Legislative
Assembly of
Ontario

Assemblée
législative de
l'Ontario

# SELECT COMMITTEE ON DEVELOPMENTAL SERVICES

## Interim Report

2nd Session, 40th Parliament
63 Elizabeth II

ISBN 978-1-4606-3755-5 (Print)
ISBN 978-1-4606-3753-1 [English] (PDF)
ISBN 978-1-4606-3754-8 [French] (PDF)
ISBN 978-1-4606-3798-2 [English] (HTML)
ISBN 978-1-4606-3799-9 [French] (HTML)

Legislative
Assembly of
Ontario

Assemblée
législative de
l'Ontario

The Honourable Dave Levac, MPP
Speaker of the Legislative Assembly

Sir,

Your Select Committee on Developmental Services has the honour to present its Interim Report and commends it to the House.

Laura Albanese, MPP
Chair

Queen's Park
March 2014

SELECT COMMITTEE ON DEVELOPMENTAL SERVICES
COMITÉ SPÉCIAL DES SERVICES AUX PERSONNES AYANT UNE DÉFICIENCE INTELLECTUELLE
Toronto, Ontario M7A 1A2

# SELECT COMMITTEE ON DEVELOPMENTAL SERVICES

## MEMBERSHIP LIST

2nd Session, 40th Parliament

LAURA ALBANESE
Chair

CHRISTINE ELLIOTT
Vice-Chair

BAS BALKISSOON

SYLVIA JONES

MONIQUE TAYLOR

SOO WONG

CHERI DINOVO

MITZIE HUNTER

ROD JACKSON

Trevor Day
Clerk of Committee

Erica Simmons
Research Officer

Heather Webb
Research Officer

* Jack MacLaren regularly served as a substitute member of the Committee.

## CONTENTS

# LIST OF ABBREVIATIONS

| Abbreviation | Organization/Individual |
|---|---|
| ABA | Applied Behavioral Analysis |
| ACSD | Assistance for Children with Severe Disabilities |
| AO | Autism Ontario |
| ASD | Autism Spectrum Disorder |
| CAMH | Centre for Addiction and Mental Health |
| CCAC | Community Care Access Centres |
| CICE | Community Integration through Co-operative Education |
| DSO | Developmental Services Ontario |
| EA | Educational Assistant |
| EI | Employment Insurance |
| FASD | Fetal Alcohol Spectrum Disorder |
| H-CARDD | Health Care Access Research and Developmental Disabilities |
| IEP | Individual Education Plan |
| IBI | Intensive Behavioral Intervention |
| MAA | Ministry of Aboriginal Affairs |
| MCYS | Ministry of Children and Youth Services |
| MCSS | Ministry of Community and Social Services |
| MEDTE | Ministry of Economic Development, Trade and Employment |
| MEDU | Ministry of Education |
| MOHLTC | Ministry of Health and Long-Term Care |
| MMAH | Ministry of Municipal Affairs and Housing |
| MTCU | Ministry of Training, Colleges and Universities |
| OT | Occupational Therapy |
| OPGT | Office of the Public Guardian and Trustee |
| ODSP | Ontario Disability Support Program |
| PT | Physiotherapy |
| QAM | Quality Assurance Measures |
| RDSP | Registered Disability Savings Plan |
| RNAO | Registered Nurses Association of Ontario |
| SEAC | Special Education Advisory Committee |
| SSAH | Special Services at Home |
| SIL | Supported Independent Living |

## INTRODUCTION

The Select Committee on Developmental Services is pleased to present this interim report. Each of our Members volunteered to serve on the Select Committee out of a deep commitment to Ontarians with developmental disabilities and their families.

At the public hearings, we were moved by the presenters' willingness to share the intimate and often very emotional details of their families' lives and struggles. The Committee members were also struck by the extent to which witnesses from across the province expressed very similar concerns about developmental services, and their many thoughtful ideas and recommendations for improvement.

The interim report summarizes the work of the Committee to date and is structured around the Committee's mandate. It provides background information about the Committee's mandate and the dates and locations of its hearings. It focuses on the concerns of individuals and stakeholder organizations that were raised in written submissions and during public hearings held in locations around the province. The interim report does not refer to individuals directly, but uses the names of some organizations.

While this report highlights some of the comments and recommendations made by witnesses, the Committee has maintained an open and neutral approach. Our final report (due in May 2014) will outline a series of recommendations for the development of a provincial strategy on developmental services.

### Committee Mandate

On October 3, 2013, the Legislative Assembly of Ontario gave unanimous consent to a motion to appoint a Select Committee on Developmental Services that would consider and report to the House its observations and recommendations with respect to the urgent need for a comprehensive developmental services strategy to address the needs of children, youth and adults in Ontario with an intellectual disability or who are dually diagnosed with an intellectual disability and a mental illness, and to coordinate the delivery of developmental programs and services across many provincial ministries in addition to the Ministry of Community and Social Services. In addition, in developing its strategy and recommendations, the Committee would focus on

- the elementary and secondary school educational needs of children and youth;
- the educational and workplace needs of youth upon completion of secondary school;
- the need to provide social, recreational and inclusionary opportunities for children, youth and adults;

- the need for a range of available and affordable housing options for youth and adults;
- the respite and support needs of families; and
- how government should most appropriately support these needs and provide these opportunities.

## Background

The Committee appreciates the important research and reports that have preceded its own consideration of developmental services in Ontario. Recent relevant work includes the 2007, 2011, and 2013 *Annual Reports* of the Office of the Auditor General of Ontario; the Ministry of Community and Social Services report *Opportunities and Action: Transforming Supports in Ontario For People Who Have a Developmental Disability*, released May 2006; the 2010 Final Report of the Select Committee on Mental Health and Addictions, *Navigating the Journey to Wellness: The Comprehensive Mental Health and Addictions Action Plan for Ontarians*; the Initial Report of the Housing Study Group (Developmental Services Sector–Ministry of Community and Social Services Partnership Table), *Ending the Wait: An Action Agenda to Address the Housing Crisis Confronting Ontario Adults with Developmental Disabilities,* released in September 2013; and Yona Lunsky et al., *Atlas on the Primary Care of Adults with Developmental Disabilities in Ontario* (Centre for Addiction and Mental Health & Institute for Clinical Evaluative Services), released in December 2013.

When the transformation of developmental services was first announced in 2004, a Joint Developmental Services Partnership Table was established to represent both the Ministry of Community and Social Services and the Ministry of Children and Youth Services, as well as associations of self-advocates, families, and service providers in the sector. Some of those who made presentations to the Committee have been involved in the Partnership Table.

On May 16 2013, a motion by Christine Elliott (Whitby–Oshawa) that the Legislative Assembly immediately establish a Select Committee "to develop recommendations on a comprehensive developmental services strategy to address the needs of children, youth and adults in Ontario with an intellectual disability or who are dually diagnosed with an intellectual disability and a mental illness" was debated during Private Members' Public Business. The motion carried unanimously.[1] (See Appendix A for the complete wording of the motion.)

## Committee Meetings

The Committee met for the purpose of organization and to discuss business matters in October and early November 2013. Public hearings were held in

---

[1] Ontario, Legislative Assembly, *Official Report of Debates (Hansard),* 2nd Sess., 40th Parl. (16 May 2013): 2173.

Toronto and other locations around Ontario beginning on November 13, 2013 and ending on January 21, 2014.

The November hearings included presentations by government ministries involved in delivering services and supports to people with developmental disabilities, including the Ministry of Community and Social Services (MCSS), the Ministry of Children and Youth Services (MCYS), the Ministry of Education (MEDU), the Ministry of Municipal Affairs and Housing (MMAH), the Ministry of the Attorney General, the Ministry of Training, Colleges and Universities (MTCU), the Ministry of Community Safety and Correctional Services (MCSCS), the Ministry of Health and Long-Term Care (MOHLTC), the Ministry of Aboriginal Affairs (MAA), and the Ministry of Economic Development, Trade and Employment (MEDTE). The Committee also heard from the Provincial Advocate for Children and Youth.

Representatives of stakeholder groups also attended as invited guests. In the weeks following, the Committee heard from people across Ontario with a range of perspectives including self-advocates (people with developmental disabilities), family members, health care and social service professionals, advocates for people with developmental disabilities, and many representatives of stakeholder organizations.

The Committee heard from agencies and organizations that provide a wide range of services including respite care, residential care, day programs, intensive therapy for autistic children, and advocacy and support to families.

Some stakeholder organizations focused on the needs of those with specific conditions such as autism spectrum disorder (ASD) or fetal alcohol spectrum disorder (FASD), and people with a dual diagnosis. Clinicians, parents, and advocates urged that Ontario develop provincial strategies on ASD and FASD.

A number of medical professionals spoke to the Committee about a lack of capacity in the system to address the needs of those with developmental disabilities or a dual diagnosis.

During its travels, the Committee also made a site visit to the Billy Bayou Centre in Moose Factory, where the Moose Cree Education Authority operates a day program for adults with developmental disabilities.

Along with written submissions, many individuals and organizations sent the Committee reports and studies that they feel relate to the Committee's work, and many also brought to the Members' attention examples of jurisdictions that have managed to eliminate waitlists and provide inclusive education, meaningful apprenticeships, and better social integration for people with developmental disabilities and/or a dual diagnosis.

## EVOLUTION OF DEVELOPMENTAL SERVICES

The developmental services system has undergone a number of changes in recent decades. Until the 1970s, many people with developmental disabilities lived in large government-run institutions where they were isolated from the community. According to the MCSS, more than 10,000 people were living in 16 such provincially-run facilities in 1976.

