eyeglasses or contact lenses (which do not completely correct their seeing disability) as aids/devices in this analysis.

person who requires learning-related aids or devices is twice as likely as someone who requires mobility-related aids or devices to have an unmet need.

It is interesting to note that those requiring speech-related aids and devices and those requiring learning-related aids and devices are the most likely to have a *completely unmet need* (46% and 43% respectively of those requiring that type of aid or device)—meaning that they have none of the aids or devices that they require.

Chart 1.11



What About Unmet Needs for Specific Aids and Devices?

If we turn our attention to focus on specific aids and devices (Tables 1.3 and 1.4), we find that the greatest unmet needs in terms of sheer numbers are among those requiring ‘other aids or devices’ (Table 1.4). In particular, we find the greatest unmet need is among those requiring ‘other hearing-related aids or devices’ (144,720). As mentioned in previous sections (see also footnote 7), one reason that this number is so high might be that respondents to the PALS were not asked about unmet needs for hearing aids. It is reasonable to expect that many of the people in this ‘other hearing-related aid or device’ category are actually individuals who require hearing aids. We also find a very high number of individuals with unmet needs in the ‘other aids’ for ‘other’ disability types category (135,110 with an unmet need). (Table 1.4) This suggests again that many of the important types of aids and devices required by persons with disabilities were not included in the PALS questionnaire.

Other specific aids or devices that contribute a fair amount to the total number of people with an unmet need include: *grab bars or bathroom aids* (83,600); *canes or walking sticks* (43,710); *scooters* (47,630); *eyeglasses or contact lenses* (44,070); *lifts or lift type device* (36,380), and *grasping tools and reach extenders* (35,420). It is important to note that the aids/devices in Table 1.3 appear in order from highest to lowest in terms of overall requirements (i.e., the same order of appearance as in Table 1.1). In most

cases, it is obvious that the number of people with an unmet need is largely a function of the number of people who require the aid/device. It is also useful to look at the *rate* of unmet need.

Those Requiring Scooters and Motorized Wheelchairs Have a High *Rate* of Unmet Need

Looking at the same data in a different way, we can look at the proportion of those requiring each aid or device who have an unmet need. These are the individuals who have a requirement for a specific aid or device that is among the least likely to be met. The gap between requirement and fully met needs is proportionately largest here. In this category are those requiring: *scooters* (52% requiring them have an unmet need), *motorized wheelchairs* (52%), *communications board (e.g. Bliss)*(60%), *talking books – learning aid* (47%), *voice recognition software- learning* (46%), *voice amplifier-speech* (48%); *portable spell checkers (learning-related)* (39%); *home computers (learning-related)* (38%); and *lifts and lift-type devices* (37%). (Table 1.3)

Table 1.3
Unmet Needs for Specific Aids and Devices

	Disability Type	Unmet need	% with Unmet Need
Cane or walking stick	mobility	43,710	6%
Glasses	seeing	44,070	8%
Grab bars or bathroom aids	mobility	83,600	17%
Hearing aids* cannot be estimated	hearing		
Walker	mobility	29,520	10%
Orthopaedic footwear	mobility	30,020	13%
Braces or supportive devices	mobility	18,500	9%
Volume control telephone	hearing	35,160	18%
Respiratory aids (e.g. inhalers, puffers, oxygen)	other	6,360	3%
Manual wheelchair	mobility	14,590	9%
Magnifiers – seeing	seeing	11,280	7%
Grasping tools or reach extenders	agility	35,420	26%
Lifts or lift type devices	mobility	36,380	37%
Scooter	mobility	47,630	52%
Hand or arm brace	agility	12,830	15%
Large print materials	seeing	7,810	11%
Crutches	mobility	3,140	5%
Closed caption T.V. or decoder	hearing	13,580	23%
Pain management aids (e.g. TENS)	other	9,160	18%
Home computer – learning disability	learning	18,990	38%
Motorized wheelchair	mobility	24,100	52%
Other phone related devices hearing	hearing	8,990	19%
Computer to communicate - hearing	hearing	3,760	10%
Amplifiers (e.g. FM, acoustic, infrared)	hearing	8,320	22%
Spell/grammar checking software*	learning	5,370	18%
Talking books – seeing	seeing	2,240	8%
Scanner or printer – learning disability	learning	3,390	14%
Visual or vibrating alarms	hearing	8,070	33%
White cane (Cannot be released due to small sample size)	seeing		
TTY or TTD	hearing	5,120	27%
Message relay service	hearing	2,900	16%
Software organizational tools**	learning	5,580	34%
Pocket organizers	learning	3,400	23%
Computer with braille, large print or speech access	seeing	2,870	21%
Recording equipment	learning	5,200	38%

Table 1.3 continued
Unmet Needs for Specific Aids and Devices

Recording equipment or portable note takers	seeing	940	8%
Talking books – learning	learning	5,590	47%
Voice recognition software***	learning	5,440	46%
Computer or keyboard device to communicate	speech	4,140	35%
Closed circuit devices (e.g. CCTV's)	seeing	2,840	25%
Portable spell checker	learning	4,280	39%
Voice amplifier	speech	1,760	48%
Communications board (e.g. Bliss)	speech	1,840	60%

Source: PALS, 2001

Note: Unmet need for hearing aids cannot be estimated using PALS (see footnote 8)

Note: Numbers for ‘white cane’ cannot be released due to low sample size

- * **Spell/grammar checking software-learning:** this number includes 4,750 people who would also need a computer to go with this (i.e., don’t have the computer either)
- * * **Scanner or printer - learning:** this number includes 2,430 people who would also need a computer to go with this (i.e., don’t have the computer either)
- * * * **Software organizational tools - learning:** this number includes 4,000 people who would also need a computer to go with this (i.e., don’t have the computer either)
- * * * **Voice recognition software - learning:** this number includes 3,010 people who would also need a computer to go with this (i.e., don’t have the computer either)

Table 1.4

Unmet Needs for Specific Devices - Other Sub Categories

Other Category	Disability Type	Unmet need	% with Unmet Need
Other aids/devices for other disability types	other	135,110	36%
Other mobility related devices	mobility	56,540	39%
Other agility related devices	agility	33,990	37%
Other learning related devices	learning	23,720	60%
Other hearing related devices	hearing	144,720	95%
Other seeing related devices	seeing	14,600	52%
Other speech related devices	speech	5,950	71%

Source: PALS, 2001.

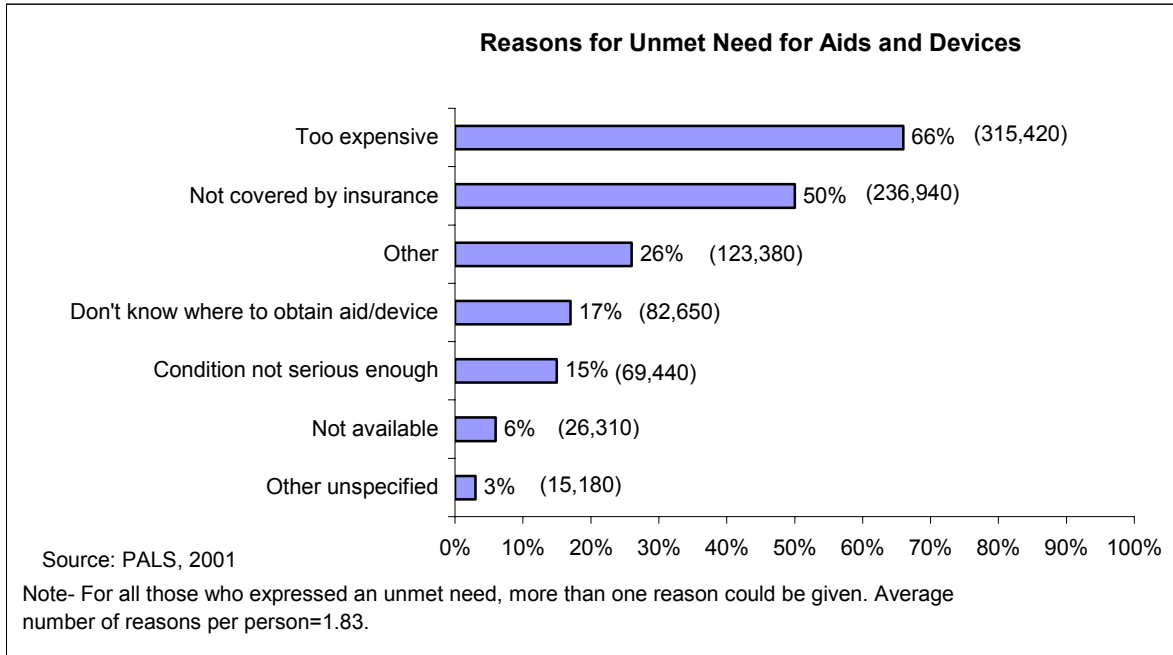
Reasons for Unmet Needs for Aids and Devices

Just as important as determining the size and nature of the unmet need, is knowing more about the reasons behind it. Nearly two-thirds (66%) of those with an unmet need for an aid/device reported that the aid/device was too expensive and half reported that the item was not covered by their insurance (some individuals reported more than one reason—in particular, people typically cited more than one ‘economic’ reason). Certainly, it appears that cost-related barriers are, by far, the most important reasons offered for not having the required item.

It is, however, useful to note that 82,650 individuals (17%) report that they didn’t know where to obtain the aid/device. This suggests that a lack of appropriate information is also a barrier of note.

As well, the high proportion of persons in the ‘other’ categories suggests that PALS failed to capture the full range of reasons.¹⁷ For some individuals, the reasons for not having a required aid or device might be so complex that the individual has difficulty articulating a reason. As well, many individuals have difficulty accepting their need for an aid or device. They may be in the early stages of a condition and have been told by a health care professional that they need to begin using an aid or device, but may have some difficulty emotionally accepting this. This is particularly likely in the case of persons who are affected by a degenerative disorder or who are experiencing early hearing loss. None of the reasons offered in the PALS questionnaire accurately depicted these situations.

Chart 1.12



Basic Demographic Profile of Unmet Need for Aids and Devices

While we know that cost is an important factor in creating unmet need for aids/devices, it is also important to understand more about the individuals who are most likely to be affected.

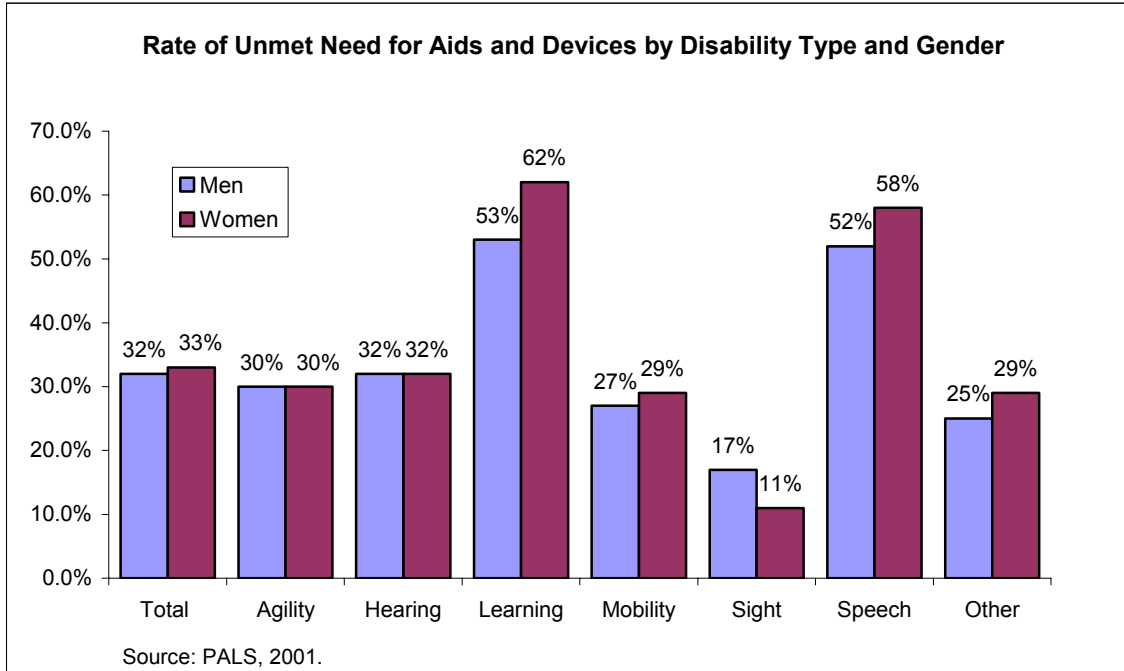
Very Little Difference in Unmet Need between Men and Women

Overall, there is very little difference in unmet need between the sexes (32% for men vs 33% for women). There are 3 exceptions – aids or devices that are related to learning, seeing and speech disabilities. Women are more likely than men to have an unmet need for aids or devices related to learning disabilities (62% compared with 53%). Similarly, women are more likely than men to have an

¹⁷ There are two categories of “other”. The category labelled here as simply “other” includes those who wrote in an answer on the questionnaire in an effort to specify a reason that was not listed. Unfortunately, we did not have access to these comments at the time of analysis and cannot, therefore, group them into additional categories. Some of these people may also have answered “yes” to some of the other reasons listed. The “other – unspecified” category includes those individuals who answered “no” to all of the reasons listed and did not “specify” what the reason was by writing in a comment on the questionnaire.

unmet need for aids or devices related to speech disabilities (58% compared with 52%). In both these cases, the rate of unmet need is also unusually high for both genders. Men were more likely than women to express an unmet need for aids and devices related to seeing disabilities (17% compared with 11%).

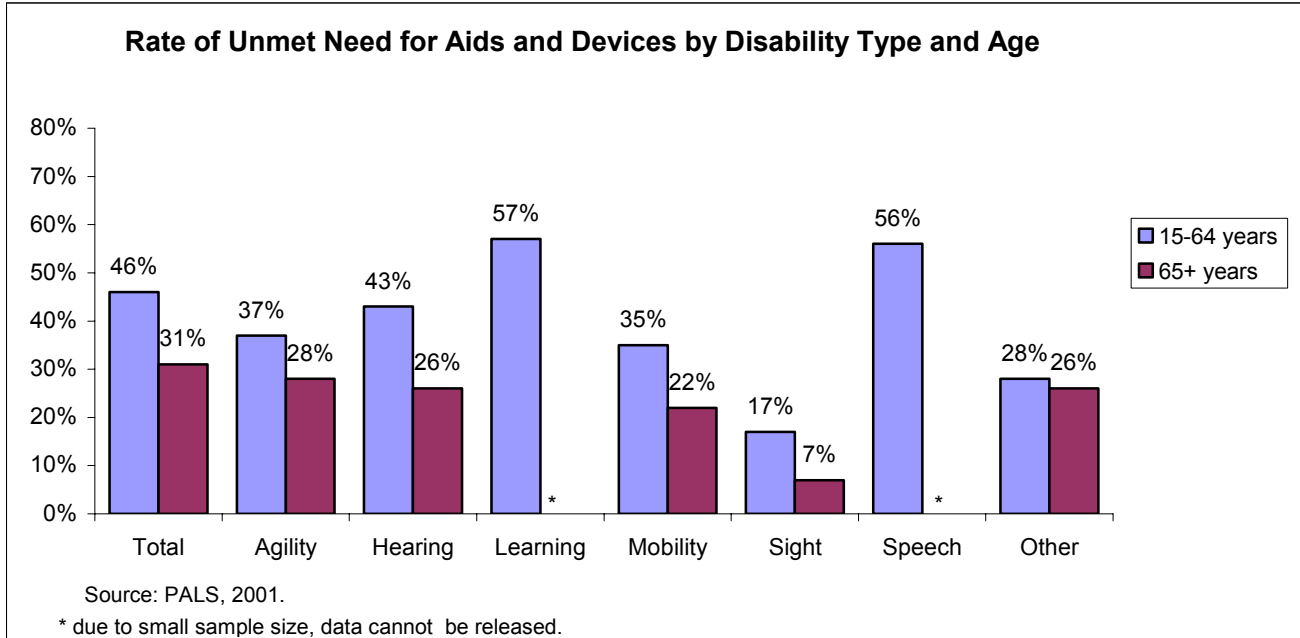
Chart 1.13



Working-age Adults with Disabilities More Likely than Seniors to Have Unmet Needs

Overall, 39% of working-age adults with disabilities had unmet needs compared to 26% of seniors with disabilities. Within each disability type, non-seniors had higher rates of unmet need than seniors

Chart 1.14

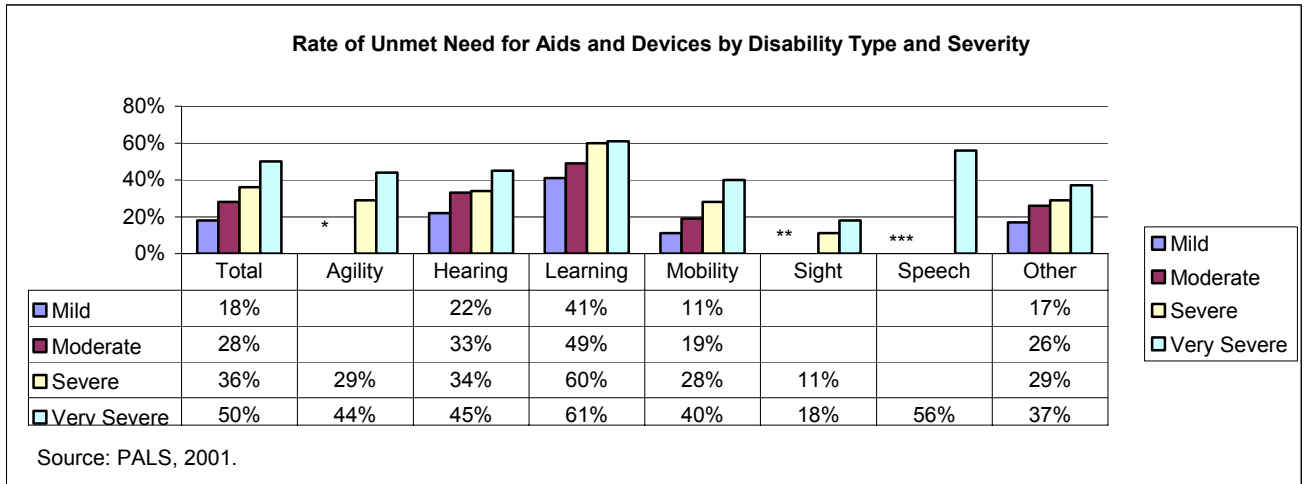


People with Severe Disabilities More Likely to Have Needs Go Unmet

Overall, the proportion of those with unmet needs clearly increases with the severity of the disability. This is evident as 18% of those with mild disabilities had unmet needs compared with 50% of those with very severe disabilities.

The same relationship holds true across all categories of disabilities. It appears that those who most need these devices are most likely to have their needs go unmet. This is most evident among person with mobility and agility limitations.

Chart 1.15



Notes:

- * Neither mild nor moderate estimates can be released for *agility-related* aids/devices due to small sample size. When merged, mild and moderate categories have a combined rate of 15%.
- ** Neither mild nor moderate estimates can be released for *sight-related* aids/devices due to small sample size. When merged, mild and moderate categories have a combined rate of 9%.
- *** Mild, moderate, and severe categories cannot be released for *speech-related* aids/devices due to small sample size. When all three categories are merged, their combined rate is 50%.

A Final Note About Disability Type

The discussion thus far regarding disability type has revolved around those with a particular type of disability and their requirements (and unmet needs) for aids/devices *related specifically to that type of disability*. There are some disability types that have not been represented here since PALS did not pose any questions regarding aids/devices targeted to those particular types of disabilities. Most notably, there are no aids/devices specifically targeted toward those with developmental, memory-related, or psychological disabilities. As well, many individuals have multiple disability types and often face complications obtaining aids/devices because they have varied requirements. In this final sub-section, we examine requirements and unmet needs for ‘any aid or device’ by the person’s disability type. Of course, these categories are not mutually exclusive since many individuals have more than one type of disability. Here we are examining the requirement for any type of aid or device (regardless of whether it is related to the disability type in question). In Table 1.5, we find the percentage and number of individuals with each type of disability who require some type of aid or device. Of course, the high percentage listed for those with sight-related disabilities is largely due to the inclusion of eyeglasses and contact lenses in this analysis. Despite no aid/device categories aimed at memory, developmental, or psychological disabilities, we find a surprising percentage of individuals with these types of disabilities who have some requirement for some of the aids/devices that were listed under other disability types (71%, 52%, and 63% respectively). This suggests that these types of disabilities often go along with another type of disability for which the individual might require an aid or device.

Table 1.5
Percentage and Number Requiring Some Type
of Aid or Device by Person's Type of Disability

	Number	%
agility	1,529,480	67%
hearing	858,050	78%
learning	282,490	63%
mobility	1,614,000	66%
sight	568,020	96%
speech	250,360	69%
memory	297,270	71%
developmental	62,930	52%
pain	1,456,970	61%
psychological	331,990	63%

Source: PALS, 2001.

In Table 1.6, we examine unmet needs for any type of aid/device by the person's type of disability. Perhaps most noteworthy is the very high percentage of individuals with a developmental disability who have an unmet need for some type of aid or device (42% with a partially unmet need and 15% with a totally unmet need). In fact, the success rate for obtaining aids/devices is lowest among those with three types of non-physical disabilities: developmental, learning, and psychological.

Table 1.6
Percentage Unmet, Met Needs for Some Type of Aid or Device
by Person's Disability Type

	Partially Met	Totally Unmet	Totally Met
agility	28%	7%	65%
hearing	29%	9%	63%
learning	38%	12%	50%
mobility	27%	7%	66%
sight	32%	2%	66%
speech	35%	9%	55%
memory	35%	7%	57%
developmental	42%	15%	43%
pain	28%	8%	64%
psychological	35%	10%	55%

Source: PALS, 2001.

