SUPPORTS AND SERVICES FOR OLDER ADULTS WITH DEVELOPMENTAL DISABILITIES STUDY – Supplementary Reports

Calgary Region Community Board
Persons with Developmental Disabilities

In 2012 Calgary Region Persons with Developmental Disabilities (CRCB PDD) commissioned a study to assist them in the development of community-based services for older adults with developmental disabilities as well as to contribute to provincial policy and research on this population and the ministry's framework on aging. *Supports and Services for Older Adults with Developmental Disabilities Study- Final Report* was completed in July 2012 and can be found on the Government of Alberta Persons with Developmental Disabilities website.

Seven reports were completed by the study team as part of this study. The final report summarizes these reports and provides additional material on promising practices in the development of services and supports for older adults with developmental disabilities. These reports include:

- *Aging with a Developmental Disability: A Health Perspective;*
- *Projections of the Population of Older Persons;*
- *Assessing the Health of Older Adults with Developmental Disabilities;*
- *Family and Guardian Focus Groups Summary Report;*
- *Individual Financial Support for Older Adults with Developmental Disabilities;*
- *Guidelines for Using the Supports Intensity Scale (SIS with Older Adults with Developmental Disabilities; and,*
- *Six Critical Factors Organizations Need to Think about when Providing Services and Supports to Older Individuals with Developmental Disabilities.*

This document includes the detailed reports noted above. Please refer to the Table of Contents for each report.

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Projections of the Population of Older Persons

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1. Introduction

1.1 Purpose and Objectives

The purpose of this report is to provide projections of the population of persons with developmental disabilities for the Calgary PDD Region. These projections will be used as part of the Supports and Services for Aging Adults with Disabilities Study to determine future need for supports and services for aging adults with developmental disabilities. The objectives of the report are to:

- Provide a profile of the current population of persons with developmental disabilities in the Calgary Region for both urban and rural areas;
- Provide an estimate of the future population of persons with developmental disabilities by sex, specifically older adults, for both the urban and rural areas of the Calgary Region, for the next 3, 5 and 10 years;
- Provide an estimate of the future service needs of older adults with developmental disabilities in the Calgary Region.

1.2 Methodology

This report utilized Statistics Canada data from the 2006 Participation and Activity Limitations Survey (PALS) to develop a profile of the population of persons with developmental disabilities[1] in the Calgary Metropolitan Area (CMA).

Population projections were developed using PDD Board administrative records to establish a current (2009/10) age profile of the PDD population as a basis for 3, 5 and 10 year projections. This population was then projected based on the following formula:

$$\text{Age}_x^{t2} = \text{Age}_x^{t1}+(\text{Age}_x^{t1}*\text{attrition})$$

The attrition rate was calculated by using PDD population data from 2006/07 as a comparator year. The 2006/07 population was projected forward to 2009/10 to establish a baseline population assuming no mortality or migration. The difference between the projected and actual 2009/10 population was expressed as an age-specific (5 year cohort) annualized attrition rate to reflect the impacts

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[1] Statistics Canada defines “developmental disability” in PALS as “Cognitive limitations due to an intellectual disability or developmental disorder such as Down's syndrome, autism or an intellectual disability caused by a lack of oxygen at birth (Statistics Canada, 2010)”.

of mortality and migration. These age-specific attrition rates were then used to discount the future population projected from 2009/10 to 2019/20.

Population data was analyzed by gender and region. The Calgary Region was divided into its urban (Calgary) and rural components which were analyzed separately. Records were considered to be within the Calgary Region from the communities of Airdrie, Balzac, Banff, Bassano, Black Diamond, Blackie, Bragg Creek, Calgary, Canmore, Chestemere, Cluny, Cochrane, Crossfield, Dewinton, Gleichen, High River, Irricana, Langdon, Longview, Okotoks, Piddis, Rocky Ford, Rocky View, Strathmore, and Turner Valley. Records from outside the Calgary Region or of unknown location were excluded from the analysis.

Service projections were developed by establishing usage rates for 10 year age cohorts for the population age 35+ based on 2009/10 administrative records. These age specific usage rates were then applied to the future population to estimate future service demand based on the projected population age structure.

1.3 Assumptions and Limitations

This projection is based on the assumption that factors affecting attrition between 2006/07 and 2009/10 remain constant. Such factors include not only mortality, but net migration. Deviation in the attrition rate from the 06/07 – 09/10 pattern will affect the projection.

As PDD provides services to persons age 18+, there is no data from administrative records for the population under the age of 18. Consequently, there is no estimate of the population under the age of 18 on which to base projections and these projections are therefore unable to determine the movement of younger age cohorts into the PDD range. As a result, this population projection is restricted to persons age 35+ as the lack of movement of younger age cohorts into the age 18+ population will not affect the age 35+ population projections.

Service projections are based on the assumption that differential rates of service use by different age groups reflect different age-related service needs. The assumption therefore that service demand is related to age is critical for the estimate of future service demand. As other factors affecting service demand were not considered, the influence of such factors is unknown and may affect the service projections.

2. Developmental Disability Population Profile

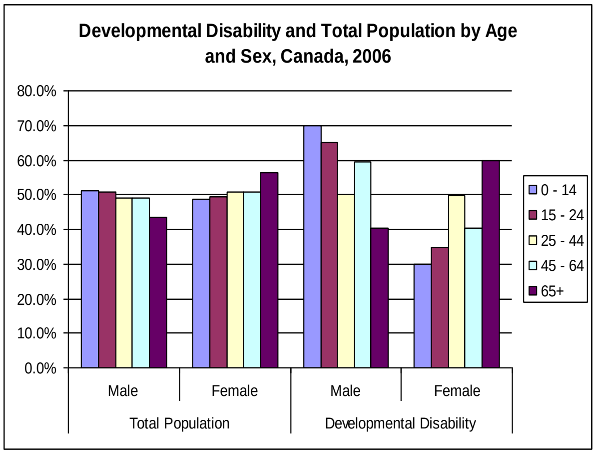
In 2006, there were 136,570 adults age 15+ with a developmental disability in Canada, a rate of 0.5%. Developmental disabilities accounted for 3.2% of all disabilities reported in Canada. In Alberta, there were 19,590 persons with a developmental disability in 2006 (Statistics Canada, 2010). In Calgary, estimates of the developmental disability population can be derived from administrative data. Kneebone (2005) reports that 23% of AISH recipients in Calgary reported a developmental disability in 2005. In 2009, there were 9,319 AISH recipients in Calgary. Applying the rate of 23% to the AISH population yields a total developmental disability population of 2,143 people in 2009. This is roughly in line with the population of 2,443 in 2007 reported by the Vocational Rehabilitation Research Institute (VRRI) based on PDD records (VRRI, 2007).

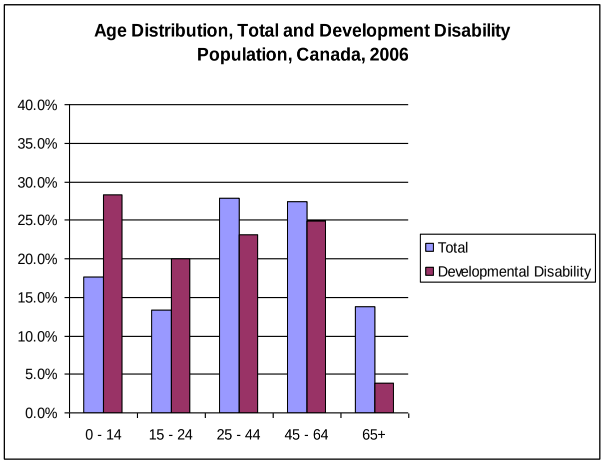
The developmental disability population in Canada grew by 14.4% between 2001 and 2006, roughly three times the rate of growth of the total population. The developmental disability population in Alberta grew by roughly the same percentage (14.2%) over the same period of time, compared to an overall population growth rate of 10.6% for the province (Statistics Canada, 2010).

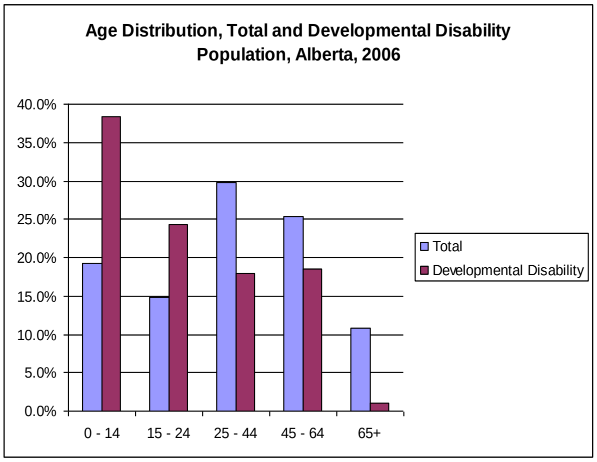
The developmental disability population in both Canada and Alberta tends to be younger than the population as a whole. In 2006, 17.7% of the Canadian population was under the age of 15, compared to 28.2% of the developmental disability population. In Alberta, the proportions were 19.2% to 38.3% respectively.

Conversely, while 13.7% of the Canadian population was over the age of 65 in 2006, only 3.8% of the developmental disability population was 65 or older. In Alberta, the respective proportions were 10.7% and 1.0% (Statistics Canada, 2010).

As compared to the total population, males significantly outnumber females in the development disability population, particularly among younger cohorts (<25). Only among seniors (age 65+) do females outnumber males (Statistics Canada, 2010).







Persons with Developmental Disabilities, All Ages, Canada and Alberta, 2001 and 2006

	2001		**2006**		**Percent Change**	
	Canada	**Alberta**	**Canada**	**Alberta**	**Canada**	**Alberta**
Total Population	30,007,095	2,974,805	31,612,895	3,290,350	5.4%	10.6%
Developmental Disability Population	166,320	17,160	190,310	19,590	14.4%	14.2%

Source: Statistics Canada, Participation and Activity Limitation Survey, 2006.

Age Distribution of Developmental Disability Population, Canada and Alberta, 2006

	Canada		**Alberta**	
	Total	**Developmental Disability**	**Total**	**Developmental Disability**
0 - 14	17.7%	28.2%	19.2%	38.3%
15 - 24	13.4%	19.9%	14.9%	24.2%
25 - 44	27.9%	23.2%	29.8%	17.9%
45 - 64	27.4%	24.8%	25.4%	18.6%
65+	13.7%	3.8%	10.7%	1.0%

Source: Statistics Canada, Participation and Activity Limitation Survey, 2006.

Population by Age and Sex, Canada, 2006

	Total Population		**Developmental Disability**	
	Male	**Female**	**Male**	**Female**
0 - 14	51.2%	48.8%	70.1%	29.9%
15 - 24	50.8%	49.2%	65.2%	34.8%
25 - 44	49.1%	50.9%	50.2%	49.8%
45 - 64	49.2%	50.8%	59.6%	40.4%
65+	43.5%	56.5%	40.2%	59.8%

Source: Statistics Canada, Participation and Activity Limitation Survey, 2006.

3. PDD Board – Calgary Region – Population Profile

In 2009/10, there were 2,487 persons age 18+ with developmental disabilities receiving PDD services in the Calgary Region. Males tended to be more prevalent than females, accounting for 57% of the client population.

The vast majority (91%) of the PDD population lived within the urban area (city of Calgary). The PDD urban population was 2,268, and the rural population was 219.

Older adults (age 45+) accounted for 29% of the PDD population, while seniors (age 65+) accounted for just 2.7%. In 2009/10, there were 60 persons age 65+ with developmental disabilities in the city of Calgary, and 6 in the rural area.

PDD Population, Calgary Region, by Age and Sex, Urban and Rural Areas, 2009-2010									
Age Range	**Calgary Region**			**Urban Area**			**Rural Area**		
	Total	**Male**	**Female**	**Total**	**Male**	**Female**	**Total**	**Male**	**Female**
18-19	126	74	52	109	67	42	17	7	10
20-24	436	259	177	381	227	154	55	32	23
25-29	365	216	149	332	198	134	33	18	15
30-34	327	179	148	294	161	133	33	18	15
35-39	239	141	98	217	130	87	22	11	11
40-44	261	141	120	250	135	115	11	6	5
45-49	243	130	113	228	124	104	15	6	9
50-54	201	109	92	192	106	86	9	3	6
55-59	136	76	60	122	67	55	14	9	5
60-64	87	51	36	83	49	34	4	2	2
65-69	34	15	19	33	14	19	1	1	0
70-74	19	13	6	17	11	6	2	2	0
75-79	10	5	5	9	4	5	1	1	0
80+	3	1	2	1	0	1	2	1	1
Total	2,487	1,410	1,077	2,268	1,293	975	219	117	102
Total 35+	1,233	682	551	1,152	640	512	81	42	39
Total 65+	66	34	32	60	29	31	6	5	1

4. PDD Board – Calgary Region – Population Projections

The total number of PDD clients (age 35+) in the Calgary Region is expected to grow by 30.6% between 2010 and 2020. The population is projected to grow by 7.6% by 2013 to 1,336, and by 13.0% to a total of 1,393 by 2015. By 2020, the total population is projected to be 1,611.

Population growth is expected to be most significant among seniors (age 65+) and older adults (age 55-64). Between 2010 and 2013, the number of seniors with developmental disabilities is expected to grow by 44.5% from 66 to 95. By 2015, the seniors population will have grown by 74.9% to 115, and by 2020 by 169.3% to 178.

Projected Age Distribution (#) of PDD Population, Calgary Region							
					Percentage Change		
	2010	**2013**	**2015**	**2020**	**2010-13**	**2010-15**	**2010-20**
35 - 44	500	493	527	680	-1.4%	5.4%	36.0%
45 - 54	444	475	453	397	7.0%	2.0%	-10.6%
55 - 64	223	264	298	356	18.3%	33.7%	59.6%
65+	66	95	115	178	44.5%	74.9%	169.3%
Total	**1,233**	**1,327**	**1,393**	**1,611**	7.6%	13.0%	30.6%

Among those age 35+, males exceed females. Between 2010 and 2020, the male population is expected to grow at a slightly higher rate than the female population. Among those age 65+, males also exceed females, with the male population also expected to grow at a slightly higher rate than the female population.

PDD Population Projection by Sex, Calgary Region							
Age 35+	2010	2013	2015	2020	2010-13	2010-15	2010-20
Male	682	714	752	868	4.7%	10.2%	27.2%
Female	551	573	603	684	3.9%	9.4%	24.2%
Age 65+							
Male	34	44	56	94	29.7%	65.8%	175.6%
Female	32	39	47	73	20.9%	47.4%	128.5%

Urban Area

The PDD population in the urban area (Calgary) is expected to grow by 28.9% between 2010 and 2020 from 1,153 to 1,486. Between 2010 and 2013, the population will grow by 7.4% to 1,239, and by 2015 by 12.1% to 1,292.

Population growth will be greatest among seniors (age 65+). Between 2010 and 2013, the seniors population is expected to grow by 44.4% from 61 to 88, and by 79.2% by 2015 to 109. By 2020, the seniors population is expected to have grown by 168.7% to 164. Meanwhile, the population age 45 – 54 is expected to drop by 11.7% by 2020.

Projected Age Distribution (#) of PDD Population, Calgary Region - Urban Area							
					Percentage Change		
	2010	2013	2015	2020	2010-13	2010-15	2010-20
35 - 44	467	453	475	615	-2.9%	1.8%	31.7%
45 - 54	420	450	430	371	7.1%	2.3%	-11.7%
55 - 64	205	247	278	337	20.6%	35.5%	64.2%
65+	61	88	109	164	44.4%	79.2%	168.7%
Total	1,153	1,239	1,292	1,486	7.4%	12.1%	28.9%

Among those age 35+, males in Calgary outnumber females, with the male population growing at a slightly higher rate than the female population over the forecast period. Among those aged 65+ the male population is expected to grow at a significantly greater rate than the female population over the forecast period.

PDD Population Projection by Sex, Calgary Region – Urban Area							
Age 35+	2010	2013	2015	2020	2010-13	2010-15	2010-20
Male	641	689	715	840	7.5%	11.6%	31.0%
Female	512	550	577	647	7.3%	12.6%	26.3%
Age 65+							
Male	30	45	60	90	48.3%	100.5%	201.1%
Female	31	44	49	74	40.6%	58.5%	137.4%

Rural Area

Within the Calgary Region, the rate of population growth will be highest in the rural areas. Between 2010 and 2020, the rural PDD population (age 35+) is projected to rise by 55.4% from 80 to 124.

Over the forecast period, the seniors PDD population in the rural area is expected to grow at a similar rate to that of the urban area, rising by 45.4% by 2013, by 22.8% by 2015 and by 177.2% by 2020. Unlike the urban area, however, the rural area is projected to experience significant growth in the younger age cohort (35-44) which is expected to grow by 97.2% by 2020.

Projected Age Distribution (#) of PDD Population, Calgary Region - Rural Area

					Percentage Change		
	2010	**2013**	**2015**	**2020**	**2010-13**	**2010-15**	**2010-20**
35 - 44	33	40	52	65	19.8%	56.5%	97.2%
45 - 54	24	25	23	26	5.7%	-2.7%	8.3%
55 - 64	18	16	20	19	-8.5%	12.3%	7.7%
65+	5	7	6	14	45.4%	22.8%	177.2%
Total	**80**	**89**	**101**	**124**	10.8%	26.7%	55.4%

While the male and female populations (age 35+) are roughly equal in 2009/10, the male population is expected to grow at a faster rate than the female population over the forecast period. Between 2010 and 2020, the male population is expected to grow by 58.3% compared to a growth rate of only 52.3% among females.

PDD Population Projection by Sex, Calgary Region – Rural Area

Age 35+	**2010**	**2013**	**2015**	**2020**	**2010-13**	**2010-15**	**2010-20**
Male	41	45	53	65	10.3%	29.1%	58.3%
Female	39	43	48	59	11.3%	24.2%	52.3%
Age 65+							
Male	4	5	4	9	23.2%	4.3%	120.5%
Female	1	2	2	5	134.2%	96.8%	404.3%

5. PDD Board – Calgary Region – Estimates of Future Service Demand

Estimates of future service demand are based on the population projections above. Age-based rates of current service usage were calculated for the 2010 population, and these usage rates were applied to the projected future population to provide an estimated total service demand.

Between 2010 and 2020, the greatest growth in demand among the PDD population age 35+ is expected to be for respite services, which will increase by 34.2%. Over that time period, the number of people utilizing such services is expected to rise from 238 to 320. Following respite services, demand increases will be greatest for supported / independent living (+31.3%), community access (+31.2%) and overnight residential services (+30.7%).

Service Projections (Age 35+), Calgary Region							
	2010	**2013**	**2015**	**2020**	**2010-13**	**2010-15**	**2010-20**
Overnight Residential	151	164	172	198	8.5%	13.6%	30.7%
Supported / Independent Living	733	789	830	963	7.6%	13.1%	31.3%
Respite	238	256	272	320	7.7%	14.2%	34.2%
Employment	355	371	383	433	4.5%	7.8%	21.9%
Community Access	897	969	1,018	1,176	8.1%	13.6%	31.2%
Behavioural Support	124	132	137	154	6.8%	10.5%	24.2%
Professional Support	360	386	400	443	7.1%	11.0%	23.0%
Other	89	98	103	115	10.7%	16.1%	29.3%

Among the seniors population, demand is expected to rise significantly for all services. Demand will continue to be greatest for community access and supported / independent living services.