In the 1960s and 70s advocates of community living began arguing for the right of people with developmental disabilities to live in and participate in their communities. In 1977 the government began to close provincially-run institutions, with the final three facilities closing in 2009. Over the past few decades as the number of people living in institutions decreased, community-based services expanded.

In 2004 the government began to investigate how the developmental services sector could be transformed to improve support for people with developmental disabilities. New legislation passed in 2008 established the framework for transforming the developmental services sector based on the principles of social inclusion, although further work is required to ensure that that these principles become a reality.[2]

## DEVELOPMENTAL DISABILITIES

The Committee heard from many people across the province about their experiences with and views of the current developmental services sector, some of whom gave their testimony in person, others via teleconference or written submissions. A significant number of witnesses, including those who spoke in their capacity as representatives of stakeholder organizations and service providers, were also parents or family members of individuals with developmental disabilities.

Presenters talked about their experiences parenting children with developmental disabilities from early childhood through middle age and beyond. Many parents described their own struggles, as they reached their sixties and seventies, in coping with continued caregiving for adult children. The Committee also heard from people with developmental disabilities as well as from siblings of people with developmental disabilities, some of whom act as primary caregivers.

The Committee heard that there is a paucity of data regarding the number and needs of persons with developmental disabilities. Researchers from Health Care Access Research and Developmental Disabilities (H-CARDD) told the Committee that they identified 66,482 adults (ages 18 to 64 years) with developmental disabilities in Ontario as of 2009-10 and that the number is likely higher now. The MCSS estimates that there are about 62,000 adults with a developmental disability in Ontario. Staff from the MCYS explained that they do not currently have an estimate of the population of children with developmental

---

[2] For more about the transformation of developmental services please see p. 25.

disabilities as distinct from the broad group of children with special needs which includes children with physical, intellectual, behavioral, and/or cognitive issues. The Committee will be obtaining an estimate of the number of children with developmental disabilities in Ontario from H-CARDD.

The last government-run institutions for people with developmental disabilities closed in 2009. Ontario is now seeing more people with developmental disabilities than ever before who are growing up in family homes and aging in the community.

The needs of people with developmental disabilities can vary greatly in terms of the type and intensity of the supports required. Many people with developmental disabilities also have very complex health needs. The Committee heard from the MOHLTC that people with developmental disabilities tend to age at a more rapid rate and as a result may experience age-related health problems earlier than people without developmental disabilities.

The difficulty of getting an early diagnosis and intervention, compounded by a shortage of services, supports, and residential spaces for people with developmental disabilities, means that too many end up in long-term care, hospital beds, psychiatric wards, homeless, or incarcerated. The Registered Nurses' Association of Ontario told the Committee that Canadian data shows that youth with FASD are 19 times more likely to be incarcerated than youth without FASD in a given year and that there is a 10 times greater incidence of FASD in the correctional population than in the general population.

The Committee heard that, across the province, families of people with developmental disabilities are in crisis. Many parents appearing before the Committee broke down in tears as they described their failed efforts to access services and supports, and the toll taken by exhaustion and constant anxiety about what will happen to their developmentally disabled child when they die or are otherwise unable to continue caring for them. The toll on families includes a high frequency of marriage breakdown and stress-related illnesses. Siblings too pay a price for these difficulties, sometimes at the expense of their own education and future. Parents described how their state of constant uncertainty about the future led to feelings of "terror," "panic," and a "paralysis of worry and fear." They emphasized that they love their children, and want to care for them at home, but in the absence of adequate funding and supports, feel overwhelmed.

Community Living Ontario explained that "reduced availability of supports has meant increasingly that people must be heading for a crisis, or already in crisis to access services. . . . crisis is now a necessary prerequisite for service." Families expressed anger that they must be pushed to the brink of disaster in order to be fast-tracked for supports. Presenters described the developmental services system as "dysfunctional," "a travesty," and "a violation of the rights of Ontario's most vulnerable citizens."

Parents stressed that developmental disabilities are lifelong, and spoke about their frustration at having to repeatedly endure lengthy and intrusive assessments to determine eligibility for services, only to spend years on waitlists to access those services. Many presenters suggested that caring for people with developmental disabilities is a social responsibility and that developmental services should be seen, like health care and education, as an entitlement rather than a discretionary social welfare program. However, the Committee heard from the MCSS that the provision of developmental services in Ontario is currently operated as a discretionary program and that funding for programming is subject to specific budget allocations.

The Committee heard about the importance of including people with developmental disabilities in decision making regarding their care and life goals. People with developmental disabilities are too often excluded from meetings and decisions about employment or volunteer options, where they live and who they live with, how and by whom their health care will be provided, and how they will participate in their communities. A self-advocate told the Committee, "all we are asking is to have a chance to prove ourselves . . . I would like to participate . . . We are people like anybody else."

Several presenters called upon the government to follow through on the Premier's December 9, 2013 apology to former residents of government-run institutions by ensuring better treatment of Ontarians with developmental disabilities. Many witnesses described the placement of developmentally disabled people in hospitals and long-term care homes as a form of "re-institutionalization" and a betrayal of the promise of social inclusion and community integration.

Parents also demanded to be heard. "I am the expert," one mother told the Committee. "I live it 24 hours a day, every single day [for] 20 long years. So ask me. Utilize my experience. Don't tell me what I need. Listen to my voice. Hear me. I'm more than willing to help. . . . I'm willing to offer up solutions and to work with you."

## DUAL DIAGNOSIS

An estimated 40 percent of people with developmental disabilities have a dual diagnosis of a concurrent mental health issue. Developmental psychiatrists from the Centre for Addiction and Mental Health (CAMH) explained that "dual diagnosis" is not a medical term but rather an "administrative convenience" that helps to identify a particular type of service a person may require. They told the Committee that it is essential to have specialized mental health services for adults with developmental disabilities; these services must be provided early in order to be most effective, and they must be personalized.

The Committee heard that the needs of people with a dual diagnosis are not well met; community resources are not readily customized to meet the needs of these individuals, and many are placed in custody because of aggressive behaviour rather than criminal activity. Families told the Committee that there is a shortage of residential and day care options for people with a dual diagnosis.

Some parents said they were frightened that their child would end up like Ashley Smith, a troubled New Brunswick teenager who died while in custody.

Parents whose daughter is developmentally disabled, dually diagnosed with psychosis, and violent, told the Committee that "we are scared for her, and scared of her." They described how the hospital psychiatric ward will not admit their daughter because of her seizures, and the neurology ward will not admit her because of her violent behaviour. She was turned down by two residential placements because of her complex needs. Her parents applied for crisis funding but were told there was none left and were advised to call the police. "I had to choose between the safety of myself," said her mother, "and the safety of my daughter."

The Committee heard that the MOHLTC and the MCSS are looking at creating a dual diagnosis framework that would set out expectations for the services provided to persons with a dual diagnosis and improve the delivery of services and programs.

## POPULATION GROUPS

### Children and Youth

The MCYS, the MCSS, and the MEDU all share responsibility for the delivery of services for children and youth with developmental disabilities, and the MOHLTC has a role in the delivery of medical services. The Committee heard from presenters who believe that despite this shared responsibility, the ministries operate in "silos" and fail to exchange information. As one noted,

> in reading the presentations from various ministries, it is apparent that, despite claims of inter-ministerial cooperation, this clearly is not happening. MCSS does not appear to know how many young people with developmental disabilities are living in long-term-care facilities. How can that be? People receiving services as a child need to reapply for services as an adult. The list goes on and on.

Parents and medical experts consistently reiterated the importance of early diagnosis and intervention for children with developmental disabilities. The Committee heard that a shortage of physicians and specialists with expertise in FASD, ASD, and other developmental disabilities in Ontario makes it much more difficult for families to get an early diagnosis. Once a diagnosis is obtained, families are put on waitlists for services.

Families of children with ASD told the Committee about the heart-breaking experience of waiting to access specialized Intensive Behavioural Analysis (IBI) or Applied Behavioural Analysis (ABA) therapies while their children are still young enough to benefit. Long waitlists mean that many families have resorted to paying for these services privately and gone deeply into debt.

The Committee heard that the number of children with developmental disabilities is growing, as is the complexity of lifelong care required by these individuals. Further, the prevalence of some specific disorders has increased quickly and significantly; for example, ASD is now thought to affect one in 88 children, an increase from one in 150 in 2008.

The Committee also heard from presenters who identified a severe shortage of respite services for children, especially for those with behavioural issues such as aggression. The Committee heard that the MCSS does not fund dedicated respite beds for children with developmental disabilities and does not collect information on the number of children waiting for respite. The MCYS does fund respite beds for children but also does not collect information on waitlists for respite care.

## Young Adults

The Committee heard that graduation from secondary school is a “key transition point” for young people with developmental disabilities because they lose the school-based services they have come to rely upon and families then must search for day programs or other productive activity to fill their days.

This transition is complicated by a relatively recent change to the structure for direct funding: as of April 1, 2012, Special Services at Home (SSAH) funding is no longer available to support people with developmental disabilities past the age of 18. Instead, families must apply for new “Passport” funding for adult services after a child’s eighteenth birthday. The Passport program provides a maximum of $25,000 per year.