Section II: Help with Daily Activities

Some persons with disabilities also require assistance with some basic daily activities within or around the home due to their disability. Examples of these activities are: meal preparation, light housework, heavy household chores, running errands or going to appointments, paying bills, personal finances, child care, personal care, specialized care (medical) and moving inside one's residence.

Magnitude of Requirement for Help with Daily Activities

Some 2.4 Million Persons with Disabilities Reported a Requirement for Help with Daily Activities¹⁸

70% of all adults with disabilities required help with everyday activities such as meal preparation, light housework, heavy household chores, etc.¹⁹

Women and Seniors More Likely to Require Help with Daily Activities

Overall, 79% of women with disabilities (1,494,050) stated that they required help compared with 59% of men (904,670).

Not surprisingly, seniors were more likely than working-age adults to require assistance. 75% (1,094,960) of seniors required help compared to 66% of working-age adults (1,303,740). However, it is also the case that, in terms of sheer numbers, working-age adults comprise the largest population requiring help with everyday activities (54% of all those requiring help or 1,303,740/2,398,720).

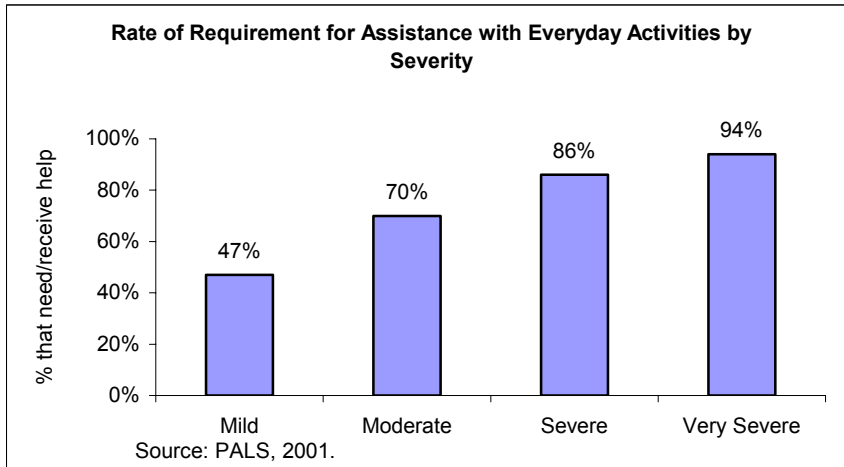
The severity of the disability also increases the likelihood that a person with a disability will require help with everyday tasks. As the severity level increases, so does the requirement: 47% of those with mild disabilities required assistance compared to 94% of those with very severe disabilities.²⁰

¹⁸ These include help with meal preparation, light housework, heavy chores, running errands or going to appointments, paying bills, personal finances, child care, personal care, specialized care (medical) and moving inside residence. (Source: Statistics Canada catalogue # 89-581 table 14.1—PALS 2001.)

¹⁹ Includes those who receive help because of their condition, those who state that they need help and those who feel that they need additional help.

²⁰ Preliminary investigation suggests that requirements for help with daily activities also vary by disability type. Initial research indicates that those with developmental and memory-related disabilities, for example, may have a higher than average requirement for this type of support. Further investigation is required to examine combinations of disability types and how these combinations might have an impact on requirements for supports with daily living.

Chart 1.16



Those With Memory and Developmental Disabilities Most Likely to Require Support with Daily Activities

As summarized in Table 1.7, those with memory and developmental disabilities are the most likely to require some type of support with daily activities (86% of each). Those with hearing disabilities were the least likely to report such a requirement (65%).

Table 1.7
Percentage and Number Requiring for Support with Daily Activities by Person's Type of Disability

	Number	%
agility	1,855,260	81%
hearing	724,640	66%
learning	352,680	78%
mobility	1,975,280	81%
sight	498,590	84%
speech	302,560	83%
memory	361,010	86%
developmental	103,860	86%
pain	1,828,190	77%
psychological	423,000	81%

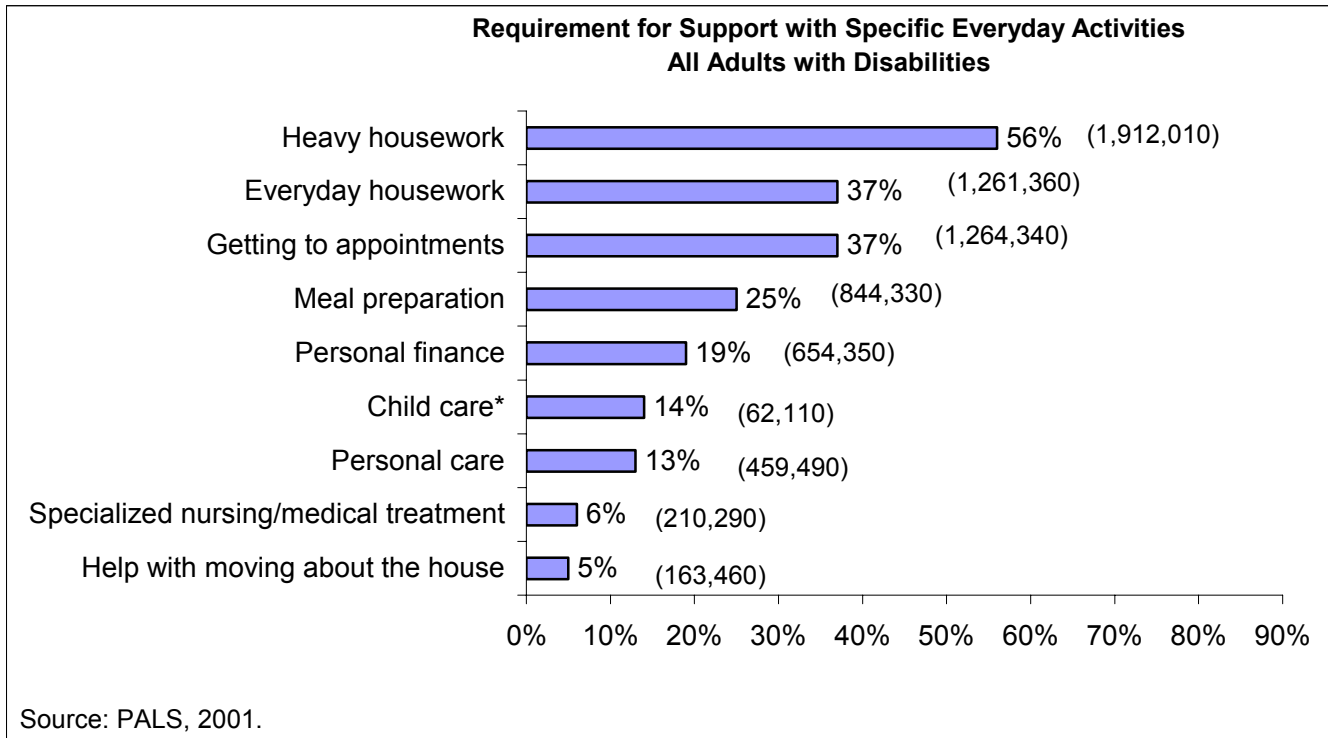
Source: PALS, 2001.

Type of Support with Daily Activities

The Majority Need Help with Heavy Household Chores

Help is required more often with tasks commonly considered ‘housework’ or ‘domestic labour’ such as – heavy housework, everyday housework, and meal preparation. In particular, the greatest requirement for assistance involves heavy household chores with over half of all persons with disabilities requiring assistance with this particular group of tasks. Less often, there is a requirement for more personalized assistance such as “help moving about the house”, “specialized nursing/medical treatment,” “personal care,” or “personal finance”. Less often, as well, there is a requirement for “childcare”; this question, however, was asked only of those who had children under the age of 15 living with them. There is, however, a considerable need for assistance in getting to appointments outside of the home.

Chart 1.17



* **Note:** The percentage for childcare is based upon only those who have children under the age of 15 living with them (n=437,134)

Note: more than one activity could be listed per person. These are not mutually exclusive categories.

Unmet Need for Support with Daily Activities

Overall, Most People Requiring Support with Daily Activities Receive It

Two-thirds (1,615,460) of all those with disabilities who required help with everyday activities stated that they received all the help they required. Just over a quarter (27% or 652,660) received some of the help they required but still needed more; and 5% (130,590) of those who required supports received none at all.²¹

There is a High Unmet Need for Support with Childcare

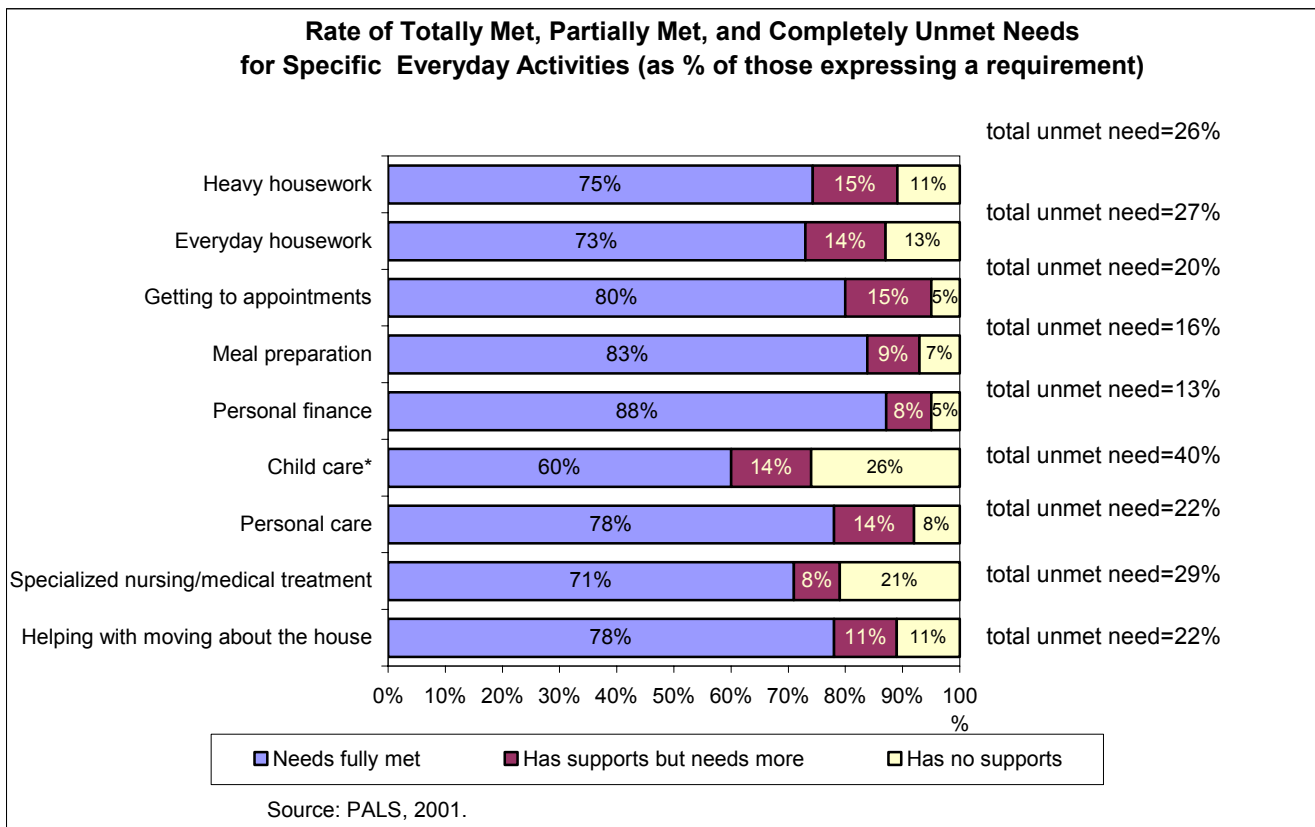
While only a small proportion (5%) of individuals who require assistance with any everyday activities overall report a totally unmet need (i.e., no supports at all for any of the required services), there are some very noteworthy exceptions when examining specific types of assistance. For those who require childcare, for example, there is a high unmet need of 40%; and most of this unmet need is among those who have no childcare supports at all (26% have no supports at all and 14% have some childcare supports, but not enough).

Similarly, those who require specialized nursing/medical treatment also represent a small proportion of the total requiring some form of help (6% or 210,290). However, if you require this type of help, you are likely to face some challenges in getting it. The total unmet need for specialized nursing/medical treatment is 29% of those requiring it and most have no help at all (21% have no help and 8% have some help but need more).

Help with everyday housework is another area where there are gaps between requirements and actual supports that exceed the average as 13% of those requiring such help have none at all and another 14% have some, but not all, the help they need (for a total unmet need of 27%).

²¹ Of those who received some or all the help that was needed, 9% reported difficulties in obtaining the help. Many of these individuals reported multiple difficulties: 48% experienced a delay in obtaining help; 47% reported help was too expensive; 37% reported difficulty finding qualified help; 37% reported 'other reasons'; and 26% had difficulty knowing where to look for the help they needed.

Chart 1.18



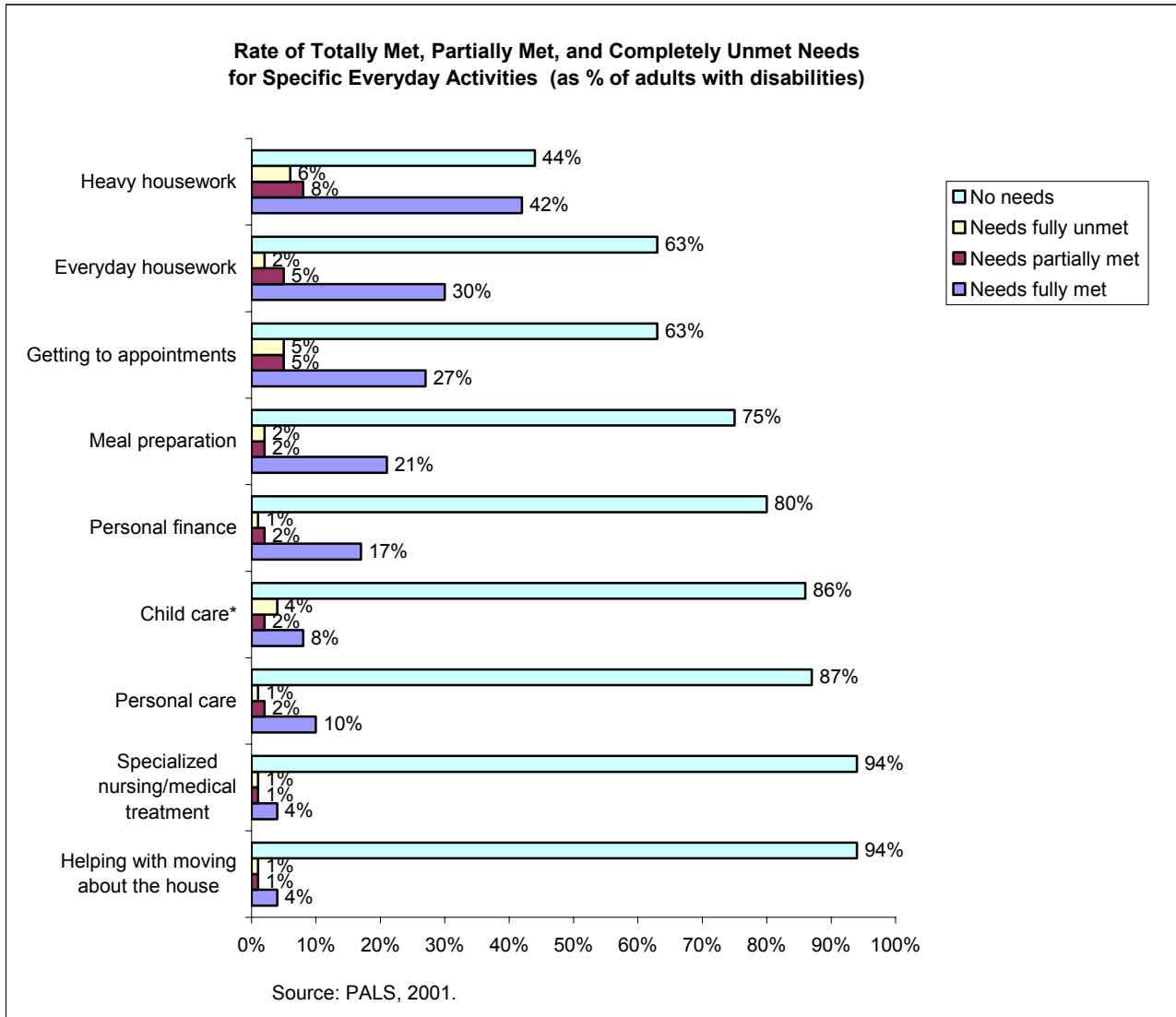
* **Note:** The percentage for childcare is based upon only those who have children under the age of 15 living with them.²²

In terms of sheer numbers, the unmet need for childcare and specialized nursing care/medical treatment represent a relatively small number of persons with disabilities-- 25,130 and 60,640 respectively. When compared with the 484,180 who have an unmet need for heavy housework, these groups seem rather small. However, this is due to the fact that a smaller proportion of this population have any requirement for childcare or specialized nursing care/medical treatment (see Chart 1.19 for full summary). If we were to look at rates of success when there is a need, however, we would see a different story. If you happen to require either of these two supports, you are less likely to be successful in obtaining them than other supports like heavy housework. Worse still, you are much more likely to have no support at all (i.e., most of the unmet need is among those who have none of what they need).

²² The numbers of adults with an unmet need (partially unmet + completely unmet) to go with these percentages are:

Heavy housework	(26%)	484,180
Everyday housework	(27%)	340,050
Getting to appointments	(20%)	252,390
Meal preparation	(16%)	141,380
Personal finance	(13%)	81,310
Childcare	(40%)	25,130 (asked only of those living with children under 15)
Personal care	(22%)	99,710
Specialized nursing/med.	(29%)	60,640
Help moving about house	(22%)	35,830

Chart 1.19



*Only asked of those living with children under 15 years.

Because the most commonly required support among all persons with disabilities is for assistance with heavy household chores, the largest unmet need in terms of sheer numbers (not percentage of those who actually require it) is also for assistance with heavy household chores. This is true of all disability types, except for those with developmental disabilities who are most likely (in terms of sheer numbers) to have an unmet need for assistance getting to and from appointments (not shown in graph).

Those with Memory-related Disabilities Most Likely to Have Unmet Needs for Support with Daily Activities

Those with memory-related disabilities are one of the most likely to require supports with daily activities and are also the most likely not to receive the supports required. As summarized in Table 1.8, 45% of those with a memory-related disability have an unmet need for such supports (40% partially unmet and 5% totally unmet). The rate of unmet need is also high among those with learning disabilities (43%), sight disabilities (42%), and psychological disabilities (43%).

Table 1.8
Percentage Partially Unmet, Completely Unmet and Fully Met Need for Support with Daily Activities by Person's Disability Type

	Partially Unmet Need	Completely Unmet Need	Total Unmet Need	Fully Met Need
agility	30%	5%	35%	65%
hearing	27%	6%	33%	67%
learning	37%	6%	43%	57%
mobility	29%	5%	34%	66%
sight	37%	5%	42%	58%
speech	36%	4%	40%	60%
memory	40%	5%	45%	55%
developmental	33%	3%	35%	65%
pain	29%	6%	35%	65%
psychological	36%	7%	43%	57%

Source: PALS, 2001.

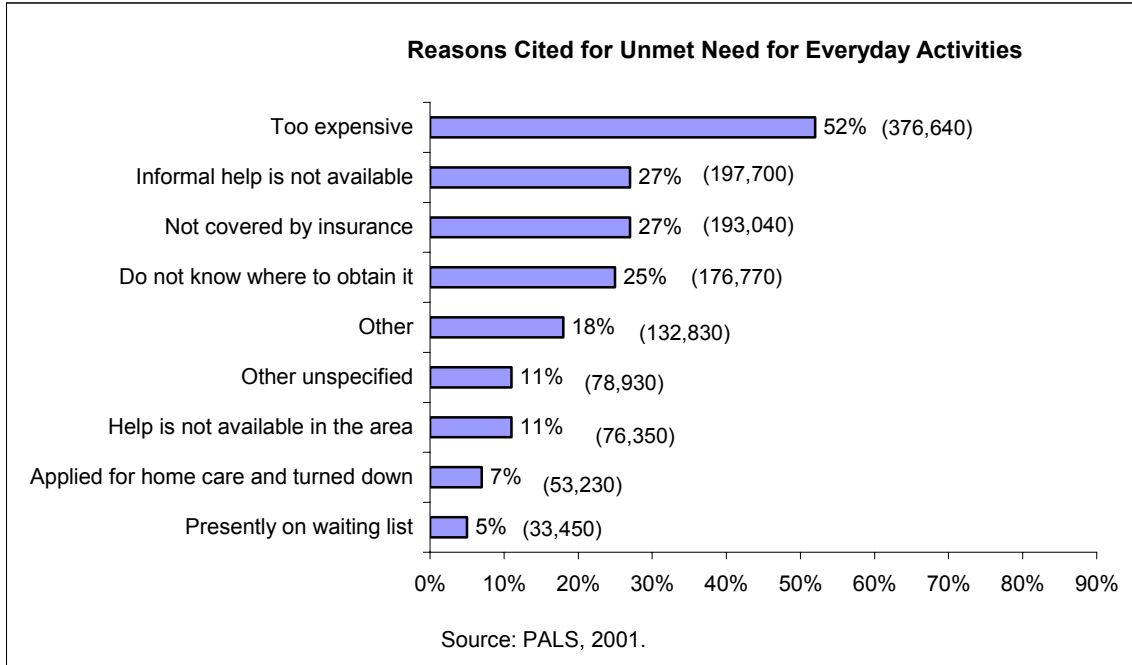
Reasons Cited for Unmet Need for Support with Daily Activities

Cost Main Reason for Unmet Need

It is evident that cost is a major factor in unmet need--both directly and indirectly. One can easily interpret reasons such as "not covered by insurance" and "informal help is not available" and "applied for home care and turned down" as indirectly flowing from cost. It is interesting, however, that a quarter of those with unmet needs cited "did not know where to obtain it" as the underlying reason. This might also be related to cost (it might really mean: "did not know where to obtain it for a low price or for free"). However, it is just as likely that this represent a gap in the communication system around disability supports. Similarly, "help is not available in the area" which is cited by 11% with an unmet need indicates that some areas are less well serviced than others for at least a tenth of the population. A further analysis of the gap in supports and services examining the impact of community size would be advised.