Service Projections (Age 65+), Calgary Region							
	2010	**2013**	**2015**	**2020**	**2010-13**	**2010-15**	**2010-20**
Overnight Residential	11	16	20	30	44.4%	78.6%	168.8%
Supported / Independent Living	38	55	66	103	44.5%	73.0%	169.6%
Respite	14	20	23	36	44.6%	68.7%	170.3%
Employment	3	4	5	8	44.4%	79.2%	168.7%
Community Access	52	74	91	139	44.5%	76.4%	169.1%
Behavioural Support	3	4	5	8	44.4%	79.2%	168.7%
Professional Support	8	12	14	21	44.4%	79.2%	168.7%
Other	89	98	103	115	10.7%	16.1%	29.3%

Urban Area

Demand for services among adults with development disabilities (age 35+) within Calgary will be greatest for community access services, followed by supported / independent living services, and professional support.

Service Projections (Age 35+), Calgary Region – Urban Area							
	2010	**2013**	**2015**	**2020**	**2010-13**	**2010-15**	**2010-20**
Overnight Residential	150	154	157	163	8.4%	13.3%	30.1%
Supported / Independent Living	669	718	750	866	7.5%	13.2%	31.1%
Respite	199	213	222	258	7.6%	14.4%	33.8%
Employment	341	355	364	410	4.5%	7.9%	21.8%
Community Access	842	909	949	1,093	8.0%	13.6%	31.0%
Behavioural Support	122	130	135	151	6.8%	10.5%	24.1%
Professional Support	343	367	378	418	7.1%	11.1%	22.9%
Other	87	96	100	111	10.8%	16.2%	29.3%

Among seniors (age 65+), demand will rise significantly for all services. The demand for community access services for this population is expected to more than double from 49 in 2009/10 to 132 by 2020, while demand for supported / independent living will rise from 34 to 91 spaces over the same time.

Service Projections (Age 65+), Calgary Region – Urban Area							
	2010	2013	2015	2020	2010-13	2010-15	2010-20
Overnight Residential	11	16	20	30	44.4%	79.2%	168.7%
Supported / Independent Living	34	49	61	91	43.2%	72.9%	167.9%
Respite	11	16	20	30	42.4%	68.6%	167.4%
Employment	3	4	5	8	44.4%	79.2%	168.7%
Community Access	49	71	88	132	43.9%	76.3%	168.4%
Behavioural Support	3	4	5	8	44.4%	79.2%	168.7%
Professional Support	8	12	14	21	44.4%	79.2%	168.7%
Other	87	96	100	111	10.8%	16.2%	29.3%

Rural Area

In the rural areas of the Calgary Region, the greatest increase in demand for service for adults with developmental disabilities (age 35+) is expected to be for employment services. Between 2010 and 2020, demand for employment services is expected to rise by 62.8%, though the number of people requiring such services remains small. The demand for respite services and supported / independent living is also expected to grow appreciably.

Service Projections (Age 35+), Calgary Region - Rural Area							
	2010	2013	2015	2020	2010-13	2010-15	2010-20
Overnight Residential	1	2	2	3	21.8%	53.8%	103.6%
Supported / Independent Living	64	71	79	97	9.9%	23.3%	50.4%
Respite	39	44	50	62	11.7%	27.4%	57.5%
Employment	14	16	19	23	13.4%	34.6%	62.8%
Community Access	55	60	69	83	10.3%	26.2%	52.7%
Behavioural Support	2	2	2	3	12.9%	27.8%	54.0%
Professional Support	17	19	22	25	7.4%	27.6%	46.7%
Other	2	2	3	4	19.8%	56.5%	97.2%

The number of seniors with developmental disabilities (age 65+) remains low in the rural area, so service demands also remain significantly below that of the urban area over the forecast period. Demand will grow appreciably however for overnight / residential care as well as supported / independent living services.

Service Projections (Age 65+), Calgary Region - Rural Area							
	2010	2013	2015	2020	2010-13	2010-15	2010-20
Overnight Residential	0	0	0	0	---	---	---
Supported / Independent Living	4	6	5	12	45.4%	22.8%	177.2%
Respite	3	4	3	7	45.4%	22.8%	177.2%
Employment	0	0	0	0	---	---	---
Community Access	3	4	3	7	45.4%	22.8%	177.2%
Behavioural Support	0	0	0	0	---	---	---

Professional Support	0	0	0	0	---	---	---
Other	2	2	3	4	19.8%	56.5%	97.2%

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Aging with a Developmental Disability: A Health Perspective

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EXECUTIVE SUMMARY

Health is a broad term that implies a number of concepts and characteristics. However, defining the term and understanding how it is used within the context of individuals who are aging with developmental disabilities is important from both a policy maker and service provider perspective because of its association with funding and the potential for the linkage of service provision to the health status of these unique individuals.

An extensive review of the literature was conducted specific to the health and health related challenges for those who are aging with a developmental disability. The following questions were asked:

- What is unique about individuals who are aging with a developmental disability?
- Are there health challenges that this unique group of adults face? and
- Are there interventions that might have enhanced benefit for this group, specific to identified health challenges?

In brief, the literature indicates that:

- The onset of age-related changes for individuals with developmental disabilities is similar to that of the general population unless they have severe levels of cognitive impairment, Down syndrome, cerebral palsy, or multiple disabilities.

- The potential synergistic effects of increasing age with concomitant membership in a vulnerable population increases the risk of experiencing poor health.

- The multiple health problems that sometimes accompany aging present challenges for those individuals with developmental disabilities. For example, they may have additional difficulty in explaining and understanding symptoms and treatments, which can contribute to problems going unrecognized and untreated.

Aging with a developmental disability presents significant challenges, the breadth and scope of which are only beginning to be understood.

Introduction

Health is a broad term that implies a number of concepts and characteristics. However, defining the term is important from both a policy maker and service provider perspective because of its association with funding and the potential for linkage of service provision to the health status of individuals who are aging with a developmental disability. The World Health Organization (1946) defined the term as: health is a state of complete physical, mental and social well-being and not merely the absence of disease or infirmity.

Developmental disability is characterized by lifelong mental or physical functional limitation that manifests early in life after birth (Crews, 2011). Developmental disability, a term more recently used instead of the phrase mental retardation (Schalock, Luckasson & Shogren, 2007), describes the population of individuals with significant limitations in intellectual functioning and adaptive conceptual, social, and practical behaviour skills that commence before the age of 18 years (Schalock, Borthwick-Duffy et al., 2010) and is commonly associated with neurological disorders such as cerebral palsy (Patja, Molsa & Livanainen, 2001) and Down syndrome (Sherman, Allen, Bean & Freeman, 2007).

1.1 Life Expectancy for Individuals Aging with Developmental Disabilities

Due to advances in medicine and related health care, there is an increasing percentage of individuals with developmental disabilities living into late adulthood. Individuals with moderate or severe disability are "now routinely living into their late 60s and 50s, respectively (Bittles, et al. 2002, p. 470). In a sample of 29,290 individuals with developmental disabilities living in residential facilities in the Netherlands, those that were 20-years old had a life expectancy of 44 more years; thus into their early 60s (Maaskant, Gevers & Wierda, 2002).

Syndrome specifically, Yang, Rasmussen, and Friedman (2002) examined the death certificates of 17,897 individuals with Down syndrome in the United States in the period from 1983 to 1997; the median age of death rose significantly from 25 years in 1983 to 49 years in 1997. In a Dutch study, individuals with Down syndrome at the age of 20 years old lived an additional 35 years, into their mid 50s (Maaskant et al., 2002). In a cohort of 341 individuals with cerebral palsy, individuals in their 20s showed nearly an 85% survival rate to age 50 years, but comparatively the rate for the general population was 96% survival (Hemming, Hutton & Pharoah, 2006).

1.2 Normal Aging Changes

Aging is the manifestation of physical and psychosocial events that occur over a span of time. People age differently. Some systems slow down, while others lose their "fine tuning." As a general rule, slight, gradual changes are common, and most of these are not problems to the person who experiences them. This section is provided so that following comments about changes to health status with age to individuals with developmental dis abilities are reviewed within the context of normative aging changes.

Nervous System

- The brain atrophies.
- There is shrinkage of large neurons resulting in loss of large neurons with an increase in smaller neurons.
- Functional changes include slowing of response to tasks and the increase in time to recover from physical exertion.
- Cognitive changes include memory loss, decrease in perceptual ability, and decrease in proficiency.
- Takes longer to fall asleep and may awake more often during the night..

Sensory Changes

Eyes

- The cornea flattens which reduces the refractory power.
- The retina becomes thinner because of fewer neural cells and receives only about 1/3rd of the amount of light that of a younger person.
- Consequently, not being able to see in dim light and difficulty in colour perception.

Ear

- Cerumen glands are reduced in number; dry and hard ear wax, along with itching.
- Degenerative changes occur in ossicles contributing to hearing loss.
- Loss of cochlear hair cells leading to hearing loss.

Taste

- Taste perception and taste discrimination decreases.

Integumentary System

- Systemic decrease in circulation, loss of cells and loss of elastic collagen fibers, and muscle mass; outcome may be fragile skin which tears easily.
- Number of pressure and light touch sensors decreases.

Cardiovascular System

- Valves of the heart become thicker and more rigid as a result of calcification.
- The SA node is infiltrated by fat and connective tissue resulting in a decrease in the heart's ability to regulate the rate of the node, causing a slowing of electrical impulses through the AV tissue.
- There is a 10% decrease in the number of pacemaker cells in the SA node by age 75 years.
- Many of the arrhythmias seen in the older person are a result of either the decrease in pacemaker cells or the infiltration of fat in the SA node.

Respiratory System

- Degeneration of the intervertebral discs leading to development of kyphosis and scoliosis.
- The trachea and large bronchi are also increased in diameter because of the calcified cartilage changes.
- The muscles involved in respiration weaken with age. It contributes to less forceful contraction which decreases inspiratory and expiratory effort.
- The combination of increased stiffness of the chest wall and decreased muscle strength results in less efficient breathing.

Musculoskeletal System

- Bone resorption occurs without the successful formation of new bone mass leading to radual bone loss.
- In women, estrogen deficiency, calcium malabsorption, lifestyle factors (calcium intake and exercise) can result in bone loss.
- Decline in numbers of muscles resulting in reduced muscle mass.

Urinary System

- In men, benign prostate can contribute to urinary incontinence (dribbling).
- In women, estrogen deficiency causes changes in the squamous epithelium of the distal urethral and vaginal wall, a decrease in the vaginal muscular tone and vascular profusion. These changes contribute to urinary incontinence.
- With age an increase in involuntary bladder contractions, a reduction in bladder capacity and an increase in residual volume. These contribute to development of incontinence.
- Weak pelvic muscles causes stress incontinence.

Gastrointestinal System

- Teeth become brittle; there is resorption of bone in the jaw leading to loosening of teeth, increased infections of teeth and gums, and sometimes loss of teeth.
- Difficult to chew food because of loose teeth.
- Presence of gall stones increases with age.
- There is decrease in number of hepatic cells and as a result, a diminished capacity for metabolism of drugs and hormones.

Reproductive System

Changes in women

- May experience hot flashes due to vasomotor instability related to menopause.
- Bone loss leading to osteoporosis.
- Decrease in estrogen production leads to reduced vaginal lubrication, the vaginal mucosa becomes thin and the vagina shortens in length and width.
- Sexual arousal is reduced which may results in painful intercourse and vulvo-vaginitis.

Changes in men

- Takes longer time for erection, amount of semen is reduced, and intensity of ejaculation is reduced.

Memory functioning

- Short term memory deteriorates with age.
- Time required for memory scanning is longer for both recent and remote recall.

Intellectual functioning

- Fluid abilities or abilities involved in solving novel problems tend to decline. High degree of regularity in intellectual function present.

Psychological functioning

- The need for attachment is consistent throughout the life span.
- Self-concept and self-identity appears to remain stable over life time.

1.3 Guiding Questions

Based upon this context, the following questions were asked:

- What is unique about individuals who are aging with a developmental disability?
- Are there health challenges that this unique group of adults face? and
- Are there interventions that might have enhanced benefit for this group, specific to identified health challenges?

METHOD

2.1 Overview

A review of the literature was conducted using the following on line databases: Medline, CINAHL, ERIC, Psychlit, Sociological Abstracts, PubMed, and Dissertation Abstracts. These databases were searched for the time period between 1990 and the present. The key search terms included: aging, older adults, disability, aging with a disability, developmental disability, intellectual disability, health, and chronicity. Words were used in combination so that most articles specific to young children and adolescents were eliminated. The query produced numerous studies and topical articles. Articles were obtained via electronic library sources, interlibrary loan, and support from the provincial gerontological health care library. A hand search was then completed of the reference lists of obtained articles to supplement the initial literature base. The majority of research studies located and obtained were quantitative in design.

2.2 Methodological Issues

During the course of the literature review, methodological issues in numerous studies were identified. These included:

- most studies are prevalence based because of limited financial resources / resource timelines;
- most studies used different definitions of older adult;
- measurement tools differed; and
- small numbers and small sample size were used.

The majority of the quantitative reviewed studies suffered from small samples sizes and less rigorous methodologies that employed non random sampling. Definitions of populations varied across studies making comparisons difficult. One specific example is the age that is used to identify an older adult e.g. 45, 50 or 65 years of age. In addition, chart review studies only examined reported cases of health challenges while the actual number is probably greater. Furthermore, data collected by the researcher or agency may differ in terms of severity and complexity, from cases that are not reported. The results of several studies may not be generalizable to other specific subpopulations of adults who are aging with developmental disabilities based on where the data collection took place due to cultural differences and the reporting requirements of the region/country.

Findings

3.1 Aging with a Developmental Disability

Due to their preexisting neurological, functional, and physical impairments, individuals with developmental disabilities demonstrated signs of aging in their 40s and 50s that the general population traditionally may not experience until 20 to 30 years later (Olive & Holland, 1986; Thomas, Strax, Luciani, Dunn & Quevedo, 2010). Adults with Down syndrome are likely to experience premature aging with marked biological age-related changes occurring from about 40 years.

For those adults who are aging with an underlying developmental disability, they experience an augmented burden by age-related conditions that are in addition to their primary disability (Crews, 2011). As a group, older people with developmental disabilities have an increased frequency of thyroid disorders, heart disorders, and sensory impairments (Kapell et al. 1998). The cumulative evidence suggests that older adults with developmental disabilities have rates of common adult and older age-related conditions that are comparable to or even higher than that of the general population (Evanhus, Henderson et al. 2001, p. 181).

3.1.1 Physical Activity

A lack of regular physical activity and unhealthy eating habits, common factors associated with obesity in the general population of older adults are also prevalent health challenges for adults with developmental disabilities (Rimmer, Heller, Wang & Valerio, 2004; Rimmer & Yamaki, 2006;).

Strauss and associates (2004) studied the pattern of functional abilities and declines in 904 adults with cerebral palsy over the age of 60 who were registered in the California Developmental Disabilities data base. In those who were ambulant in adulthood, there was a marked decline past the age of 60. The survival of individuals who had lost mobility in later life was poorer than in the general community.

Inactivity and obesity are risk factors for hypertension (Bhaumik, Watson, Thorp, Tyrer & McGrother, 2008).

The finding that the rate of obesity among some adults with developmental disabilities is of concern since extreme obesity is strongly associated with higher rates of morbidity and mortality (Fontaine, Redden, Wang, et al., 2003).

3.1.2 Oral Health

Periodontal disease in adults with Down syndrome develops earlier and is more rapid and extensive than in age-matched persons drawn from the general population (Zigmond et al, 2006). At the same time, evidence demonstrates that older adults are likely to take medications that can impact oral health and affect dental treatment. There are numerous common medications (e.g. analgesics, antidepressants, antihistamines, antihypertensives, diuretics) that can cause side effects such as dry mouth, soft tissue changes, taste changes, and gingival overgrowth. Dry mouth leaves the mouth without enough saliva to wash away food and neutralize plaque, leaving an individual susceptible to tooth decay and possible periodontal disease. In addition, dry mouth can cause difficulty in swallowing, hoarseness, problems with speaking, and sore throat.

Owen et al (2006) reported that older adults tended to have a higher prevalence of gingivitis; however, Corbin, Malina, and Shepherd (2005) found that the prevalence varied with age (42% among 8–17 years, 58% among 18–34 years, 62% among 35–50 years, and 48% among 51–70 years) for participants of the World Games in the summer of 2003. Higher levels of gum inflammation were also identified for older participants of the Special Olympics held in the United Kingdom by Turner, Sweeney, Kennedy, and Macpherson (2008).

Sanders and associates (2009) reported a link between quality of life and oral health that is of relevance for adults who are aging; as did Kandelman, Petersen, and Ueda (2008). Since adults tend to experience more oral health care problems as they age, the potential impact upon their quality of life is notable.

3.1.3 Disturbances of Vision

There has been substantial research done about vision in individuals with developmental disabilities. In an early study conducted in New York, Kapell and colleagues (1998) found that 9-16% of those 45 to 64 years of age and 17 to 50% of those 65 to 74 year old with developmental disabilities had vision problems. The comparable rate for the United States population was 5% for the younger group and 7% for those over 65 years of age.

Current research findings indicate that vision problems (e.g. cataracts, refractive errors, strabismus) are more common among individuals with developmental disabilities than those without. These same visual challenges are also more common in old age.

3.1.4 Gender Specific

Brambilla and McKinlay (1989) estimated the median age for menopause in the general population to be 51.2 years; however, in women with developmental disabilities the age was younger, 45.8 to 47.1 years. This is about a five year difference in age of onset. This has been supported in more recent research, Carr and Hollins (1995) reported women with Down syndrome experienced menopause three to five years earlier than other women.

In a related prospective longitudinal cohort study of dementia and mortality in persons with Down syndrome aged 45 years and older, 85 postmenopausal women were followed for a mean follow-up time of 4.3 years (Coppus et al. 2010). The effect of age at menopause on age at diagnosis of dementia and survival was estimated using correlation analysis and Cox Proportional Hazard Model. They found a significant correlation between age at menopause and age at diagnosis of dementia, and between age at menopause and age at death. Early age at menopause was associated with a 1.8 fold increased risk of dementia and with risk of death. Findings suggest that age at menopause in women with Down syndrome is a determinant of age at onset of dementia and mortality. The earlier age of onset suggests that women with developmental disabilities are at increased risk for post menopausal health disorders, such as heart disease, depression, breast cancer, and osteoporosis as a result of the cessation of estrogen production.

In a sample of 9,409 individuals with developmental disabilities, in Australia over a 19 year period, males had a greater risk for leukemia, brain, and stomach cancer and women had a higher risk for leukemia, corpus uteri, and colorectal cancers (Sullivan, Hussain, Threlfall & Bittles, 2004).

3.1.5 Loss and Grief

Individuals with developmental disabilities are living longer and experiencing death among their family and peers; however, their grieving is not well recognized (Dodd, Dowling & Hollins, 2005; Stoddart, Burke & Temple, 2002). Mid to older life changes such as loss through the death of a parent or sibling may have a greater impact and consequently a greater likelihood of adverse functional outcome.

Key points:

- ***Older adults with developmental disabilities may show age-related changes in health, cognitive, and functional capacities indicative of accelerated aging.***
- ***The earlier age of onset of menopause suggests that women with developmental disabilities are at increased risk for post menopausal health disorders, such as heart***

disease, depression, breast cancer, and osteoporosis as a result of the cessation of estrogen production.

- ***Obesity levels and related lack of exercise should be a concern because of their strong association with higher rates of morbidity and mortality.***

3.2 A Subpopulation Lens to Aging with a Developmental Disability

3.2.1 Cerebral Palsy

Whether due to early aging processes or the progressive effects of disability, the physical health of adults with cerebral palsy begins to deteriorate as early as middle age. People with cerebral palsy reported reduced mobility, increased pain, and bowel and bladder problems from their forties onward (Balandin & Morgan, 1997).