The Committee heard that after spending years on waitlists, struggling to get funding, services, and supports in place for their child, families find themselves having to start all over again when their child is 18. Some witnesses described this as being like “dropping off a cliff.” “In one fell swoop,” explained one mother, “we lost our pediatrician, our family support worker, and our respite.” Parents have to contact their regional Developmental Services Ontario (DSO) office to have their child reassessed for eligibility for Passport funding and put on a new set of waitlists, often many years long, in the hope of accessing services and supports.

Many parents noted that while entering adulthood is an important milestone for other young adults, marking their increasing maturity and independence, it does not signify any comparable maturation or change for developmentally disabled young people. For this reason, families see the age 18 cut-off for SSAH funding as arbitrary and unfair. The funding ends “because you’re 18,” said one mother, “not because your life has changed or your requirements or your need for support has changed.” Parents insisted that the provision of services and supports should be based on the individual’s needs, and not on his or her age. As one parent put it, “there should be no sense that, somehow when you turn 18, your disability disappears.”

One mother said: “In theory there are adult services but in practice we have nothing.” She said that a DSO worker told her that her daughter is on an 18-month waiting list but “it doesn’t really matter when she gets to the top of the list because there’s no money for anything anyway.” A father described the experience of searching for funding and services for his 20-year-old son—a quadriplegic with cerebral palsy who needs round-the-clock care—as “frightening and profoundly discouraging.”

Many parents and other caregivers described the graduation from high school as a particularly difficult and traumatic transition for young people who cannot understand why their daily routine has changed and why they cannot see their friends and school staff every day. A developmental psychiatrist explained that for young people with autism, who find any change in routine difficult to handle, this transition is “a disaster.” The Committee heard that this distressing experience is exacerbated when young people who are used to daily activities and social interaction are suddenly stuck at home all day, as one mother put it, “with nowhere to go and nothing to do.” Young people in this situation often regress and develop depression, aggression, and other challenging behaviours.

A retired special education teacher told the Committee that “many of the achievements and gains my students have made over the years during their school career fade away due to the lack of further training, stimulation, retention and review” after they leave school. He explained that some of his former students “have lost their ability to speak or copy sign language words through a lack of practice. Some are no longer following instructions from their parents; they’ve become very non-compliant.” Some children “no longer have use of or access to a voice output communication aid” like a computer, tablet, or iPad. Their parents are afraid to take them out into the community because of their unpredictable behaviour, and so these young people have less and less social interaction. Many become obese from “sitting on the couch and eating and watching TV all day.”

This witness recommended that school boards use a “transition coordinator” to facilitate the development, implementation, and monitoring of transition plans for students with complex behavioural needs. He also suggested the creation of drop-in day programs to help parents and students with developmental disabilities bridge the gap while on waitlists for appropriate adult services.

Ministry staff told the Committee that in 2011, the MCYS and the MCSS introduced a policy framework, *Transition Planning for Young People with Developmental Disabilities*, to improve the experience for youth who are preparing to transition to adulthood. The framework, which also includes participation by the MEDU, formalizes the responsibilities of the ministries, service agencies, and other community partners in the transition process through regional protocols. Communities began implementing the framework in September 2013 and the MEDU advised the Committee that as of September 2014, all students with an Individual Education Plan (IEP) must have an integrated transition plan mapping out their path from school into programs provided by other ministries.

## Adults

In addition to accessing MCSS-funded programs and services specifically for persons with developmental disabilities, adults may also access the same MOHLTC-funded programs that are available to the broader population. These programs cover primary care services, mental health and addictions services, home care and community care, and long-term care home beds.

The community care programs funded by the MOHLTC are intended to promote independence in the community and may be accessed without a referral. Because adults with developmental disabilities tend to age more quickly, they may need to access services aimed at seniors (for example, meals on wheels, transportation, and adult day programs) at a younger age.

The Committee heard that many of the difficulties of looking after a developmentally disabled child are magnified when that child becomes an adult. Emotional outbursts and physical aggression from a developmentally disabled adult can present more of a danger to family members. Further, an adult's need for help with basic personal care, or using a wheelchair or other mobility aid, is more physically demanding for caregivers, especially those who are aging.

Like other adults, people with developmental disabilities yearn for independence. As one woman told the Committee,

> I would like to live on my own one day. Right now I have to live with my parents because I don't have enough money to live in my own place, buy groceries and participate in society. . . . The greatest challenge for me is that people think I am not able to do things. When people take the time to work with me, they get to know me and are able to see what I can do. I am a human being and I am capable of living a full life.

## Aging with Developmental Disabilities

As seniors, developmentally disabled people often fall between the cracks: their behavioural issues often mean that long-term care homes are unable to accommodate them, while group homes and residences for developmentally disabled people are mostly geared towards the needs of younger people. A personal support worker told the Committee about the impact of increasing numbers of older people with developmental disabilities "who would benefit from retirement or slower-paced day programming but are forced to attend regular programming, and keep up with their younger counterparts."

Only a small number of long-term care homes receive MCSS funding to provide enhanced services and programming for residents with developmental disabilities. The Committee heard testimony from a woman whose 63-year-old developmentally disabled sister-in-law lives in a long-term care home that is not equipped to handle her developmental needs. Other family members are aging, she said, and it is increasingly difficult for them to lobby for funding and services: "Pretty soon she'll have nobody to advocate for her."

As people with developmental disabilities age, their needs change and they require more supports in different areas. For example, many experience early onset of dementia which means that residential care homes require higher staffing levels both during the day and overnight. Some may need wheelchairs or other mobility aids. The Committee heard that developmental services agencies do not have the resources to provide increased mobility and accessibility supports either for individuals or for private or group homes. Presenters requested more partnerships between the MCSS and the MOHLTC to help organizations put accessibility supports in place.

## Parents/Families

While families are the primary caregivers for most people with developmental disabilities, parents too are getting older and finding it ever harder to care for their adult children at home. It is likely that growing numbers of people with developmental disabilities will outlive their parents and require supportive living arrangements in the community. Aging parents worry that when they die or become incapacitated, their grieving child will be abruptly moved away from their home and community without any chance to plan or prepare for this transition, and without any understanding of what is happening.

Aging parents, often in declining health, told the Committee about their efforts to cope with the physical challenges of caring for adult children at home. Grandparents too are aging and are no longer able to provide respite and other supports. Siblings whose help is needed at home have been unable to finish their education, and feel obliged to take over the caregiver role when parents cannot continue. Many caregivers feel socially isolated, cut off from friends, extended families, and communities. Some parents told the Committee that caregiving responsibilities meant that they had little free time to spend with their other children and grandchildren.

Parents repeatedly noted the importance of respite care; even a few hours of regular weekly respite allows them to go to their own medical appointments, buy groceries, or accomplish other vital household tasks. Many described respite as a make-or-break service: without access to adequate respite, the difficulties of looking after developmentally disabled family members who need round-the-clock care and supervision can be crushing, leading some families to feel that they cannot continue to care for their children at home.

The Committee heard from many families in which one parent had to quit work in order to stay at home and provide care to a child with a developmental disability. With reduced income and the higher expenses of having to pay for support services privately, many families have been plunged into debt. Many have used up or forgone their retirement savings and some have sold their family homes.

One mother told the Committee that younger parents like her are also struggling: "We can't work, be parents, and be the support workers for our children." She described herself as one of the "sandwich" generation with both elderly parents and adult children to support.

One witness pointed out that "not everyone has a family to advocate on their behalf." At least one-half of the population of people with developmental disabilities, as an advocate noted, "have only their parents, and possibly one other person in their life, that they can count on for regular support. Individuals with a developmental disability are living increasingly isolated lives."

One parent spoke of a lack of culturally-appropriate supports, noting that "I also speak as a visible minority family—Black Canadian—in a mixed-race family, dealing with the issues of race and racism in trying to get services in a sector that is uncomfortable and unwilling to incorporate cross-cultural understanding." Language was also raised as a barrier to service for people who do not speak English or French, particularly in First Nations communities.

Families asked for better communication from the MCSS and DSO offices about what services and funding are available, noting that other parents are their primary sources of information. An agency representative said that families need help to navigate the system, explaining that most families do not know what they need, are not aware that they can ask for assistance, and require advice on how to utilize the few services that are available.

Several presenters said that families feel that they are "penalized" for trying to find solutions and that they would like more support from government for innovative solutions, such as, for example, families coming together to organize shared accommodation for people with developmental disabilities. One witness called the developmental services sector "a system of closed doors."

The mother of a child with autism noted that parents face an

> inordinate amount of stress, part of which comes from coping with the actual situation, but a great deal of which comes from the very preventable stresses of navigating the system. It is very difficult to be constantly reminded by every government agency of the urgent need for intervention before the age of six, while simultaneously being presented with every obstacle possible to receiving

> that intervention. This takes a toll on your physical and mental health.

### *"Abandonment"*

The Committee is very aware of a number of well-publicized cases of parents "abandoning" their developmentally disabled children to the care of social services, and Members were very moved to hear from some parents who have made this excruciating decision. These parents told the Committee that they surrendered care of their children in a desperate, last-ditch attempt to enable their children to access services. A mother who gave up custody of her son explained that parents like her "often feel abandoned and betrayed by our governments and by our communities."

One mother struggling to look after both her terminally ill husband and her severely disabled daughter, told the Committee that she had "begged" for help. Told that there was no funding available, she made the "horrendous" decision to relinquish custody by refusing to bring her daughter home from temporary respite care. "It was heart-breaking, painful, and unthinkable, but it was all we could do to cope with the situation. What we did got out, and the word 'abandonment' was used. It was devastating. It is my belief that our family was abandoned, and it forced us to surrender care."