Some 783,250 persons with disabilities reported unmet need. The expense of obtaining help was cited by 52% as the main reason. Over one quarter reported that they did not have informal care (care provided by family and friends) and over a quarter indicated that the costs were not covered by their insurance. One-quarter did not know where to obtain help.

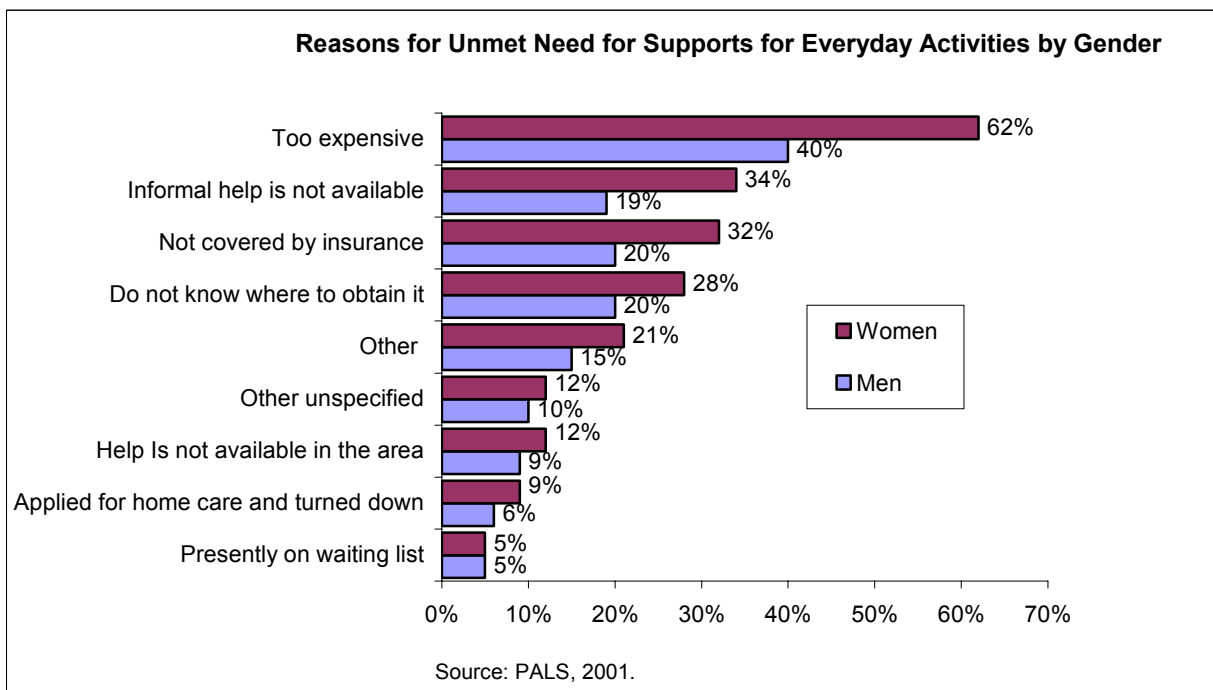
Chart 1.20



Note: Individuals could cite more than one reason for their unmet need.

Women are more likely than men to state that the costs of obtaining supports for daily activities were prohibitive (62% compared with 40%); that they did not have the luxury of receiving help from friends and family (34% compared with 19%); and that their insurance did not cover these costs (32% compared with 20%). (Chart 1.21) Working age women were more likely than their senior counterparts to cite expense and lack of informal help as barriers (not shown).

Chart 1.21

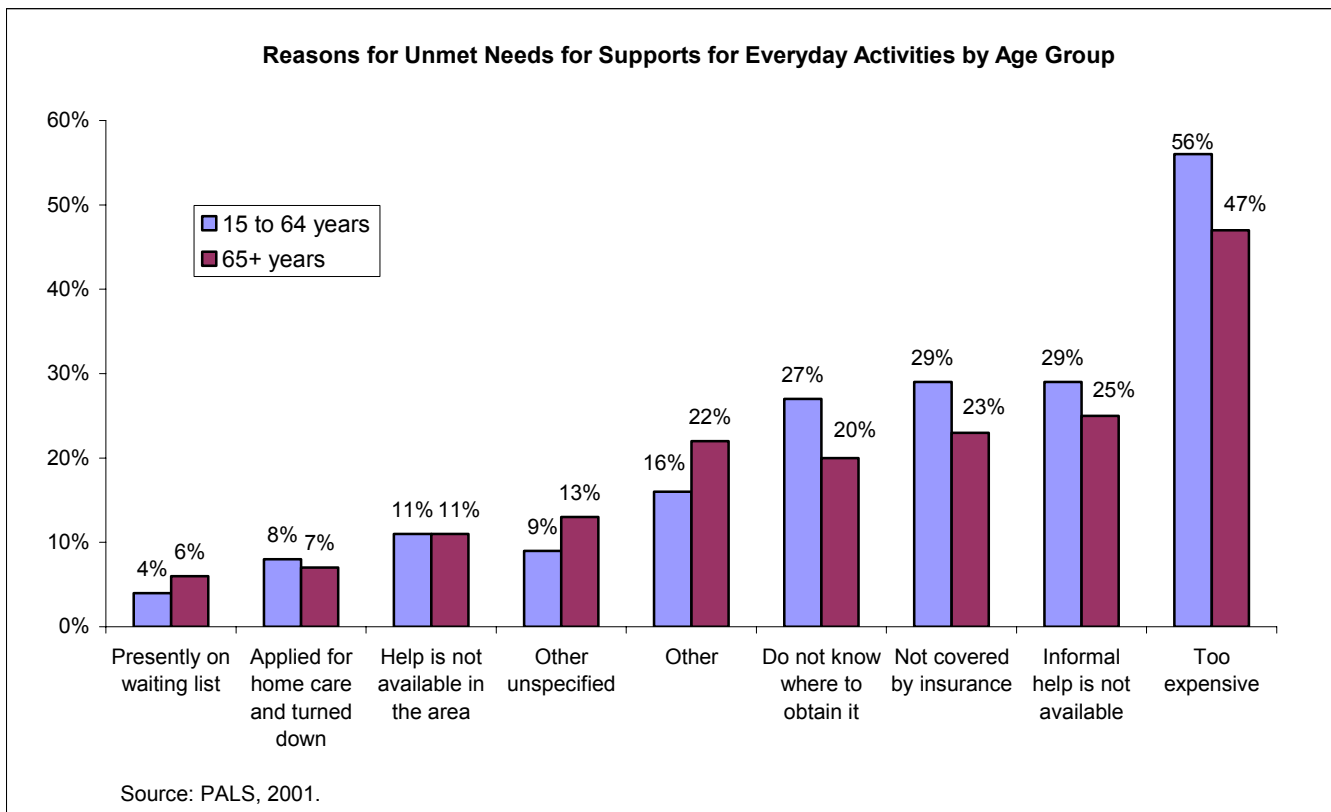


Note: Individuals could cite more than one reason for their unmet need.

Expense-related Reasons May be Even More Important to Working-age than to Seniors

Both working-age adults and seniors cite expense as a major barrier. (Chart 1.22) Working-age adults were more likely than seniors to feel expense was a barrier (56% versus 47%). Working-age adults were also more likely to cite barriers such as lack of insurance coverage (29% versus 23% for seniors); the lack of informal help (29% versus 25%) and lack of knowledge of where to obtain supports (27% versus 20%). Working-age adults cited an average of 2.1 reasons per person and seniors cited an average of 1.9 reasons per person.

Chart 1.22

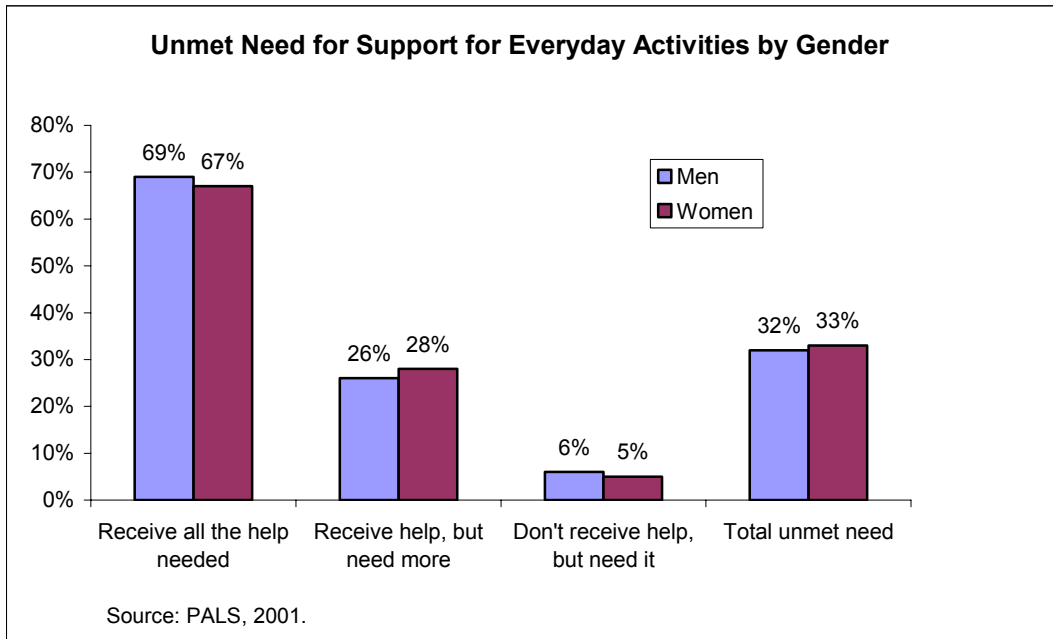


Note: Individuals could cite more than one reason for their unmet need.

Basic Demographic Profile of Unmet Need for Support with Daily Activities

When it comes to an overall requirement for supports for daily activities, men are very slightly more likely than women to have their needs met fully (69% compared to 66%). Gender differences, overall, are very slight when we examine support for all everyday activities.

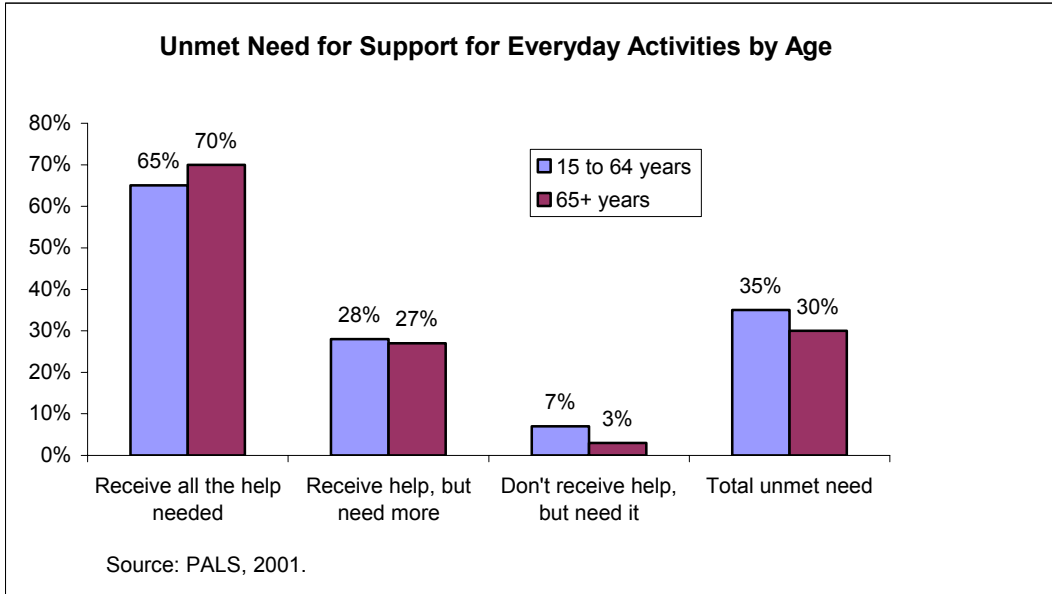
Chart 1.23



Seniors More Likely than Non-seniors to Receive All the Help Needed with Daily Activities

Seniors (70%) were more likely than working-age adults (65%) to receive all the help they required to perform their everyday activities. Some 7% of those aged 15 to 64 received none of the help they felt was required compared to 3% for seniors. Overall, working-age adults were more likely to have unmet needs with respect to receiving support with everyday activities.

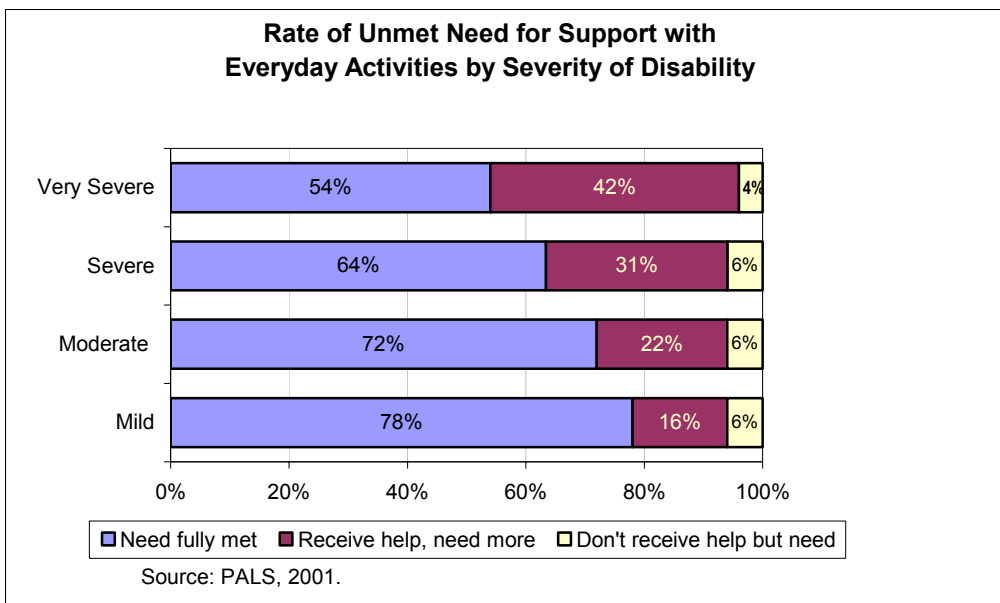
Chart 1.24



Unmet Need for Support with Daily Activities Increases with Severity of the Disability

The more severe the disability, the less likely one is to have their requirements for support with everyday activities met. For example, 22% of those with mild disabilities had unmet needs for support with everyday activities compared with 46% of those with very severe disabilities. This means that 78% of those with mild disabilities have their requirements fully met compared with 54% of those with very severe disabilities.

Chart 1.25



Who Provides Assistance with Daily Activities?

Help Comes Primarily from Family and Friends

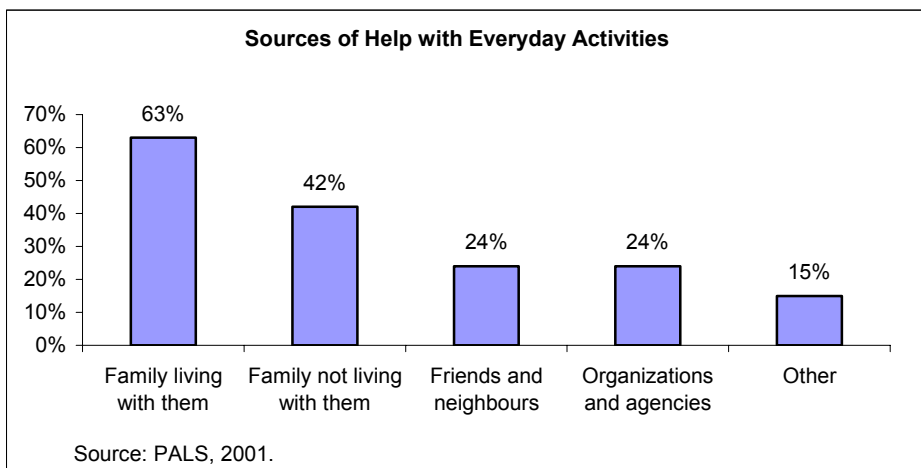
Help with everyday activities can come from a variety of sources - family, friends or neighbours, organizations, agencies or other sources.

The majority of persons with disabilities who received help with everyday activities received help from family members living with them (63%) and family members who did not live with them (42%). Less than a quarter (24%) of these individuals received help from organizations or agencies. In fact, people were just as likely to receive help from friends and neighbours (24%) as they were from organizations or agencies. (Chart 1.26)

Men were very slightly more likely than women to report receiving help from friends and neighbours (27% compared to 22%) and very slightly less likely than women to report help from organizations and agencies (22% compared with 25%). (Not shown in chart.)

Non-seniors were most likely to receive assistance with everyday tasks from family living with them (73%) and family not living with them (38%). Among seniors, there was a slight shift indicative of age differences in family composition. Family assistance was also very important for seniors; 52% received help from family living with them (lower than for non-seniors which is indicative of the greater tendency among seniors to live alone) and 48% received help from family not living with them. Among seniors, the family caregivers not living with them are most likely to be grown children—in many cases, these children will be part of the baby-boom generation. The longer term implication of this is that, as the ‘baby-boom’ generation ages into their senior years, the available pool of younger relatives able to pitch in will be much lower than it is at present. The reduction in the birth rate after the ‘baby-boom’ generation will result in fewer potential ‘helpers’ being available to an increased number of seniors in years to come. Among seniors, 34% receive help from organizations or agencies compared with 16% among non-seniors. As individuals age, there is likely to be greater reliance upon caregivers outside the home. Where there is a shortage of family members, the need for organizations and agencies to fill the gap increases. (Not shown in chart)

Chart 1.26

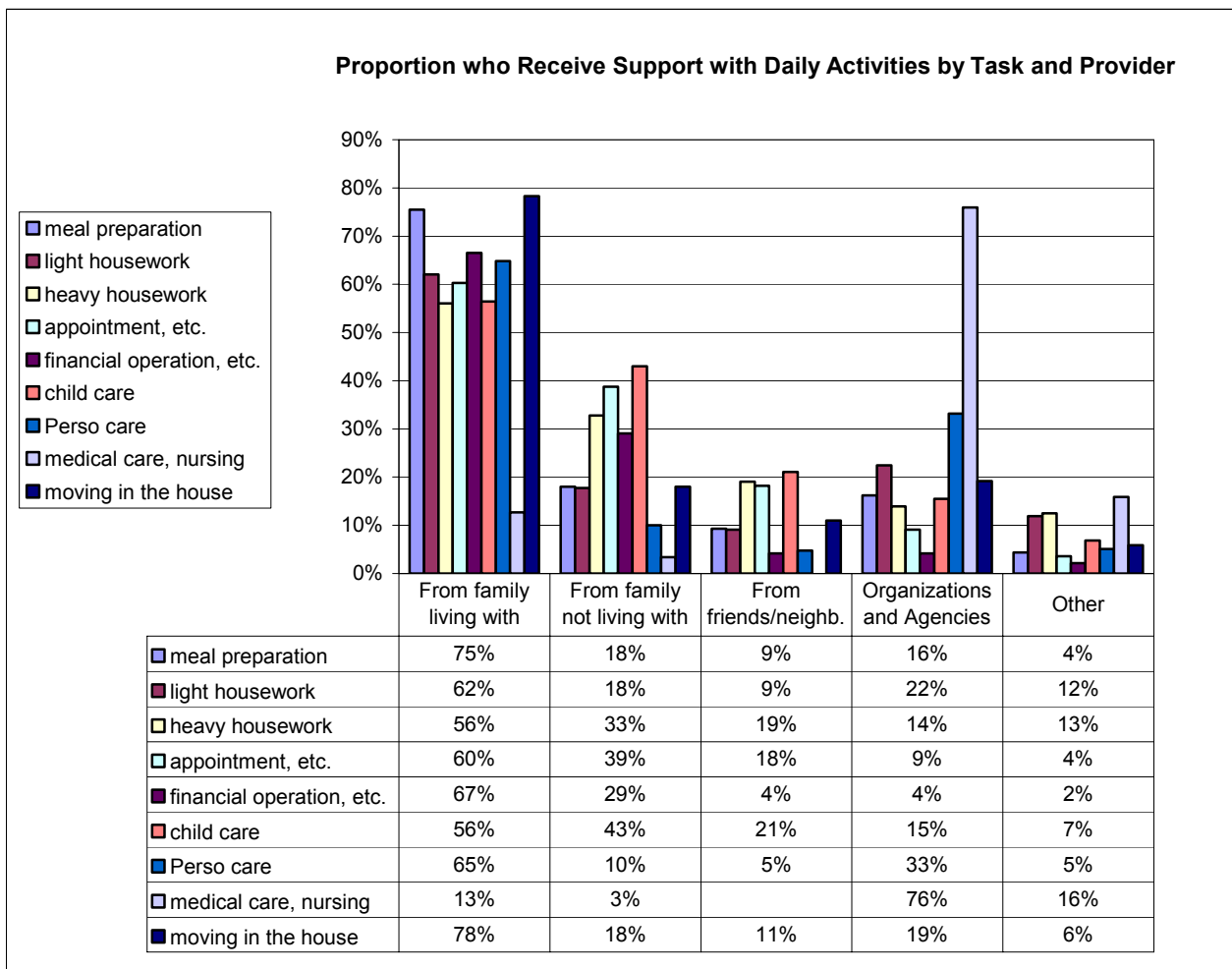


Note: More than one source of help could be cited.