Reduced muscle tone may exacerbate swallowing problems and recurrent reflex esophagitis potentially increases the risks of esophageal cancer. Poor long-term posture may increase the risks of respiratory disease as well as arthritis. Existing bladder and bowel dysfunction and associated incontinence or urinary tract infections are likely to be further exacerbated by age-related changes. Immobility, small body size, poor diet, and prolonged use of anticonvulsant drugs contribute to increased risk of osteoporosis and a high risk for falls and fractures. These changes impact on the functional ability of adults with cerebral palsy, in particular their mobility.

While all older adults with developmental disabilities have high levels of dental and gum disease, those with cerebral palsy are particularly at risk (Liptak, 2008). This is due to poor access to dental services, difficulties experienced with brushing, and long-term use of medication associated with gum disease. Older adults are more likely to keep their teeth for a lifetime than they were a decade ago. However, studies indicate that they have the highest rates of periodontal disease and need to do more to maintain good oral health.

For older adults in their 40s and 50s with cerebral palsy, this population has a greater likelihood of death from neoplasms than the general United Kingdom population (Hemming, Hutton & Pharoah, 2006). In an American longitudinal population of individuals with cerebral palsy, the number of cancer related deaths was significantly higher than the general population, with high rates of digestive systems and brain cancers, and threefold increase in breast cancers (Strauss, Cable & Shavelle, 1999).

3.2.2 Down syndrome

The specific health conditions that affect younger people with Down syndrome continue to have an impact in their later years. Their high level of pre-existing sensory impairment compounds the impact of later changes and in later life they have high rates of vision and hearing loss and eye disorders. They also have a higher risk of cardiovascular problems, dermatological problems, heart disease, and thyroid disorders (Evanhuis, Henderson et al. 2001).

Alzheimer’s disease is one of the most common conditions among older adults with developmental disabilities and particularly those with Down syndrome. For example, one study found that 22% of adults with Down syndrome over the age of 40 had Alzheimer’s disease, rising to 56% after age 60 years. This compares with 3% and 6% respectively in the general population (Janiciki & Dalton, 2000). In the United Kingdom, the rates of Alzheimer’s disease among people with Down syndrome reported by Prasher (1995) are 2% between 30 and 39 years, 9.4% between 40 and 49 years, 36% between 50 and 59 years increasing to 1.4% between 65 and 69 years, and reaching 13% in those over 80 years. In a large dementia study within a population of 506 individuals with Down syndrome under the age of 45 years old living in the Netherlands, the prevalence of dementia was 16.8 % (Coppus, Evenhuis, Verberne, Visser, Van Gool, Eikelenboom & Van Duijin, 2006). The prevalence of dementia doubled with every 5-year increment of age; for example, the prevalence was 8.9% in those 45 to 49 years old, 17.7 % in those 50 to 54, and 32.1 % in those 55 to 59 years old (Coppus et al., 2006).

It is important to note that not all adults with Down syndrome will have symptoms of Alzheimer’s.

3.3 A Disease Lens to Aging with a Developmental Disability

Within the group of older adults with developmental disabilities, one might expect a similar prevalence and incidence rates of chronic and age-related diseases as that in the general public. The results are inconsistent. Some of the differences in the studies may be due to age differences, age ranges, and severity of disability. To illustrate, some of the age-related disorders found in a Dutch study (Van Schrojenstein Lantman-deValk et al, 1997) showed prevalence and incidence patterns that resemble those in the general population such as affective disorder, hypertension, cardiovascular disease, diabetes, and osteoarthritis. Others were higher like dementia, gastric and esophageal disorders, or started in younger age groups such as visual and hearing impairment.

3.3.1 Dementia / Alzheimer

Alzheimer’s disease is the most common form of dementia. It causes progressive deterioration of mental ability, leading to the eventual loss of cognitive and adaptive skills necessary for everyday functioning. People forget how to carry out everyday tasks and have no capacity to relearn. Deterioration in skills is accompanied by changes to mental status and behaviour, such as depression, psychosis, aggression, and irritability.

Dementia in general and Alzheimer’s disease in particular are growing concerns for the population of adults aging with developmental disabilities. In a cross sectional study, Alzheimer’s dementia was three time more prevalent in those with developmental disabilities than the general population, with a significant prevalence of 8.6% (Styrdom, Livingston, King & Hassiotis, 2007). The implication of this finding is evident in a British study of 2995 individuals with developmental disabilities. During a 14-year study period, the standardized mortality ratios indicated that the degree of mortality due to dementia was twofold greater than the general population (Tyrer & McGrother, 2009).

Strydom and colleagues (2010) conducted a comprehensive review of the published literature from 1997 to 2008 with a specific focus on the epidemiology of dementia in developmental disability in general as well as in specific syndromes. They reported varied methodologies in diagnosis yielded a wide range of reported prevalence rates of dementia. They found that rates of dementia in the population under study not because of Down syndrome are comparable or higher than the general population. Alzheimer's Disease onset in individuals with Down syndrome appears earlier and the prevalence increases from under 10% in the 40s to more than 30% in the 50s, with varying prevalence reported for those aged 60 and over. Coppus and associates (2008) in a prospective longitudinal cohort study of dementia and mortality tested 506 adults with Down syndrome, aged 45 and over. They found that relative preservation of cognitive and functional ability was associated with better survival.

Standardized mortality odds ratios in a population of individuals with Down syndrome showed that this population had a significantly greater likelihood of having a diagnosis of dementia on their death certificate (Yang et al., 2002). In a study of 4872 individuals with Down syndrome in Sweden and Denmark, there was also a high mortality from dementia and Alzheimer disease (Hill et al., 2003). The average age on dementia onset was 53 years old for those with Down syndrome, compared to onset at age 67 for those with other intellectual disabilities (Janicki & Dalton, 2000).

Key points:

- ***The course of Alzheimer's disease for people with Down syndrome is atypical, onset is earlier, and its course is more rapid.***
- ***Relative preservation of cognitive and functional ability is associated with better survival for aging adults with Down syndrome.***
- ***For persons with Down syndrome, symptoms of dementia may often be caused by other conditions that are treatable such as hyper/hypothyroidism, depression, and sensory impairments.***
- ***Diagnosis and management of dementia is complicated by the high prevalence rates of co-morbid physical and mental health problems.***

3.3.2 Cardiovascular Disorders (CVD)

Draheim (2006) conducted a review of cardiovascular disease prevalence, CVD related mortality, physiological CVD risk factors, and behavioural CVD related factors in adults with developmental disabilities as cited in the literature. His findings indicated that adults with developmental disabilities living in the community appear to have an elevated disease prevalence, elevated CVD related mortality, more adverse physiological CVD risk factors (e.g. cholesterol levels, obese), and elevated behavioural risk compared to those without developmental disabilities.

Cardiovascular conditions are a primary health problem for adults aging with developmental disabilities. In a sample of adults aged 40 to 89 with developmental disabilities living in community residences in New York State, cardiovascular conditions increased in prevalence with age (Janicki et al., 2002). Cardiovascular disease was a common causes of death for adults with developmental disabilities, in a Finnish population based study, accounting for 36% of primary cause of death, 35% immediate cause, and 19% contributing cause of death (Patja et al., 2001). In those under forty years of age, the most common cardiac concerns were congestive heart failure, aortic aneurysm, and cardiomyopathy; often related to malformations as seen with Down syndrome (Patja et al, 2001). Regarding vascular diseases causes, 38% were due to acute cardiac infarct, 33% to cerebral infarct or bleeding, 18% to congenital heart disease and 6% to pulmonary infarct (Patja, et al, 2001). Sixty-three was the average age of death for cardiac related disease (Patja, et al, 2001). In a British study of 2,995 individuals with developmental disabilities, cerebrovascular disease accounted for a 2.4 fold increase in death compared to the general population, 1.5 fold increase for ischemic heart disease, and 1.78 fold increase for other circulatory system disease (Tyrer & McGrother, 2009).

According to Kozma (2008), in adults with Down syndrome the incidence of congenital heart defects is 45%; acquired valvuval lesions is 17% incidence, mitral valve prolapse is 57% incidence, and arteriosclerosis incidence is 13%. Cardiac failure was the second leading cause of death in individuals with Down syndrome and no dementia, in a prospective longitudinal cohort study of 506 individuals with Down syndrome (Coopus, Evenhuis, Verberne, Visser, Oostra, Eikelenboom et al., 2008). In another study of Americans with Down syndrome, cardiac conditions were again attributed as the second most frequent rationale for death, with a standard mortality odds ratio of 29.1 for congenital heart defects and 0.42 for ischemic heart disease (Yang et al., 2002). In an Australian study of 1,332 individuals with Down syndrome, in those over 40 years coronary artery disease was the cause of mortality in 10% (Bittles et al., 2007).

3.3.3 Respiratory Disorders

Individuals with developmental disabilities have a higher risk than the general population for respiratory disorders. In a Finnish study of 2,369 adults with developmental disabilities, followed from 1962-1997, the risk for of mortality due to respiratory disease was 5.4 for 20 to 39 year olds, 5.5 for 40 to 59 year olds and 2.7 for those greater than 60 years old (Patja et al., 2001). Since 1.0 equals the risk of the general population, it is evident that all age ranges of individuals with developmental disability are at greater risk for respiratory illness. Respiratory disease was the second largest cause of death for this population, accounting for 22% of the primary causes of death, 29% of the immediate cases and 5% of the contributing causes (Patja et al, 2001). Pneumonia was primary attributed to 83% of deaths; 16 causes related to a foreign body and 11 due to aspiration (Patja et al, 2001). Chronic Obstructive Pulmonary Disease accounted as the primary cause of death for 11% of the population with developmental disability (Patja et al, 2001). In those individuals younger than 39 years old, men were at higher risk, but women were at higher risk in the age group older than 60 years. The average age of death from respiratory causes was 54.3 years old (Patja et al, 2001). In a United Kingdom population of 2995 individuals with developmental disabilities, during a 14 year study period, 503 deaths occurred indicating a 6.5 fold increase in bronchopneumonia than the general population and 4.6 fold increase for other respiratory infections (Tyrer et al., 2009).

From a syndrome specific perspective, these health challenges have particular relevance for individuals with cerebral palsy, as they often lack coordination to expectorate effectively, thus causing a greater risk of pneumonia; those with oropharyngeal involvement experience the added complication being at risk for aspiration (Blair, 2010). Death due to respiratory causes are more common in the population of individuals with cerebral palsy compared to the general United Kingdom population in 2001, especially for those younger than 40 years (Hemming et al., 2006).

Respiratory conditions were the leading cause of death upon examination of the death certificates of 17,897 individuals with Down syndrome from the United States during 1983 to 1997 (Yang et al., 2002). Standardized mortality odds ratios showed that individuals with Down syndrome had a greater likelihood of having aspiration, pneumonia or influenza on their death certificate (Yang et al., 2002). In an Australian study of 1,332 individuals with Down syndrome, health records from 1953 to 2000 indicated that respiratory infections or pneumonia were the leading cause of death for 40% of those older than 40 years (Bittles, Bower, Hussain & Glasson, 2006).

3.3.4 Hypothyroidism

Thyroid conditions are also a health challenge for adults with developmental disabilities. In a 10 year longitudinal study of individuals with Down syndrome, the prevalence rate of hypothyroidism was 10.5%, with the majority being over 40 years old, and those with subclinical hypothyroidism having a 13.6% incidence rate of developing clinical hypothyroidism over a ten year period (Prasher & Gomez, 2006). Of 17,897 Americans with Down syndrome, standardized mortality odds ratios showed a greater likelihood of having hypothyroidism (Yang et al., 2002).

Monitoring is importance because if hypothyroidism is left untreated symptoms may go unnoticed because they are characteristic of individuals with Down syndrome, such a reduced energy or motivation, dry skin, excess weight, and bradycardia (Smith, 2001). A decline in cognitive functioning, due to hypothyroidism, may be wrongly attributed to Alzheimer's disease (Prasher & Gomez, 2006).

3.3.5 Cancer

Higher rates of certain types of cancers are evidenced in adults aging with developmental disabilities. As cited under gender earlier in a sample of 9409 individuals with developmental disabilities, males had a greater risk for leukemia, brain and stomach cancer and women had a higher risk for leukemia, corpus uteri, and colorectal cancers (Sullivan, Hussain, Threlfall & Bittles, 2004). Another study identified cancer of the gallbladder, brain and testicular cancer to have a higher risk among individuals with developmental disabilities (Patja & Livananien, 2001). The frequent occurrence of Helicobacter pylori infections among those with developmental disabilities is a concern, evidenced in an Australian study as double the rate in the normal population; 87% for those in institutionalized settings, 79% in previously institutionalized settings and 44% in community settings (Wallance, Schluter & Webb, 2002). This rate is noteworthy because stomach cancer, attributed to helicobater pylori, contributes to nearly half of all cancer related deaths for adults with developmental disabilities in a 50 year retrospective analysis of cancer deaths in the United Kingdom (Duff, Scheepers, Cooper, Hoghton & Baddeley, 2001).

From a syndrome specific perspective, the incidence of cancer is high in those with Down syndrome. In a cohort of 4872 individuals with Down syndrome from Sweden and Denmark, from 1965 to 1989, there was an elevated risk of incident acute lymphatic and nonlymphotic leukemias, testicular cancer, liver cancer, and stomach cancer (Hill, Gridley, Cnattingius, Mellemkjaer, Linet, Adami, et al., 2003). The death certificates of 17,897 individuals with Down syndrome from the United States were studied from 1983 to 1997 showing that those with Down syndrome had a greater likelihood of having a leukemia diagnosis on their death certificate, than those without Down syndrome (Yang et al., 2002). In a Finnish study of 3,581 individuals with Down syndrome, Patja and colleagues (2006) found a significantly high standardized incidence ratio for risk of leukemia and testicular cancer.

Few studies have examined the rates of breast cancer in women with developmental disabilities; one exception is Sullivan et al. (2003). The researchers identified breast cancer incidence from 1982-2000 using data from a national cancer registry. While findings reflected lower rates of the disease in women with developmental disability compared to the general population, a significant increase was noted in the rate for this population group in the latter years of the study.

Key points:

- ***Higher rates of certain types of cancers are evidenced in adults aging with developmental disabilities.***

3.4 Impediments to Aging Well with a Developmental Disability

The challenges of health promotion, the prevention, detection, treatment, management of health conditions, and minimization of their impact on well-being are similar for all individuals across the life course. However, adults with developmental disabilities may experience the aging process from different and disadvantageous starting points than the general population. Factors such as genetic make-up, lifestyle, health conditions and medical treatments, disadvantaged socio-economic status, and poor healthcare experienced in the earlier parts of their lives singly or in combination have a detrimentally impact on the aging process and quality of life.

3.4.1 Identification and Diagnosis of Health Challenges

In a study in the United Kingdom in the late 1990s, the majority of 126 general practitioners believed that they had a responsibility to provide medical services to adults with developmental disabilities but they strongly disagreed whether they should perform annual health checks or hearing /vision tests (Kerr, Dunstan & Thapar, 1996). At the same time, the literature shows that in a population of individuals with Down syndrome, nearly half lacked physician care within a year and 38% had not seen a physician in three years (Henderson, Lynch & Wilkinson, 2007). Whereas, Kirby and Hegarty (2010) reported that nurses working in developmental disability settings did not promote breast awareness for women with developmental disabilities.

Many adults with developmental disabilities are not included in screening programs for age-related conditions such as prostate cancer or breast cancer. It is not clear whether the reasons for this relate to their omission from databases and therefore a failure to invite participation or whether such invitations are not seen as relevant by them or care providers supporting them. One British study suggested the former might be the case (Davies & Duff, 2010). The result of this may be that health problems are not identified until they are well advanced, meaning that treatment may be more invasive or less effective.

The early symptoms of Alzheimer's disease are similar to those of a number of conditions, many of which can be treated. These include depression, thyroid dysfunction, diabetes, poor diet, sensory loss, and urinary tract infections. It is important to pursue a thorough diagnostic procedure to identify such conditions rather than assume an individual has Alzheimer's disease. This imperative is complicated by the inherent difficulties of diagnosing Alzheimer's disease in adults with developmental disabilities. Essentially diagnosis involves identifying a pattern of change in an individual's functional capacity over time and must therefore use previous levels of functioning as the benchmark. Standard measures of functioning and diagnostic tests based on population norms are not appropriate for use with adults with developmental disabilities. In addition, the interactions of age-related change with long-term conditions may mean atypical presentation of conditions which contributes to a timely diagnosis.

Communication problems often make the identification of ill health or pain difficult. The difficulties of trying to communicate what is happening in one's body, the way it feels, and the discomfort experienced are magnified for adults with communication problems. Strauss et al. (1999) suggested that verbal communication impairments could impact the reporting of symptoms and subsequent early screening and recognition of cancer in populations of individuals with developmental disabilities.

Even when health practitioners are skilled in communicating with adults with developmental disabilities, additional time is required and heavy reliance may have to be placed on second hand descriptions of symptoms and changes. Placing these in the context an individual's medical history may be difficult. For those who live in supported accommodation, staff turnover or the process of deinstitutionalize may means that an individual's history is lost or forgotten (Bigby et al. 2002).

Individuals with developmental disabilities often have little understanding of the aging process and may have had poor experiences of health treatment in the past. Lack of health knowledge or understanding of procedures diminishes one's confidence and can result in confusion and lack of cooperation. The physical inaccessibility or equipment of examination rooms for adults with physical disabilities adds to the difficulties of diagnoses.

Assessment for health conditions is often confounded with co-morbidities in addition to underlying cognitive and functional impairments related to the presence of a developmental disability. Because cognitive or communication impairments many contribute to delayed reporting of symptoms with this population, there is a greater need for interprofessional communication between disciplines to achieve quality health care (Sullivan, Hussain, Threlfall & Bittles, 2004). In the case of assessing dementia in this population, for example, it must be integration of complex medical histories, mental status, cognitive functioning, and physical findings (Torr, 2010).

Coppus et al. (2006) noted a significant relationship between dementia and depression history and the use of anti-epileptic medications. This finding highlights the importance of carefully assessment and monitoring to avoid misdiagnosis of dementia due to an underlying depression or epilepsy. Hypothyroidism is another differential diagnosis that the literature suggests ought to be considered because symptoms can be confused for dementia (Deb, 2003).

Cooper et al.'s (2006)'s study provided evidence of the value of health screening compared to standard treatment in a sample of people with developmental disability; reporting a twofold increase in the identification of health needs as well as a significant increase in meeting these new health needs, health promotion and health monitoring. Other health risks for aging individuals with developmental disabilities that should be monitored include hearing, vision, nutrition, activity, obesity, oral health, gastroesophageal reflux disease, constipation, osteoporosis, and tobacco use (Haveman et al. 2010; Krahn, Hammond & Turner, 2006).

Key points:

- ***Many adults with developmental disabilities are not included in screening programs for age-related conditions such as prostate cancer or breast cancer.***
- ***Communication problems often make the identification of ill health or pain difficult***

3.4.2 Pain

A particular difficult health challenge for adults with developmental disabilities is identification of pain and expression of the need for relief of it. It is surprising that the topic of pain has not been well discussed in the published literature of adults with who are aging with developmental disabilities. While Svien and associates (2008) for example address the occurrence of pain in adults aging with cerebral palsy, they do and Rosenbloom (2004).

Pain may be communicated in different ways for this unique group of aging adults. Examples of pain related behaviour may include self-distracting activities such as rocking or pacing, withdrawal, and autonomic changes (increased pulse rate).