The story became public and hit the national news. Finally funding was provided to enable the daughter to stay permanently in the respite home where she has two caregivers at all times. "She is still the light of my life," her mother said. "I wish I could have kept her with me and been able to care for her, but the reality is that I am unable to."

The Committee heard that there is no government ministry or office keeping track of these cases of abandonment. However, the Peel Crisis Capacity Network indicated that between January 2011 and August 2013, 44 individuals were "abandoned" in the Peel and Halton regions.

## Remote / Rural Communities

The Committee heard that in smaller communities, a lack of residential options for children with complex medical and behavioural needs means that they are often sent away from home. At the same time, there are few services available locally for people with developmental disabilities after age 18. The mother of a 20-year-old with a dual diagnosis said that after her daughter turned 18, "there was nothing in our rural county. No emergency beds, no centre-based crisis intervention, no respite, only hopelessness." She urged the Committee to find "rural solutions, not just urban solutions" to this problem.

People living in northern communities requested additional support for high-cost items like winter clothing, food, utilities, gas, and housing and suggested that their funding amounts need to reflect better the actual costs of life in northern Ontario.

They noted that there are fewer social and recreational opportunities in northern communities and it is more difficult for people to go to another community for services than it is for people living in southern Ontario.

Staff from MEDU explained that rural and northern school boards often receive a higher proportion of funding for special education programming; despite this, students from these school boards often have to relocate to the Greater Toronto Areas or other urban centres for needed services and supports.

## First Nations

The Committee heard that developmentally disabled people in First Nations communities face many of the same challenges as other Ontarians who live in small communities, such as social isolation and a severe lack of resources for specialized and accessible programming. For people living in isolated and remote communities, these problems are even more acute. Like families across the province, parents in First Nations communities told the Committee about their frustration at the lack of services and supports such as day programs and respite, and their fears for their children’s future without them. Lacking access to clinicians, it is extremely difficult to access specialized medical care and to obtain an early diagnosis.

Staff of the Sioux Lookout First Nations Health Authority explained the challenges of providing a range of health care services to approximately 21,000 people living in 31 First Nations communities, many of them remote fly-in communities. The Committee heard from presenters that many people with developmental disabilities and their parents are unable to participate in community events and are virtually held hostage in their homes. People with developmental disabilities are socially isolated and more likely to suffer neglect or abuse, or attempt suicide.

The funding structure for programing offered to Aboriginal persons in Ontario is complicated. The federal government funds a major income-dependent, residency-based program for adults and children with disabilities, as well as educational and health services. The Ontario government also funds Aboriginal-specific health programs and services, some of which are delivered on reserves. The vast majority (about 80 percent) of Aboriginal people in Ontario live off-reserve and have access to the same programs and health services as other Ontarians. The MAA does not directly fund major programs or services, although it does liaise with the federal government and other ministries to maximize federal funding.

The Committee visited the island community of Moose Factory, accessible by boat or airplane in the summer and an ice road in the winter. The Committee heard that, after being refused funding from the MCSS, the Moose Cree First Nation provided operational funding to the Moose Cree Education Authority to open the Billy Bayou Program for adults with developmental disabilities as a pilot project. This day program offers one-on-one personal support workers for adults with developmental disabilities, enabling them to stay in their home community.

The Committee heard that the community is hoping for a long-term funding commitment from the government to help ensure the program's survival, and hopes to offer residential care options in the community.

Representatives of the Nishnawbe Aski Nation asked for greater inter-ministerial cooperation, and adequate resources to conduct a review of services and supports and develop a comprehensive plan to provide services. They described the dire situation for people with developmental disabilities in their 49 communities, 32 of which are fly-in only. With an "alarming lack of services," they told the Committee, "the stress and despair is incredible."

The Committee heard that the MAA faces major challenges around the lack of specific data regarding the incidence of developmental disabilities among the Aboriginal population. However, estimates suggest that the incidence of certain developmental disabilities is much higher in First Nations communities than in the general population (for example, the MAA indicated that FASD is estimated to affect up to 120 out of 1000 live births in First Nation communities, as opposed to 3 to 5 out of 1000 in the general population).

The MAA also spoke to challenges around a paucity of culturally-appropriate services and programs for Aboriginal persons with developmental disabilities, including "virtually non-existent" adult housing with appropriate cultural supports. Given the painful history of governments removing First Nations children from their homes and communities, presenters noted that there is an understandable reluctance to send family members away to other communities to access services. But with no respite care, and no residential options in most small communities, some families feel they have no choice but to relocate or send their family member with a developmental disability away.

## FUNDING AND ACCESS TO SERVICES

Individuals with developmental disabilities may obtain government-funded services in two ways: through "direct funding," which provides funding to their family to purchase services privately, or through "direct service," where they receive service directly from a government-funded community-based service agency at little or no cost.

Numerous individuals and service agencies described what they considered to be the systemic, continuous underfunding of the developmental services sector. They noted that underfunding impacts all areas of the sector, including the quality of care and services, working conditions for personal support workers, and waitlists for programs. They also noted the inherent unfairness in asking overburdened families and individuals to self-advocate for better funding and services when there is no more funding available. As the Committee heard from one parent:

> I'm thinking that the long waitlists that have been created and the underfunding have created an acceptable level of

> discrimination in our province. Because of that, the issues facing people with disabilities never become an election platform, because of that level of discrimination. That comes from the waitlist, that it’s okay to let people with disabilities sit on waitlists and wait until they go into crisis.
>
> So families can’t make noise. They’re tied down, looking after their children. . . . [O]ur children look to us, we look to our advocates, the advocates look to the government, and I really believe that the government needs to make that noise for us.

Presenters noted that funding for developmental services should be measured by fairness in outcomes rather than in dollar amounts received. The Committee heard that the demand for constant assessments and reassessments of their children’s needs left many families feeling that the government does not trust them to spend funds received for their children’s care appropriately. Parents requested better information sharing between ministries in order to reduce the need for lengthy assessments each time a different ministry is approached for support.

There was a consensus among presenters that supports need to be seamless, and portable. Many argued that funding should be grandfathered for continuity of supports and that SSAH funding should not be cut off until adult supports are in place.

Many witnesses felt that individualized direct funding is essential. They pointed out that it is more cost effective for families to directly purchase care for a developmentally disabled family member who lives at home, independently, or in shared accommodation than to pay for a bed in a hospital or long-term care facility. However, they also noted that direct funding must be sufficient to actually cover the cost of purchasing community services. Some presenters spoke of finally receiving direct funding, only to realize that it was not sufficient to pay for the services needed.

The mother of a child with autism told the Committee that as parents,

> we were left to put the pieces together on our own: to make the endless phone calls, fill out the same information on numerous application forms, to advocate tirelessly with multiple levels of government on behalf of our child. More often than not, we simply had to resort to privately funding interventions for lack of any other option. My husband and I are both university-educated, English is our first language, we are trained researchers both, and my husband has a law degree. And yet, with all these strengths, we could barely cope with the strain of finding services, understanding the larger system, including the education system—just understanding it—and struggling to pay for private services

> when we could not bear the thought of wasting precious time on waitlists.

Several presenters suggested that developmentally disabled people who are deemed eligible for supports and services should also be entitled to independent facilitation and planning. Witnesses emphasized that this planning should take place early in the process with the assistance of a neutral planner, as opposed to through an agency with a vested interest in the services and support being offered. Referencing the slogan "no decision about me, without me," they stressed that individuals with a developmental disability should be key stakeholders in all decisions about their lives.

Finally, the Committee heard from witnesses requesting better inter-ministerial coordination that would allow ministries to blend their budgets, providing more effective support for individuals. Regardless of how funding is delivered, however, the most important element is that it gets into the hands of the families when and how they need it, a frustration highlighted by the Provincial Advocate for Children and Youth:

> Who cares what ministry the money comes from? Get the support that this mother needs and this family needs. Figure it out. I don't care which silo or which department or which jurisdiction. Just figure it out. It's a human solution.

## PRIMARY (MEDICAL) CARE

Like the broader population, many people with developmental disabilities are living longer. At the same time, the Committee heard that this population tends to age more rapidly than the broader population, experiencing earlier onset of dementia and other age-related illnesses, and needing more extensive health care.

Persons with developmental disabilities have access to the same primary care services as the general population. However, the authors of *Atlas on the Primary Care of Adults with Developmental Disabilities in Ontario,* a study published by the Institute for Clinical Evaluative Sciences and CAMH, told the Committee that, compared to people without developmental disabilities, people with developmental disabilities have many unmet health needs and that they experience significant barriers to high-quality health care.

One problem is that Ontario has a severe shortage of medical specialists with expertise in developmental disabilities. As a result, people with developmental disabilities, and especially those with a dual diagnosis of mental illness, are marginalized within the medical system. The Committee heard that it is very difficult for people with complex medical needs, as well as behavioural issues, to find primary care physicians.

Presenters from H-CARDD explained that persons with developmental disabilities have higher incidences of many chronic diseases common to the adult population. Their rates of emergency department use are much higher. The likelihood of these individuals being hospitalized, either for a psychiatric or a medical issue, is also higher. At the same time, individuals with developmental disabilities have a higher rate of avoidable hospitalizations.