Sources of Help Related to Type of Task

The majority of those who receive help with everyday activities rely on their families. This is evident in Chart 1.27, which summarizes the proportion of individuals receiving help from various sources with nine different everyday activities. The most obvious exception is in the case of specialized nursing or medical care where only 13% of the individuals receiving such help get it from family living with them and 3% from family not living with them. Among those who received help with specialized nursing or medical care, over three-quarters of them (76%) relied on agencies and organizations. Overall, however, it is families, friends and neighbours who provide the majority of the help to persons with disabilities.

Chart 1.27



Source: PALS, 2001

Who Pays for Help with Daily Activities?

Much of the help with daily activities that is received is provided free of charge; 70% of individuals with disabilities who received help with daily activities report that the help for some or all of the support they received was provided free of charge.²³ Given the high percentage of people receiving help from family members, this is not surprising. About one third of those receiving some type of assistance report that they paid for some or all of it themselves (or their immediate family).²⁴ Only 3% report that some of their assistance was paid for by some type of home care program²⁵ and 3% report some other type of publicly funded program paid for some of their support.²⁶

Table 1.9
Who Pays for the Help with Daily Activities?

	Number	%
Help is free	1,402,110	70%
Individual (or immediate family) pays	664,050	33%
Family not living with individual pays	34,160	2%
Home care program pays	65,180	3%
Other public source pays	65,180	3%

Source: PALS, 2001

Note: Categories are not mutually exclusive. Some individuals reported more than one source of payment.

Note: Sources of payment reported by less than 1% are not listed.

Over half a million individuals with some type of support with daily activities (664,050) reported paying for some or all of that support themselves. Of these, only 8% reported being reimbursed (either partially or fully) for these costs. Of those who were reimbursed (either partially or fully), 46% had some reimbursement directly from some level of government; 21% had some reimbursement from some private health care plan; 21% had some reimbursement through a tax credit; and 19% had some ‘other’ type of reimbursement source. Obviously, some individuals were reimbursed through more than one source. It is important to note, however, that only 8% with direct costs to themselves for support with daily activities received any form of reimbursement.

²³ Working-age individuals were more likely than seniors to report that the cost of support with daily activities was free (79% compared with 60%).

²⁴ Seniors were more likely than working-age individuals to report that they or their immediate family paid directly for some of the help that they received (43% compared with 25%).

²⁵ Seniors were more likely than working-age individuals to report that either some home care program or some other public program paid for the cost of some of their support with daily activities (5% compared with 1% in both cases).

²⁶ Some individuals may have received some assistance that was from a free source and some assistance that was paid for by some other source. However, the majority (90%) reported a single source (another 8% reported only 2 sources).

Section III: School Supports

Many persons with disabilities do not become disabled until later in life (after they have finished their formal education). However, for those who have a disability from a young age, the impact of barriers faced in the education system can be cumulative. Difficulties encountered in progressing through school can limit employment opportunities and economic security. It is important to ensure that young people with disabilities have the supports that they need to be successful in obtaining their education. In PALS, supports and services within the school system are categorized into two distinct areas:

- (1) *structures*: modified building features or services (supports at the infrastructure level)
- (2) *aids/devices*: assistive aids or devices or services (supports at a more personal level)

The data presented in this section examine only those adults aged 15 years or older who were in attendance at school in 2001 (either full-time or part-time) as well as those who were in attendance at school within the previous 5 years (between 1996 and 2001 inclusive).²⁷ This forms the ‘recent’ student population.

Magnitude of Requirement for School Supports

Structures: About 8% of the recent student population reported a requirement for some type of *modified building feature or service* in order to attend to school.

Such structures include: accessible classrooms, accessible washrooms, accessible residences, accessible buildings, and accessible transportation. About 3% reported a requirement for each of these structures; overall, about 8% required at least one of them.

Aids/Devices: About 14% of the recent student population reported a requirement for some type of *aid or device* in order to attend school.

Such aids and devices include: notetakers (5%); tutor/teacher aid (9%); computer with Braille, large print or speech access (2%); talking books (2%); magnifiers or close circuit television readers (*); Braille or large print reading materials (*); sign language interpreter (*); recording equipment or portable notetakers (4%); attendant care service (2%); other (4%).²⁸

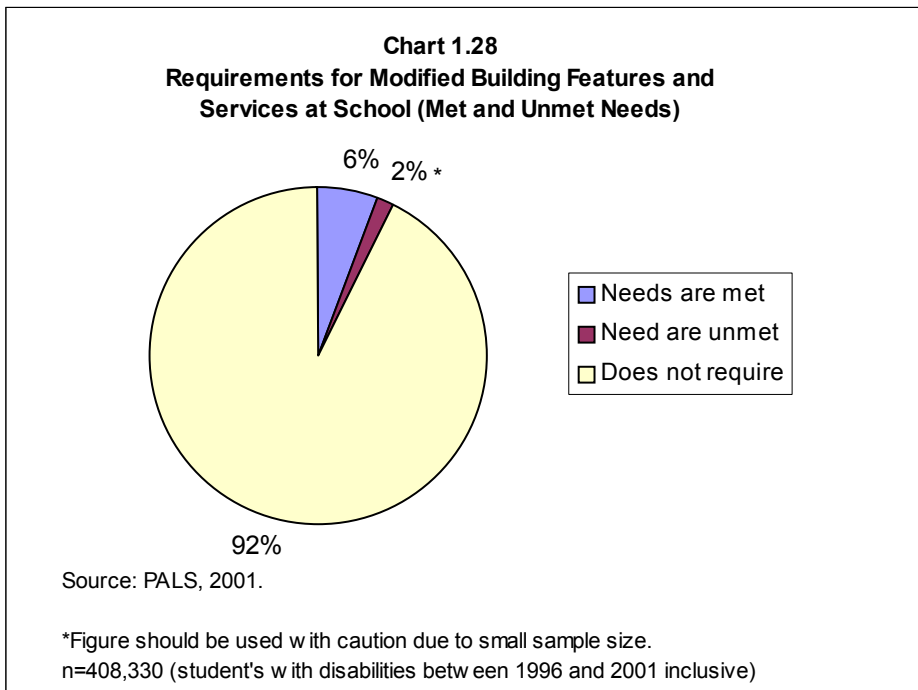
²⁷ Both groups of students are utilized in this analysis due to small sample size. In an effort to provide more detailed information about the requirements and unmet needs among students in Canada, both individuals enrolled in school at the time of the survey as well as recent graduates were pooled to provide information about their school experiences. Initial examination of the two groups suggests that they are fairly similar with respect to requirements for supports.

²⁸ Aids and devices listed with (*) have low sample size restrictions. The percentage requiring these aids/devices cannot be released as a result.

Unmet Need for School Supports

Structures:

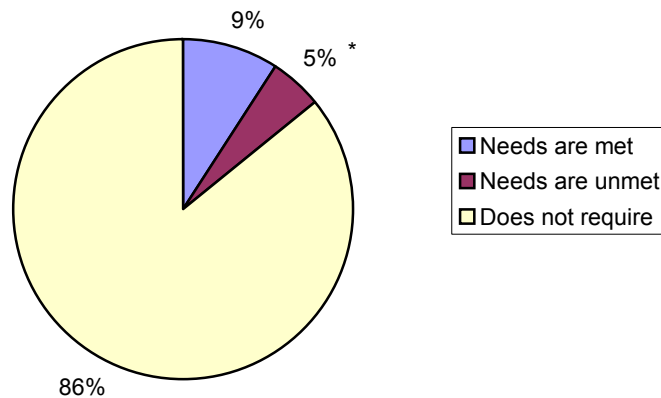
The vast majority (92%) of recent students with disabilities do not report a requirement for modified building features or services at school. Of those who did require some type of accessible structure, the majority report having had it. Among recent students with disabilities, 6% had their needs met and another 2% had requirements for some type of accessible structure but did not have what they needed. (Chart 1.28)



Aids/Devices:

Again, the majority (86%) of recent students with disabilities do not report a requirement for aids or devices at school. Of those who did require some type of aid or device, the majority report having had it. Among recent students with disabilities, 9% had their needs for aids/devices met and another 5% had a requirement for some type of aid/device but did not have what they needed. (Chart 1.29)

Chart 1.29
Requirements for Aids and Devices at School
(Met and Unmet Needs)



Source: PALS, 2001.

*Figure should be used with caution due to small sample size.
n=412,960 (student's with disabilities between 1996 and 2001 inclusive)

Basic Demographic Profile of Those Who Require School Supports

Gender: Fairly Similar Rates

Male and female students have a very similar rate of requirement for modified buildings and services at school (about 7% and 8% respectively). However, male students with disabilities were somewhat more likely than their female counterparts to report a requirement for some type of aid or device at school (18% compared with 11%). Among those who do have a requirement for aids/devices at school, there is only a very slight gender difference in the success rate in obtaining the aids/devices. Nearly two-thirds of both genders (63% of males and 65% of females) reportedly had the aids/devices needed; while just over a third did not.²⁹

²⁹ The percentages for unmet need for aids/devices by gender must be used with caution due to low sample size. Given this caution, gender differences here should not be considered noteworthy.

Severity: More Severe Disabilities Associated with Greater Requirements for Structures and Aids/Devices

Students with severe or very severe disabilities are more likely to report a requirement for modified buildings and services at school than those with mild or moderate disabilities (13% compared with 4%).³⁰

Severity level is clearly linked with requirements for aids and devices at school. Among students with mild or moderate disabilities, 9% reported a requirement for some type of aid or device at school. This compares with 18% of those with severe disabilities and 35% of those with very severe disabilities.³¹

Type of Disability

Some disability types are more likely to be associated with a requirement for supports within the school system. For example, developmental disabilities and speech disabilities are associated with higher levels of requirements for modified structures as noted in Table 1.10. Unfortunately, due to low sample size, we are unable to determine which modified structures and services are required most by these individuals.³²

Table 1.10
Requirements for Modified Building Features and Services at School by Type of Student's Disability

	Requires	Does Not Require
agility	11%	89%
hearing	6%*	94%
learning	10%	90%
mobility	11%	89%
sight	13%*	87%
speech	16%*	84%
memory	13%*	87%
developmental	21%	79%
pain	7%*	93%
psychological	9%*	91%

Source: PALS, 2001.

* Figures should be used with caution due to small sample size.

Students with developmental disabilities are also the most likely to report a requirement for aids and devices in school (see Table 1.11). Those with learning disabilities, speech disabilities, and memory disabilities also have high requirements for aids and devices. One might typically associate requirements for supports within the school system with those with physical disabilities. However, it is obvious that those with non-physical disabilities also have needs.³³

³⁰ Due to low sample size, numbers for unmet need cannot be released.

³¹ Among those with a requirement for aids/devices at school, 26% of those with severe disabilities report an unmet need and 43% of those with very severe disabilities report an unmet need. These numbers should be used with caution, however, due to low sample size; the numbers for those with mild/moderate disabilities cannot be released due to low sample size.

³² Developmental and speech disabilities, for example, may be more likely to be found in combination with other disability types. It may be the combination that results in greater requirements.

³³ Due to low sample size some of the percentages for met and unmet needs cannot be released or must have a caution placed upon them. However, some of this material is 'releasable' and will be included in this footnote. When we examine those who require some type of aid or device in school by disability type, we find that those with developmental and speech related disabilities are actually the most likely to have their needs met (80% and 75% respectively). Among the least likely to have

Table 1.11
Requirements for Aids and Devices in School
by Type of Disability

	Requires		Does Not Require
agility	15%	*	85%
hearing	19%	*	81%
learning	33%	*	67%
mobility	13%	*	87%
sight	21%	*	79%
speech	33%	*	67%
memory	33%	*	67%
developmental	46%	*	54%
pain	11%	*	89%
psychological	20%	*	80%

Source: PALS, 2001

* Use with caution due to low sample size.

Level of Schooling

Students in this analysis ranged from those in high school to those in post-secondary school. In an effort to determine where the needs are greater, we have examined those who would likely have been referring to an experience in secondary school (or lower) and those who would likely have been referring to an experience in post-secondary school. There is little difference in the requirement for modified buildings and services (9% requiring this in secondary school or lower and 7% in post-secondary school). There is, however, a difference when we examine a requirement for aids/devices in school; 21% of those in secondary school or lower reported a requirement for an aid/device in school compared with 10% in post-secondary school.³⁴ Logically, one would not expect a reduction in the requirement for school supports as individuals make the transition from secondary to post-secondary school. If they required these supports in the lower levels of school, one would think that they would also require them at the higher levels as well. In fact, one might have expected an increase in requirements. We see the exact opposite. Since one would not expect requirements to decrease, this suggests that those who have a need for such aids/devices may be less likely to go on to post-secondary education. A lack of such aids/devices could well be a serious barrier for this group. Given the importance of education to labour market success, this may be a critical area to examine further.

their needs met are those with: psychological disabilities (60% with needs met); pain disabilities (54% with needs met); memory disabilities (57% with needs met); and agility disabilities (58% with needs met).

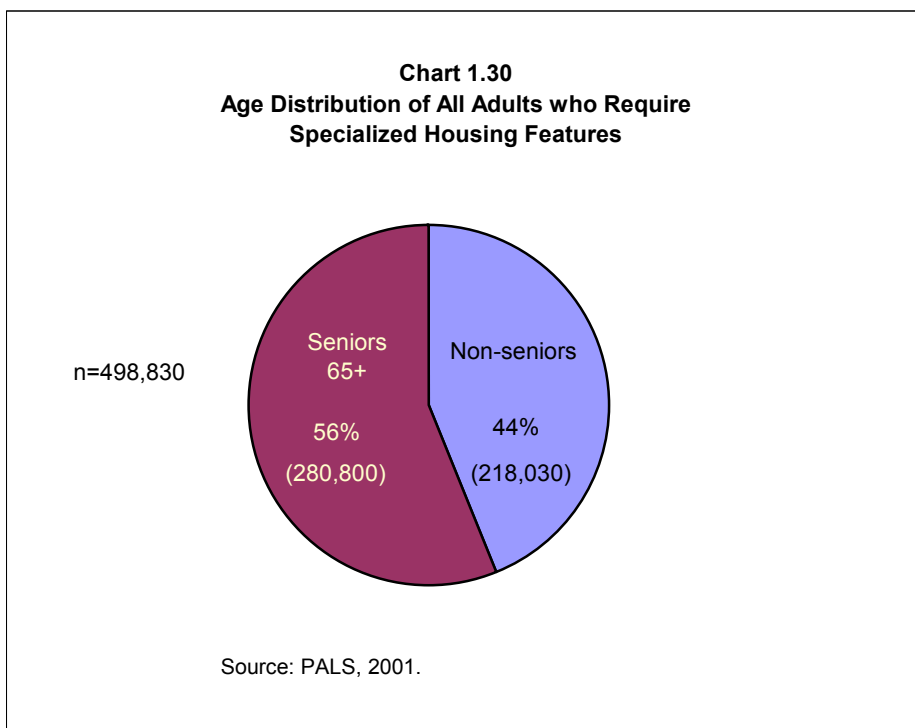
³⁴ Students in post-secondary school were also more likely to have an unmet need when they did require an aid or device (42% compared with 32% of those in secondary school or lower). These numbers, however, should be used with caution due to low sample size.

Section IV: Housing Features

Persons with disabilities often require specialized features within and around their homes. These features can include: ramps or street level entrances; automatic or easy to open doors; widened doorways or hallways; elevator or lift devices; visual alarms or audio warning devices; grab bars or a bath lift; and lowered counters in the kitchen.

Magnitude and Nature of the Requirements

Nearly half a million adults with disabilities (15% of the adult population with disabilities) have some requirement for a specialized housing feature. Just over half of these individuals (56%) are seniors (Chart 1.30).

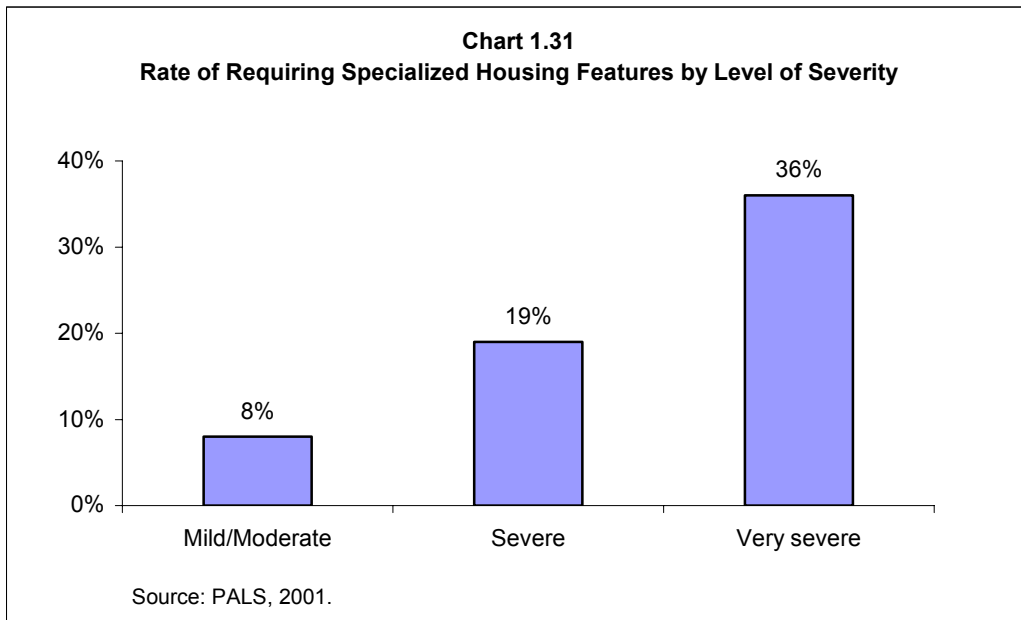


Seniors –vs- Working-age

In addition to comprising a slightly larger proportion of those requiring specialized housing features, seniors also have a higher *rate* of requiring such features (19% compared with 11% among working-age individuals).

Gender and Severity Level

Women (17%) are slightly more likely than men (11%) to require specialized housing features. As well, the likelihood of requiring specialized housing features increases with level of severity of the disability. As indicated in Chart 1.31, 8% of those with a mild or moderate disability reported a requirement for specialized housing features; this increased to 19% among those with severe disabilities and to 36% among those with very severe disabilities.



Type of Disability

Persons with mobility disabilities contribute most overall to the requirement for specialized housing features (464,570 of them reported some type of requirement). Persons with agility disabilities also contribute a great deal to the overall requirement for specialized housing features (448,430). It is important to note, however, that a high proportion of people have both mobility and agility disabilities. Similarly, there is a high degree of overlap with these two disability types and pain-related disabilities (also contributing highly to the requirement for specialized housing features with 381,110 people).

Table 1.12

Percentage and Number of Persons Requiring Specialized Housing Features by Type of Disability

	%	Number
Agility	20%	448,430
Hearing	16%	172,900
Learning	16%	70,390
Mobility	19%	464,570
Sight	23%	138,870
Speech	25%	89,320
Memory	22%	92,460
Developmental	11%	12,780
Pain	16%	381,110
Psychological	17%	90,820

Source: PALS, 2001.

While agility, mobility, and pain-related disabilities (and, to a lesser degree, hearing and sight) contribute most to the overall need for specialized housing features, the greatest *rate* of requirement (i.e., the proportion of those with a particular type of disability who have the requirement) is found among those with speech (25%), sight (23%), and memory (22%) disabilities. (Table 1.12)

Which Specific Specialized Housing Feature is Most Required?

The most required specialized housing feature is the ‘grab bar/bath lift’ which is required by 353,580 adults with disabilities. ‘Ramps or street level entrances’ are the second most required specialized housing feature with 210,610 people reporting a requirement. Table 1.13 summarizes the requirements for specific specialized housing features from most required to least required of those covered in PALS, 2001.

Table 1.13
Requirements for Specific Specialized Housing Features
Number and Percent of all Adults with Disabilities

	Number	Percent
Grab bars/bath lift	353,580	10%
Ramps/street level entrance	210,610	6%
Other	138,640	4%
Elevator/lift service	135,040	4%
Automatic door	122,930	4%
Widened doorway/hallways	100,610	3%
Visual alarm/audio warning device	67,680	2%
Lowered counters in the kitchen	39,560	1%

Source: PALS, 2001

What is the Gap between Requirements and Reality— What is the Unmet Need for Specialized Housing Features?

Of those who do require some type of specialized housing feature, 63% report that their needs are fully met; another 11% report that they have some of what they need, but require more (needs partially met); and 26% report that their needs are completely unmet. When we look at specific features, we see that there is a high unmet need for lowered kitchen counters and “other” specialized features not specified in PALS (45% and 43% unmet need respectively).

Specific Specialized Housing Features

Table 1.14
Met and Unmet Needs for Specific Specialized Housing Features

	% Needs Unmet	% Needs Met	% Total Need	Total Need Number
Grab bars/bath lift	25%	75%	100%	353,580
Ramps/street level entrance	25%	75%	100%	210,610
Other	43%	57%	100%	138,640
Elevator/lift service	29%	71%	100%	135,040
Automatic door	23%	77%	100%	122,930
Widened doorway/hallways	*21%	79%	100%	100,610
Visual alarm/audio warning device	*20%	80%	100%	67,680
Lowered counters in the kitchen	*45%	55%	100%	39,560

Source: PALS, 2001

* Figure should be used with caution due to low sample size.