Key points:

- ***The lived experience of pain in individuals who are aging with a developmental disability is under investigated.***

3.4.3 Socio / Economic / Environmental Factors

Adults with developmental disabilities are especially vulnerable to poverty and restricted access to medical, dental, and related health services that arise from this reality. Availability of medications, alternative therapies, health care supports, and environmental modifications may be beyond available financial resources.

A study was done in Ontario by Cleaver and associates (2008) to determine the relationship between mobility limitations and place of residence for adults with developmental disabilities over 45 years of age. A proxy response telephone survey was conducted for 128 adults. A participant's place of residence was classified as high support (e.g. group home, nursing home) and low support (living alone, with family, roommate). After adjusting for age, sex, presence of cerebral palsy, communication and behaviour problems, adults with mobility problems had a 3.6 times greater odds of living in high support settings. This is noteworthy for with age comes mobility restrictions, which are associated with increased mortality and negative health as mentioned earlier.

Key points:

- ***Individuals who are aging with disabilities are particularly vulnerable to poverty and restricted access to medical, dental, and allied health services.***

3.4.4 Institutionalization: Helicobater phlori (HP)

Findings by Clarke and associates (2007) suggested that adults hospitalized with developmental disabilities experienced Helicobater phlori (HP) infections at rates higher than those for adults in the general population. This recent finding supported the earlier work of Kennedy (2002), in Canada, who identified that 80% of participants who had formerly been institutionalized experienced Helicobater phlori (HP) infections. The latter reported HP prevalence rates for adults with developmental disabilities seem to be higher than in the general population where rates vary from 25-30%.

These high rates are disconcerting since HP can contribute to more serious health challenges, e.g. peptic ulcers and gastric cancer.

3.5 Promising Practices

Adults with developmental disabilities are not generally included in health promotion programs and have poor access to screening programs and accessible information about health (Heller & Marks, 2002; Howells, 1986; Lennox et al. 2001). The implication is that these adults experience aging from a position of vulnerability rather than strength.

Supporting individuals who are aging with developmental disabilities to change aspects of their lifestyle and health behaviours is an important strategy. Participation in structured exercise programs, restructuring everyday life to extend the amount of physical activity and health education have the potential to build a healthier lifestyle. Research by Heller and colleagues (2004) demonstrated the ability of older adults with developmental disabilities to participate and enjoy structured exercise programs as well as exercise choice and gain new knowledge and skills.

Key points:

- ***Individuals who are aging with developmental disabilities have the ability to be active participants in their own aging and health care.***
- ***Elements of good practice in working with adults who are aging with developmental disabilities are similar across the life course.***

Discussion of Findings

4.1 Interrelationship of Existing Conditions with Age-related Changes

There is a need to understand biological aging and functioning throughout the life span of adults who are aging with developmental disabilities. The pre-existing health conditions of some adults with developmental disabilities may increase their risk of or the impact of age-related diseases. For example, many people with Down's syndrome experience sensory loss in childhood. Thus for them the impact of age-related sensory change will be much higher than if no previous loss has been experienced. Long-term use of medication to control seizures may also increase the risk of osteoporosis. Chronic health conditions may be compounded by age-related changes.

Many of the impediments to optimal health for adults who are aging with developmental disabilities are the same as those encountered earlier on the life course, although they may be compounded by age-related factors. They stem from individual characteristics and the social context. The nature of formal supports, in particular the skills and knowledge of support or health care staff involved in individual planning and delivery of personal care, is critical. These in turn are allied to the nature of organizations, service systems, and the socio-political environment that guide their actions.

Health-related changes will be greater when compounded or interrelated with pre-existing health conditions or physical and sensory impairment. The impact may also be greater because of the reduced adaptive capacity of adults with developmental disabilities. For example, difficulties if adapting to or learning to use aids such as hearing aids, glasses, or walkers may be exacerbated in adults with developmental disabilities. Staff attitudes and support to learn or persevere with such aids are critical in this respect. If staff underestimates an individual's potential for social engagement, they unlikely to encourage the wearing of glasses or a hearing aid.

4.2 Individual Adaptation

Adults aging with developmental disabilities have very little general health or sex education and thus limited knowledge on which to build understanding of age specific challenges. For example, work by McCarthy (2002) demonstrated the absence of knowledge about menopause and its symptoms amongst women with developmental disability. This finding illustrate some obstacles to promote learning about age-related issues for individuals, and the importance of supportive staff and / or family members who in turn have access to education, support, or specialist materials.

Adequate surveillance of individual health conditions by regular participation in health screening and comprehensive health checks are essential to early detection and treatment of health conditions. It is recommended that, like the general population of older adults, adults who are aging with a developmental disability have regular screening for age onset conditions such as breast, skin, prostate, cervical and colon cancer, diabetes, and regular hearing, dental and vision evaluations (Evenhuis, Henderson, et al. 2001). In addition, blood pressure, cholesterol and iron levels should be regularly checked. A proactive approach to such health screens by building them into a yearly calendar will help ensure regularity and reduce reliance on sometimes inefficient invitations from health care providers.

4.3 Issues of Dying

Death and dying remain largely neglected issues. One of the few studies about death was completed by Brown et al. (2002) who found that while specialist developmental disability services were willing to accommodate death and support people to die at home, they were generally unprepared for the issues that arose.

Dilemmas exist across the life course in respect to decisions regarding the provision of health care for people with developmental disabilities - its initiation, continuation, withholding, and withdrawal. These persons, when are alternative legal decision-making processes necessary, aim upon what basis are decisions made by others - notions of best interest or substituted judgment. Many of these issues are particularly relevant to adults who are aging with developmental disabilities in regard to whom decisions such as the withdrawal of active treatment, transition from curative to palliative care, and where to die will be confronted more often as they are supported to die.

The unique circumstances of each individual should determine the nature of decisions about health treatment and appropriate decision-making processes. However, these should be informed by best practices surrounding a 'good' death. Throughout their life, many decisions for adults with developmental disabilities are informally made by others, usually parents, without recourse to formal legal processes, informed by the principle of the least restrictive alternative. Reliance on the informal may however be more difficult for an older adult whose parents have died and for whom an informal substitute decision maker may not be apparent. To ensure speedy decisions that do not disadvantage the adult by delaying appropriate actions, decision-making processes and preferences articulated by the person themselves or others close to them should be clearly documented and acknowledged by all those involved with their care. Decisions about day-to-day care should be made by those carers most involved with the person and this approach documented in a care plan. Decisions that depart from normal clinical pathways or other significant end-of-life decisions, such as cessation of active treatment, should be made in a formal case conference involving those providing care and others who are close to the adult who is aging with a developmental disability.

The obstacles experienced by adults with developmental disabilities in dealing with grief following the death of loved ones, (such as a father or mother) arises from the misconceptions of others and from their own individual characteristics such as communication difficulties and negative life experiences. If older adults with developmental disabilities are to negotiate and cope with the multiple changes and losses that occur in later life, a critical first step is the acknowledgement of them of as emotional beings, with similar feelings and needs to express and resolve them as do all older adults in the general population. This means the adoption of strategies across the lifecycle to increase protective factors and bolster their coping skills are important health care strategies.

Individuals with developmental disabilities should have the same access to palliative care as other members of the community, although its provision must take account their social context and possible communication difficulties. For example, the focus of palliative care is usually the patient and family, but for adults with developmental disabilities living in supported accommodation this may have to be broadened to include formal care givers. However, support staff may have little knowledge or experience of death and dying and require education so that they may better support an aging adult with a developmental disability who is grieving.

Key points:

- ***Death and dying remain largely neglected issues***

4.4 Promoting Health in Individuals Aging with a Developmental Disability

Good health is the outcome of the complex interaction of a multiple of factors stemming from both the individual and the environment. Access to quality healthcare is a necessary but not sufficient condition for maintaining health into later life. Multiple strategies that address prevention, surveillance, treatment, and adaption are necessary.

Preventative strategies should start early in life and be supported by prompt identification and recognition of problems, assessment, and appropriate treatment throughout life. As with physical heath, a key to ensuring good mental health is good communication, an orientation by professionals and family that is sensitive to and explores any changes in behaviour and a dogged approach to; ensuring appropriate investigation occurs, and treatment and support provided. In relation to aging, this necessitates combining knowledge and understanding from multiple sectors, developmental disability, mental health, dual diagnosis, and pyschogeriatrics.

Elements of good practice in working with adults who are aging with developmental disability are similar to those implemented across the life course. For example, attention to communication strategies and simple adaptations to the environment can optimize involvement and social and their ability to engage in daily activities. Similarly, these elements can compensate for age-related changes, particularly those of a sensory nature.

With increasing age, research has validated the expected belief that engagement and minimization of life stressor have preventative value and can lead to prolonged life and stable health status. Life factors that provide for sound nutrition, access to valued activities, safe and pleasant housing, and intellectual challenge can minimize stress organic or environmentally derived psychopathology and reactive behaviours. A quality old age for adults who are aging with developmental disabilities will be based on the same factors that provide for quality old age among other persons (Thorpe et al. 2001). By normative standards adults who are aging with developmental disabilities will have fulfilled few of the standard life goals in terms of occupation, family formation, or social status.

FUTURE DIRECTIONS

There are a number of possible directions that might be followed based upon this review, which includes:

Dialogue with adults who are aging with a developmental disability how to best empower them to participate in their own health care.
Rationale: Such action is consistent with basic principles and practices of normalization and rights recognition.

Consider the development of a health promotion policy / program specific to aging with a developmental disability for adults who are aging with a developmental disability.
Rationale: Interventions need to target these health inequalities and focus on health promotion and prevention to reduce the mortality rate of individuals aging with developmental disabilities (Long & Kavarian, 2008; Tyrer & McGrother, 2009).

Adults who are aging with a developmental disability need to be educated, as they tend to lack knowledge of the age related issues they face. Providing them with accessible information at a level they can understand will in turn enhance their ability to communicate with health care professionals or at least communicate with their support workers who can then relay the information if needed.
Establish a task force of health care professionals, practitioners, and policy makers to create curricula to improve knowledge and clinical practice skills.
Rationale: health care professionals lack knowledge and skills specific to the health care needs of adults who are aging with developmental disabilities. Since many health problems go undetected by the population of individuals with developmental disabilities, it is important that primary care health care professionals are aware of the increased risk for specific health conditions that can impact quality of life for this population, are

watchful for these conditions, and ensure periodic monitoring for potential complications (Baxter et al., 2006; Finesilver, 2002).

Expand the current research base by including qualitative studies.
Rationale: while adults with developmental disabilities are living longer, relatively little is known about their day-to-day "lived" experience of aging with health concerns. An exception is the work of Salvatori, Tremblay, and Tryssenaar (2003) who completed a qualitative study on this topic in Ontario.

Conclusion

Life expectancy for adults aging with developmental disabilities is lengthening towards that of adults without such disabilities. However, research findings indicate that this aging is relatively often not a healthy one.

Adults aging with development disabilities probably encompass an even greater heterogeneity than is found in the general aging population. Every individual needs to be evaluated individually in the context of his or her unique history and special concerns.

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Assessing the Health of Older Adults with Developmental Disabilities

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Introduction

Older people with developmental disabilities are living longer due to a number of factors including advances in medical and social services, advocacy of families and people with disabilities, the adoption of de-institutionalization practices and normalization philosophies by most governments, and the development of community-based services with professionally-trained staff. In fact, most people with developmental disabilities have a life expectancy similar to that of other people without developmental disabilities, although people with Down's syndrome tend to have a shortened lifespan.[2]

As people age they are more likely to develop age-related health concerns. Early detection and intervention is critical because many of these health concerns are preventable treatable and can be made less problematic. This is particularly true of older adults with developmental disabilities.

Some adults with developmental disabilities have a higher level of unmet health needs as compared to adults without developmental disabilities in the general population.[3] However, these older adults can experience a delay in treatment due to a number of issues including: poor or non-existent health screening; a communication issues between the individual with the developmental disability and the provider as well as between health and disability providers; an over-shadowing of the developmental disability; a lack of knowledge and training of those (e.g., staff, family, friends) supporting the older adult; a lack of age appropriate health care service; and, a lack of non-paid social connections for people with developmental disabilities which increases the risk of neglect, abuse, and complacency with the status quo.

The purpose of this paper is to provide guidance regarding screening strategies and tools which would contribute to the monitoring and enhancement of the health, function and safety of older adults with developmental disabilities. This paper is part of a larger study initiated by the Calgary Region Community Board, Persons with Developmental Disabilities in May 2011. An earlier paper, as part of this study, provided an overview of the manifestation of age-related diseases and syndromes in adults with developmental disabilities.[4] This paper is designed to provide guidance for administrators, service providers and families and guardians of older adults with developmental disabilities and considers the screening and prevention of health concerns from the perspective of the disability services and funders' perspective.

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[3] Cooper, S.A., Morrison, J., Melville, C., Finlayson, J., Allan, L., Martin, G., & Robinson, N. (2006). Improving the health of people with intellectual disabilities: Outcomes of a health screening program after 1 year. Journal of Intellectual Disability Research, 50, 667-677.

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Maintaining the health and safety of older adults with developmental disabilities requires a collaborative effort with health care professionals and funders. Health care providers have their own screening, assessment, and intervention strategies for older adults in general. The approach and choice of the assessment and screening tool tends to be dependent upon the professionals' discipline, their employer, their role, and the resources available to them. Many health care providers offer little or no training to their staff in working with older adults with developmental disabilities. This paper is not meant to be redundant on their practices but rather to compliment and inform them. Specifically, this paper addresses the following five questions:

1. How to best capture data on health data for the population of adults with developmental disabilities in the greater Calgary area?
2. What data should be captured on health status and needs?
3. What measures exist or could be adapted for capturing health status and needs data?
4. What are the practicalities of maintaining a health surveillance and health data system?
5. How should these assessments might contribute to an overall ascertainment of risk or need due to age?
6. What are the recommendations for implementing such an effort?

Health Status of Older Adults with Developmental Disabilities

Surveillance Strategies

The monitoring of the health of individual adults with developmental disabilities should be a standard practice of disability service providers. Monitoring any changes in the physical and mental health, sleep and eating patterns, functional skills, cognitive functioning, motivation and socialization of the men and women for whom they are responsible to provide services is part of a comprehensive support model. Disability agencies may be hampered in completing this responsibility for a number of reasons including: poorly trained and supervised personnel, inability to access proper medical support, and an emphasis on program planning rather than holistic service management. Every effort needs to be made by CRCB to identify those agencies that are having difficulty fulfilling this responsibility and provide them with the necessary support so that adults with developmental disabilities are at a reduced risk of having their health concerns neglected.

Health surveillance of the population of adults with developmental disabilities in the Calgary Region would assist CRCB and others (e.g., Integrated Seniors Health - Alberta Health Services, Addictions and Mental Health Services – Alberta Health Services) in planning and the allocation of resources and maintaining long range plans to support this population.

CRCB currently collects information on the level and type of supports adults with developmental disabilities who are receiving Persons with Developmental Disabilities (PDD) funds in the region. This information is acquired through a number of sources including funding requests. Recently, the Supports Intensity Scale (SIS) has been introduced as a systematic strategy to document this information at an individual level, which in turn, at an aggregate-results level, could be used as a population-based planning tool. Although the SIS will be useful in planning for services for older adults with developmental disabilities other strategies and tools which should be used in conjunction with the SIS to specifically monitor the health of the population of individuals with developmental disabilities.

According to the Public Health Agency of Canada, health surveillance strategies should be: sensitive, specific, easy to perform and interpret, safe, non-invasive, and acceptable.[5] For people with developmental disabilities and their families the strategies employed would need to reflect a respect for individual choice and confidentiality. Disability service organizations would be more likely to implement the strategies if they did not require a lot of administrative work and recording and if they were viewed as part of the annual planning sessions with adults with disabilities and their families.

Health surveillance is important as people are both to track the trajectories of existing and newly emerging conditions and for planning prevention and life-enhancing strategies. Any regional health monitoring process should have as its goals, the improvement of health status in the early aging populations – so as to ensure healthy aging and longevity, and the early identification and treatment of age-related health conditions so as minimize the incidence of life-threatening or impairing disease and improve overall quality of life.

People with Developmental Disabilities' Role

Older adults with developmental disabilities should be active participants in managing and monitoring their health. In order to fulfill this role, these individuals will need assistance and support from their social support network, and their staff. Adults with developmental disabilities would need to give permission for disability agencies and other organizations to maintain health surveillance information on them.

Families, Guardians and Advocates' Role

Families, guardians and advocates of older adults with developmental disabilities can assist in the maintenance and monitoring of the health of these adults. Given that a number of older adults are living with their parents and/or siblings or are involved in Family Managed Supports, health-related decisions are managed directly by the families and guardians, depending on the level of independence the person with the developmental disability has in this area. For older adults residing in a residential situation monitored by a disability service provider, both the provider and the family will work together to ensure that the individual has their health care needs identified and met.

Disability Service Provider's Role

Having well-qualified personnel who understand the importance of health care monitoring and who know the person with the developmental disability will be critical in the proper monitoring of health care issues and status. Given that a number of adults with developmental disabilities may have communication it will be important for the disability services professionals to attend to nuances in the person's behaviour which may indicate a change in their health status. Documentation of the health status of the individual will be important given the changes in staffing due to staff shifts, multiple agencies providing services, and staff turnover rates. Disability service providers also have a role in ensuring the individual is receiving proper health care, is involved in making health decisions (e.g., him or herself or via a health advocate), and is involved in activities that contribute to the enhancement or maintenance of the person's health

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[5] http://www.agius.com/hew/resource/surv.htm

status. The disability service provider will need to work collaboratively with health care providers, including home care, to ensure the older adult with developmental disabilities has the health care services they require.

CRCB's Role

Working with disability service providers and health care providers to clarify the minimum standards for health care monitoring utilized by disability services providers would be a role CRCB may assume. Similarly CRCB may consider working with multiple stakeholders to identify strategies to fund the on-going development of disability service personnel in relation to their skills and awareness of the importance of maintaining and monitoring the health status of adults with the development disabilities.

Primary Health Care Providers' Role

Providing appropriate, adequate and accessible health care for adults with developmental disabilities is a critical role of health care providers. Unfortunately in Calgary there is a shortage of primary health care physicians. Also, historically family physicians have not received a lot of training in providing health care support to people with developmental disabilities. The Canadian Medical Association has released guidelines for family physicians on the providing medical care to a person with a developmental disability.[6] The American Board of Family Medicine also published a paper which provides guidance regarding strategies to make screening procedures less stressful for adults with developmental disabilities.[7] On-going education of health professionals that addresses attitudinal, communication, programmatic, and physical barriers experienced by people with developmental disabilities accessing the health care system will also necessary.

Public Health Professionals' Role

Public health information is generally not being used with older adults with developmental disabilities, although it would contribute to their health.[8] This would include the education of the adults, their service providers, and family members of what constitutes a healthy lifestyle for the older adult with developmental disabilities. This lifestyle information would include information on diet and exercise given the incidence of obesity and the lack of exercise in adults with developmental disabilities.[9] Health promotion material designed for people with developmental disabilities (e.g., *Taking charge: Responding to Abuse, Neglect, and Financial Exploitation,* and *Looking after My Own Breasts)* would facilitate their active participation in their own health care.[10]

Health Information Requirements

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[6] http://171.66.125.180/content/52/11/1410.full.pdf

[7] Wilkinson, J. E., Culpepper, L. and Cerreto, M. (2007). Screening Tests for Adults with Intellectual Disabilities, Journal of the American Board of Family Medicine, 20(4), 399-407.

[8] Marks, B. A. and Heller, T. (2003). Bridging the equity gap: health promotion for adults with intellectual and developmental disabilities, Nursing Clinics of North America, 38, 205-228.