People with developmental disabilities are less likely to receive preventive care such as mammography, and colorectal and cervical cancer screens. Presenters from the Surrey Place Centre explained that many preventable medical conditions, such as gastrointestinal, metabolic, nutritional, and neurological disorders, are often undetected and as a result are untreated or inappropriately treated. These witnesses also noted that problem behaviours, such as aggressiveness and self-injury, are often symptoms of a physical health disorder.

Presenters from H-CARDD indicated that one-third of the individuals with developmental disabilities who are prescribed five or more medications at the same time were not receiving regular follow up care with their primary care physician, while the most commonly prescribed medications for these individuals were psychiatric medications, specifically antipsychotic medications.

Psychiatrists from Queen’s University recommended that academic health science centres be resourced to help build capacity by producing more clinical educators with specialized knowledge. They noted that it may be necessary to recruit faculty with the necessary expertise from other jurisdictions. The Committee heard that all health professionals in the United Kingdom, no matter what their speciality, have a mandatory rotation working with developmentally disabled patients.

## SPECIFIC DIAGNOSES

The Committee received much testimony on two of the most common developmental disabilities: ASD and FASD.

### Autism Spectrum Disorder

ASD is one of the most common developmental disabilities, affecting roughly one percent of Ontario’s population. However, only 50 percent of adults with ASD also have an intellectual disability (that is, an IQ below 70).[3] The Committee heard that individuals with ASD are often refused services from the developmental disability sector because of their high IQ and by the mental health sector because of their developmental disability, leaving them with nowhere to turn for support.

Developmental psychiatrists from the Centre for Addiction and Mental Health (CAMH) told the Committee that the province must develop more capacity to deal with new cases of individuals with ASD who have less cognitive impairment and more challenging behaviours.

---

[3] For more about the IQ threshold please see p. 27.

Parents and health professionals alike emphasized the importance of early diagnosis and intervention such as ABA and IBI in helping children with ASD to reach their full potential. The *2013 Annual Report* by the Office of the Auditor General of Ontario noted that the median age at which children with autism are diagnosed in Ontario is a little over 3 years, yet the screening period endorsed by the Canadian Paediatric Society is 18 to 24 months. The Committee heard that that decisions about how much IBI or ABA a child qualifies for are being driven by financial, rather than clinical, considerations. Many parents, afraid that their child will not receive the appropriate amount of early intervention, go into debt in order to pay for private services.

Several witnesses cited the Auditor General's *2013 Annual Report* which found a wide variation in how long children with autism must wait for services across the province. The MCSS advised the Committee that the waitlist for IBI ranged from 2 months in the North East region to 47 months in the Central East region, although it also noted that many young people are receiving other provincially-funded services during this time. One presenter noted that "children need the same quality of autism services no matter where they live."

The crucial importance of early diagnosis and intervention was illustrated by a grandmother who shared the story of her two young grandsons. One boy was not diagnosed with autism until he was two-and-a-half years old, and then waited almost a year for speech therapy and ten months for occupational therapy. He was four-and-a-half when he began IBI. In the meantime, his grandmother said, he "regressed, behaviours became ingrained, and the window of opportunity was missed."

In contrast, when this boy's younger brother was diagnosed with autism at 21 months, said his grandmother, "we knew what we needed to do." The family paid for private speech therapy immediately. By age two, the boy was in a private IBI program. He is now doing very well in a regular class at his local school. Having received appropriate intervention earlier, the younger boy has much better prospects than his older brother. At the same time, the grandmother pointed out, by reducing the ongoing need for intensive services across the lifespan, early intervention is also more cost-effective.

Some parents said they would like to be able to apply for government loans to help pay for a child's autism therapy. There was also a suggestion to create a governing board and standards for autism therapies in order to cap fees and ensure consistent professional standards. Several presenters urged the development of a provincial strategy on autism.

## Fetal Alcohol Spectrum Disorder

FASD is a brain-based developmental disability resulting from maternal alcohol use during pregnancy. FASD is one of the most common developmental disabilities in Canada, affecting an estimated one in 100 births. The Committee heard that FASD is poorly understood and largely invisible because people affected often show no visible signs of their disability. As a result, many people with FASD are never diagnosed, or are misdiagnosed, and never receive proper support. Many people with FASD do not qualify for developmental services because their IQ is over 70.

Because of their brain injury, people with FASD face a wide spectrum of lifetime challenges, from mild to very serious physical, mental, and emotional disabilities. As the mother of one child explained:

> The cognitive impairments in children and adults with FASD can cause them to have poor memory, lack of impulse control, poor judgment, and difficulty with cause-and-effect reasoning. This means they often need support from others to help them think through their decisions, behaviours and consequences, as well as help them remember their routine, schedule, and how to complete tasks assigned to them. In other words, those living with FASD need a trusted person to act as their external brain 24/7 through their complete lifespan.

Parents of children with FASD reported feeling socially isolated, facing a lack of understanding from family members, health care professionals, and educators.

Many parents, unable to cope with their child’s aggressive behaviour, surrender custody to child protective service agencies. It is estimated that close to 90 percent of children with FASD are in the care of agencies or people other than their biological parents. The mother of a child with FASD told the Committee

> No one really understands what our day-to-day life is like. They see a beautiful, blonde, blue-eyed little girl who is full of life. We see the same, but what others don’t see is the constant, behind-the-scenes managing of her behaviour, emotions, sensory dysfunction and social interactions. Our lives revolve around supporting our daughter 24 hours a day, seven days a week.

The Committee heard that children and adults with FASD are at a higher risk of developing addiction and mental health problems, have difficulty learning and staying in school, and are often unable to hold a job. They are more likely than others to find themselves in trouble with the law and incarcerated. Research indicates that there is a significant overrepresentation of adults with FASD in the prison population. “In addition to the human cost of suffering for people living with FASD,” the Registered Nurses Association of Ontario (RNAO) noted, “there is great strain on health care, education, community, and criminal justice services.”

Presenters emphasized that FASD is a fully preventable developmental disability. They urged the province to implement screening for maternal alcohol use, and to develop public education campaigns, suggesting, for example, the importance of reaching young women in postsecondary institutions. They asked that curricula for health professionals include mandatory training on FASD. They want FASD to be recognized as a developmental disability and urged the funding of more clinical specialists and FASD diagnostic centres.

The Committee was warned that the incidence of FASD is expected to rise as a result of the increase in binge drinking (four or more drinks within a short period of time) among young women of child-bearing age. The RNAO called for a provincial strategy on FASD, noting that Ontario is one of the only provinces "without a provincial framework to address FASD through an integrated, interdisciplinary strategy for prevention and diagnosis, and the care of individuals and families living with FASD."

## SERVICES AND SUPPORTS FOR CHILDREN AND YOUTH

The MCYS, the MCSS, and the MEDU share primary responsibility for delivering services for children and youth with developmental disabilities. This support is delivered through a mix of community-based services, direct funding to families to purchase supports, and in-school support.

### MCYS-Funded Support

The MCYS has responsibility for children and youth up to the age of 18 with special needs. It funds a range of services, including rehabilitation services (speech and language therapy, occupational therapy, and physiotherapy), respite programs, Early Years programs for infants and preschool-aged children, child and youth mental health services, and residential services.

The Committee heard that with the exception of autism-related programs, the MCYS does not provide specific support programs based on a child's diagnosis but rather according to a child's special needs in the areas of physical, intellectual, emotional, social, and/or behavioural development. The Committee heard that this approach provides greater flexibility for children and youth to access support, regardless of their official diagnosis.

The MCYS has recently carried out public stakeholder engagement regarding general services for children and youth with special needs, as well as specialized autism services. The MCYS, along with MEDU and MOHLTC, has also launched seven integrated speech and language program sites across Ontario and preliminary findings indicate that these sites have been successful in improving service for children and families.

### MCSS-Funded Support

The MCSS has direct responsibility for the Children's Developmental Services program, which includes residential services and community-based services for children with developmental disabilities. The MCSS also provides families with direct funding through the Assistance for Children with Severe Disabilities (ACSD) program and the SSAH program. These programs are available for children under the age of 18.

Some witnesses questioned the efficiency of having programs for children and youth with developmental disabilities being delivered by both the MCYS and the MCSS. Presenters from the Community Living agencies of Owen Sound and District and Walkerton and District noted that in the past, infant development programs, Early Years programs, and Complex Special Needs funding were all provided through the MCSS as part of a holistic developmental services model for children and adults. One speaker from a service-providing agency explained that having two ministries involved means that

> a new transition point is created. Children with complex special needs become adults with complex special needs, and this dual authority creates inefficiencies, gaps and . . . undue stress for families and individuals.
>
> [A] young adult who was involved in a complex special needs program now has his adult funding spread over two different service agreements, one with MCSS and one with MCYS, and that budget is also spread over three separate line budgets, all within the same agency. So when each of his team members sees him, works with him, we as a service provider need to allocate costs across three different budgets. It’s the same worker, same person, no difference in the service area or the support being provided, but the cost splits three ways, and not in three equal amounts, either. Also, each budget has its own service targets and reporting requirements.

## Education (Primary and Secondary)

The MEDU is responsible for funding school boards to provide special education programs and services to students with special education needs. (There is no breakdown available to show what proportion of students with special needs have a developmental disability.) It is estimated that approximately 15.56 percent of the student population, or 319,214 students, were receiving special education programs and services in 2010-11. Special education programs and services funded by the MEDU are available up to the age of 21.

Presenters noted that education is an important element of a child’s citizenship and that it is central to a person’s opportunities for employment and inclusion. However, the Committee heard repeatedly that educators and school administrators are ill-prepared to understand the needs of children with developmental disabilities.