Gender and Age: Little Difference by Gender -but- Non-seniors More Likely than Seniors to Have Unmet Needs

Men and women are equally likely to have an unmet need (11% partially unmet and 26% completely unmet for both genders). However, working-age individuals are more likely than seniors to have an unmet need. Of those who require some type of specialized housing feature, nearly three-quarters (73%) of seniors have their needs fully met compared with half of working-age persons with disabilities. A fairly high proportion (36%) of working age persons who require specialized housing features report that they have none of what they need (compared with 18% of seniors). (Table 1.15)

Table 1.15
Met and Unmet Needs for Specialized Housing Features by Age Group

	% Partially Met Need	% Fully Unmet Need	% Fully Met Need	% Total Who Require	Number Total Who Require
Working age	14%	36%	50%	100%	218,030
Seniors	9%	18%	73%	100%	280,800

Source: PALS, 2001

Severity: Those with More Severe Disabilities Less Likely to Have Needs Met

As the severity of the disability increases, so does the likelihood of requiring some type of specialized housing feature (refer back to Chart 1.31). Among those who do require such features, increasing levels of severity are also associated with a greater rate of unmet need. We can see that 69% of those with mild/moderate disabilities who require specialized features have their needs fully met compared with 58% of those with very severe disabilities. This means that the total unmet need for those with very severe disabilities is 42% compared with 31% for those with mild/moderate disabilities. The greatest difference, however, seems to be in the rate of partially unmet/met need. (Table 1.16)

Table 1.16
Met and Unmet Needs for Specialized Housing Features by Level of Severity

	% Partially Met Need	% Fully Unmet Need	% Fully Met Need	% Total Who Require	Number Total Who Require
Mild/Moderate	*	25%	69%	100%	153,020
Severe	11%	26%	63%	100%	173,280
Very Severe	15%	26%	58%	100%	172,530

Source: PALS, 2001

* Percentage cannot be released due to low sample size.

Disability Type

Some disability types are associated with a higher *rate* of unmet need. Among those with a psychological disability who require some type of specialized housing feature, for example, half have an unmet need (31% have a completely unmet need). Similarly, among those with a developmental disability who require some type of specialized housing feature, 45% have an unmet need. (Table 1.17) As summarized in Table 1.12 earlier, neither of these types is associated with the highest rates of requiring such features to begin with; and neither contributes in a particularly large way to the overall requirement in terms of sheer numbers. However, these findings tend to suggest that there may be some type of barrier facing individuals with these disabilities types when they do require something.

Table 1.17**Met and Unmet Needs for Specialized Housing Features by Disability Type**

	%Partially Met Need	%Fully Unmet Need	%Fully Met Need	%Total Who Require	Number Total Who Require
Agility	11%	25%	64%	100%	448,430
Hearing	9%	24%	67%	100%	172,900
Learning	*15%	25%	60%	100%	70,390
Mobility	11%	25%	64%	100%	464,570
Sight	13%	25%	62%	100%	138,870
Speech	*16%	23%	61%	100%	89,320
Memory	*9%	23%	68%	100%	92,460
Developmental	*20%	25%	*55%	100%	12,780
Pain	11%	28%	61%	100%	381,110
Psychological	*19%	31%	50%	100%	90,820

Source: PALS, 2001

* Percentage cannot be released due to low sample size.

Section V: Work Supports

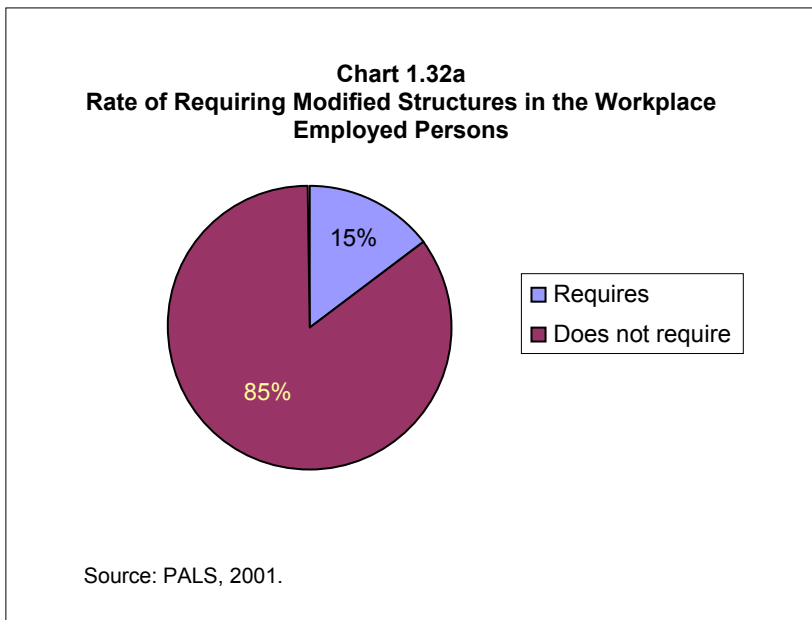
Work supports can be a vital part of getting a job, keeping a job, and advancing in a job for persons with disabilities. In this section, we examine two types of supports (similar to those in the section on school supports):

- (1) *structures*: modified structures in the workplace (infrastructure supports)
- (2) *aids/devices*: work aids or job modification (more personal supports)

We concentrate on those who are officially in the labour force (employed and unemployed); and the data from PALS in this regard are limited to those between the ages of 15 and 64. Whenever possible, we provide the comparison between those who are employed and those who are unemployed.³⁵

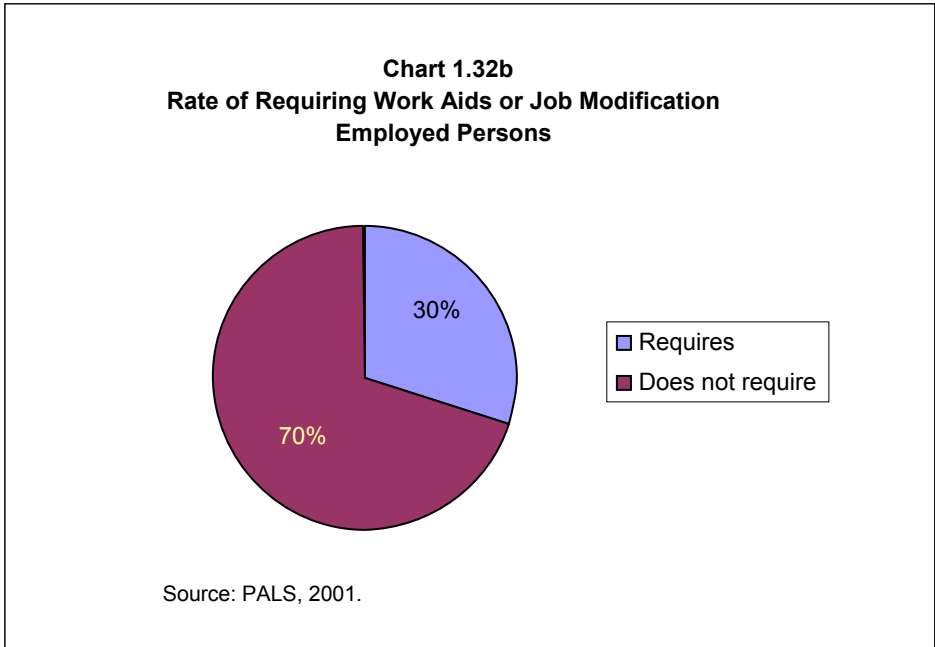
Magnitude of Requirement for Work Supports

Among employed persons, 15% report requiring some type of modified structure in the workplace. (Chart 1.32a) Modified structures include: *handrails/ramps*; *accessible parking*; *accessible elevator*; *modified workstation*; *accessible washroom*; *accessible transportation*; and *other*.



Employed persons are even more likely to report a requirement for a more personal type of support; 30% report requiring some type of work aid or job modification. (Chart 1.32b) Work aids or job modifications include: *job redesign* (modified or different duties); *modified hours*; *human supports* (readers, sign language interpreters, job coaches, personal assistant); *technical aids* (voice synthesizer, TTY or TDD, infrared system, portable note-takers); *computer with Braille, large print or speech access or a scanner*; *communication aids* (such as Braille or large print reading material or recording equipment); and *other*.

³⁵ We had hoped to include an analysis of those who were not in the labour force (NILF) who were not retired. Unfortunately, as noted in the methods section at the end of this report, there was an error on the PALS file with respect to selecting out the retired persons. This error was corrected by Statistics Canada too late to be included in our analysis here.



Unemployed Persons Have Greater Requirements than Employed Persons for Work Supports

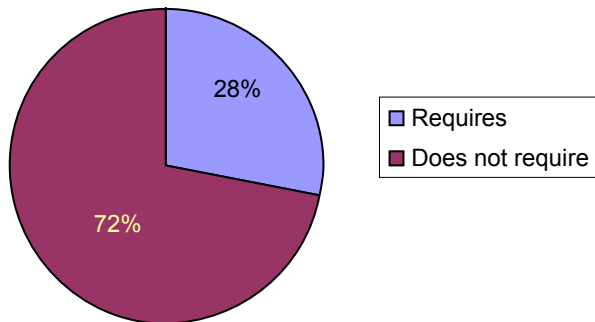
While 15% of employed persons had a requirement for modified workplace structures, nearly double that amount (28%) of unemployed persons reported such a requirement. (Chart 1.33a)

Similarly, while 30% of employed persons had a requirement for work aids or job modification, 56% of their unemployed counterparts reported such a requirement. (Chart 1.33b)

A greater requirement for work supports among the unemployed may be indicative of their greater vulnerability in the labour market.³⁶

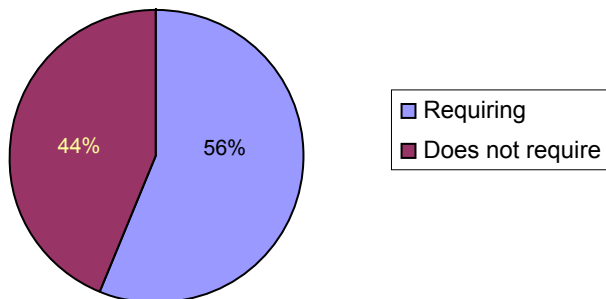
³⁶ Further analysis of the PALS indicates that those with more severe disabilities are more likely to experience periods of unemployment. It is likely that higher levels of severity and requirements for work supports (which are related to each other) make some workers more vulnerable to unemployment.

Chart 1.33a
Rate of Requiring Modified Structures in the Workplace
Unemployed Persons



Source: PALS, 2001.

Chart 1.33b
Rate of Requiring Work Aids or Job Modification
Unemployed Persons



Source: PALS, 2001.

Which Specific Modified Structures Are Most in Demand?

Those who were unemployed were more likely to require each of the specific modified structures included in the PALS. Accessible parking, modified workstations, and accessible elevators were the most popular supports overall. (Table 1.18a)

Table 1.18a**Rate of Requiring Specific Modified Structures in the Workplace**

	% Employed who require	% Unemployed who require
Handrails/ramps	3%	6% *
Parking	5%	12%
Accessible elevator	4%	10% *
Modified workstation	7%	12% *
Accessible washroom	4%	8% *
Accessible transportation	3%	8% *
Other	1% *	1% *

Source: PALS, 2001

*figures should be used with caution due to small sample size.

Which Specific Work Aids or Job Modifications Are Most in Demand?

Job redesign and modified hours are the work aids/job modifications most in demand. While they are mentioned by employed persons as important required supports (17% and 19% respectively), they are even more in demand among those who are unemployed. About 42% of those who were unemployed reported a requirement for job redesign and 35% reported a requirement for modified hours. (Table 1.18b)

Table 1.18b**Rate of Requiring Specific Work Aids or Job Modifications**

	% Employed who require	% Unemployed who require
Job redesign	17%	42%
Modified hours	19%	35%
Human supports	3%	10% *
Technical aids	2% *	4% *
Computer with braille, etc	1% *	**
Communication aids	**	**
Other	5%	6% *

Source: PALS, 2001

*figures should be used with caution due to small sample size.

**figures cannot be released due to low sample size.

These two supports appear to be key requirements for those who are unemployed. This tends to suggest that they may be key factors in their unemployment as well. The other supports listed in the PALS questionnaire (human supports, technical aids, computer with Braille, communication aids, etc.) seem to involve supports that have the potential to be funded from a variety of sources. This suggests that a number of options might be available to assist people in acquiring these supports (i.e., they lend themselves to a variety of funding options and programs). However, the two types of supports most required (job redesign and modified hours) are really within the purview of the employer. Options for providing these supports are more limited (particularly with respect to public programs).

Unmet Need for Work Supports

Overall, 24% of employed persons who require some type of modified structure in the workplace have an unmet need. Similarly, 22% who require some type of work aid or job modification have an unmet need.³⁷

As summarized in Table 1.19, the greatest *rate* of unmet need in terms of specific modified structures is for accessible parking (26% with an unmet need) while accessible washrooms are the least likely of those listed to result in an unmet need (12%). However, it is a requirement for modified workstations that contributes most to the overall unmet need in terms of sheer numbers (with 10,900 persons reporting an unmet need for modified workstations).

Table 1.19

**Rate of Met/Unmet Need for Specific Modified Structures in the Workplace
Employed Persons Only**

	%Needs Met	# Needs Met	%Needs Unmet	#Needs Unmet	Total Requiring
Handrails/ramps	81%	19,940	19% *	4760 *	24,700
Parking	79%	31,240	21% *	8140 *	39,380
Accessible elevator	79%	26,490	21% *	7180 *	33,670
Modified workstation	80%	44,170	20%	10900	55,070
Accessible washroom	88%	26,420	12% *	3610 *	30,030
Accessible transportation	74%	17,680	26% *	6150 *	23,830
Other	**	**	**	**	**

Source: PALS, 2001

*figures should be used with caution due to small sample size.

**figures cannot be released due to small sample size.

Table 1.20

**Rate of Met/Unmet Need for Specific Work Aids or Job Modifications
Employed Persons Only**

	%Needs Met	# Needs Met	%Needs Unmet	#Needs Unmet	Total Requiring
Job redesign	80%	110,140	20%	28,050	138,190
Modified hours	83%	125,990	17%	26,290	152,280
Human supports	83%	18,370	17% *	3,700 *	22,070
Technical aids	73% *	9,290 *	27% *	3,470 *	12,760
Computer with braille, etc	**	**	**	**	**
Communication aids	**	**	**	**	**
Other	71% *	26,240 *	29% *	10,670 *	36,910

Source: PALS, 2001

*figures should be used with caution due to small sample size.

**figures cannot be released due to low sample size.

As summarized in Table 1.20, the greatest *rate* of unmet need in terms of specific work aids or job modifications is for ‘other’ and ‘technical aids’ (29% and 27% with an unmet need). However, job redesign and modified hours contribute most to overall unmet need in terms of sheer numbers (with 28,050 and 26,290 with an unmet need respectively).

(Table 1.20)

³⁷ Unmet need cannot be calculated for the unemployed since the appropriate questions were not asked.

As Severity of Disability Increases, So Does the Likelihood of Requiring Work Supports as well as the Unmet Need for Work Supports

As summarized in Table 1.21a, employed persons with very severe disabilities are the most likely to require some type of modified structure in the workplace (65%); this compares with 24% among those with severe disabilities, 14% among those with moderate disabilities, and 7% among those with mild disabilities.

While they are the most likely to require some type of modified structure, those with very severe disabilities are also those most likely to have an unmet need for it. As summarized in Table 1.21b, 28% of those with very severe disabilities had an unmet need for some type of modified structures compared with 18% of those with mild disabilities.

Table 1.21a

Rate of Requiring and Met/Unmet Need for Modified Structures in the Workplace by Level of Severity (for those Employed)

	#Needs Met	%Needs Met	#Needs Unmet	%Needs Unmet	#Do Not Need	%Do Not Need	Total
Mild	22,187	6%	4,845 *	1% *	349,856	93%	376,888
Moderate	25,705	11%	8,647 *	4% *	205,143	86%	239,495
Severe	28,567	18%	9,652	6%	118,126	76%	156,345
Very severe	13,654 *	40% *	5,383 *	16% *	15,354 *	45% *	34,392

Source: PALS, 2001

*figures should be used with caution due to small sample size.

Table 1.21b

Rate of Met/Unmet Need for Modified Structures in the Workplace for those Requiring by Level of Severity (for those Employed)

	#Needs Met	%Needs met	#Needs Unmet	%Needs Unmet	Total
Mild	22,187	82%	4,845	18%	27,032
Moderate	25,705	75%	8,647	25%	34,352
Severe	28,567	75%	9,652	25%	38,218
Very severe	13,654 *	72% *	5,383	28%	19,038

Source: PALS, 2001

*figures should be used with caution due to small sample size.

There is a similar finding for work aids and job modifications; 59% of those with a very severe disability report a requirement for some type of work aid or job modification compared with 18% of those with a mild disability. (Table 1.22a) Similarly, those with very severe disabilities are also the most likely to report an unmet need in this regard (32% compared with 22% among those with mild disabilities). (Table 1.22b)

Table 1.22a**Rate of Requiring and Met/Unmet Need for Work Aids or Job Modifications
by Level of Severity (for those Employed)**

	#Needs Met	%Needs Met	#Needs Unmet	%Needs Unmet	#Do Not Need	%Do Not Need	Total
Mild	52,516	14%	14,654 *	4% *	308,069	82%	375,239
Moderate	68,598	29%	14,081	6%	157,052	66%	239,731
Severe	56,127	36%	19,354	12%	79,917	51%	155,397
Very severe	13,813 *	41% *	6,410 *	19% *	13,774 *	41% *	33,996

Source: PALS, 2001

*figures should be used with caution due to small sample size.

Table 1.22b**Rate of Met/Unmet Need for Work Aids or Job Modifications for Those Requiring
by Level of Severity (for those Employed)**

	#Needs Met	%Needs Met	#Needs Unmet	%Needs Unmet	Total
Mild	52,516	78%	14,654 *	22% *	67,170
Moderate	68,598	83%	14,081	17%	82,679
Severe	56,127	74%	19,354	26%	75,481
Very severe	13,813 *	68% *	6,410 *	32% *	20,222

Source: PALS, 2001

*figures should be used with caution due to small sample size.

Certain types of disabilities are more likely to result in a requirement for work supports than others. As summarized in Table 1.23a, requirements for modified structures in the workplace range from 10% for those with hearing disabilities to 29% for those with memory-related disabilities. Requirements are fairly high among those with mobility, sight, speech, and psychological disabilities as well.³⁸

³⁸ Overall, in terms of sheer numbers, those with agility, mobility, and pain related disabilities contribute most to the unmet needs for these types of requirements.

Table 1.23a
% Requiring Modified Structures in the Workplace
by Type of Disability (Employed Only)

	% Require	%Don't Require
agility	21%	79%
hearing	10%	90%
learning	19%	81%
mobility	23%	77%
sight	23%	77%
speech	24%	76%
memory	29%	71%
developmental*	22%	78%
pain	17%	83%
psychological	23%	77%

Source: PALS, 2001

*figures should be used with caution due to small sample size.

Table 1.23b
% Requiring Work Aids or Job Modifications
by Type of Disability (Employed Only)

	% Require	%Don't Require
agility	36%	64%
hearing	24%	76%
learning	44%	56%
mobility	38%	62%
sight	37%	63%
speech	47%	53%
memory	47%	53%
developmental*	64%	36%
pain	34%	66%
psychological	46%	54%

Source: PALS, 2001

*figures should be used with caution due to small sample size.

With respect to work aids and job modifications, those with developmental disabilities are the most likely to report a need (64%), while those with hearing disabilities are the least likely (24%).³⁹ (Table 1.23b)

³⁹ Those with sight disabilities have the highest rate of unmet need here (31%) while those with developmental disabilities have the lowest (12% - use with caution due to low sample size). However, it is those with pain, agility and mobility disabilities who contribute most to overall unmet need in terms of sheer numbers.

Section VI: Profile of Unmet Need

Throughout the descriptive sections outlining requirements for supports in a variety of areas (aids and devices; supports with daily activities; school supports; specialized housing features; and work supports), it has become apparent that level of severity is a key element. Those with higher levels of severity of disability are more likely to require some type of support—regardless of the area. Certainly, this comes as no surprise. However, higher levels of severity of disability are also associated with a greater likelihood of having an unmet need—regardless of the area. While this may not be surprising either, it is certainly not what we would have hoped to find. Those most in need are also the least likely to have their needs met.

Another recurring theme throughout is that working age persons tend to have higher levels of unmet need than seniors. However, seniors are typically more likely to have a need to begin with (except with respect to school and work supports).

Where reasons for unmet need are available, we typically find that cost and cost-related reasons dominate. With respect to aids and devices, we also found that the more costly items tended to have a high unmet need attached.

In this section, we build on our profile of unmet needs by examining a few other key variables. These key variables are also associated with aspects of economic vulnerability (which seems to be an element in unmet need) and with eligibility requirements for some programs. We examine, unmet needs in a variety of areas with respect to the low income cut-off (LICO), source of income, and labour force status.