[9] Haveman, M., Heller, T., Lee, L., Maaskant, M. Shooshtari, S. and Strydom (2010), A. Major health risks in aging persons with intellectual disabilities: An overview of recent studies, Journal of Policy and Practice in Intellectual Disabilities, 7(1), 59-69.

[10] Marks, B. A. and Heller, T. (2003). Bridging the equity gap: health promotion for adults with intellectual and developmental disabilities, Nursing Clinics of North America, 38, 205-228.

The general health information that needs to be collected and maintained on older adults with developmental disabilities is similar to the information that should be gathered throughout their lifetime with the exception of a greater focus on issues related to aging. Specifically, at a minimum an annual health status screening conducted by the disability service provider needs to document changes in the individual which may be related to aging and so that long-term support and financial plans can be developed.

The functional assessment needs to document the individual's current abilities and/or levels of support in relation to those they have demonstrated or required throughout their lifetime. This functional assessment should be based on observation, self-report, and informant input.

Similar to other adults without developmental disabilities we would except to see changes in four areas: mobility (e.g., strength, endurance, balance, reaction time, self-care), sensory ability (i.e., vision, hearing), overall physical health, and cognitive functioning (e.g., memory). Appropriate screening should ensure that the presenting changes in behaviour are not related to a non-age-related illness. Assessments that distinguish between changes in behaviour due to aging and those related to a lifelong developmental disability will assist with differentiating age-related issues from disability or secondary condition issues. Middle-age health surveillance should begin in the 40s, with special attention to adults with syndromes that present with particular risk (e.g., Down syndrome) in this age group due to precocious aging or impaired reserve.

Disability services and health care providers will each have their own strategies and tools for collecting health care information on older adults with developmental disabilities. Collaboration between the two sectors that would reduce redundancy or inconsistencies in screening and assessment and lead to quicker and appropriate health care support for older adults with developmental disabilities would be beneficial.

The following is a suggested series of questions in four areas: general health, social supports/community inclusion, and support services which may be beneficial as a checklist for disability service providers and may be useful information for health surveillance of the adults with developmental disability population.

Figure 1. Questions for Health Status Surveillance

General Health

- Is there a concern that the older adult is demonstrating: increased risk of falling;
- increased lack of memory or confusion regarding names, places, events; and, increased fatigue?
- Has the adult had an annual comprehensive preventive care assessment including physical, dental, and optical examinations and the appropriate age-related, dementia, sex-related screening, and medication review completed?
- Have possible mental health causes of the changes in behaviour and support needs been eliminated?
- Have risk factors such as caregiver stress, abuse, neglect been eliminated as contributing factors in the changes in behaviour and support needs?
- Is the adult involved in leisure, recreation, and physical exercise activities appropriate to his/her age and health needs?
- Is the adult eating a well-balanced and nutritious diet appropriate to their age and activity level?
- Is the adult being taught how to be an active member in their own health maintenance?

Social Supports/Community Inclusion

- Does the individual have a well-developed social support network? How often is she or he able to communicate/engage with each member of their network? What types of supports does each member of the network provide (e.g., emotional, advice, financial, instrumental)? What types of supports does the person need?
- Does the adult have a non-paid individual(s) who the adult with the disability can confide in and who is willing and able to advocate for them?

Support Services

- Are the adult’s residential and day services: available, appropriate, accessible, acceptable and adequate?
- Are the personnel in these support services adequately trained and supervised to support an older adult with a developmental disability?
- Are physical modifications to the environment necessary to support the older adult with a developmental disability?
- Are there potential issues that will impact the permanency of the current residential placement?
- How is the day support being modified to reflect the needs of the older adult with a developmental disability?

Health Status Measures

Health Screening Tools used with the Non-developmental Disabled Population

There are numerous tools identified in the literature and in clinical practice that are relevant to the health assessment of older adults. The following are a sample of tools recommended as best practices by the John A. Hartford Foundation, the Canadian Coalition for Seniors Mental Health, and Registered Nurses Association of Ontario (RNAO) Best Practice Guidelines. In this section the tools are divided into those used to screen general health, those used for screening specific issues (e.g., dementia), and those focused on screening for changes in daily living activities. It should be noted that these tools may be appropriated with some older adults with developmental disabilities, - those marginally impaired and integrated into the general population.

Screening for General Health

The following screening tools are used to screen for general health of older adults.

SPICES

Fulmer SPICES is a framework for assessing older adults. It focuses on six common "marker conditions": sleep problems, problems with eating and feeding, incontinence, confusion, evidence of falls, and skin breakdown. These conditions provide a snapshot of a patient's overall health and the quality of care. The SPICES assessment, done regularly, can signal the need for more specific assessment and lead to the prevention and treatment of these common conditions.[11] SPICES is an acronym for the common syndromes of the elderly requiring nursing intervention: S is for Sleep Disorders, P is for Problems with Eating or Feeding, I is for Incontinence, C is for Confusion, E is for Evidence of Falls, S is for Skin Breakdown. It should be noted that validity and reliability measures have not been completed on SPICES. SPICE is typically used in a hospital setting.

Geriatric Health Questionnaire

The Geriatric Health Questionnaire is nine-question self-report interview form. It covers items of general health, activities of daily living, hearing, memory, ability to read time, depression, risk of falling, and sexual activity. Completing the form does not require any professional training. The results provide a broad and general baseline of the person’s perceived health, ability, and activity levels.

The Resident Assessment Instrument (InteRAI - Home Care)

The Resident Assessment Instrument Minimum Data Set 2.0 (RAI-MDS2.0) is a standardized, automated common assessment instrument that is implemented in all long-term care facilities across Alberta and in many other Canadian provinces. It may be defined as "a core set of screening, clinical and functional status elements, including common definitions and coding categories, that forms the foundation of the comprehensive assessment for all residents of long-term care facilities”.[12] In brief, it is a comprehensive, standardized tool to assess residents in long-term care settings. Assessment with this tool enables detection of residents' strengths, needs, and potential risks to inform individualized care planning and monitoring. Typically, data collected from residents in a facility is aggregated to produce indicators of the quality of care provided (i.e., quality indicators) at both individual and

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[11] http://www.nursingcenter.com/prodev/ce_article.asp?tid=742423

[12] http://www.virec.research.va.gov/DataSourcesName/RAI-MDS/RAI-MDS.htm

facility levels. It should be noted that there is currently a transition to MDS 3. This tool can be modified depending on population group.[13]

Screening for Specific Issues

The following screening tools are used to screen for abnormalities or pathologies in specific areas of functioning.

Mini-Mental StateExam[14]

The Mini-Mental State Examination (MMSE) is a widely used, well-validated screening tool for cognitive impairment in the general population. It briefly measures orientation to time and place, immediate recall, short-term verbal memory, calculation, language, and construct ability. Each area tested has a designated point value, with the maximum possible score on the MMSE being 30/30. Since 1993 the MMSE has been available with an attached table that enables patient–specific norms to be identified on the basis of age and educational level. The MMSE tends not to be used with individuals with intellectually-based developmental disabilities.

Sleep Quality - The Pittsburgh Sleep Quality Index (PSQI)

The Pittsburgh Sleep Quality Index (PSQI) is an effective instrument used to measure the quality and patterns of sleep in the older adult. It differentiates “poor” from “good” sleep by measuring seven areas: subjective sleep quality, sleep latency, sleep duration, habitual sleep efficiency, sleep disturbances, use of sleeping medication, and daytime dysfunction over the last month. The client self-rates each of these seven areas of sleep. Scoring of answers is based on a 0 to 3 scale, whereby a score of 3 reflects the negative extreme on the Likert Scale.[15] A global sum of “5” or greater indicates a “poor” sleeper. Although there are several questions that request the evaluation of the client’s bedmate or roommate, these are not scored.

The Kayser-Jones Brief Oral Health Status Examination (BOHSE)

The 10-item examiner-rated BOHSE reflects oral health status and a higher score indicates more problems identified. The BOHSE assessment begins with observation and palpation for enlarged lymph nodes in the neck and ends with oral cavity evaluation. Using a pen light, tongue depressor, and gauze, the conditions of the oral cavity, surrounding tissues, and natural/artificial teeth are examined and graded on three descriptors. It has been primarily used in long-term care and community settings.[16]

Katz’s Activities of Daily Living

The Katz Index of Independence in Activities of Daily Living, commonly referred to as the Katz ADL, is the most appropriate instrument to assess functional status as a measurement of the client’s ability to perform activities of daily living independently. Clinicians typically use the tool to detect problems in performing activities of daily living and to plan care accordingly. The Index ranks adequacy of performance in the six functions of bathing, dressing, toileting, transferring, continence, and feeding. Clients are scored yes/no for

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[13] http://www.interrai.org

[14] http://www.palliative.org/PC/ClinicalInfo/AssessmentTools/instruct%20for%20admin%20mmse.pdf

[15] http://consultgerirn.org/uploads/File/trythis/try_this_6_1.pdf

[16] http://consultgerirn.org/uploads/File/trythis/try_this_18.pdf

independence in each of the six functions. A score of 6 indicates full function, 4 indicates moderate impairment, and 2 or less indicates severe functional impairment.[17] Although the Katz ADL Index is sensitive to changes in declining health status, it is limited in its ability to measure small increments of change seen in the rehabilitation of older adults. A full comprehensive geriatric assessment should follow when appropriate.[18]

Health Screening Tools for Older Adults with Developmental Disabilities

Regular screening for functional and cognitive decline can assist disability service organizations supporting an older adult with developmental disabilities in their individual client planning as well as developing a resource allocation for the organization.

Mental Health Screening[19]

Screening instruments exist for various mental disorders in intellectual disabilities, including the Reiss screen, the Mini-PAS-ADD, and the PASS-ADD Checklist. These instruments are not sufficiently specific or sensitive to make a diagnosis, but are useful to indicate the need to obtain further mental health assessment. Instruments designed for specific disorders, such as the Beck Depression Inventory and the Depression Scale have been adapted and simplified for use in intellectual disabilities. These, as well as others such as the Hamilton Rating Scale for Depression have been used successfully to assess depression in people with intellectual disabilities and mental disorders. Typically, the disability service provider in discussions with the family and/or guardians and through on-going observations recognizes a pattern or change in the individual’s behaviour that they feel warrants closer examination and treatment by a health care professional. A direct referral or one through the individual’s family physician is made to the mental health providers for a detailed assessment.

Dementia screening- Dementia Screening Questionnaire for individuals with Intellectual Disabilities (DSQIID)[20]

This is one of the instruments in use for assessing behaviour and indicating whether the changes are due to a disease or organic process leading to dementia. One instrument examined appeared to have the most utility for use by staff and family carers as a ‘first-instance’ screen. The Dementia Screening Questionnaire for individuals with Intellectual Disabilities (DSQIID), developed by Dr. Shoumitro Deb at the University of Birmingham. The DSQIID, which is used in a various parts of the world, is an informant-based instrument which would enable agencies to record change in behaviors typically noted as indicators or warning signs for dementia, and might be useful for the cognitive impairment aspect of the annual wellness visit screening. This tool is currently being used in the Victoria Health Region in British Columbia.

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[17] http://www.annalsoflongtermcare.com/article/6412

[18] Ibid

[19] http://www.who.int/mental_health/media/en/24.pdf

[20] National Task Group on Intellectual Disabilities and Dementia Practice. (2011). ‘My Thinker’s Not Working’: A National Strategy for Enabling Adults with Intellectual Disabilities Affected by Dementia to Remain in Their Community and Receive Quality Supports. www.aadmd.org/ntg/thinker

InterRAI - The Intellectual Disability

A Canadian tool, The Intellectual Disability (ID)[21]assessment tool is under development by InterRAI for use in community-based and facility based settings. The target population group is adults aged 18 years and over with developmental disabilities (e.g., Down syndrome, Autism). Domains of assessment include: Identification Information, Intake and Initial History, Education, Employment, and Recreation, Psychosocial Well-Being and Social Supports, Lifestyle, Environmental Assessment, Communication and Vision, Cognition, Health Conditions, Functional Status, Oral and Nutritional Status, Mood and Behaviour, Medications, Service Utilization and Interventions, and Diagnostic Information Assessment Information.

Level of Support Needs – Support Intensity Scale[22]

The Support Intensity Scale (SIS) measures the individual's support needs in personal, work-related, and social activities in order to identify and describe the types and intensity of the supports an individual requires. The SIS measures support requirements in 57 life activities and 28 behavioural and medical areas (e.g. home living, community living, lifelong learning, employment, health and safety, social activities, and protection and advocacy. The Scale ranks each activity according to frequency (none, at least once a month), amount (none, less than 30 minutes), and type of support (monitoring, verbal gesturing). A Supports Intensity Level is determined based on the Total Support Needs Index, which is a standard score generated from scores on all the items tested by the Scale. The assessment is done through an interview with the consumer, and those who know the person well. However, this tool like many others is behaviour (or ability focused) and does not provide for physical examination or screening for the presence of emerging health conditions. This tool is currently being used in Calgary and across Alberta.

Changes in the individual's Support Intensity Scale profile which would reflect the adult with the developmental disability has entered the "older adult" stage would be: an increase in the frequency of support, the daily support time, and the type of support rating in all areas; and, a possible lack of applicability of the Employment Activities rating scale. Changes in the individual's Personal Outcomes Index Survey which would reflect the adult with the developmental disability has entered the "older adult" stage would be: a decrease in satisfaction in the physical well-being section; and a decrease in satisfaction in the "other questions" – Are you able to get around in your community easily? and Do you have a job that pays you money?

Health and Function – Longitudinal Health and Intellectual Disability Survey

The Longitudinal Health and Intellectual Disability Survey, developed at the University of Illinois in Chicago, is useful for collection health and function information on adults with developmental disabilities. The LHIDS collects data lifestyle differences in adults with ID including general function, smoking and alcohol consumption, levels of physical activity, dietary habits, oral health, and coincident conditions and is useful for longitudinal tracking of health and function. A supplement form collects information on dementia.

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[21] http://www.interrai.org/section/view/?fnode=24

[22] http://www.siswebsite.org/page.ww?section=Product+Info&name=Product+Info).

Maintaining a Health Surveillance and Health Data System

In order to maintain a health surveillance and health data system collaboration will be required among all stakeholders. This collaboration will need to articulate a health status monitoring system, an agreed upon strategy for screening, collecting and reporting of health status data, and on-going staff training strategies.

Strategies will need to be easy for disability agencies to complete and agreed to by older adults with developmental disabilities, their families and guardians. Their on-going involvement throughout the design and implementation of the surveillance system will contribute to its realization and continuance.

Currently, public health and health status information is monitored and reported by Alberta Health for various communities in Calgary. It may be worth exploring if similar information could be maintained and reported for adults with developmental disabilities in Calgary.

Application

Annual agency, regional and provincial level summaries of the health status of various populations of people with developmental disabilities would assist in administrative, program, and policy planning and resource allocation. The establishment of health targets as well as health status completion targets will contribute to the development of a healthy developmental disability population and an increase in the number of “well-elderly” population of adults with developmental disabilities in the future.

It is suggested that CRCB may want to consider taking a profile from the data or set of scores to help determine the degree of investment of resources to ameliorate or compensate for any functional loss or need the older adult with the developmental may need. Changes in the individual health screening and SIS tools at an individual level may warrant CRCB to adjust the amount of resources provided to the supports and services for the individual. At a population level, changes reported at an agency or regional level may also warrant a review and adjustment in resource allocations.

Emerging Directions

The following emerging directions are presented here for consideration:

1. Individuals with developmental disabilities should have an annual medical health status exam.

   Basic health information should be maintained by disability service providers on individuals with a developmental disability and stored as part of the individual permanent record or program plan
2. The Supports Intensity Scale should be completed annually on individuals over the age of 50 years, with the exception of people who have Down syndrome where annual SIS assessments should be completed after age 40 years.
3. The SPICE screening tool should be completed on all adults with developmental disabilities over the age over the age of 50 years, with the exception of people who have

Down syndrome where annual SPICE assessments should be completed after age 40 years.

4. Discussions with disability service providers should focus on the possibility of summarizing SPICE and SIS data at an agency and regional level for planning and administrative reasons.
5. Discussions with the Integrated Seniors Health –Alberta Health Services and Addictions and Mental Health Services-Alberta Health Services should focus on the types of screening tools they are currently using with the older population and those they would recommend should be used with older adults with developmental disabilities.
6. Consider collaborating with Alberta Health Services to provide joint training sessions for health care, disability services, and mental health professionals.
7. Work with a select group of health care providers to develop their expertise in this area.

Services and Supports to Older Adults with Developmental Disabilities: Family and Guardian Focus Groups

Chris MacFarlane, PhD Possberg and Associates Ltd.

Background

The Calgary Region Community Board (CRCB) identified the development of appropriate services for older adults with developmental disabilities as an emerging issue in their region and commissioned a study to review the services and supports required for older adults with developmental disabilities, including those with dementia. Their goal was to support these individuals so that they can continue to participate in their communities and live healthy and meaningful lives.

A mixed methods gap analysis study was completed by Possberg and Associates Ltd. The study included an analysis of the current service recipients' data maintained by CRCB, a review of the supports and services currently available in Calgary, focus groups with family members, and interviews with health care and disability service professionals. Three reviews of the literature were completed. The first examined health issues and concerns that are unique to people with developmental disabilities as they age, a second focused on assessment tools and processes, and a third provided a summary of promising practices in supports and services.

This brief summarizes the information gleaned from the focus groups designed to have input from family members and guardians. Five groups were scheduled during May and June, 2011.

Invitations were sent to the family member or guardian of adults receiving funding from the Calgary Region community Board Persons with Developmental disabilities (CRCB PDD). One hundred and thirty-four (134) people signed up to attend. Ninety (90) people did attend the sessions and 82 completed the pre-session survey.

Focus Group Discussion

For two hours participants, divided into small groups, discussed their concerns and recommendations surrounding the aging of their adult with a developmental disability

Concerns and Recommendations

Focus group participants identified three main areas of concern. These were expressed as the need for: quality services, and planning support, support for families.

Quality services

Participants shared numerous experiences they had had with poorly trained and supervised personnel which had negative implications for the care and inclusion of the person with developmental disability. Participants expressed concern with the quality of staff currently attracted to the disability services field because of the perceived reduction in government funding for non-profit organizations. They felt if this trend were to continue their adult with a developmental disability would be at risk of not getting appropriate and safe services now and in the future as they age.

> *"Caregivers must be incorporated into a professional association that is governed and regulated. Access to good caregivers is extremely limited."*
> *"To get good people adequate funding is critical, but this doesn't seem to be in place due to government cutbacks."*
> *"As care needs change the staff need training in geriatric care. "*

The participants felt that quality could be maintained if the government assumed an enhanced role in the monitoring and evaluation of services provided by non-profit organizations.

> *"Professionals follow through in making sure that appropriate services are provided in a timely manner."*
> *"Need to have people accountable in the system."*

Finally, participants noted that the funding and services their older adult with a developmental disability received to date was due, in a large part, to consistent monitoring and advocacy by them. They were concerned with who would continue this in the future when they would not be in a position to continue.

> *"What is going to happen as we age?"*
> *"It is very difficult to get siblings to take over guardianship. "*
> *"Will the Public Trustee and Public Guardian's offices have adequate staffing and funding to meet the needs of our sons and daughters after we have passed away if there are no other guardians?"*

Focus Group Recommendations

- **Ensure adequate wages for quality staff.**
- **Provide staff education and training programs, with scholarships allotted through agencies for up-grading.**
- **PDD monitor services closely.**
- **Create an ombudsman for parents and guardians of disabled persons.**
- **Create a joint task force between Alberta Health Services and PDD.**
- **Increase access to transportation services.**

Increased planning support

Participants expressed frustration with the lack of access to accurate and timely information. They felt they spent a considerable amount of time tracking down the information they needed for their adult with a developmental disability.