Witnesses told the Committee that children with FASD and ASD are often suspended or expelled from schools under *The Safe Schools Act*.[4] They explained that because these children look "normal," educators have difficulty understanding that their challenging behaviour is due to a developmental disability. These children may then languish on waitlists for academic help for months or even years. Presenters called for schools to recognize FASD as a developmental disability caused by organic brain damage rather than a behavioural problem.

A recommendation was made that an evaluation be conducted to show whether the school system is meeting the needs of students with developmental disabilities.

### *Special Education*

The *Education Act* requires that all school boards provide special education programs and/or services to students who are identified as exceptional students. Students may be identified as having a number of different exceptionalities, including autism, developmental disability, and mild intellectual disability. Students with an identified exceptionality will be assessed to determine what supports they require, as well as what school placement will be most appropriate. These supports are provided through an Individual Education Plan (IEP). School boards also have the discretion to provide special education programs and services to students who have not been formally identified as exceptional.

While schools are allowed to develop an IEP for a child prior to formal assessments, the Committee heard that many schools will not do so. Lengthy waitlists (as long as two years) for assessment through the school board mean that many parents resort to paying for a private assessment. The Committee heard that even when an assessment shows that a child needs a full-time Educational Assistant (EA), budgetary restraints mean that an EA is not always provided.

The Committee heard from many presenters who strongly advocated in favour of an inclusive education for all students. The MEDU told the Committee that approximately 83 percent of all students receiving special education programs or services (86 percent at the secondary level) are placed in regular classrooms for more than half the day.

However, the Committee also heard from parents that the education system continues to exclude and segregate students with intellectual disabilities especially at the high school level. Staff of the MEDU explained that many of the students who are identified as having a developmental disability, either a severe disability or a mild intellectual disability, do not access the full provincial curriculum. In secondary school, many of these students are in programs with a

---

[4] Data from the MEDU indicates that 474 students with a developmental disability were suspended from publically-funded day schools in 2011-12.

modified curriculum that may not count for credit, where the courses are designed to fit with the learning needs of the individual student.

Many parents praised the inclusive education model which accommodates students with developmental disabilities in regular classrooms. The publicly-funded specialized schools for students with developmental disabilities in six Ontario school boards were criticized by some parents as evidence of segregation and exclusion. However, other parents said that only such a specialized school could offer their child sufficient educational supports, including individual attention and opportunities for physical education.

Several presenters called for changes to give parents a stronger voice on their local Special Education Advisory Committee (SEAC) and to be able to participate as individuals rather than having to do so as members of provincial associations.[5] Witnesses asked that MEDU issue clear guidelines and psychometrics on exceptionalities for special education, and to ensure that FASD is one of the exceptionalities meeting the criteria for special education.

### *Teacher Education*

Presenters noted that greater inclusion in the classroom will only be accomplished when teachers are appropriately trained and staffed to recognize each child's unique needs. They called for teacher education programs to include mandatory courses about developmental disabilities such as ASD and FASD, and about inclusion for students with special needs. One suggested that schools should use "inclusion coaches" to help teachers to create and deliver "accommodated curriculum" in the classroom.

### *Educational Assistants*

A mother noted that while EAs are usually assigned to help children with developmental disabilities in the classroom, there is no requirement that an EA have any relevant skills training, expertise, or even basic understanding of the more common developmental disabilities such as FASD and ASD. She noted that principals are required to ensure that ABA is incorporated into the IEP for students with ASD.[6] However there is no concomitant requirement that an EA who is assigned to work with a child with ASD have training in how to use these specific approaches. "We all recognize that early intervention is essential for success," said this mother. "The EA spends more time with that child than anyone else. Shouldn't they be trained to succeed?"

The importance of adequate training for EAs was echoed by another mother, who said, "if children with special needs are to truly be given the opportunity to learn to the best of their ability, they need educational assistants who are skilled at

---

[5] MEDU, "SEAC Membership," May 2013. As outlined in O. Reg. 464/97, SEACs are comprised of members from local provincial associations; a parent needs to be a member and then nominated by the local association to represent it on the SEAC.

[6] This responsibility is set out in Ministry of Education, Policy/Program Memorandum No. 140 (May 17, 2007).

helping them with their specific support needs—people who take their responsibilities seriously."

A recommendation was made that the MEDU set standards of qualifications for EAs and oblige school boards to require that EAs meet these standards. There was also a recommendation that EAs receive mandatory skills training without being required to pay tuition.

## SERVICES AND SUPPORTS FOR ADULTS

### Transformation and Legislation

Since the mid-2000s the government has been transforming the adult developmental services sector in Ontario. The framework for this transformation is set out in the *Services and Supports to Promote the Social Inclusion of Persons with Developmental Disabilities Act, 2008* (SIPPDA).[7] The key goals of this legislation are to include greater support for

- social inclusion;
- respite for caregivers;
- residential partnerships with families;
- critical life transitions;
- people with specialized needs; and
- quality supports and services.

To achieve system-wide transformation, SIPPDA was also meant to incorporate elements of independent planning, standardize eligibility and assessment processes, streamline access, and promote new funding approaches.

A key element of the legislation is its emphasis on person-directed planning, which is meant to assist individuals to identify their life vision and goals, and link them with supports to meet those goals. Many presenters commented on the importance of giving individuals a voice throughout the planning process, and as the Committee heard from the Provincial Advocate for Children and Youth: "Ensuring that our services listen to young people and children and adults and give them a voice: It doesn't cost any money, but it's a huge shift . . . that's going to be tough to make happen, but it will pay dividends."

Although most of the SIPPDA came into force in 2010 and 2011, some provisions remain unproclaimed – specifically, those provisions governing direct funding

---

[7] *Social Inclusion of Persons with Developmental Disabilities Act, 2008*, S.O. 2008, c. 14 (SIPPDA).

agreements. It was noted by at least one service agency that the full picture of transformation may not be well understood until the entirety of the legislation is proclaimed and the full range of tools is available.

## MCSS-Funded Services

### *Direct (Agency-Based) Services*

The MCSS funds many services and supports through service agencies operating in the community. Agency-based services may offer community participation support, caregiver respite, and professional and specialized services. Support may also take the form of residential services, including group homes, supported independent living (SIL) arrangements, and specialized accommodation arrangements.

### *Direct Funding*

The MCSS funds two main programs that provide direct funding to individuals so that they may purchase their own supports. The SSAH program previously provided support to both children and adults with a developmental and/or physical disability, but now funds only children. Adults with a developmental disability now receive their direct funding through the MCSS “Passport” program, which supports participation in the community and caregiver respite. There are 30,000 individuals receiving services from the SSAH and Passport programs, while 10,000 more are waiting for service.

The Committee heard a range of opinions about direct funding. Some witnesses felt strongly that direct funding is a necessary and creative option that allows families to choose support options tailored to their individual needs. Many families would rather see it referred to as “individualized” funding, which reflects the flexible and customized opportunities that this option can offer. Several presenters recommended that a larger proportion of the developmental services budget be used for direct services (currently eight percent of global expenditures).

Other presenters said that direct funding encourages a two-tiered system and privatization by drawing public investment away from community services. Presenters were concerned that this downloads responsibility to families, who must then use direct funding to seek out and privately purchase services and supports. These witnesses noted that under a direct funding model, families must subsidize the cost of private services themselves if the amount of funding provided is insufficient.

## Developmental Services Ontario

The creation of Developmental Services Ontario (DSO) organizations is one of the key elements of SIPPDA. The DSO offices were established to create a fair, equitable, and provincially consistent application process for MCSS-funded adult developmental services and supports.  The DSO offices were set up through an

Expression of Interest process conducted by the MCSS, whereby service providing agencies interested in assuming the role of being designated as DSO offices submitted applications to the MCSS. The MCSS announced the names of the service providers chosen in November of 2010 and the nine DSO offices began operating in July of 2011.[8] The DSO offices operate as a discretionary program, subject to specific budget allocations.

The DSO offices are intended to serve as the single point of access, or gateway, for adult developmental services and supports – a "one-stop shop." Their role includes

- providing information to the public about relevant community-based services;
- confirming eligibility for adult developmental services and supports in accordance with provincially-consistent eligibility standards;
- administering the application process for services and supports once their eligibility has been confirmed; and
- managing service and resource vacancies.

The Committee heard that since the DSO offices began operation, they have faced a number of external challenges that impact on their ability to fulfill their mandate. These challenges include a lack of direction from the MCSS around key DSO functions and a semi-operational MCSS database that was intended to be used by the DSO offices to manage their work. The Committee also heard that the DSO offices were faced at the outset with a volume of applications that was exceptionally higher than the estimates provided by the MCSS during the Expression of Interest process, along with a corresponding lack of funds.

## Assessment Process

In order to obtain support and services through DSO, applicants must first have their eligibility for service assessed by the DSO office and, if their eligibility is confirmed, they must undergo an assessment designed to ascertain their needs.

### *Confirming Eligibility*

Although the DSO process was intended to streamline and standardize eligibility for services, presenters described waiting for months just to be scheduled for an initial eligibility assessment.