LICO

The rate of unmet need for almost all supports is higher among those living below the low income cut-off (LICO). For example, 41% of persons living below LICO had an unmet need for aids/devices compared with 30% of those living above LICO. (See Table 1.24) Only unmet need for specialized housing features fails to follow this trend. Those below LICO are less likely to have an unmet need for specialized housing (31%) than those above (39%). Given the prominence of ‘cost’ as a reason offered for not having a particular support, this is somewhat contrary to our expectations. Further investigation is warranted. There are, however, a number of possible explanations that should be investigated. We need to examine the overall housing situations of persons with disabilities. Persons living on higher incomes may be more likely to live in single family dwellings which typically do not come equipped with ramps, street level entrances, elevators, or automatic doors, etc. For this reason, this sub-population may be more likely to be in the position of having to renovate an existing home to meet their needs after becoming disabled. Even on a higher income, this might be difficult; for example, lift devices which might be used to help persons with mobility disabilities move from one floor to another can easily cost between \$3,000 and \$7,000. Many with lower levels of income do not own their own home. They may be more likely to live in apartments or some form of housing which may also be more likely to provide many of the specialized

features required. We may simply be picking up differences between homeowners and renters. More investigation is required.⁴⁰

Table 1.24

Percent and Number of those Requiring Selected Supports Who Have an Unmet Need by LICO

Type of Support	% Unmet Need	# Unmet Need	% Unmet Need	# Unmet Need
	Below LICO	Below LICO	Above LICO	Above LICO
Aids/Devices	41%	189,670	30%	463,960
Support with Daily Activities	41%	240,250	30%	540,760
Specialized Housing Features	31%	44,500	39%	137,220
Work Supports - Structures*	**33%	**5,920	22%	21,910
Work Supports - Aid/Job Mod	**31%	**11,150	21%	42,730

Source: PALS, 2001

* Applies to employed only

** Use with caution due to low sample size

Main Source of Income

We compared unmet needs for two different sources of income. We isolated a group of individuals who reported income largely from market sources (i.e., employment and self-employment)⁴¹. We compared this with a group of individuals who reported income largely from welfare.⁴² We find very large rates of unmet need among those on welfare income for aids/devices and supports with daily activities (56% and 45%) as compared with those with largely market income (34% and 28%). Curiously, we find the same unexpected pattern with respect to specialized housing features that we did with LICO. One might have expected those with welfare income to have higher rates of unmet need than those with market income. Yet we find that 41% of those with welfare income have an unmet need for specialized housing features compared with 49% for those with largely market income. Again, this requires more investigation. While those with welfare income have a lower rate of unmet need here, it is important to note that the unmet need is still 41%. (Table 1.25)

⁴⁰ It has come to our attention at the CCSD, through individuals who contact us with information requests, that even among ‘renters’ there are vastly different possibilities. Those with very low income levels report that they cannot afford the accessible apartment buildings (which may be less expensive than single family dwellings, but still more expensive than many other alternatives). They report that the lowest rents are often in older buildings without elevators, etc. We may actually be looking at several different sub-populations facing very different levels of unmet need for housing.

⁴¹ We did not base this on proportion of income from a particular source. Rather, we isolated a group who reported market income and no other major income source (no CPP, no worker’s compensation, no welfare, no disability pension, etc.)—only minor other sources were tolerated.

⁴² Similarly, we isolated a group who reported welfare income and no other major income source (no CPP, no worker’s compensation, no market income, no disability pension, etc.).

Table 1.25

**Percent and Number of those Requiring Selected Supports
Who Have an Unmet Need by Main Income Source**

Type of Support	% Unmet Need	# Unmet Need	% Unmet Need	# Unmet Need
	Market Inc.	Market Inc.	Welfare	Welfare
Aids/Devices	34%	111,890	56%	58,970
Support with Daily Activities	28%	102,190	45%	65,730
Specialized Housing Features	*49%	*19,580	*41%	*10,150

Source: PALS, 2001

* Use with caution due to low sample size

Labour Force Status

Those who are employed are the least likely to report an unmet need for aids/devices or support with daily activities. It is actually those who are unemployed (rather than those not in the labour force) who have the highest level of unmet need. (Table 1.26)

Table. 1.26

**Percent and Number of those Requiring Selected Supports
Who Have an Unmet Need by Labour Force Status**

Type of Support	% Unmet Need	# Unmet Need	% Unmet Need	# Unmet Need	% Unmet Need	# Unmet Need
	Employed	Employed	Unemployed	Unemployed	NILF	NILF
Aids/Devices	34%	131,720	45%	21,970	42%	192,884
Support with Daily Activities	32%	147,920	41%	26,350	36%	219,780

Source: PALS, 2001.

Section VII: Conclusion

Overall, just over half (57% or 2,008,460) of adult Canadians with disabilities require some type of aid or device related to their disabilities and just over two-thirds (70% or 2,398,720) of them require some type of support with activities of daily living (such as meal preparation, housework, shopping, etc.). The more severe the disability, the more likely one is to require supports. As well, seniors are more likely than working-age adults to have such requirements.

Since mobility disabilities are the most prevalent disability type (72% of all adults with a disability), it is not surprising that mobility-related aids/devices are among the most commonly required aids/devices reported by adults with disabilities—with just over one million individuals reporting a requirement from that grouping. When we look at specific aids/devices, mobility-related devices such as canes/walking sticks (required by 679,560), grab bars/bathroom aids (required by 501,980), walkers (required by 294,410), orthopaedic footwear (required by 227,530) and braces/supportive devices (for mobility) (required by 204,480) rank among the most commonly required. Among the specific aids/devices reported in the 2001 PALS, eyeglasses and contact lenses ranked second with 520,170 requiring them⁴³ and hearing aids also figured prominently (in fourth place with 397,970 using them). Unfortunately the estimate for hearing aids provided by PALS is incomplete. Due to an oversight in the questionnaire, we are unable to determine the number of individuals who actually require hearing aids, but don't have what they require. It is quite likely that the actual requirement for hearing aids is considerably higher than listed here.

Overall, two-thirds (67% or 1,351,450/2,008,460) of adults who require some type of aid/device have their needs fully met; a quarter (25% or 496,630) have their needs partially met and partially unmet; and less than one tenth (8% or 160,370) have none of their needs met. While mobility-related aids/devices and hearing-related aids/devices contribute most to the overall unmet need (because such a high proportion of individuals require them to begin with), there are certain groups that do appear to have low rates of success with respect to having their needs met. Those requiring learning-related aids and devices are among those most likely to have an unmet need—in fact, 58% of those requiring some type of learning-related aid/device have an unmet need; more importantly, the majority of these have their needs completely unmet (43% of those requiring it). It is likely that a substantial proportion of the unmet need with respect to learning aids/devices is among those who are still in school.⁴⁵

It is also interesting to note that persons with learning disabilities often require 'talking books'; in fact, 12,010 individuals with learning disabilities reported such a need. Of these, 47 % (5,590) reported an unmet need. 'Talking books' are also used by persons with seeing disabilities; in fact, 26,460 individuals with seeing disabilities reported such a need. Of these, 8% (2,240) reported an unmet need. This suggests that those with seeing disabilities are more successful at obtaining this type of aid/device than those with learning disabilities. There may be some important differences with respect to the nature of the books required by these two populations. There might also be some important differences with respect to these two populations in terms of eligibility (labour force status, student status, age, program eligibility, etc.).

⁴³ Those with eyeglasses and contact lenses are included if these aids do not completely correct the individual's vision; those who wear eyeglasses and contact lenses whose vision is corrected are not in this analysis. Therefore, this estimate does not represent the number of individuals actually requiring glasses and contacts.

⁴⁵ Preliminary analysis supports this assumption.

There are other aids/devices which have a high rate of ‘unmet need’ attached to them (for example, scooters, motorized wheelchairs, and lifts/lift type devices). In many instances, these aids/devices also have a high unit cost attached. In the *Price Survey of Assistive Devices and Supports for Persons with Disabilities* (author: Aron Spector, Applied Research, HRDC, December 2003), for example, scooters are listed as having an average cost of \$3,991.47; and, motorized wheelchairs are listed as having an average cost of \$6,094.37 (with the most frequently purchased models ranging from \$4,230.81 to \$9,358.23).

It is interesting to note, that while cost is obviously the greatest barrier (both directly and indirectly), a substantial proportion of individuals note that a lack of information about where to obtain the required supports and services plays a major role in their unmet needs.

A striking finding from this research thus far is that there is a very large requirement for support with activities of daily living and that these supports are presently being provided primarily through informal sources such as families and friends. Only 24% of the support with activities of daily living was being provided by organizations and agencies (and 15% by ‘other sources’).

The huge proportion of informal care now being provided by family and friends suggests that the formal infrastructure for the provision of such supports (i.e., organizations and agencies) is adequate to service *only a small fraction of those in need*; 70% of adults who receive help with daily activities report that some or all of the help they get is free. When the total need in the population begins to increase (which will happen when the baby boomers enter their seniors years) at the same time that we see a decrease in the potential pool of free or informal help (fewer children born to baby boomers on average), we will likely see the demands on the formal infrastructure skyrocket during a relatively short period of time.

Of those who report that they or their immediate family pay directly for at least some of their support with daily activities (only about one third of those receiving help report this), only 8% report receiving any form of reimbursement. Of those who receive help with daily activities, 3% report that they get some help from ‘home care’ and 3% report that they get some help from some other publicly funded source.⁴⁷ The provision of support with daily activities operates primarily within the family. Very little of the help that is provided comes from any public source. With the demographic changes that are taking place and will continue to take place in our population, there should be tremendous concern about the lack of formal infrastructure available to provide support when the ‘family’ can no longer continue to do so for free. Among those with an unmet need for supports with daily living, 52% report that the reason for their unmet need was cost; 27% report that informal help was not available; 27% report that the support was not covered by their insurance (this is really cost-related); and 24% did not know where to obtain help.

Perhaps one of the most telling findings of this research is that those with the most severe disabilities are also the most likely to have some requirement for all types of supports. They are also the most likely to experience an unmet need. More information is required to determine what factors are important in determining whether those with severe disabilities get the supports and services that they need. One obvious barrier is likely cost. While cost is a large barrier for most, it is important to remember that all socio-economic research on this population indicates that as severity of disability increases, income decreases. In other words, this population is the least likely of all to be able to afford the cost of many of

⁴⁷ The numbers attached to these percentages for home care and publicly funded sources in PALS appear quite low. It would be useful to compare these numbers with the caseload numbers for the various programs across the country.

these aids/devices and supports with activities of daily living. They may also be unable to afford user fees that can be attached to some programs offered to provide these supports and services.

Another important avenue of investigation involves the capacity of many of these individuals to navigate their way through a complex system of supports and services. Those with more severe disabilities are also more likely to have multiple types of disabilities and, therefore, may need to access multiple programs. This might be one area where improved communication (possibly through brokerage services) could be important. In some instances, the complexity of this search might be exhausting for individuals who might be dealing with multiple disabilities. A substantial number of individuals report that at least one reason for their unmet need is due to not knowing where to find the support that is needed. For example, 25% (176,770) of those who have an unmet need for some type of support with daily living report that they didn't know where to find the support; similarly, 17% (82,650) of those who have an unmet need for aids/devices also reported that they didn't know how to go about obtaining what they needed. This strongly suggests that there may be an information gap when it comes to connecting people in need with the support required. New approaches to increase program awareness appears to be an area that could use further development.

We found some results that appeared 'odd' with respect to unmet needs for specialized features within the home. As with the other types of supports, we found that those with greater levels of severity were more likely to have an unmet need for this type of support. The vulnerability of those with severe disabilities was consistent throughout our analysis. However, unlike the other types of supports, we found that economic situation was not as good at predicting an unmet need when it came to specialized features within the home. For the other types of supports, those living below LICO and those whose income is derived primarily from welfare (as opposed to market income) appeared to be more vulnerable to unmet need.⁴⁸ With cost being mentioned by individuals as such an important factor, this is what one might have expected. However, those living above LICO and those relying primarily on market income are actually more likely to have unmet needs with respect to specialized features within the home. These results demand further investigation into the housing situation of persons with disabilities.

Those in a slightly less vulnerable economic situation may be more likely to live in their own home. The onset of a disability may necessitate expensive renovations in order to make that home accessible. Whereas, those in a more vulnerable economic situation may be more likely to be living in apartment buildings or some form of public housing that is accessible. We must be very careful in our assumptions, however. There is also much evidence to suggest that for those at the lowest levels of income (particularly for the working-poor), housing options may be very limited. The least expensive housing (i.e., the only thing these individuals can afford on their income) may be in an older building which is quite inaccessible.⁴⁹

With respect to students, we find that about 8% of the recent student population (in this age group) required some type of modified building feature and 14% required some type of aid/device in order to

⁴⁸ There has been some speculation that those with welfare income might be more likely to have their needs met since most welfare programs tend to provide supports along with income. However, there is little indication of this in our overall findings. Those relying primarily on welfare income are more likely to have unmet needs (except in the case of specialized household features) for almost all types of supports. Typically, most of the unmet need will be partially met/partially unmet. This means that those relying on welfare income typically have some of what they need, but still require more.

⁴⁹ At the CCSD, we recently received an e-mail from an individual who was considering quitting her low paying job because she could not find housing that was both accessible and affordable on her income. While she derived a great deal of pride in her ability to earn a living despite having a severe disability, she believed that her only option for obtaining accessible housing was to quit her job and rely upon welfare income which would qualify her for accessible public housing.

attend school. We also find that there is a greater requirement for supports in schools which are below post-secondary in level. This tends to suggest that students with requirements for supports may not be continuing their education at the post-secondary level. A lack of such aids/devices could well be a serious barrier for this group. Given the link between education and economic security for persons with disabilities, this should be investigated further to determine if everything is being done to provide supports at all levels of the education system.⁵⁰ In a 1996 study by the National Educational Association of Disabled Students (NEADS), it was reported that 58.6% of the post-secondary student respondents (to a survey conducted by NEADS) indicated the support that they had received from student aid programs was not "...sufficient to cover all costs associated with education (i.e. tuition, books, assistive aids or services etc.)."

An examination of supports in the workplace indicated a fairly high requirement for supports by those who were employed and an even higher level of requirement by those who were unemployed. Among those who were employed, 15% reported a requirement for some type of modified structure in the workplace compared with 28% of their unemployed counterparts. Similarly, 30% of those who were employed reported a requirement for some type of work aid or job modification compared with 56% of their unemployed counterparts. The greater requirement for supports among those who were unemployed suggests that their requirement for supports may make them more vulnerable to unemployment. Perhaps one of the most interesting findings is that the two specific types of supports most required (particularly by those who are unemployed) are: 'job redesign' and 'modified hours'. Both of these supports are primarily within the purview of the employer. Options for providing programs for these types of supports are likely to be limited.

Clearly there are gaps in the system in a variety of areas as outlined in this report. Those who are most vulnerable-- those with severe and very severe disabilities--are the most likely to experience unmet needs. Cost and information also seem to be important factors in unmet need.

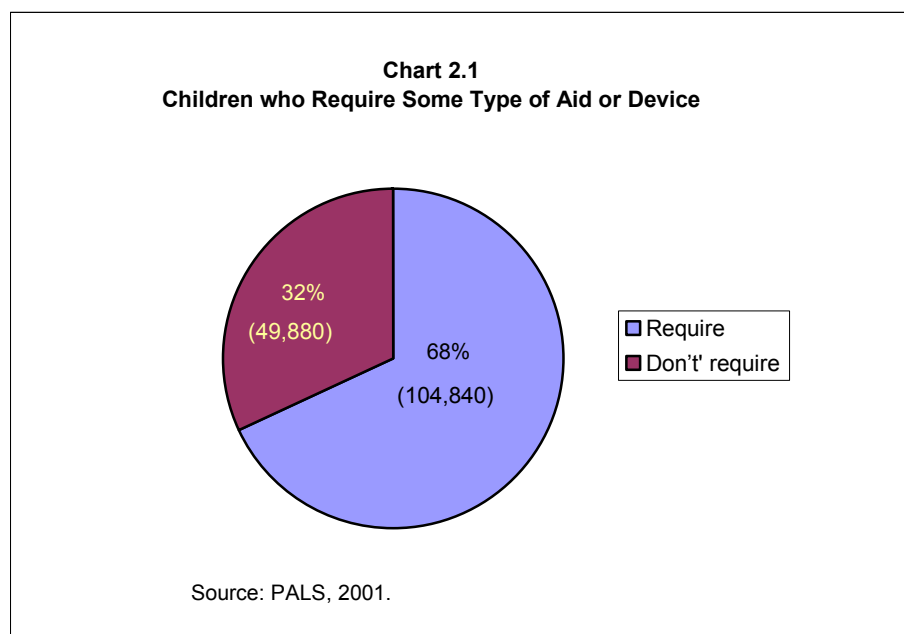
⁵⁰ One study that will be of interest is The National Educational Association of Disabled Students (NEADS) new initiative called "Inclusion of Students with Disabilities in College and University-Sponsored Activities." Areas of focus include new student orientation, student elections, and campus clubs/organizations.

PART TWO

DISABILITY SUPPORTS IN CANADA FOR CHILDREN WITH DISABILITIES AGED 5 – 14⁵¹: NEEDS AND GAPS

Section I: Aids and Devices

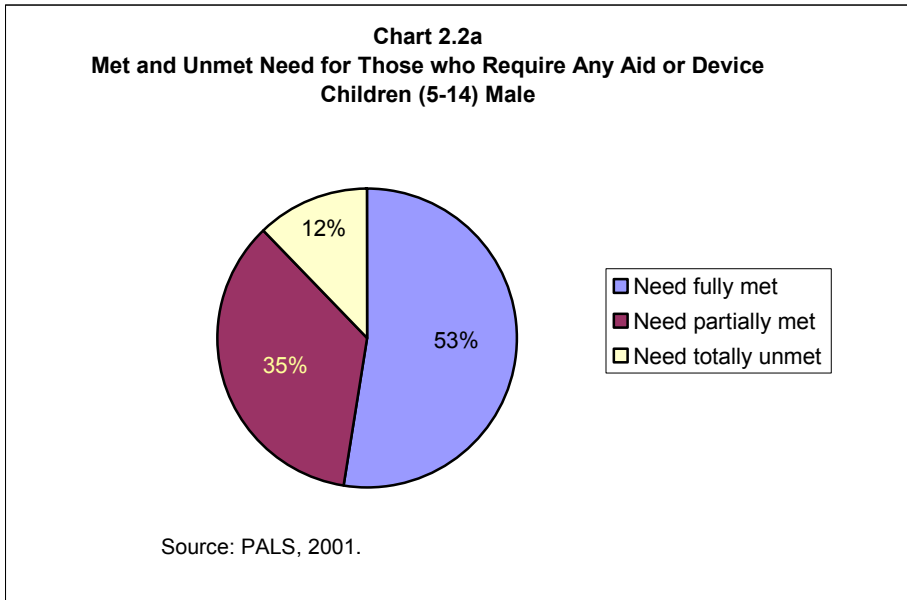
Over two-thirds (68%) of children aged 5-14 with a disability in Canada have a requirement for some type of aid or device related to their disability. This represents 104,840 school-age children.



⁵¹ Our examination of supports for children with disabilities is limited to those aged 5 to 14 because most of the relevant information from PALS is available only for that age group. Most of the questions regarding supports and services were not asked of those under the age of 5.

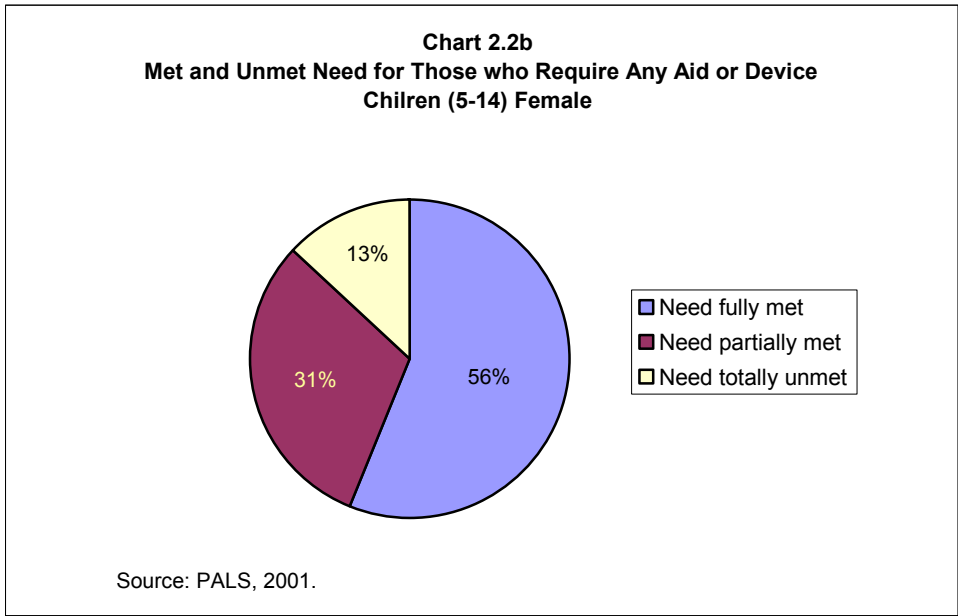
Just under half of those who require some type of aid or device have some level of unmet need. This represents 48,610 children with disabilities aged 5 to 14 with some level of unmet need for an aid or device.

Gender:



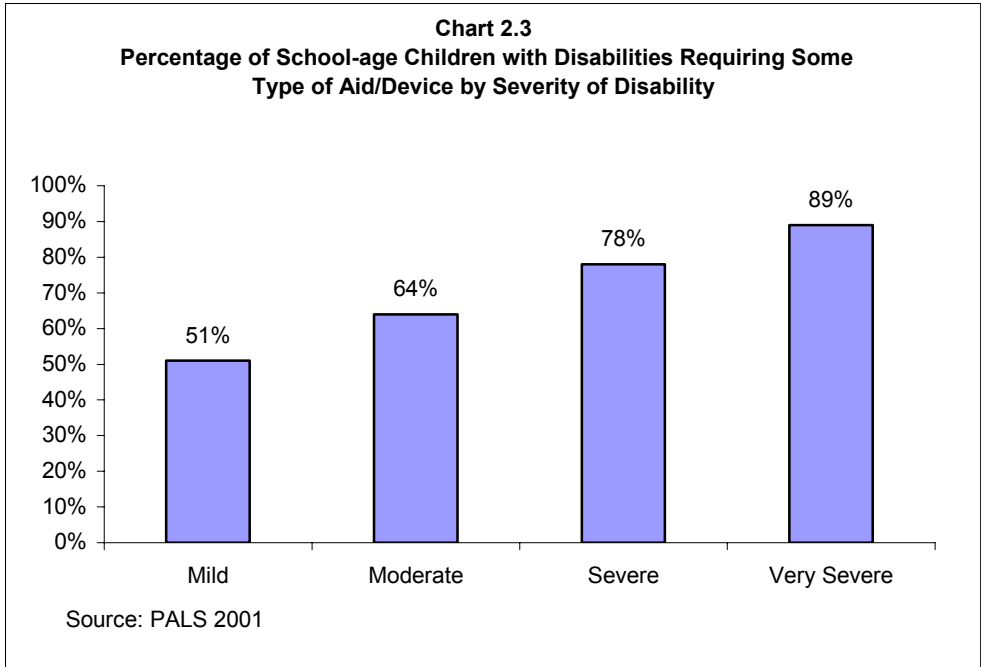
Boys are very slightly more likely to have an unmet need for some type of aid or device. Among those who actually require some type of aid or device, 47% of the boys had an unmet need compared with 44% of the girls.