> *"We need a one-stop shopping for accessible and accurate information."*
>
> *"There should be documents with all proper phone numbers, websites, addresses, agency, people to contacts for what, situations to contact who and for what. Booklets or pamphlets should be available so people can find the supports within their city."*

Participants also noted that they needed assistance with future care planning. During the focus group discussion a significant number of families indicated they did not know of any organizations or professionals who could assist them with this activity (e.g., PLAN, AACL, Family-managed Supports Resource Centre)

> *"We need to know what is available for them as they age; need support for the transition from AISH to OAS so it does not diminish their funds."*
>
> *"We need to be informed more about RDSP, trusts, and wills is needed so we can plan."*
> *"There needs to be clarification regarding the role of the guardians with respect to doing a personal directive for son or daughter."*

Focus Group Recommendations

- **Make information accessible; use technology to get information to families and guardians as well as to provide agencies with best practice information.**
- **Provide information on how to age-in-place.**

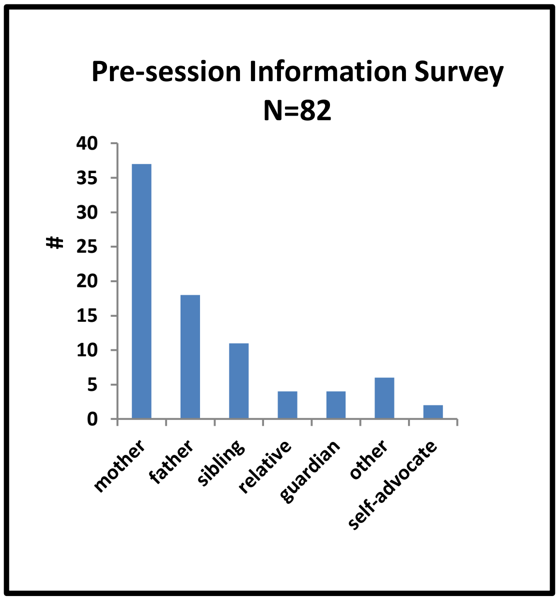
Support for family members

Participants expressed concern that they were not being supported while the adult with a developmental disability was living with them. The services that were mentioned including adequate funding for the support they were giving, adequate respite care including assistance with locating respite options, a registry of respite providers and increased funding for respite hours.

> *"There is a need for adequate funding for supportive respite, help locating respite,*
> *and a respite registry."*
>
> *"PDD not paying for relative support; need proper funding to family for family care."*

A number of participants over the course of the five focus groups shared that the agency placements their son or daughter was in had terminated under short notice requiring the family to provide the necessary residential and/or day supports. These participants felt that either due to their work commitment, their own age, or their son or daughter's behaviour this responsibility created an undue amount of stress for them.

> *"We need someone to step in when parents or current care giver cannot provide support - have a temporary relief residence for people in transition between residential services."*



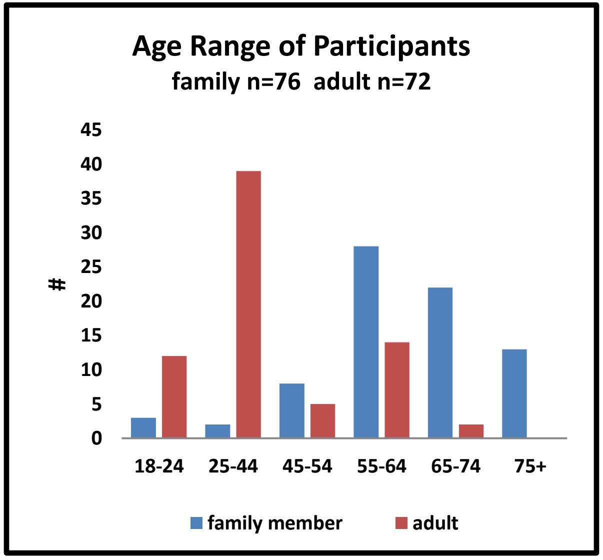
Pre-session Information Survey

Focus Group Participants

Based on the survey results, the majority of the people who attended the sessions were mothers followed by fathers. There were a number of siblings who also attended.

Individuals identified under "other" were supportive room mates who also attended the session.

Although two adults with developmental disabilities identified themselves as self-advocates and completed the pre-session information survey there were a number of other adults who attended the session with their parents.



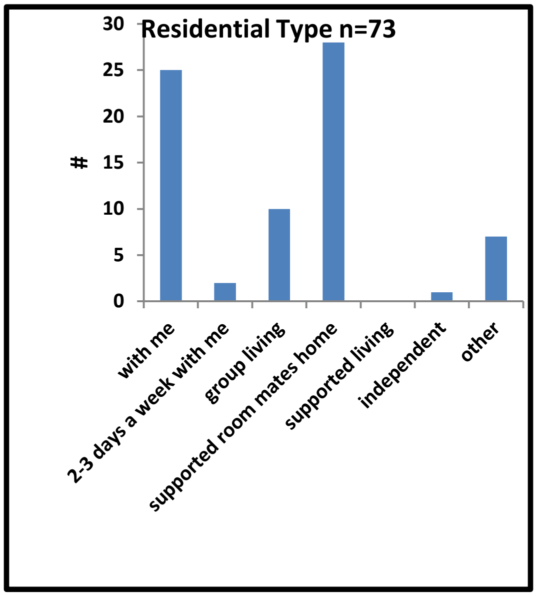
Participant and Adult with Developmental Disability Age Ranges

Participants were asked to indicate their age and that of the adult with developmental disabilities they were related or in some way connected.

As might be expected, given the topic, a significant number of the family members were 55+ years of age. Thirty-five (35) of these individuals were older adults themselves (i.e., 65+ years of age; thirteen (13) were over 75 years of age.

There were a number of younger siblings represented in the groups (i.e., age 18-24), as well as siblings and supportive roommates in the young adult age range (i.e., 25-44 years of age). Siblings, with a few exceptions, tended to be within one or two years of their brother or sister with a developmental disability.

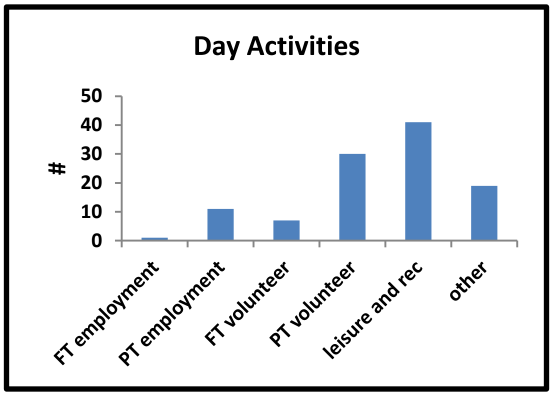
The ages of the adults with developmental disabilities ranged from 18-74 years of age. Fifty-four percent were in the 25-44 age range, while almost twenty percent (i.e., 19.4 percent) were adults between 55-64 years of age.



Residences

Participants indicated were the adult with the disability resided. Twenty-five adults with developmental disabilities lived with their parents. This constitutes 34 percent of the individuals.

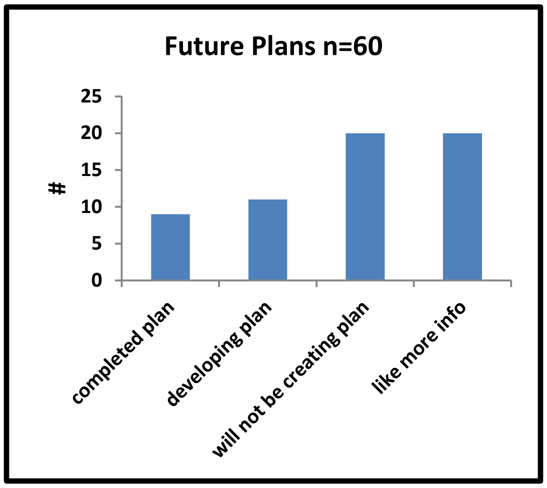
Twenty-eight individuals (i.e., 38 percent) resided in a supportive roommate's home. Ten people lived in group living situations. Seven people lived in other situations. These included one person who lives with his/her sister and her family, three people who own or rent their own home and receive 24 hour staffing support. The living situations for 3 people in the "other" category are not available.



Day Activities

Participants were asked to identify all the activities the adult with the developmental disability currently engages during the day. According to the participants, the adults with developmental disabilities tend to be involved in recreation, leisure, and volunteering activities.

The "other" category included individuals who were receiving "comprehensive care", school, or programs at University of Calgary or Mount Royal University. Twelve adults were involved in either full or part-time employment.



Future Care Planning

Nine individuals (i.e., 15 percent) indicated that they had completed a future care plan. Twenty individuals indicated they will not completing a plan, while another twenty indicated they would like more information of future care planning.

It should be noted that 22 people completing the pre-session survey did not answer this question.

Support Networks

Participants were asked to describe the adult with the developmental disabilities supportive network. They were given five types of network descriptions to choose from, including:

- *Private restricted networks* – small and primarily composed of family members living far away;
- *Local family dependent networks* – small primarily composed of family members living nearby and staff;
- *Local self*-contained networks – smaller and primarily composed of staff followed by family members who live some distance away;
- *Locally integrated networks* – larger and include close relationships with family, friends, neighbours, people with and without disabilities and staff; and,
- *Wider community-focused networks* – larger than average and primarily made up of friends living close by, family members living far away, neighbours, and people with and without disabilities and staff.

Twenty-two participants (i.e., 32 percent) indicated that the adult with the developmental disability had either a network that could be described as integrated or a wider community-focused type.

Thirty-two (i.e., 46 percent) of the participants indicated that a local family-dependent network best described the adult with developmental disability's network.

Focus Group Recommendations

- **Provide a registry of respite service providers.**
- **Increase funding for respite services.**
- **Engage siblings in the planning process and support them in assuming responsibility.**
- **Work with the Public Guardian's and Trustee's office to plan to support this population.**

Individual Financial Support for Older Adults with Developmental Disabilities

Chris MacFarlane, PhD Possberg and Associates Ltd.

This paper focuses on the financial support an older adult with developmental disabilities receives as they age out of provincial disability benefits and begin to receive federal and provincial benefits for older adults.

Financial Assistance Prior to Age 65 for Adults with Developmental Disabilities

Federal Disability Financial Assistance

The Canadian government has a number of programs which when accessed could assist adults with developmental disabilities in saving towards their retirement.

Registered Disability Savings Plan (RDSP)

The Registered Disability Savings Plan, the Canada Disability Savings Grant and the Canada Disability Savings Bond help individuals with disabilities and their families save for the future.

An RDSP is a savings plan that is intended to help parents and others save for the long-term financial security of a person with a severe and prolonged disability. To be eligible for an RDSP, an individual must be under the age of 60, a Canadian resident with a social insurance number and eligible for the Disability Tax Credit (DTC). Parents or tutors may open an RDSP for a minor.

Once an individual has opened an RDSP the Government of Canada pays matching grants and bonds directly into the RDSP of the beneficiary.

To be eligible for the Registered Disability Savings Plan, a person must be:

- eligible for the Disability Tax Credit (DTC);
- a Canadian resident with a social insurance number; and
- under 60 years of age.

Canada Disability Savings Grant

The Canada Disability Savings Grant is a matching grant that the Government of Canada deposits directly into a Registered Disability Savings Plan (RDSP). The Government of

Canada provides matching grants of up to 300%, depending on the amount contributed and the beneficiary's family income. The maximum grant is $3,500 annually, with a lifetime limit of $70,000. Grants are paid into the RDSP until the year the beneficiary turns 49 years old.

Canada Disability Savings Bond

The Canada Disability Savings Bond is money that the Government of Canada deposits directly into the Registered Disability Savings Plans (RDSPs) of low-income and modest-income Canadians. Depending on the beneficiary's family income, the Government of Canada will contribute up to $1,000 annually. The lifetime bond limit is $20,000. No contributions are needed to receive the bond. Bonds are paid into the RDSP until the year in which the beneficiary turns 49 years old.

Disability Tax Credit (DTC)

The Disability Tax Credit (DTC) is a non-refundable credit that reduces the amount of income tax that an individual with a severe and prolonged impairment in physical or mental functions may have to pay. To qualify for the Disability Tax Credit, a qualified practitioner must certify that the person with the impairment meets the criteria established under *the Income Tax Act* (ITA). The Canada Revenue Agency (CRA) must approve the form.

Provincial Financial Assistance

In Alberta an adult with developmental disabilities, if they qualify, can receive a provincial benefit, the Assured Income for the Severely Handicapped (AISH). The Assured Income for the Severely Handicapped (AISH) program provides financial and health-related assistance to eligible adults with a disability. The disability must be permanent and substantially limit the person's ability to earn a living.

The current monthly amount of this benefit is $1188. At this time, the living allowance may be reduced if a client and their cohabiting partner receive non-exempt income, or if a client resides in an Alberta government group home. AISH clients are provided with the following health benefits:

- Premium-free Alberta Health Care Insurance
- Prescription drugs
- Essential diabetic supplies
- Optical
- Dental
- Emergency ambulance services

- Exemption from the Alberta Aids to Daily Living (AADL) co-pay fees

AISH provides health benefits to assist clients, their cohabiting partners and dependent children with expenses related to their medical needs. All other available health benefit plans should be accessed first. When a health benefit from another program or source is not equal to a health benefit AISH provides, AISH may cover the difference.

AISH payments are discontinued at age 65. The adult with a developmental disability must apply for federal assistance before seeking financial assistance from the Alberta government.

Aids to Daily Living

According to their website[23], the AADL program helps Albertans with a long-term disability, chronic illness or terminal illness to maintain their independence at home, in lodges or group homes by providing financial assistance to buy medical equipment and supplies. An assessment by a health care professional determines the equipment and supplies that an Albertan can receive through this program. Albertans pay 25 per cent of the benefit cost to a maximum of $500 per individual or family per year. Low-income Albertans and also those receiving income assistance do not pay the up to $500 cost-share portion.

Families and guardians interviewed as part of this study indicated that the current AADL guidelines regarding equipment replacement (e.g., 4-10 years to replace wheelchair) and the types of equipment that is not covered (e.g., special mattress) mat have negative implications for older adults with developmental disabilities as they age, in particular those with complex medical issue. They suggested that the AADL guidelines should be reviewed to ensure they are responsive to the needs of this aging population.

Financial Assistance after Age 65 for Adults with Developmental Disabilities

There are also a number of programs that assist the older adults with developmental disabilities after 65 years of age. It is necessary for the older adult to apply for these benefits. According to one interviewee it takes approximately 8 weeks for the application to be processed so applying well before the person turns 65 years of age is necessary.

Federal Pensions and Grants[24]

The Federal Government has a number of benefit programs to assist older adults.

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[23] http://www.seniors.alberta.ca/aadl/

[24] https://srv111.services.gc.ca/OAS_11.aspx and the Service Canada help line 1-800-277-9914

Canadian Pension Plan
The Canada Pension Plan (CPP) provides a monthly taxable retirement pension to contributors (i.e., those who have worked and contributed to the plan). The maximum amount at age 65 for a CPP retirement pension is $960 per month/ $11,520 per year (as of 2011).

Although most contributors draw on CPP at age 65 years, they can begin to draw on CPP at a reduced amount at age 60 years. If they choose to work after the age of 65 years and draw from CPP they can. Their employer and the older adult both continue to contribute to the plan and once the person has turned 70 years of age, one year after they discontinue working, their CPP benefits will return to the full amount.

Canada Pension Plan Disability Benefits (CPPD)
To qualify for benefits, the applicant must: have contributed to the CPP for a minimum number of years (e.g., 4 of last six years made contributions, contributed for 25 years); be under the age of 65 and not be in receipt of retirement benefits for more than 15 months; have a severe and prolonged disability as defined by CPP legislation; and apply in writing and provide a physician's medical report. According to CPP Legislation, a person is considered disabled if they are determined to have a physical and/or mental disability that is both severe and prolonged.

Old Age Security Pension
The Old Age Security pension is a monthly benefit available, if applied for, to most Canadians 65 years of age or over. Old Age Security legal status and residence requirements must also be met. An applicant's employment history is not a factor in determining eligibility, nor does the applicant need to be retired. Old Age Security pensioners pay federal and provincial income tax. Higher income pensioners also repay part or all of their benefit through the tax system. A minimum of 10 years of residence in Canada after reaching age 18 is required to receive a pension in Canada.

Guaranteed Income Supplement
To receive the Guaranteed Income Supplement benefit, a person must be receiving an Old Age Security pension. The yearly income of the applicant or, in the case of a couple, the combined income of the applicant and spouse or common-law partner, cannot exceed certain limits.

Residential Rehabilitation Assistance Program - RRAP for Persons with Disabilities
The Residential Rehabilitation Assistance Program - RRAP for Persons with Disabilities provides funding to homeowners and landlords of dwellings for low-income persons with disabilities so that they can carry out renovations to improve accessibility. This

grant is delivered by Canada Mortgage and Housing Corporation (CMHC). Homeowner eligibility is based on household income and the cost of the renovations. The value of the house must not exceed a set amount. Landlord eligibility is based on the rent and the tenant's household income. Dwellings must meet minimum health and safety standards.

Alberta Government Benefits and Grants

Special Needs Assistance for Seniors

The Special Needs Assistance for Seniors program is available to help seniors with the cost of appliances, minor home repairs and some medical costs. Only one-time extraordinary expenses are funded. The program provides a lump-sum payment to eligible low-income seniors. The maximum assistance available is $5,000 in a benefit year (July 1 to June 30).

Residential Access Modification Program (RAMP)

Provides grants for low to moderate-income Albertans who use wheelchairs to make permanent and temporary modifications that will increase the mobility into and within their personal, principal home

Alberta Seniors Benefit

The Alberta Seniors Benefit program provides support in addition to the federal benefits received under Old Age Security, Guaranteed Income Supplement, Federal Allowance and the GST credit. It is based on income and provides monthly benefits to eligible seniors. The following chart was developed to contrast the difference between financial supports and benefits for an older adult in Alberta, before and after they turn 65 years of age. It appears that the older adult may have more financial resources after the age of 65, if they qualify for federal support, but they will have less health coverage.

Summary

There are a number of financial supports and community services that are available to older adults through the Government of Canada, the Alberta Government, and the City of Calgary. Some of these benefits and grants are not available until the individual is 55+ years of age (e.g., Community Based Snow Removal Programs) or even 65+ years of age (e.g., Old Age Security).

Some adults with developmental disabilities demonstrate limitations in their functional ability at a younger age than other adults without developmental disabilities, but because of the age criteria associated with these financial and community services they are not accessible to these adults. The lack of awareness of family members and/or disability service personnel of the existence of these resources also contributes to these resources not being fully utilized by older adults with developmental disabilities. Further, some individuals with developmental disabilities may not have been employed sufficiently to qualify for some of these benefits (e.g., Canadian Pension Plan) nor do they have access to sufficient funds to apply for some of the benefits (e.g., Canada Disability Savings Grant) which require a contribution from the financial benefit recipient.

Addressing these potential policy inequities will be necessary in developing supports and services for older adults with developmental disabilities.