Many witnesses told the Committee that they were dissatisfied with how DSO offices determine a person's eligibility for supports and services. DSO offices determine eligibility based on the SIPPDA definition of a person with a developmental disability as someone who has the prescribed significant

---

[8] Please see Appendix C for a list of the nine DSO offices.

limitations in cognitive and adaptive functioning.[9] The general regulation under SIPPDA incorporates the use of standardized intelligence testing in interpreting a "significant limitation in cognitive functioning."[10] The MCSS advised the Committee that individuals will meet this requirement where

- their overall IQ score is 70 or below;
- their scores in two IQ test areas is less than 70 and they have a history of needing rehabilitative support; or
- a clinical determination by a psychologist or psychological associate finds that they demonstrate significant cognitive limitations and they have a history of needing rehabilitative support.

The Committee heard from a number of presenters who stated that as a result of these criteria, developmentally disabled individuals with an IQ higher than 70 have been told they are not eligible for services and supports. Witnesses noted that 50 percent of adults with ASD who have a developmental disability have an IQ over 70, as do many people with FASD. For this reason, many presenters recommended basing eligibility criteria on adaptive functioning and individual needs, rather than IQ.

### *Needs Assessment*

Once individuals are deemed eligible for developmental services, they must then complete an application package and needs assessment to determine what specific supports and services they will be provided. The needs-based assessment process was described by numerous presenters as lengthy, complex, intrusive, and poorly tailored to the specific individual being assessed. The Committee heard that there are currently 8,000 people on waiting lists for this needs assessment and that once this stage is complete, many individuals are then waitlisted for different types of services.

Many parents spoke of their frustration that their children needed to be assessed numerous times by schools, service providers, and DSO offices upon their transition to adulthood. They described having to tell their story repeatedly to receive services and supports that they felt were obviously required, given their children's lifelong diagnosis. As one presenter told the Committee,

> to send a family off to meet with strangers to tell their story again and to have to go through a process really just doesn't make sense. Families feel like they are reapplying for supports that they know they need and that we know they need and that they have continued to need, and yet they're having to go through this process.

---

[9] SIPPDA, s. 3(1).

[10] O. Reg. 276/10, s. 2(1).

The Committee heard parents describe the DSO process as “dehumanizing,” “demoralizing,” and “humiliating.” One parent asked: “Why is there always a need to fight for and justify our funding every year?” Others said that the “DSO is a layer of infrastructure – to tell you there is no money,” and that “DSO should have the disclaimer: ‘While in theory everyone receives these services, at this time there are only waitlists available.’” One mother, noting that she had initially welcomed the idea of streamlined access to developmental services, said: “DSO is a behemoth. I wanted one-stop shopping and I got Godzilla.”

Some presenters also noted the potential for a conflict of interest where a regional DSO office also functions as a service agency. As service agency programs need clients in order to continue operating, the risk is that the DSO office will encourage clients to enrol in agency programs and discourage direct funding options that would allow clients to take their business to another provider.

## Service Agencies and Direct Services

### *Service Contracts and Funding*

Another key element of SIPPDA is the designation of community agencies that receive funding from the MCSS as “service agencies.” These service agencies operate as transfer payment agencies that are accountable to the MCSS. The MCSS provides funding to approximately 370 service agencies in the community through service contracts. These contracts determine the services and supports that will be offered by each service agency and set out the terms and conditions of the transfer agreement, including service targets and funding levels.

The Committee heard that DSO contracts with service agencies narrowly restrict the kind of services an agency is funded to provide. This results in a reduced menu of service options available to families. Agencies may no longer have the flexibility to offer general support services, such as community integration activities or last-minute respite, unless the family has another source of funding to pay for it.

Service agencies spoke to the fact that they have not seen budget increases in a number of years, even to keep pace with inflation. Many also noted that their funding is assured only for short periods of time, leading to an inability to make long-term service plans and to retain qualified staff.

### *Relationship with DSO Offices*

Many service agencies noted that the arrival of DSO offices has resulted in a loss of longstanding relationships between families and their local agencies. They said that the DSO process prevents local service agencies from continuing to develop and maintain supportive relationships with individuals and families as they have in the past. This “formalization” has limited the ability of families and community organizations to work together to create solutions and supports in traditional, informal ways.

The Committee also heard that the creation of the DSO offices and the “one-stop shop” through specific regional centres has in reality limited families’ access to services, as they are no longer able to seek out their own solutions through community agencies without passing through the DSO offices first. A community agency representative explained that from the perspective of families, the DSO structure is “complex. It’s not natural. It’s intrusive on relationships [with community agencies] that are already built. . . . The relationships are already formed with the families; we’re already clear about what kinds of supports are needed.”

### *Regulation: Quality Assurance Measures, Fire Code, Building Code, and Pay Equity*

Through a regulation made under SIPPDA, service agencies are required to comply with a number of quality assurance measures (QAMs).[11] Some QAMs are general in nature and relate to items such as management of clients’ finances, abuse prevention and reporting, confidentiality and privacy, and human resource practices. Other QAMs are directed to the specific areas of behaviour intervention strategies and residential services/supports. DSO offices are also required to comply with a set of QAMs.

The Committee heard from a number of service agencies that achieving compliance with the QAMs has been time-consuming, expensive, and sometimes redundant. Agencies reported spending an inordinate amount of time on achieving compliance with the large number of QAMs, which meant that less time has been devoted to actual client service. Financially, agencies reported having to let go of staff in order to fund QAM initiatives. Some presenters questioned the appropriateness of certain QAMs in the context of their particular agency; for example, why an agency with a strict no-restraint policy or clients with extremely limited mobility should be required to train all their employees in the use of physical restraint. As noted by one agency,

> We also need some flexibility and interpretation around compliance standards . . . . It’s our belief that the standards set in the quality assurance measures are well intended and are to set a foundation for minimum standards and safeguards around service delivery. The challenge is that some of these standards do not make sense.

The Committee heard similar concerns from service agencies regarding the application of *Fire Code* and the *Building Code* provisions, which they say requires them to undertake expensive retrofitting at the expense of client service.

Finally, several agencies noted that proxy pay equity obligations are a heavy financial burden, and are creating a wage gap between agencies offering the same services within the sector.

---

[11] O. Reg. 299/10.

### *Labour and Staffing*

The Committee heard that due to increasing financial pressures, agencies are increasingly relying on cuts to front-line staff positions and hours. The Committee heard that agencies are reducing staff direct support hours, declining to fill vacant positions, and shifting from full-time to part-time work due to ongoing financial pressures. Agencies felt that these measures compromise the quality and continuity of care for supported individuals.

The Toronto Developmental Services Alliance told the Committee that "although we continue to provide service, we're not continuing to provide service at the level that we really should be . . . how much lower can you go than one staff on shift? You really can't, but many of us are doing that." In a survey, agencies reported that as a result of cuts, "they're able to provide less individualized care, fewer specialized services, a decreased prevention service ability, elimination of recreation activities and community outings, elimination of quality-of-life activities, and being forced to introduce new user fees for transportation and day programs."

Service agencies also noted their difficulty hiring and retaining qualified staff since they tend to move to comparable jobs in health and education where the wages are higher. Personal support workers told the Committee that they are worried about their job security and workload. "We have been told we have to do more with less," said one, but "the people we support deserve better and so do the staff." Facilities rely heavily on donations and staff members bring their own laptops, musical instruments, and other equipment from home for residents to use.

A personal support worker in Thunder Bay said that she and other staff members have second jobs in order to make ends meet. When there are not enough support workers to escort residents outside the facility, it becomes impossible for residents to participate in community activities. Understaffing also compromises workers' safety. A personal support worker in Thunder Bay said that in his facility, despite training in nonviolent crisis intervention, staff members are frequently assaulted by residents. "I actually was assaulted and had a concussion because there was not enough staff on . . . For staff to get assaulted on a daily basis is not right. The people who we're trying to support—it's not fair to them, and it's not their fault. We don't have enough staffing. That's where things need to change."

A number of presenters focused on improving working conditions for personal support workers. There was a recommendation to create incentives for support workers who are employed in home settings by establishing a provincial benefits and pension plan, and making the payments tax deductible. One witness suggested setting up a registry of graduates of developmental service worker programs so parents could find personal support workers to employ in their homes.

## TRANSITION FROM YOUTH TO ADULT SERVICES

In the developmental services sector, a young person's 18th birthday marks the moment they must move from child-based support services to adult support services. The loss of school-based services at the age of 21 makes the transition into adulthood even more difficult. Before the age of 21, children and young adults have the opportunity to interact with peers and develop skills through their schools. However, when school-based services are cut off at the age of 21, there are few choices and opportunities for young adults to participate meaningfully in the community. Further, many parents told the Committee that they felt they had no choice but to quit their jobs and become full-time caregivers again when their children were no longer able to attend school during the day. For many families, the loss of services designated for children is a social, developmental, and financial disaster.

Many parents of children with developmental disabilities commented on the kind of support and services they would like to see in place as their children transition into adulthood. The Committee heard from many witnesses about the importance of belonging for persons with developmental disabilities and their families. Presenters from Queen's University noted that for persons with intellectual disabilities and their parents, the most important element when trying to improve social inclusion is to ensure that individuals feel that they are part of a network of friends and acquaintances. These witnesses noted that maximizing social inclusion can be accomplished through day programs, apprenticeships and training, volunteer work, and employment. Involvement in these opportunities allows individuals to build skills, satisfy personal goals, make contributions to society, and increase their incomes.

### Day Programs and Respite

The urgent need for adult day programs and respite care, even for a few hours during the week, was highlighted again and again by families in all areas of the province. The Committee heard that in 2012-13, the MCSS funded approximately 225 respite beds for adults in Ontario. At the end of 2012-13, approximately 2300 adults had requested, and were waiting for, MCSS-funded adult respite services and supports.