Most of the gender differences, however, are in terms of ‘partially met need’; where 31% of girls with a requirement have a partially met need compared with 35% of the boys. Girls and boys are almost equally likely to have their needs completely unmet (13% and 12% respectively). [Charts 2.2a and 2.2b]



Severity:

The requirement for aids and devices increases with the level of severity of the disability; for example, 51% of children with mild disabilities require some type of aid or device compared with 89% of those with very severe disabilities. (Chart 2.3)



Not only does the likelihood of requiring some type of aid or device increase with level of severity, so does the likelihood of having an unmet need; for example, 19% (10% partially unmet and 9% fully unmet) of children with mild disabilities who require some type of aid or device have an unmet need compared with 69% (57% partially unmet and 12% fully unmet) of those with very severe disabilities (Table 2.1).

Table 2.1:

Rate of Met/Unmet Need for Aids/Devices Among School-age Children with Disabilities by Level of Severity

	% Partially Met Need	% Fully Unmet Need	% Fully Met Need	% Total Requiring Aids/Dev.	Number Total Requiring Aids/Dev.
Mild	*10%	*9%	80%	**99%	25,440
Moderate	30%	*12%	58%	100%	24,860
Severe	39%	*16%	46%	100%	30,950
Very Severe	57%	*12%	31%	100%	23,590

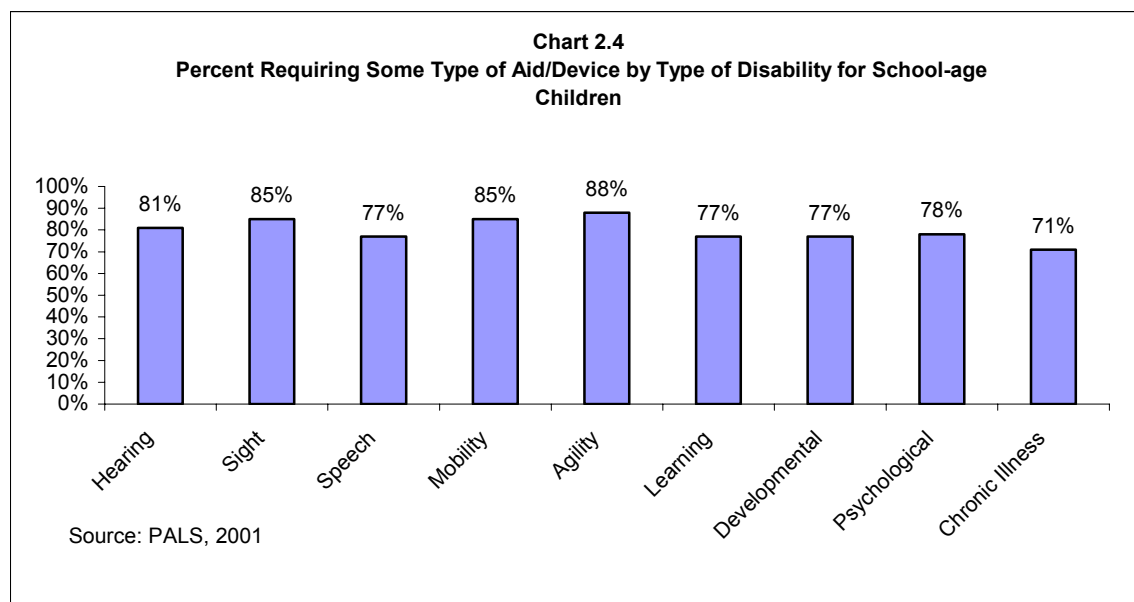
* Due to low sample size, use % with caution.

** Error due to rounding.

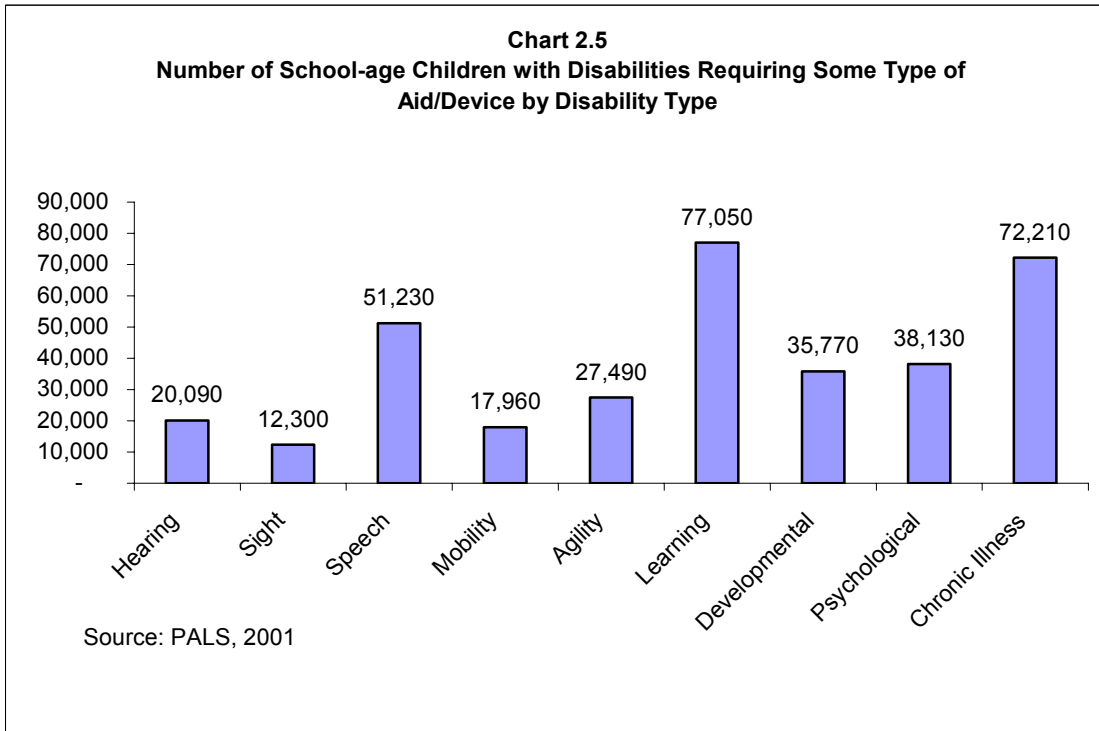
Source: PALS 2001

Type of Disability:

Children with agility disabilities are the most likely to require some type of aid or device (88%). They are followed closely by those with mobility (85%) and sight (85%) disabilities. While children with chronic illnesses are the least likely to require an aid or device (71%), it is important to note that the majority of them still have such a requirement.

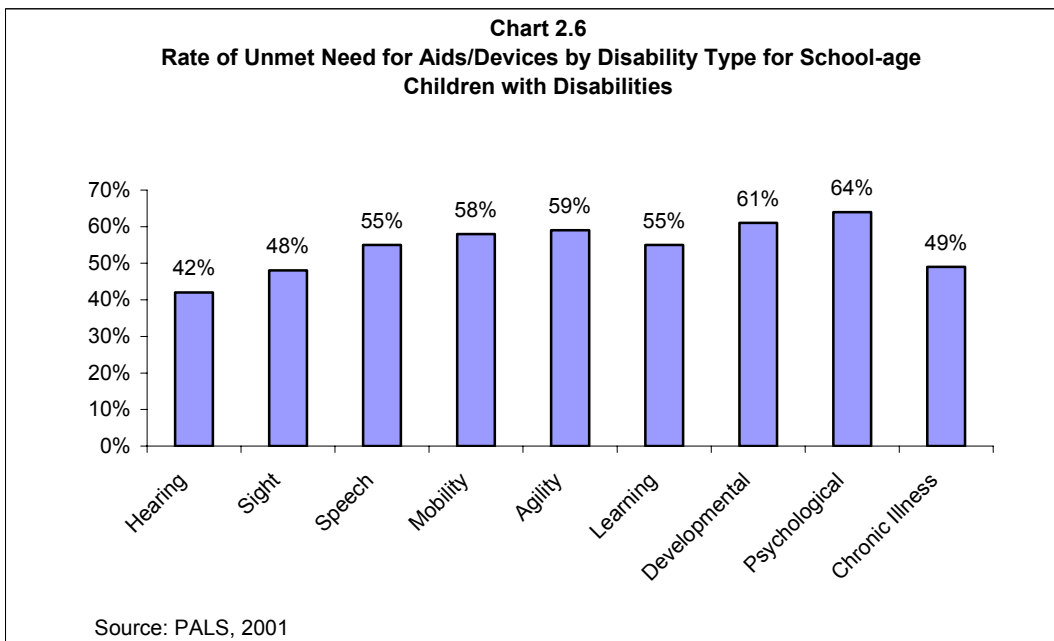


In terms of sheer numbers, however, the greatest requirement for aids and devices comes from those with learning disabilities. As noted in Chart 2.5, 77,050 children with learning disabilities report a requirement for some type of aid or device. While children with chronic illnesses have the lowest rate of requiring an aid or device, they contribute greatly to the overall number of children with a requirement (72,210).

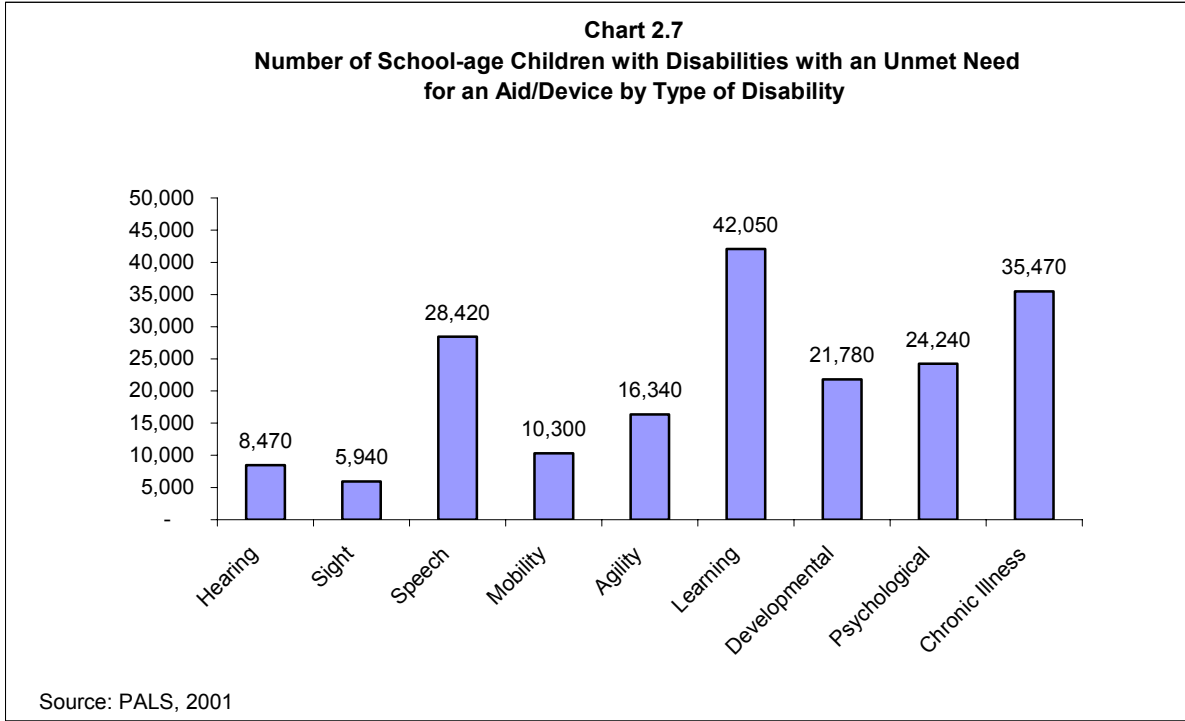


Note: Some children have more than one type of disability; therefore, categories are not mutually exclusive.

There is a fairly high rate of unmet need for aids and devices across all types of disabilities (between 42% and 64%). Children with psychological disabilities have the highest rate of unmet need (64%), while those with hearing disabilities have the lowest (42%). (Chart 2.6)



In terms of sheer numbers, however, children with learning disabilities contribute the most to unmet need for aids and devices (42,050). Also making a greater than average contribution to overall unmet need are children with chronic illnesses (35,470) and children with speech disabilities (28,420).



Specific Aids and Devices

In terms of specific aids and devices that are required by children with disabilities (school age), those related to learning disabilities top the list. As summarized in Table 2.2, computers for learning disabilities are the most required item listed in PALS 2001 (40,280 children with such a requirement) and tutors for those with learning disabilities are the second most required item (39,050 children with such a requirement). (Table 2.2)

There are, however, varying degrees of success in actually obtaining what is required. Children who require a ‘computer to communicate’ due to a speech-related disability and those who require ‘voice activated or synthesis software’ for a learning disability are the most likely to have an unmet need (63% unmet and 48% unmet respectively).

Table 2.2

Number of School-age Children with Disabilities Requiring Specific Aids/Devices and Percent with an Unmet Need

	Number Requiring	% Unmet Need
Computer (learning)	40,280	21%
Tutor (learning)	39,050	28%
Recording equipment (learning)	10,450	*20%
Talking books (learning)	10,340	*26%
Hearing aids	10,200	**
Voice activated or synthesis software (learning)	8,700	48%
Glasses	7,870	*9%
Orthopaedic footwear	*4,190	*24%
Walker	*3,620	**
Computer to communicate (speech)	*3,610	*63%
Amplifier (hearing)	*3,280	*17%
Lift devices (mobility)	*2,130	*45%

* Due to low sample size, use number with caution

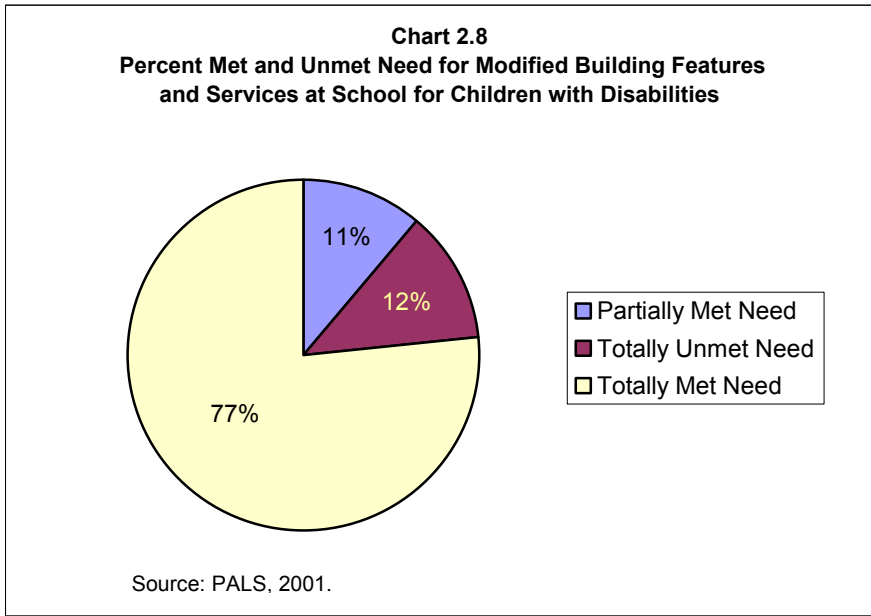
** Due to low sample size, estimate cannot be released

Source: PALS, 2001

Section II: School Supports

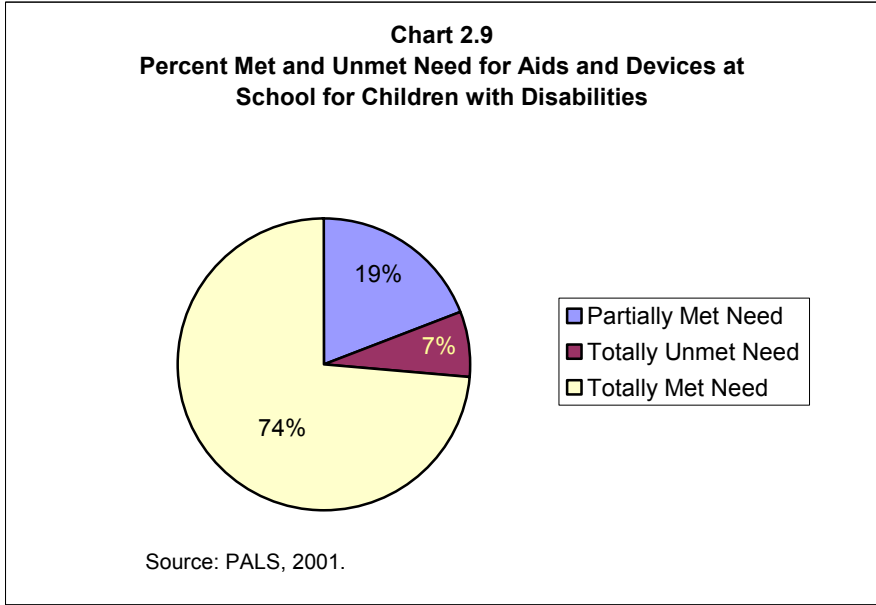
Children with disabilities can also have requirements for modified building features and services at school as well as aids and devices related to school. Modified building features are at a more structural level, while aids and devices are more personal. There is actually a very low requirement for any type of modified building feature at school among children with disabilities; only about 7% of children with disabilities aged 5 to 14 attending school report such a requirement (9,760 children). Children with disabilities are far more likely to require some type of aid or assistive device within the school system; 70% reported a requirement for some type of aid or device at school (102,950 children).

Among those who do require some type of modified building feature or service at school, over three-quarters of them have their needs fully met; 11% have their needs partially met; while, 12% have their needs completely unmet. (Chart 2.8)



Note: Use 11% and 12% with caution due to low sample size.

Nearly three-quarters of those requiring some type of aid or device at school also had their needs met; 19% had their needs partially met; while 7% had their needs completely unmet. (Chart 2.9)



The most commonly required modified building features among children with disabilities at school are ramps and street level entrances (required by 7,720 children). (Table 2.3)

Table 2.3**Number of Children with Disabilities Requiring Specific Modified Building Features at School**

	Number Requiring
Ramp or street level entrance	7,720
Automatic or easy to open doors	5,450
Elevator or lift device	*4,040

* Due to low sample size, use number with caution
Source: PALS, 2001

The most commonly required aids or devices at school are tutors or teacher's aides (required by 91,560 children with disabilities); and 24,590 children report a requirement for note-takers. The vast majority of requirements for aids and devices in school are met; however, the unmet need is greatest among those requiring tutors or teacher's aides (8%).

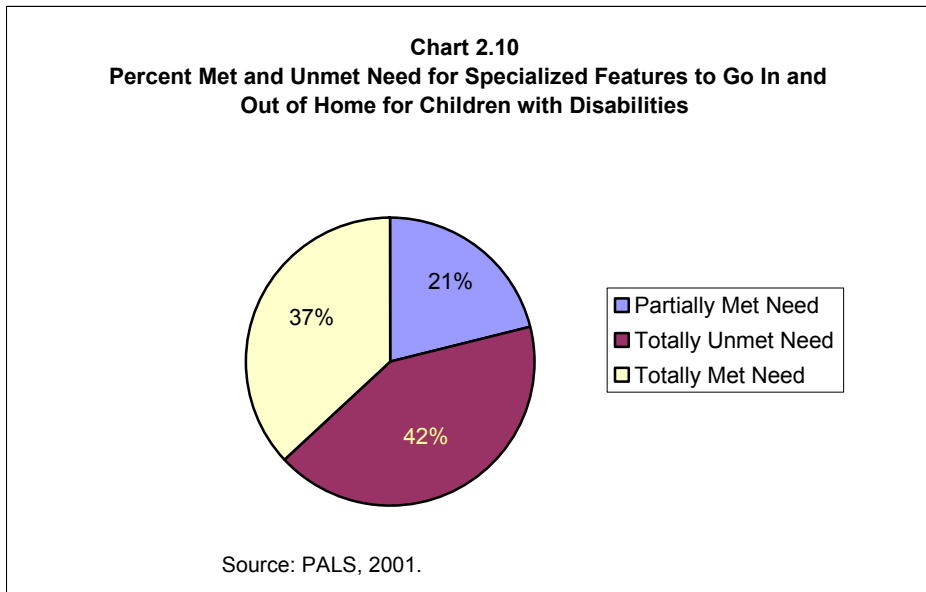
Table 2.4**Number of Children with Disabilities Requiring Specific Aids/Devices at School and Percent with an Unmet Need**

	Number Requiring	% Unmet Need
Tutor or teacher's aides	91,560	8%
Note takers	24,590	*1%
Recording equipment	9,530	*1%
Talking books	8,770	*1%
Amplifiers	7,550	**
Computer with Braille	5,760	*1%

* Due to low sample size, use number with caution
** Due to low sample size, estimate cannot be released
Source: PALS, 2001

Section III: Home Supports

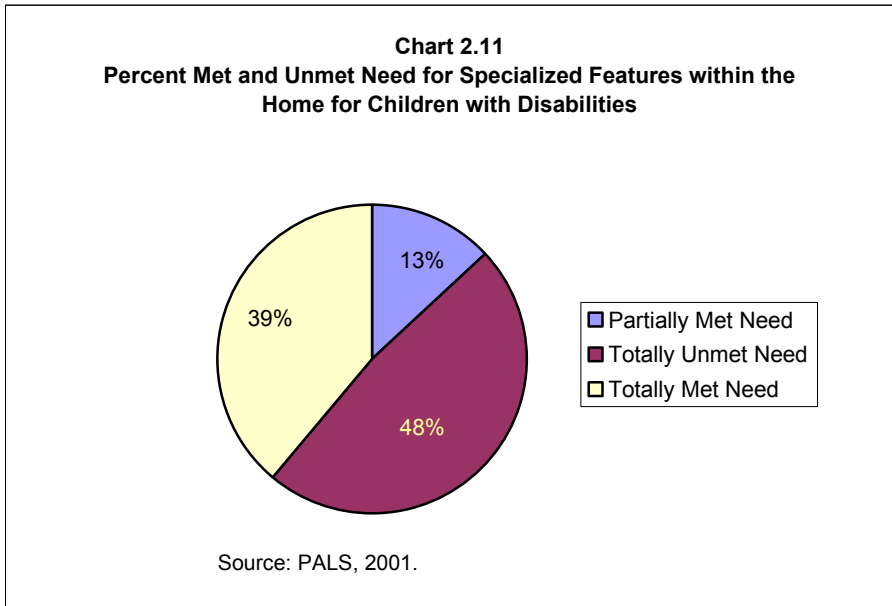
A small percentage of children with disabilities require special features to go in and out of their home (4% or 6,600 children) or to use inside their home (6% or 10,000 children).