Monthly Income	**Adult with Developmental Disability***	
	< 65 yrs.	**65+ yrs.**
AISH	$1,188.00	0
Old Age Security (Fed)	0	$533.70
Guarantee Income Supplement (Fed)	0	$723.65
Alberta Seniors Benefit (Prov)	0	$72.00
Total	**$1,188.00**	**$1,329.35**

<u>Health Coverage</u>

Before age 65

Medication (as per AISH): 100% coverage; no pre- or co-payments.

Dental(as per AISH): Basic dental coverage includes complete, recall and emergency examinations, teeth cleaning, x-rays, restorations (fillings), extractions, dentures as well as other dental services.

Optical (as per AISH): payment for one routine and other exams as deemed necessary annually; payment for one pair of glasses every 24 months.

ADL: can apply for cost exception.

Funeral Expense: assists with cost of funeral as per agreement with funeral provider if family is unable to cover costs.

After age 65

Medication: coverage through Alberta Blue Cross; 70-80% coverage if the person qualifies they can apply for Special Needs which require the person to pay $45/month and pre-pay unless they also submit an estimate of annual costs.

Dental: 100 % of the fee maximums for allowable procedures, up to a maximum of $5,000 every five years.

Optical: $230 every three years for the purchase of eyeglasses.

ADL: does not appear to have to re-apply for the cost exception if accepted before age 65.

Funeral Expense: federal funding which is limited to only spouse applying.

*Based on a prior annual income of $14,256 (AISH) and no RRSP, CPP, CPPD, paying rent.

Services and Supports for Older Adults: Age Criteria

Programs and Services		Age Criteria			
	18+	< 55	55+	60+	65+
Local Senior's Centres and Major Services					
Senior's Resource Centre					🟥
Seniors Connect					🟥
Kerby Centre			🟥	🟥	🟥
Meals on Wheels	🟥	🟥	🟥	🟥	🟥
Golden Age Club		🟥	🟥	🟥	🟥
MCF Housing					🟥
Trinity Place Foundation of Alberta (has a few younger individuals with disabilities as well)					🟥
City of Calgary					
Community Based Snow Removal Programs Several community-based and regional seniors' organizations provide assistance to Seniors (including snow and removal and projects).		🟥	🟥	🟥	🟥
Seniors Citizens' Transit Pass The Senior Citizens' Yearly Transit Pass enables individuals 65 years and older to ride City transit at a reduced rate.					🟥
Home Maintenance Services This program helps low-income seniors to live safely in their homes by providing basic yard care, snow removal, house cleaning, interior and exterior house painting, and minor home repairs.					🟥
Education Property Tax Assistance for Seniors Program The Province's Alberta Seniors and Community Supports in partnership with The City will provide an annual rebate to assist senior homeowners with the year-to-year increases in the education portion of their property taxes.					🟥
Recreation Fee Assistance Program Fee Assistance is available for Calgary residents in financial need to help make recreation more affordable.	🟥	🟥	🟥	🟥	🟥
Province of Alberta					
Property Tax Assistance for Seniors					🟥
Alberta Seniors Benefit					🟥

Aids to Daily Living	🟥	🟥	🟥	🟥	🟥
Blue Cross Senior's Coverage Medication*:* 70-80% coverage if the person qualifies they can apply for Special Needs which require the person to pay $45/month and pre-pay unless they also submit an estimate of annual costs. Dental: 100 % of the fee maximums for allowable procedures, up to a maximum of $5,000 every five years. Optical: $230 every three years for the purchase of eyeglasses.					🟥
Specialized Seniors Health Assessment and Rehabilitation Units - Rockyview General Hospital Patients benefit from an interdisciplinary team approach to care management with a goal to provide treatment for medical problems and to assist patients in regaining their independence by developing a plan to optimize their abilities. Families are involved in the care planning process. The average length for admission is three to four weeks in which thorough medical and functional (mobility, memory, etc.) assessments are completed. A full range of acute care services is available to assist in the medical management of patients with multiple co-morbidities. Patients typically require consultation services from a variety of Specialists such as Cardiology, Internal Medicine, GI, Orthopedics, Neurology, Psychiatry and Urology. All patients require a full range of Laboratory and Diagnostic Imaging Services.					🟥
Programs and Services		**Age Criteria**			
	18+	**< 55**	**55+**	**60+**	**65+**
Persons with Developmental Disabilities (PDD)	🟥	🟥	🟥	🟥	🟥
Public Guardian	🟥	🟥	🟥	🟥	🟥
Public Trustee	🟥	🟥	🟥	🟥	🟥
Assured Income for the Severely Disabled (AISH)	🟥	🟥	🟥	🟥	
Residential Access Modification Program (RAMP) for eligible wheelchair users or seniors + and considered medically frail (usually using a walker).					🟥
Government of Canada					
Canadian Pension Plan				🟥	🟥
Guarantee Income Supplement					🟥
Residential Rehabilitation Assistance Program - RRAP for Persons with Disabilities	🟥	🟥	🟥	🟥	🟥

Home Adaptations for Seniors' Independence (*HASI*) *that* provides a forgivable loan for adaptations to help low income seniors live in their homes longer.					🟥
Very Low-income Housing Repair Loans and Grants				🟥	🟥
Old Age Security					🟥
Funeral Expense*:* federal funding which is limited to only spouse applying.					🟥

Emerging Directions: Individual Financial Support

Advocate and work towards ensuring that older adults with developmental disabilities have access to adequate benefits and services.

- Work with Assured Income for the Severely Handicapped (AISH) to recommend changes to health benefits for adults with developmental disabilities 65+ years of age so they are able to maintain their health benefits at the level prior to turning 65 years of age.
- Work collaboratively with Aids to Daily Living to review current funding criteria to ensure it is reflective of the needs of an older adult with developmental disabilities, in particular those with complex physical and/or mental health concerns.
- Advocate for an increase the total regional funds available in the Residential Access Modification Program (RAMP). Provide key influencers and decision makers with sufficient information (e.g., research findings, economic impacts, case studies, and policy positions) regarding the need to lower the age criteria so that older adults with developmental disabilities can have access to supports and services for older adults in the general population.

Six Critical Factors Organizations Need to Think About When Providing Services and Supports to Older Individuals with Developmental Disabilities

Robert L. Schalock, PhD Possberg & Associates Ltd.

Overview

In a recently published book (Schalock & Verdugo, 2012) the author and his colleague discussed the leadership challenges faced today by organizations providing services and supports to persons with developmental disabilities to be more effective and efficient. These challenges are true of all organizations, and increasingly cogent for those Albertan organizations providing services and supports to older adults with developmental disabilities. The purpose of this document is to highlight six critical factors that organizations providing services and supports to older individuals with developmental disabilities need to think about as they are challenged to redefine their organization's service delivery system.

The material presented in this document is gleaned from the specific redefinition change strategies discussed in the book referenced above. Its full title and reference is: Schalock, R. L., and Verdugo, M.A. (2012), *A Leadership Guide for Today's Disabilities Organizations: Overcoming Challenges and Making Things Happen* (Baltimore: Brookes Publishing Company). Each redefinition change strategy discussed in this document is phrased as a suggestion "to think about……. when your organization is either planning to—or currently are—providing services and supports to older adults with developmental disabilities". Here are the six most important critical factors to think about:

1. Expanding your thinking to include three 21st century thinking styles: systems, synthesis, and alignment
2. Measuring and using personal outcomes
3. Developing support teams
4. Employing a system of supports
5. Using evidence-based practices to enhance decision making
6. Creating value through innovation

Expanding Your Thinking

Systems Thinking

Systems thinking focuses on the multiple factors at the individual, organization, and societal level that affect human functioning and organization performance. Without the benefit of systems thinking, organizations have historically viewed themselves as singular entities and closed systems that have 'provided all things to all people.'

With the benefit of systems thinking, effective and efficient organizations have begun to think of themselves as part of a larger system or network, and that their primary role is to bridge to the community. The advantages of systems thinking to organizations providing services and supports to older adults with developmental disabilities are that it leads to a more complete understanding of factors that affect human function, and the need to extend beyond the agency or organization and incorporate a broader community perspective during the planning, development, and implementation of an individual's supports plan.

Synthesis

Synthesis involves the integration of multiple sources of information to improve the precision, accuracy, and validity of a decision. The critical thinking skills involved in synthesis are *analysis* (i.e. examining the information and reducing its complexity), *evaluation* (i.e. determining the precision, accuracy, and integrity of the available information), and *interpretation* (i.e. integrating available information in light of the individual's goals and interests).

The advantages of using synthesis by an organization's support teams are that it results in the team integrating information from multiple sources to improve the precision, accuracy, and validity of their decisions. On a daily basis, support teams make decisions about how to integrate information about the support needs of their clientele into the development and implementation of individualized support plans, integrate the vast amount of organization resources into effective and efficient support strategies, and demonstrate the impact of the selected support strategies on personal outcomes.

Alignment

Alignment positions the services and supports provided by an organization into a logical sequence in which the individual's supports plan is based on the assessment of support needs and is developed using a framework that is consistent with desired outcomes. Typically, a program logic model is used to depict how the individual's goals, interests, and assessed support needs (i.e. the 'input') are related logically (i.e. aligned) with individualized support strategies (i.e. the 'throughout') and personal outcome categories (i.e. the 'output').

The advantages of using alignment by organization personnel and support teams are that it results in support teams planning and implementing supports that are in line with the individual's personal goals and interests, assessed support needs, specific support strategies, and desired personal outcomes. In addition, using a logic model to depict this alignment provides clear communication to multiple stakeholders and outlines a framework for monitoring and evaluation.

Measuring and Using Personal Outcomes

Defining Personal Outcomes

Personal outcomes are the valued benefits derived by program recipients that are the result, directly or indirectly, of program activities, services, and supports. Personal outcomes can include measures of quality of life (see next section on 'measuring personal outcomes') or measures that reflect the level of control, worthiness, involvement, dignity, and safety that an individual experiences on a daily basis.

Measuring Personal Outcomes

Alberta PDD has embraced a quality of life framework for the measurement of personal outcomes. This multidimensional quality of life conceptual and measurement framework is summarized in Table 1. The eight domains listed in Table 1 are based on cross-cultural research studies that have demonstrated the 'etic' or universal property of the domains. The same cross-cultural research has demonstrated that the exemplary indicators listed in the table are culturally sensitive (or have 'emic' properties). The specific scores obtained from the person's perception of—or current status on—the respective indicator is the metric used in measuring personal outcomes.

The importance of using this quality of life framework to develop services and supports for older adults with developmental disabilities and to incorporate the eight domains as a framework for developing an individual's supports plan is that: (a) the eight domains represent a holistic approach to the individual; and (b) the individualized supports provided in reference to each domain should enhance personal, quality of life outcomes such as those assessed on the quality of life assessment instrument currently being implemented in Alberta (*My Life: Personal Outcomes Index*). This instrument was developed based on the conceptual and measurement model summarized in Table 1.

Table 1
Quality of Life Conceptual and Measurement Model

Domain	*Exemplary Indicators*
Personal Development (cognitive,	Educational status, personal competence social, practical skills), activities of daily living and instrumental activities of daily living
Self-Determination	Choices, decision making, autonomy, personal control, personal goals
Interpersonal Relations	Social networks, family, friends, peers, social activities, relationships
Social Inclusion	Community integration/participation, community roles, volunteering
Rights	Human (respect, dignity, equality), and legal (access and due process)
Emotional Well-Being	Safety, security, positive experiences, satisfaction, contentment, self esteem/concept, predictability/ control, lack of stress
Physical Well-Being recreation/exercise	Health status, nutritional status,

Material Well-Being	Financial status, employment status, housing status, possessions, ownership

Using Personal Outcomes

Personal outcomes can be used for multiple purposes. At the individual level, their primary uses are to: (a) expand the individual's thinking beyond the his/her condition or disability and focus on other important dimensions to one's life; (b) communicate to the individual that positive change is possible on one or more of the eight quality of life domains listed in Table 1; (c) communicate to the individual and his/her family that the organization is committed to a holistic approach to the provision of services and supports; and (d) provide information to the Support Team that can be used as a basis for 'right to left' thinking, which involves identifying desired personal outcomes for the individual and then asking, "what needs to be in place for these outcomes to occur?" At the aggregate level, personal outcomes can be used by all organization personnel for continuous quality improvement that involves using tacit (i.e. experiential) and explicit (i.e. data-based) knowledge to enhance an organization's effectiveness in terms of personal outcomes, and as benchmarks to evaluate the effectiveness of potential residential support models for older adults with developmental disabilities such as aging-in-place, in-place progressions, or out-placement.

Developing Support Teams

A Support Team is composed of the individual receiving services and supports, his/her family member(s), a case manager or supports coordinator, direct support staff who work with the individual, and one or more professionals depending on the individual's support needs. The responsibilities of the Support Team involve working with the individual to: (a) determine what is important to and for the individual; (b) identifying specific support strategies to address the individual's personal goals and assessed support needs; (c) specify a specific support objective for each support strategy and indicate who is responsible for implementing each support strategy; and (d) implement and monitor the Individual Supports Plan. These responsibilities can be successfully met only through the *collective wisdom* of the team members.

Support teams are but one example of high performance teams that reflect the structural changes that are occurring in both public and private organizations. These changes stem from top-down hierarchies that are built along vertical lines of authority to organizations built along horizontal lines of action. High performance teams have emerged in the human services field within the context of the transformation of professional services, the emergence of new public management, the focus on consumer-driver and consumer-centered supports, and the need to increase the involvement and tenure-related stability of organization personnel.

Your organization can foster the development of support teams by:

- Encouraging and structuring the involvement of the support team membership described above in the services and supports offered to older adults with developmental disabilities.
- Developing an informed learning culture within the organization that recognizes and reinforces both tacit (i.e. experiential) and explicit (i.e. data and literature based) knowledge as a basis for service/support delivery and continuous quality improvement.
- Enhancing the team’s effectiveness and efficiency through clear communication, time-limited team meetings, avoiding cognitive traps, and collaborating to reduce conflict.
- Delegating and trusting, but holding the team accountable.

Employing a System of Supports

A system of supports framework aligns the supports provided to the person‘s assessed support needs and provides a structure for an organization to enhance human and one’s quality of life. Such a framework provides three essential functions to an organization providing services and supports to persons of age: (a) it organizes potential support strategies into a system through which individualized supports can be planned and implemented based on the individual’s assessed support needs; (b) it provides a framework for coordinating the procurement and application of individualized supports across the sources of support; and (c) it provides a framework for evaluating the impact of individualized supports on the person’s functioning level and quality of life.

The parameters of a system of supports are presented in Table 2. Two points need to be kept in mind in reading the contents of Table 2. First, the anticipated impacts listed in the right hand column are keyed to the eight quality of life domains listed in Table 1; and second, the anticipated impacts are generic to the source/component listed. For example, natural sources of support can impact any or all of the quality of life domains of social inclusion, interpersonal relations, and emotional well- being.

Table 2
Parameters of a System of Supports

Source/Component	*Anticipated Impact on:*
Natural sources	
-Family and friends	Social inclusion
-Support networks	Interpersonal relations
-Generic agencies/businesses	Emotional well-being
Technology-based	
-Assistive technology	Cognitive functioning
-Information technology	Independent living
-Smart technology	Living status
-Prosthetics	Sensory-motor functioning
Environment-based	

-Environmental accommodation	Personal development
-Transportation	Social inclusion
Staff directed	
-Incentives	Self-determination
-Skills/knowledge	Personal development
-Positive behavior supports	Emotional well-being
Professional services	Emotional well-being Physical well-being

Using technology and modifying the physical environment are key to successful aging. Therefore, organizations providing services and supports to older adults with developmental disabilities need to be familiar with and use support strategies that reflect these two elements. To this end, Table 3 elaborates on those two sources/components referenced in Table 2.

Table 3

Examples of Technology-Based and Environment-Based Support Strategies

Source	*Examples*
Technology-Based	Computer assisted learning, Interactional TV, Computer-based remote controls, Safety systems (e.g. on-site monitoring sensors for medical, physical activity, and physical location), Med alert devices (e.g. automated pill dispensers, seizure-alert monitors), Mobile access devices, Augmentative communication systems, Visual telephone communication, Self monitoring devices, GPS devices, iPhones/iPads, Automated light switches
Environment-Based	Ramps, Push buttons, modified counters and work spaces, Modified transportation, Adapted texts and signs

Using Evidence-Based Practices to Enhance Decision Making

Definition and Use

Evidence-based practices are practices that are based on current best evidence that is obtained from credible sources that used reliable and valid methods and is based on a clearly articulated and empirically supported theory or rationale. Evidence-based practices are used to make:

- Clinical decisions about the interventions, services, or supports that service recipients receive in specific situations. Such decisions should be consistent with the individual's values and beliefs.
- Managerial decisions about the strategies used by an organization to increase its effectiveness and efficiency.
- Policy decisions regarding strategies for enhancing an organization or system's effectiveness and efficiency.

Evidence-Based Practices Related to the Concept of Successful Aging

The concept of successful aging emphasizes the importance of both individualized supports based on the individual's assessed support needs and environmental factors as moderators of the aging process. The following principles are common throughout the literature on successful aging: there is much latent reserve existing among the elderly; knowledge-based interventions and supports can offset age-related declines in cognitive mechanisms; optimal aging occurs under development-enhancing and age-friendly environmental conditions; functioning is enhanced through factors such as active lifestyle, social supports, socioeconomic status, and minimal medication; and policy makers and service providers need to focus on outcomes that are valued by the individual and his/her family.

In addition to these common principles, one also finds the following best practice parameters related to enhancing successful aging:

- Provide individualized supports whose parameters are described in Table 2
- Provide opportunities to participate in the widest range of meaningful civic, educational, recreational, and cultural activities
- Ensure suitable housing, the needed level of physical and mental health services, ready access to effective social services, appropriate institutional care when required, and a life and death with dignity
- Develop, implement, and monitor an Individual Supports Plan whose development and implementation includes the individual, one or more family members, direct care/support staff, and a case manager/supports coordinator
- Develop and implement consumer-referenced outcome measures related to performance assessment (e.g. residential and community participation status), consumer and family appraisal of services and supports received (e.g. satisfaction surveys), functional assessment (e.g. clinical status, health status, mental health status), and personal appraisal outcomes (e.g. quality of life indices/measures)

Although many if not most of these best practices are currently used by those organizations providing services and supports to older adults with developmental disabilities, there is little published literature demonstrating that they are evidence-based. This lack is due primarily to the lack of clearly conceptualized and measured outcome measures against which the practices can be judged as effective.

Evidence-Based Practices Related to Smart Technology and Smart Homes

Current best practices for older adults with developmental disabilities are based on two methodologies that show potential, but have yet to be shown to be evidence-based. These two are the use of smart technology and smart houses.

Smart technology

Smart technology typically involves a variety of systems such as a computer, cell phone, personal digital assistant, voice activation system, touchpad controller, or other devices such as a remote control that can interact with and manipulate the devices in the home. Control can be through radio frequency, infrared extension units, or sound such as clapping one's hands to turn lights on or off. Smart technology also includes those technological advances that make it easier for individuals to operate home appliances and consumer electronics through the use of electronic control devices (i.e. ECUs) or interface devices. ECUs can be controlled through voice activation systems, remote controls, sip-n-puffs, eye gaze command, switches, or the use of smart phone applications. Smart technology can be used to track health status as well as provide many of the components to a system of supports listed in Table 2.

Smart houses

The term 'smart houses' refers to any technology that automates a home-based activity. Smart houses represent networks between systems that are controlled by smart technological devices that are then controlled by an individual. These networks can involve household items, electronics devices, and security systems. This home network, which can be accessed through electrical wiring or wireless technology, becomes all of these devices interacting with and being controlled by a device such as a smart phone.

Despite the appeal and potential effectiveness of smart technology and smart houses, implementing them is easier said than done in part due to the need to ensure that staff understand how such devices work, and develop the competencies to ensure their full and effective use. Important criteria involved in this understanding and competency development include: (a) selection of the assistive technology devices should be guided by the setting-specific demands, the capabilities a person must possess to use the device, and the individual's functional limitations for which compensation or enhanced functioning will occur by using the device; (b) the individual and relevant support staff/family members should be actively involved in both the decision making and implementation process, and should be aware of the expected outcomes; and (c) someone needs to be identified to work with the individual and support staff/family member to monitor the use and effectiveness of the device.

Once such understanding and competences are in place, the impact of their use on personal outcomes can then be established. If there is a positive effect, the specific technology used can then be referred to as an 'evidence-based practice.' In addition, when organizations begin to incorporate more technology into their supports delivery system they also need to realize that technology is a process and not just a device, and that personnel need to view adaptations as a mind-set that allows for the reduction of the discrepancy between a person's capability and the requirements of the environment(s) within which the person functions and interacts.

Creating Value Though Innovation

Organizations providing services and supports to individuals with developmental disabilities, including those individuals who are aging, need to redefine themselves in terms of how they operate and approach innovation. A big part of the redefinition process requires developing new approaches to organization services and managerial strategies—and thus create value through innovation. The new approaches should be based on the values of dignity, equality, self-determination, non-discrimination, and inclusion.

Across both public and private organizations, creativity and a learning culture are the two primary ingredients of innovation.

- Creativity is not a solitary process. It happens when talented people get together and when ideas merge with future-oriented mental models. A critical factor in innovation is that creativity needs 'hubs' such as the four paradigms that are currently impacting services and supports for older individuals with developmental disabilities: the social-ecological model of disability, the quality of life concept, the supports paradigm, and the concept of successful aging. In addition to hubs, creativity needs networks through which it is implemented. Effective organizations provide these hubs and networks.
- A learning culture is characterized by its: (a) scanning the environment continuously for new support strategies to address an individual's mobility, sensory, cognitive, and general health needs, (b) reinforcing creativity and trying new approaches, and (c) taking risks and rewarding risk taking and team efforts.

In thinking about creating value through innovation, the key issue becomes, "in reference to what?" Five strategies are summarized next that organizations providing services and supports to older individuals with developmental disabilities can implement to create value through innovation and change. These five strategies are networking, families, training, social support networks, and on-going assessment and screening.

Networking

Networking is reflected in partnerships, consortia, and active participation in pilot studies. The intent of networking is to increase an organization's effectiveness and efficiency and begin to view itself as a knowledge producer. Networking to establish smart houses and implement smart technology is a very effective value creating strategy.

Families

Organizations providing services and supports to older individuals with developmental disabilities need to increase the supports provided to families, guardians, and siblings. Families and guardians have been a critical factor in the development of progressive disability services and should not be excluded from the creativity and learning sessions underlying organization change. Furthermore, they should be active members of a Support Team that plans, develops, implements, and monitors their family members' Individual Supports Plan.

Training

Training professionals and direct support staff is essential for an organization to redefine itself. Key training areas include: (a) understanding the aging process, the multidimensionality of human functioning, and the key role that a system of supports play in enhancing human functioning and one's quality of life; (b) implementing individualized support strategies based on the individual's assessed support needs; (c) recognizing the importance of involving all members of the Support Team in planning, developing, implementing, monitoring, and evaluating the individual's supports plan; and (d) being equipped to defuse crises and engage effectively in crisis management.

Social Support Networks

Social support networks are based on the concept of social capital that refers to the connections among individuals and their social networks, and the norms of reciprocity and trust that arise from them. In reference to persons with developmental disabilities, the theory and practice of social capital appears when people form mutual support systems, personal futures planning sessions, circles of support, support communities, and social networks. Developing social networks *involves integrating and promoting the natural supports* provided by family, friends, and colleagues with *generic supports* offered by community-based groups and organizations such as Older Adult Centers, with *professional supports* provided by an outreach and service navigation teams.

On-Going Assessment and Screening

An accompanying document prepared by the author entitled, *Guidelines for Using the Supports Intensity Scale with Older Adults with Developmental Disabilities* provides specific guidelines as to how the *Supports Intensity Scale* can be used to provide information regarding the changing support needs of older adults with developmental disabilities. As stated in that document, as the individual exhibits significant changes in mobility, sensory, cognitive, and general health it may be necessary to provide additional assessments and screening. Examples are provided in MacFarlane (2011).

Conclusion

The contents of this document based on the Schalock and Verdugo (2012) text reflects the need to rethink the role of service delivery systems and organizations and redefine how they provide supports to aging individuals in light of the increasing life span of such persons. In addition, organizations need to rethink their role and redefine themselves because of these three significant ethical and moral dilemmas that constitute powerful factors potentially working against older persons: (a) a sense of respect for and obligation to others that elevates freedom and self-control, places a premium on avoiding suffering, and sees productive activity and family life as central to our well-being; (b) the understanding of what makes a full life and the things we value, such as physical and mental well-being, choices, giving and receiving, involvement, and productivity; and (c) a sense of dignity reflected in the respect received from those around us.

The intent of this document has been to focus peoples' thinking regarding six critical factors that need to be discussed, thought through, and implemented by organizations providing services and supports to older adults with developmental disabilities. When organizations and systems address these factors they will be in better position to respond to the significant social, political, and financial challenges involved in providing services and supports to this population. As multiple stakeholders within the Alberta Province continue to develop a framework for age-related policies and practices, it is important that they do not overlook the importance of expanding one's thinking, measuring and using personal outcomes, developing support teams, employing a systems of supports, using evidence-based practices to enhance decision making, and creating value through innovation.

Guidelines for Using the Supports Intensity Scale (SIS)

Robert Schalock, PhD. Possberg and Associates Ltd.

Overview

Older individuals with developmental disabilities are living longer due to a number of factors including advances in medical and social services, advocacy of families and individuals with disabilities, the adoption of de-institutionalization and normalization philosophies, and the development of community-based services with professionally trained staff. Although most individuals with developmental disabilities have a life expectancy similar to that of other individuals without disabilities, older individuals with developmental disabilities do show signs of aging at a younger age than older adults without the disability.

Generally, older adults with developmental disabilities, just as all aging persons, want to age-in-place. This desire is supported by their families and their disability service providers. Aging-in-place is a philosophical and programmatic approach to supporting older adults that has been adopted by most developed countries. Studies indicate that aging-in-place for older adults with developmental disabilities can occur if a number of factors are in place. Chief among these are that providers: are aware of the specific support needs of the individual, receive appropriate training in the provision of a system of supports, are assisted in making the necessary environmental accommodations, and provide a system of supports that is customized to what is important to and for the individual.

The *Supports Intensity Scale* (SIS) is used throughout the Alberta PDD to provide standardized information regarding the pattern and intensity of supports that are needed by a person to be more successful in major life activities, and to provide a framework for implementing a system of supports that enhances or maintains the person's medical and behavioral well-being. Information from the SIS is currently being used by support teams throughout Alberta to plan, develop, and implement Individual Supports Plans that align individualized support strategies to assessed support needs and personal outcome categories.

The assessment of an individual's support needs and the provision of individualized supports allow organizations serving older adults with developmental disabilities to focus on enhancing the person's successful aging. Successful aging is enhanced when: (a) people live within stable environments that provide continuity, familiarity, predictability, and opportunities to exhibit decision making, self-determination, and empowerment; (b) a holistic approach that reflects the multi-dimensionality of human functioning and a life of quality is used to provide services and supports; (c) a system of supports is employed that aligns the person's assessed support needs with the provision of individualized support strategies; (d) best practices are used to enhance human functioning and a life of quality; and (e) an organization monitors the impact of their services and supports on consumer outcomes and uses that information for continuous quality improvement.

As individuals age it is typical to see changes in four areas of human functioning: mobility, sensory, cognitive, and general health. Specific examples of these changes are summarized in Table 1.

Table 1
Human Functioning Areas Impacted by the Aging Process

- Mobility: changes in strength, endurance, balance, reaction time. frailty, slowed performance
- Sensory: changes in vision, hearing, taste, touch
- Cognitive: changes in short term memory, understanding, level of confusion, problem solving, information processing, orientation
- General Health
    - Medical: changes in nutrition, susceptibility to illness, diabetes, infections, thyroid, heart disease
    - Mental: changes in moods (i.e. mood swings), optimism, motivation, interest level, insomnia
    - Self-care: changes in toileting, bathing, personal hygiene

In reference to scoring the *Supports Intensity Scale*, these general changes will most likely impact the type of support required and the daily support time required to provide the supports. In addition, these changes will impact the overall SIS profile that depicts the pattern and intensity of needed supports. For the reader's clarification:

- Rating the Type of Support focuses on answering the following question: If the person were to engage in the activity on a regular basis over the next several months, what would be the nature of the extraordinary support (i.e. the assistance that most typically functioning adults would not need) that others would need to provide to enable the individual to be successful in the activity. The rating options are: 0=none, 1=monitoring, 2=verbal/gestural prompting, 3=partial physical assistance, 4=full physical assistance.
- Rating Daily Support Time focuses on answering the following question: If the person were to engage in the activity on a regular basis over the next several months, during the course of a typical 24 hour day, how much total daily time would be needed to provide extraordinary supports to enable the individual to be successful in the activity? The rating options are: 0=none,

1=less that 30 minutes, 2=30 minutes to less than 2 hours, 3=2 hours to less that 4 hours, 4=4 hours or more.

As described in the following section, using the SIS with older adults with developmental disabilities DOES NOT involve changing the administration, scoring, or data reporting/analysis procedures currently in place throughout the Province, including providing the 'My Support Profile.' However, its use with older adults with developmental disabilities DOES require that support teams: (a) analyze changes in type of support and direct support time for those items that are most sensitive to age-related changes in mobility, sensory, cognitive, and general medical and mental health (see Tables 2 and 3); and (b) identify increasing support needs in the areas of Exceptional Medical and Behavioral Support Needs (Sections 3A and 3B of the SIS).

Guidelines for Administering the SIS to Older Adults with Developmental Disabilities

Guideline # 1: Re-administer the SIS at Age 50 and Periodically Thereafter

Although it is generally accepted that the chronological age of 65 years is the criteria for identifying an individual as an older adult, for men and women with developmental disabilities an age criterion of 65 may be inappropriate even though many of these individuals will age in a similar manner to other adults without the disability. Some individuals with developmental disabilities, due to their pre-existing neurological, functional, physical impairments, and complex needs demonstrate signs of aging in their 40s and 50s. The majority of adults with Down syndrome, for example, are likely to experience premature aging with marked biological age-related changes occurring in their 40s. Therefore, since the signs of aging may well occur at a much younger age in some adults with developmental disabilities than the general population, it is recommended that the age of 50 years should be used as the criterion for identifying the individual as 'an older adult with developmental disabilities' (MacFarlane, 2011).

Guideline # 2: Use the Standardized Administration Procedure

The standardized administration procedure for the SIS involves a trained Interviewer and one or more Respondents who know the person well and who have observed the individual across multiple situations and settings. Family members and direct support staff who provide daily care and supports to the person are usually the best respondents.

Guideline # 3: Probe Respondents Regarding Observed Changes

The SIS Interviewer needs to probe respondents to share any changes they have seen in the individual's mobility, sensory acuity, cognitive functioning, and/or general medical and mental health. If significant age-related changes are observed, they should be reflected in:

- Increased scores in the type of support and the daily support time associated with those life activities and sub-activities evaluated in Sections I and II of the SIS.
- Increased listing of Exceptional Medical and Behavioral Support Needs (Section 3A and 3 B).
    - Section 3A should be used to list exceptional support needs in mobility, sensory acuity, and general medical and mental health.
    - Section 3B should be used to list exceptional support needs in cognitive functioning, mental health, and self care.

Guidelines for Analyzing Age-Related Support Needs

Although the entire SIS and the resulting SIS-related information and 'My Support Profile' are relevant to everyone regardless of age, there are some life activity areas and sub-activities within each area that are more sensitive to age-related changes and thus can be viewed as 'significant age-related indicators' (or 'triggers') by the Support Team. These are summarized in the following two guidelines.

Guideline # 1: Focus on Changes in Type of Support Scores

To facilitate the focused thinking of support teams Table 2 lists those life activity/sub-activity areas most sensitive to changes in the type of support.

Table 2

Activity/Sub-Activity Areas Most Sensitive to Changes in Type of Support

SIS Life Activity Area	*Area Sub-Activities*
Home Living	Using the toilet, Preparing food, Eating food, Dressing, Bathing and taking care of personal hygiene and grooming needs, Operating home appliances
Community Living	Getting from place to place throughout the community (transportation), Participating in recreation/leisure activities in community settings, Going to visit friends and family, Participating in preferred community activities, Shopping and purchasing goods and services, Accessing public buildings and settings
Health and Safety	Taking medications, Avoiding health and safety hazards, Ambulating and moving about

Guideline # 2: Focus on Changes in Direct Support Time

To facilitate the focused thinking of Support Teams, Table 3 lists those life activity/sub-activity areas <u>most sensitive to changes in daily support time.</u>

Table 3

Activity /Sub-Activity Areas Most Sensitive to Changes in Daily Support Time

SIS Life Activity Area	*Area Sub-Activities*
Life Long Learning	Interacting with others in learning activities, Learning and using problem-solving strategies, Using technology for learning, Accessing training/educational settings, Learning functional academics, Learning self-determination skills, Learning self-management strategies
Health and Safety	Obtaining health care services, Learning how to access emergency services, Maintaining a nutritious diet, Maintaining physical health and fitness, Maintaining emotional well-being
Social	Socializing within the household, Participating in recreation/leisure activities with others, Communicating with others about personal needs, Using appropriate social skills
Protection and Advocacy	Advocating for self, Managing money and personal finances, Protecting self from exploitation, Belonging to and participating in self-advocacy/support organizations, Obtaining legal services, Making choices and decisions, Advocating for others

Additional Factors That Support Teams Need to Consider When Planning Individualized Supports for Older Persons with Developmental Disabilities

In addition to the guidelines just discussed, there are five additional factors that Support Teams need to consider when planning, developing, and implementing individualized supports for older adults with developmental disabilities. These are to: (a) explain the SIS information to the Support Team members; (b) continue to focus on both <u>what is important to and for the individual</u>; (c) develop or revise the Individual Supports Plan (ISP) based on best practices; (d) use an ISP format that aligns individualized support strategies to assessed support needs and personal outcome categories; and (e) recognize the potential need to use additional screening tools and/or clinical assessments.

Explain SIS Information to the Support Team

An important characteristic of effective support teams is that a team member is responsible for explaining SIS information to other members of the Support Team. This process is facilitated by the significant work done by Provincial employees in developing the family friendly SIS report entitled, '*My Support Profile*.' The Profile has been developed to assist the service planning process for the individual, their family member(s), and support staff. In explaining the SIS and the support needs information obtained from it, the responsible person(s) should ensure that team members understand:

- The life activity areas assessed on the SIS, including exceptional medical and behavioral support needs.
- That the SIS is not an adaptive behavior scale or a clinical assessment but rather an assessment instrument that determines the pattern and intensity of supports needed to be more successful in major life activity areas and to maintain or enhance medical and behavioral support needs.
- The rating system used, and that higher scores represent more intense support needs.
- That the pattern and intensity of support needs may well change as the person ages, and that these changes are likely to be reflected in higher scores in the type of support needed and the daily support time required to provide the supports. SIS activity and sub-activity areas most likely reflecting these changes were listed in Tables 2 and 3.

Focus on What is Important To and For the Individual

The Support Team provides the collective wisdom that is required in selecting important support needs that will be incorporated into the individual's supports plan. Collective wisdom: (a) involves the individual stating what is important to and for him/her; (b) can be defined as a special type of wisdom whose purpose is to ensure best practices; (c) is rooted in a high level of expertise and experience and emerges directly from extensive data or information that is provided by the individual, other team members, and SIS assessment scores; (d) is based on the team members' explicit training and specific knowledge of the individual and the person's environment; and (e) is characterized by its being systematic (i.e. organized, sequential, and logical), formal (i.e. explicit and reasoned), and transparent (i.e. concrete and communicated clearly).

Selecting the important support needs that will be addressed in the ISP also *requires a 'delicate balance' between what is important to the individual and what is important for the individual*. SIS-based information focuses more on what supports the person needs to be more successful in major life activity areas, and to address the exceptional medical and behavioral supports needed. In general, SIS information relates more to what is important for the individual, and thus needs to be integrated with what is important to the individual. The following two guidelines are helpful in selecting important support need areas:

- Identifying support needs that are *important to the individual* is based on the individual's goals, desires and preferences. These should be incorporated into the ISP to ensure that the individual's support plan is the person's plan, and thus is meaningful to the individual. This inclusion ensures the individual's motivation, buy in, and commitment to being part of the Plan's successful implementation.
- Identifying support need areas that are *important for the individual* is based on: (a) high support need scores in the most relevant life activity areas; (b) needed supports in health and safety; and (c) interventions prescribed by a professional.

ISP Development Best Practices

An ISP should be developed based on a set of principles that reflects the person's support needs based on what is important to and for the individual. In addition, the ISP should incorporate a holistic perspective and contain easy to understand support objectives that facilitate the Plan's successful implementation and monitoring. The seven ISP development principles summarized in Table 4 reflect both the characteristics of an ISP and best practices regarding its development and implementation.

Table 4

Individual Supports Plan Development Principles

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1. The older adult with developmental disabilities and one or more family members and/or guardian are actively involved in the plan's development and implementation.
2. The Support Team that develops and implements the ISP is composed of agency staff who know the individual well and will be involved in the Plan's implementation and monitoring.
3. Priority is given to those outcome areas that reflect the person's goals, relevant major life activity areas, and exceptional medical and behavioral support needs.
4. A holistic approach is used that reflects the multidimensionality of human behavior within a quality of life framework.
5. Support objectives are referenced to specific support strategies composing a system of supports and not to person-specific attitudes or behaviors.
6. The ISP is implemented via multiple entities including the service/supports recipient, one or more family members direct support staff, and a case manager/ supports coordinator.
7. The ISP format should be user friendly and easy to communicate so as to facilitate effective implementation.

ISP Planning Process

Service providers throughout Alberta either have been or will be involved in a pilot project whose purpose is to assist agencies to see how SIS information can be integrated into an ISP whose format aligns individual support strategies to assessed support needs and personal outcome categories. As part of that pilot project, a '*Planning Guide for Integrating Supports Intensity Scale Information into Individual Support Plans'* has been developed and will be used to assist in implementing the Provincial approach to supports planning and providing a training tool for agency staff and support teams. The eight guidelines presented and discussed in the *Planning Guide* are:

1. Explain *Supports Intensity Scale* (SIS) information to Support Team members
2. Select important support needs
3. Align support needs to an ISP format
4. Align support needs to specific support strategies
5. Specify a specific support objective for each support strategy
6. Develop the Individual Supports Plan
7. Implement the Individual Supports Plan
8. Monitor the Individual Supports Plan

Potential Need for Additional Screening Tools and/or Clinical Assessments

Although sensitive to age-related changes in the pattern and intensity of support needs the *Supports Intensity Scale* should not be considered a standardized clinical screening tool for older adults with developmental disabilities. The SIS was not developed to be a screening tool or clinical assessment of all the age-related support needs of older adults with developmental disabilities. Therefore, depending on the type and relevance of the age-related changes, additional screening tools and/or clinical assessments will be required to provide additional information to organizations providing services and supports to older adults with developmental disabilities, and the support teams that are planning, developing, and implementing individual support plans for these persons. The following section provides a description of some of these tools.