While a low percentage of children with disabilities have requirements for specialized features to go in and out of their home or for specialized features within their home, those who do have such a requirement have a high rate of unmet need.

Among those who require specialized features to go in and out of their home, 63% have some level of unmet need and most of these (42%) have a totally unmet need (while 21% have a partially met need). (Chart 2.10)

Among those who require specialized features within their home, there is a similar situation—61% have some level of unmet need. In fact, nearly half (48%) have a completely unmet need. (Chart 2.11)



The most commonly required features for getting in and out of home for children with disabilities are ramps or street level entrances (required by 4,980 children) and 39% of these children have an unmet need for those features.⁵² (Table 2.5)

Table 2.5

Number of Children with Disabilities Requiring Specific Specialized Features for Getting In and Out of the Home and for Within the Home

Getting In and Out of Home	Number Requiring
Ramps or street level entrance	4,980
Elevator or lift device	2,950
Widened doorways or hallways	2,600
Automatic or easy to open door	2,100
Within Home	
Grab bar or bath lift device in bathroom	6,820
Elevator or lift device	2,810
Widened doorway	2,530
Automatic or easy to open door	1,610

Source: PALS, 2001

Note: All numbers should be used with caution due to small sample size.

The most commonly required specialized features within the home for children with disabilities are grab bars or bath lift devices in the bathroom (required by 6,820 children); and nearly half of the children requiring them (48%) have an unmet need.⁵³ (Table 2.5)

⁵² This number should be used with caution due to low sample size. Other rates of unmet need cannot be released due to low sample size.

⁵³ Use this number with caution due to low sample size. The only other rate of unmet need that can be released for “within home” is for elevators/lift devices--unmet need is 53% (use with caution).

In addition to the supports required within and around the home to address the needs of the child with a disability, the child’s parents often require supports with other activities. The care that they provide for their children can take time and effort away from a variety of other essential household activities. Parents of 34% of children with disabilities report that they require some type of household support due to their child’s disability. This translates into the families of 51,980 children. Support to ‘take time off for personal activities’ is required by 31% (representing 47,760 families); 24% (36,750 families) require support to take time off to attend to other family responsibilities; and 13% (20,110 families) require support with everyday housework. (Table 2.6)

Table 2.6:
Number and Percent Families of Children with Disabilities
Requiring Supports with Daily Activities Due to Child’s Disability

Type of Support	Number Requiring	Percent Requiring	Percent Unmet Need
Everyday housework	20,110	13%	80%
Take time off to attend to other family responsibilities	36,750	24%	67%
Take time off for personal activities	47,760	31%	65%
Any of these supports	51,980	34%	66%

Source: PALS, 2001

There is a high degree of unmet need for all these requirements. Among those who require support with housework, 80% have an unmet need. Overall, about two-thirds of those who require some type of support have their needs go unmet.

Section IV: Gaps

Aids and Devices:

Overall, more than two-thirds of Canadian children with disabilities aged 5 to 14 require some type of aid or device related to their disability. This represents just over 100,000 children. The likelihood of requiring an aid or device increases with the severity of the disability. Among children with mild disabilities, about half have some requirement for an aid or device; among those with very severe disabilities this increases to nine out of ten.

While some disability types have a higher rate than others of requiring an aid or device, the greatest contribution to overall requirement in terms of sheer numbers comes from children with learning disabilities; just over 77,000 children with learning disabilities have a requirement for some type of aid or device due to their disability. Individual aids/devices related to learning disabilities top the list of ‘most required’ specific aids/devices. The greatest requirements are for computers for learning disabled children (required by over 40,000) and tutors for learning disabled children (required by over 39,000).

There are actually fairly high rates of unmet need for aids and devices among Canadian children with disabilities. Just a little over half of the children who require an aid or device have their needs fully met. Among adults with disabilities, we found that over two-thirds who required something had their needs fully met. These statistics suggest that children may not be doing as well as their adult counterparts.

For children with very severe disabilities who require an aid or device, the success rate is even more discouraging—only about 3 in 10 have their needs fully met. As well, children with psychological and developmental disabilities have high rates of unmet need (64% and 61% respectively).

In terms of sheer numbers, however, the greatest contribution to unmet need for aids and devices among children comes from those with learning disabilities and chronic illnesses. Children who require a computer to communicate due to a speech-related disability and those who require voice activated or synthesis software for a learning disability have the lowest rate of success in obtaining the item required (with a success rate of 37% and 52% respectively).

Table 2.7
Reasons Offered for Unmet Need for Aids/Devices
Among School-age Children with Disabilities

	Number	Percent of
	Citing Reason	Unmet Need
Not covered by insurance	21,190	53%
Too expensive	26,830	67%
Not available locally	8,270	21%
Don't know where to obtain aid	10,041	25%
Child condition not serious enough	4,022	10%
Only need occasionally	4,420	11%
Other reason	12,710	32%

Note: Some children had more than one reason

Source: PALS, 2001

The reasons provided for unmet needs are mostly financial. While a number of individuals listed multiple reasons for not having a required aid/device, financial-based reasons were the most commonly offered ones; 67% reported that the aid/device was ‘too expensive’, while 53% mentioned they didn’t have the aid/device because it ‘wasn’t covered by insurance’ (this is really a financial-based reason). As with adults with disabilities, cost is the most important factor involved with an unmet need for an aid/device.

However, also as with adults, there seems to be some notable difficulty ‘connecting’ with what is required; 21% reported that the aid/device was ‘not available locally’ and 25% reported that they ‘didn’t know where to obtain’ it. While not as important as cost, it does appear that there is a gap with respect to knowledge about what is available and being able to access it.

Among adults, we found that there was a noticeable difference in unmet need between those living above and below the Low Income Cutoff (LICO). One could clearly see that those with higher incomes were less likely to have an unmet need. Among children, however, this difference is not as pronounced. While those living in households with an income above LICO are somewhat more likely to have their needs fully met (55%) than those below LICO (50%), the differences are not as great as one might expect. More investigation needs to be done with respect to understanding the complexities involved in acquiring aids and devices for children with disabilities. Certainly, some of the items with high unmet needs attached (computer equipment, etc.) have high price tags attached as well. It may be possible that the financial threshold for providing children with these types of aids/devices is quite high and even many living above the low income cutoff have difficulty affording them. One might also investigate how many aids/devices children ‘grow out of’ and how rapidly this might happen. There may be a compounding of the expense of the items along with the need to replace such items fairly frequently.⁵⁴

Table 2.8
Unmet Need for Aids/Devices Among School-age Children
with Disabilities by Low Income Cutoff

	%Partially Met Need	%Fully Unmet Need	%Fully Met Need
Above LICO	33%	12%	55%
Below LICO	36%	*14%	50%

* Use with caution due to low sample size

Source: PALS, 2001

Supports at School

Within the school environment, children with disabilities often require supports as well. Less than one in ten (just under 10,000 children) children with disabilities require modified building structures in their school; and three quarters of them have their needs fully met.

However, there is a considerably greater need for some type of aid/device/service within the school. Seven in ten children with disabilities require some type of aid or device or service at school to pursue their education (just over 100,000 children). Nearly three-quarters of these children had their needs fully met. The most commonly required aids/devices/services are ‘tutors’ or ‘teacher’s aides’ (required by just over 90,000); and this is where the greatest proportion and number of children with an unmet need lies.

⁵⁴ Unfortunately, there are no questions at present on the Children’s PALS which might help to answer these questions. It might be something to consider for the next PALS.

Among those with an unmet need for school supports, the most popular reason listed for the unmet need was “school funding cutbacks” (listed by 80% with an unmet need). (Table 2.9)

Table 2.9
Reasons Offered for Unmet Need for Supports at School
Among School-age Children with Disabilities

	Number Citing Reason	Percent of Unmet Need
School funding cutbacks	20,880	80%
School did not think child needed supports	6,970	27%
Child did not want to use supports	*840	*3%
Other reasons	6,150	24%

* Use with caution due to low sample size.

Note: Some children had more than one reason

Source: PALS, 2001

Supports at Home

A small percentage of children with disabilities require specialized features either to ‘get in and out’ of their home or ‘within’ their home (4% or 6,600 children and 6% or 10,000 children respectively). While only a small percentage have such a requirement, those who do face high rates of unmet need. About three in five children requiring some type of specialized feature to ‘get in or out’ of their home have an unmet need and most of these have none of what they need. Very similar results are found for those requiring some type of specialized feature within the home. Again, cost is the number one reason listed for these unmet needs as summarized in Table 2.10. The most required specialized features include: ramps and street level entrances; elevators or lift devices; widened hallways or doorways; and automatic or easy to open doors. Many of these items have a fairly high cost attached to them. For example, portable lift devices can average from about \$1,500 to over \$3,000 (see *Price Survey of Assistive Devices and Supports for Persons with Disabilities* by Aron Spector). Home elevator systems are even more expensive and can range close to \$7,000 (for an elevator between one floor with 2 stops).

Table 2.10
Reasons Offered for Unmet Need for Specialized Features at Home
Among School-age Children with Disabilities

	Number Citing Reason	Percent of Unmet Need
<i>Specialized Features Getting In and Out</i>		
Not covered by insurance	*2,680	*68%
Too expensive	*3,174	*80%
<i>Specialized Features Within Home</i>		
Not covered by insurance	*3,040	*53%
Too expensive	*4,140	*72%
Only needed occasionally	*920	*16%
Other	*1,920	*33%

* Use with caution due to low sample size

Note: Numbers and percentages from other reasons could not be released due to low sample size.

Note: Some children had more than one reason

Source: PALS, 2001

In addition to direct supports for the child, parents of children with disabilities often have requirements for supports with daily activities that they can have trouble finding the time to perform since they are likely to act as the child’s primary caregiver. About a third of parents of children with disabilities (over 50,000) require some type of assistance in this regard due to their child’s disability and most of them have their needs go unmet (two-thirds).

While there are certainly unmet needs for supports with daily activities among adults with disabilities, there is an even greater likelihood of having an unmet need for support with these activities for adults who require the support because they are caring for a disabled child. As we discovered in our analysis of adults with disabilities, most of the assistance that is given to adults with disabilities for support with daily activities is given by family and friends on an informal basis. There appears to be a fairly noteworthy gap with this type of support.

As summarized in Table 2.11, cost and cost-related reasons are typically offered as the reason for the unmet need (73% report that help is too expensive). It is important to note, however, that over a third (37%) report that they didn’t know where to look for help. Once again, we see that it can be difficult for people to connect with the right program.

Table 2.11
Reasons Offered for Unmet Need for Support with Daily Activities at Home
Among Parents of School-age Children with Disabilities

	Number	Percent of
	Citing Reason	Unmet Need
Too expensive	24,180	73%
Help from family/friend not available	21,160	64%
Service/program not available locally	14,260	43%
Child is on waiting list	4,900	15%
Don't know where to look for help	12,340	37%
Child's condition not serious enough	7,610	23%
Haven't asked for help	8,280	25%
Other reason	5,490	17%

Note: Some children had more than one reason

Source: PALS, 2001

METHODOLOGY

PALS

The data contained in this report were generated from the Participation and Activity Limitation Survey (PALS) 2001. Approximately 35,000 adults aged 15 and over with disabilities were sampled in the PALS 2001 with a response rate of 82.5%. Unlike the 1986 and 1991 HALS, which provided data on all provinces and territories, the 2001 PALS was conducted only in the ten provinces; the 2001 PALS does not cover any of the three territories. Unlike the 1986 and 1991 HALS, no time comparison is possible with the 2001 since the filter questions and sampling design have been altered considerably.

Change in Filter Question:

Like the 1986 and 1991 HALS, the 2001 PALS is a post-censal survey (i.e., the survey follows a Census and utilizes answers to filter questions contained on the census to derive its sample). The filter question that was contained on the 2001 Census was different from the one used in 1986, 1991, and 1996. In 1986 through 1996, the Census filter question was nearly identical:

1. Is this person limited in the kind or amount of activity that he/she can do because of a long-term physical condition, mental condition or health problem:
 - (a) At home?
 No, not limited
 Yes, limited
 - (b) At school or at work?
 No, not limited
 Yes, limited
 Not applicable
 - (c) In other activities, e.g., transportation to or from work, leisure time activities?
 No, not limited
 Yes, limited

2. Does this person have any long-term disabilities or handicaps?
 No
 Yes

For the 2001 Census the following new filter question was developed:

1. Does this person have any **difficulty** hearing, seeing, communicating, walking, climbing stairs, bending, learning or doing any similar activities?
 Yes, sometimes
 Yes, often
 No

-
2. Does a physical condition **or** mental condition **or** health problem **reduce the amount or the kind of activity** this person can do:
- (a) At home?
 Yes, sometimes
 Yes, often
 No
- (b) At work or at school?
 Yes, sometimes
 Yes, often
 No
 Not applicable
- (c) In other activities, for example, transportation or leisure?
 Yes, sometimes
 Yes, often
 No

Fundamental Change in Sampling Design:

Before the initial HALS, testing indicated that the short Census filter question being used was likely to yield both false positive answers and false negative answers. This means that when individuals were asked specific questions about their capacity to perform a variety of tasks (i.e., the full complement of HALS screening questions), it appeared that some individuals who had indicated a disability on the Census question appeared not to have a disability (false positives) when asked the full complement of HALS screening questions about specific tasks; these false positives could be eliminated easily during the HALS screening process.

More difficult to deal with, however, was the finding that some individuals who had indicated no disability on the Census question indeed had a disability (false negatives) when asked the full complement of HALS screening questions (which asked about one's ability to perform very specific tasks in a variety of areas). In an effort to reduce the rate of false negatives, the 1986 and 1991 HALS included a large "NO" sample. This "NO" sample included individuals who had indicated "no" on the Census filter question regarding disability. In this manner, an effort was made to include the false negatives in the final HALS.

In 2001, the "NO" sample was eliminated from the design of the PALS. As well, the filter question that was used on the 2001 Census was used on the 2001 PALS as well (rather than the 32 specific screening questions used in the 1991 HALS). Therefore, we are able to "weed out" false positives using a second asking of the new question (between the Census and PALS); however, we are not able to add back in 'false negatives'. Thus, we are likely capturing a slightly different and smaller population than before.

For more information regarding the differences between the HALS and the PALS, refer to: "A New Approach to Disability Data: Changes between the 1991 Health and Activity Limitation Survey (PALS)", December 2002, catalogue no. 89-578-XIE, Statistics Canada, Housing, Family and Social Statistics Division.

Assistive Aids and Devices:

Data regarding the use and need of assistive aids/devices among persons with disabilities are derived from several series of questions that are attached to other questions regarding the individual's ability to perform particular functions (these questions are not used as screening questions as they were in 1986 and 1991, but rather, are used to determine the type of disability). They are organized by 'disability type'. The series of questions typically begin at a basic level by asking if the respondent uses 'any aids or specialized equipment for persons with a particular difficulty'; then there is an effort made to determine more specifically what is being used. This is followed up with a question asking, at a general level, if the respondent needs something that he/she does not have; then there is an effort made to determine more specifically what is needed. From these questions, we are able to organize this information into the following basic categories:

- Uses something and doesn't need anything else
- Uses something, but still needs something
- Does not use anything, but needs something
- Does not use anything and does not need anything

This allows us to determine the number of individuals who have some type of requirement (whether it is being met or not met). It also allows us to determine the number of individuals who are having their requirements fully met and partially met.

As with any survey, there are a number of individuals who failed to provide a valid response (or responded, "I don't know") for some of these questions. In an earlier release by Statistics Canada regarding requirements for aids and devices, cases with "missing data" were eliminated from the analysis. The missing case rate was very high on these variables. In our analysis here, most of these cases are added back into the analysis. The reasoning behind this is as follows:

- If the individuals indicated that they used a device and had missing information under whether they needed anything they didn't have, we made the assumption that they had all they needed. We believe that if they truly needed something else that they didn't already have, they would have marked "yes" on the question about unmet need. Our coding was based upon "yes" and "not yes" (rather than "yes" and "no").
- If the individuals indicated that they didn't know if they used something, but that they needed something, we coded them under "does not have, but needs supports"—we interpreted this as individuals who might have altered certain things (or devised make-shift devices) in their lives to cope with their disability and aren't sure if this constitutes an aid/device—but they are certain that they need something. We did not treat these as missing cases—they were coded as not having anything, but needing something.
- If the individuals indicated that they didn't know if they used something or if they needed something, we assumed that they neither used nor needed anything. We assumed that if individuals truly use something or need something, they are likely to be quite aware of it.
- This methodology resulted in a higher rate of individuals who indicated that they did not require any aid or device at all as well as a higher rate of individuals who had their needs met. Overall, we returned over half a million weighted cases to the analysis.

Support with Daily Activities:

Questions regarding the use and need of support with daily activities among persons with disabilities were asked in a manner somewhat similar to those in the section on aids and devices. The questions begin at a basic level by asking if the respondents ‘receive any help’ with a series of specific household tasks (meal preparation, everyday housework, etc.) because of their disability; then the respondents are asked if they still ‘need’ help with these tasks. From these questions, we are able to organize this information into the following basic categories:

- Has help and doesn’t need any more
- Has help, but still needs more help
- Does not have help, but needs help
- Does not have help and does not need help

This allows us to determine the number of individuals who have some type of requirement (whether it is being met or not met). It also allows us to determine the number of individuals who are having their requirements fully met and partially met.

Again, our treatment of missing cases was designed to reduce the number of missing cases eliminated from the analysis. We again assume that if individuals were unsure (or unable to answer ‘yes’) to either having help or needing help, that they likely didn’t have it or need it. This logic is consistent with that followed for aids and devices.

School Supports

Unfortunately, the questions in the section on school supports were not asked in a manner consistent with those on ‘aids/devices’ or ‘help with daily activities’-- resulting in different and less information being available. Respondents are funnelled into the questions from a different starting point.

In the sections on aids/devices and home supports/services (as discussed above), respondents were asked first about what they “already used or had”. This forced the respondents to first think about what they did or did not have—rather than what they required. In the school supports section, the opposite was the case—respondents were forced to think first about what they required rather than what they had.

There is a ‘feeder or switch’ question at the beginning of the section on school supports that asks, in general, if the respondent required ‘something’ and then there is a series of questions designed to detect more specifically what was required. Only then is the respondent asked if he/she had what he/she needed (‘was it made available to you?’). There is no possibility of detecting partially unmet and partially met needs.

We assumed that individuals required something only if they answered “yes” to the initial question: “did you require . . .?” If they failed to answer yes, it was assumed that they do not require anything. However, if they have answered “yes” to this question and gone on to answer “yes” to a requirement for a specific item, they were then asked if they had received it. If they answered “yes, they received it”, clearly they had their needs met. If they answered “no, they didn’t receive it”, clearly they had an unmet need. If they failed to answer either “yes” or “no”, we treated them as missing cases. We were unsure just how to interpret this lack of information. There are reasonable arguments to suggest that these might actually be

people who had what they needed; as well, there are reasonable arguments to the contrary which suggest that they did not have what they needed.

In all likelihood, the inability to respond either ‘yes’ or ‘no’ to this question is likely indicative of individuals who had ‘some’ of what they needed, but not all. For those who had partially met/unmet needs, there would likely be a certain amount of dissonance involved in answering either ‘yes’ or ‘no’. The absence of a question to detect partially met needs in this section presents the possibility for confusion. We felt that the safest method of dealing with these individuals was to eliminate them as missing cases. Unlike in the section on aids and devices, where missing cases comprised a large proportion of the population, the missing case rate here is tolerable.

Respondents are asked information about two types of supports at school. First they are asked about modified building structures or services—something at the structural level. Next they are asked about assistive devices or services—something at the personal level. The same methodology applies to both types of supports.

Work Supports

The information on workplace supports that is available within the employment section of PALS is very similar to that discussed under school supports. The same methodology is applied to both.

We should point out, however, that employed and unemployed individuals were questioned in separate sections and are analyzed separately. We had initially expected to provide a section on those who were not in the labour force (NILF) who were not officially retired. The “not in the labour force” population in PALS is split into two groups: retired and non-retired. Since it makes little sense to discuss gaps in programs for workplace supports for people who claim to be retired, we had hoped to isolate the non-retired not in the labour force. Unfortunately, an error was made on the original PALS file in which some ‘retired’ individuals were classified as ‘non-retired’ for the workplace supports questions and vice-versa. Unfortunately, the data file was corrected by Statistics Canada too late for us to provide this analysis.

Specialized Features within the Home

The questions in the section on specialized features within the home were asked in a manner similar to those in the general “aids and devices” section and “supports with daily activities” section. Individuals were first asked if they used something; if so, what specifically. Then individuals were asked if they still needed anything; if so, what specifically. We adopted the same methodology here that we did in the section on aids and devices. Missing cases were minimized by assuming that if the respondent could not say that they used something, they probably didn’t use anything; and, if they couldn’t say that they needed anything, they probably didn’t.