Families emphasized that respite care should be flexible to reflect the realities of everyday life. Families also stressed that successful day programs and respite require qualified caregivers who are able to provide supported individuals with meaningful opportunities to socialize and take part in physical activity.

Service agencies spoke of the great need for consistent and planned respite services for adults in the community. The Committee heard that this service is an essential component of a proactive system of care, which provides individuals and families with lifetime support, avoiding family breakdown and the need for emergency services in a crisis situation. The cost of providing overnight respite care in a group setting may be only a fraction of the cost for full-time residential care for individuals with total care needs.

The Committee heard from presenters representing facilities in the community that are working successfully to provide families with respite and day program options. One example was the Abilities Centre in Whitby, Ontario, which provides both self-directed and instructor-led programs in fitness, recreation, sports, performing arts, arts, life skills, and music. The Committee heard that as part of a needs assessment conducted by Abilities Centre in the fall of 2012, 88% of those surveyed felt that a quality day program was needed in the Durham region. One of the Centre's fee-for-service day programs, which began with 60 available spots, is full and the Centre is immediately expanding the program to increase capacity.

## Housing

The MCSS and the MOHLTC have primary responsibility for supportive housing, which can be described as housing for clients who have both financial need and a need for support services. Housing support for persons with developmental disabilities may include

- group homes, where three or more individuals live in a home that provides 24-hour care and support;
- intensive support residences, where one or two individuals live in a staff-supported residence;
- host family arrangements, where individuals live in a host family's home, similar to foster care;
- supported independent living (SIL) arrangements, where individuals live in their own accommodation with support provided by transfer payment agencies; and
- specialized accommodation, where individuals with a developmental disability and co-existing mental illness (dual diagnosis) or behavioural challenges receive transitional or permanent support in specialized settings.

In addition, the MMAH has worked with partners at the MCSS, the MOHLTC, and municipalities to develop 3,573 supportive housing units, including 1,358 units under the Strong Communities Rent Supplement Program for, among others, persons with developmental disabilities, and 1,514 units under the Affordable Housing Program for, among others, persons with a dual diagnosis.

The Committee heard that parents of young adults with developmental disabilities want to be able to plan for a natural and gradual transition when the time comes for their children to move out of the family home. Families stressed the importance of this transition being as smooth as possible by ensuring that supported individuals continue to attend their day programs, work, participate in volunteer activities, and live full and active lives in a safe and secure environment that promotes independence and individual choice.

However, the Committee also heard that those families who try to plan ahead feel that they are undermined by a severe lack of available supportive housing options. One mother told the Committee:

> The government has suggested that families utilize creative thinking to provide a residential model for their adult child. No amount of creative thinking will provide a suitable setting for [my daughter] because of her high needs, without funding attached. And at this time, there is no funding available. Families have been asked to create a business plan for their residential model, but with no timeline for funding, this is an impossible task.

According to Community Living Ontario, approximately 12,000 adults with developmental disabilities are waiting for residential services; and more than one presenter spoke of families languishing on waitlists for 20 years. Approximately 563 adult clients with developmental disabilities remain in MCYS-funded children's residential services because no adult services are available. The Committee heard from service agencies that long waitlists result in individuals being assigned to whatever vacancy becomes available, sometimes far from their home community, as opposed to finding the housing solution that will best meet their needs.

The Committee heard that in times of crisis, young people with developmental disabilities may be placed in psychiatric wards, hospitals or long-term care homes— placements that are expensive, unsuited to individual needs, and lacking in individual choice and person-first planning. As the Committee heard from one presenter, individuals' housing decisions

> are being taken over by government rules and processes, especially discussions about with whom they live and where. This has now become a waiting-list issue of designation of spaces and determination of where people will live and with whom. These are people's homes, and there's something really wrong with that reality for many people.

A number of parents spoke of finding their own supportive housing solutions, either alone or in conjunction with other parents or non-profit organizations. Presenters noted that privately-operated living arrangements appeared to be more cost-effective than many publicly-operated options. The Committee heard about a successful business model that has been pioneered by Habitat for Humanity, whereby the homes are owned by the persons with special needs themselves. The mortgage, which is interest-free, is owned by Habitat for Humanity and the client pays back the mortgage over a 30-year period. Housing co-operatives were put forward as another successful model.

Those advocating in favour of private housing models recommended that the Ontario Disability Support Program (ODSP) rules around shared living be relaxed. There was also a recommendation that eligibility for the Healthy Homes Renovation Tax Credit be extended to anyone who is eligible for the Disability Tax Credit.

## Postsecondary Education and Job Training

The MTCU provides funding to Ontario colleges and universities, as well as employment, apprenticeship, and foundational skills training. The MTCU offers direct financial support for students with disabilities (including those with developmental disabilities) through a range of bursaries, disability benefits, tuition repayment assistance, and tuition grants. It also provides a range of support to postsecondary institutions, including

- funding for programs that prepare students for careers supporting individuals with disabilities;
- the Support for Apprentices with Disabilities program, which covers staffing and expenses for students with disabilities; and
- funding for Community Integration through Co-operative Education (CICE) programs, which are designed for persons aged 19 and over with developmental disabilities who wish to further their education and/or vocational training in a community college setting.

Many witnesses spoke favourably of an apprenticeship or co-operative education model, such as the CICE model, which allows individuals to learn hands-on skills. The Committee heard that the CICE model is currently operating through eight colleges. Several presenters said they would like to see all colleges offer CICE programs.

Witnesses noted that college programs created to accommodate the needs of people with disabilities provide these individuals with the opportunity to learn valuable trades and skills. These programs not only promote employability but also improve the students’ quality of life in many ways by providing them the opportunity to develop a sense of self-confidence, self-sufficiency, friendship, and community. Speaking of the inclusive post-secondary education experience in Alberta, one presenter noted that the model

> offer[s] opportunities where students can participate in classes and programs of their interest, as well as participate in campus life. . . . Many of these students have been able to go on and get real jobs in their community due to this experience. In addition to enhanced employment opportunities, these students have also had the pleasure of building friendships and relationships within their networks

> of supports that are lasting. It is our hope that this can happen in Ontario for adults who experience disabilities.

## Employment

The MTCU promotes employment for persons with disabilities through Employment Ontario labour market programs. Support offered through these programs includes job matching, placement, and incentives; job and training retention support; and, for persons with disabilities, support for accommodation of workplace needs.

Many presenters told the Committee that people with developmental disabilities are eager to hold jobs and contribute to society. A woman with Down Syndrome explained: “I hope to have a job one day. I would like to work at something that I enjoy, am good at and will support me. I know it will take time to learn to do a job well, but I have a lot of practice at hard work. I have volunteered for many years, and I am ready to be paid for my work.” Another woman with a developmental disability told the Committee that her experience working at a clothing store “is really great. They’re really understanding. Nobody picks on me there. In other jobs I’ve had, unless I’ve worked alone, coworkers would give me a hard time and they would pick at every little thing I did every single day.”

The Committee heard that a very high proportion of persons with intellectual disabilities are unemployed, even though they have the capacity to work. Witnesses noted that there are significant barriers for persons with developmental disabilities entering the workforce. Several presenters said that that employers need to be better educated about the abilities of people with developmental disabilities. The mother of one unemployed CICE graduate explained that

> part of the reason that employers don’t want to hire students with disabilities, youth with disabilities, is because the stigma still exists out there. They don’t know the capabilities. They underestimate the capabilities of these students. There’s also a disconnect between post-secondary education for students with disabilities and the workplace. Even though you’ve got co-op placements, there’s that disconnect in the wider workplace once they leave the safe environment of school.

Her son, a CICE graduate, explained that his goal was to become a car salesman but “I apply for those jobs. They don’t call me back. I don’t think they even bother to look at my resumé.” He added, “I just think that if there was more education for employers, they’d be more likely to hire people like me.”

The Committee heard from a number of community organizations that build relationships with employers and match clients to positions within the business community, as well as from organizations that train and employ individuals for long-term employment within their own social enterprise setting, such as operating a catering and retail business. One mother told the Committee about an agency that helped her son to find a job:

> We have young adults who, until now, were sitting at home doing absolutely nothing, and they work in a restaurant. They come up to me and they say it’s the first time ever that somebody looked up at them instead of down at them. Can you imagine? You can’t put dollar figures on this; you really can’t.

The MEDTE plays a role in promoting the employment of persons with disabilities by developing relationships with businesses and enforcing the provisions of the *Accessibility for Ontarians with Disabilities Act, 2005*, although the Committee heard that there is work to be done in ensuring that organizations are meeting their accessibility obligations under this legislation. The Committee heard that in some jurisdictions, public sector organizations and private sector employers are required to ensure that a certain proportion of employees will be individuals with special needs. Presenters noted that while this is a necessary step in providing persons with developmental disabilities the opportunity to contribute their skills and earn some income, it is also good business practice for employers – a win-win.

## Ontario Disability Support Program Income

The Committee heard that many individuals with developmental disabilities are willing and able to work and to contribute to society; despite this, almost 75 percent of adult Canadians with an intellectual disability who live alone are also living in poverty.

ODSP is an entitlement program funded by the MCSS that is available to those who meet the eligibility criteria. The program is intended to assist Ontarians with the cost of shelter, food, clothing, transportation, and other personal needs. The MCSS reported that as of March 2013, there were 61,595 ODSP recipients who identified developmental disability as a primary or secondary condition, representing about 20 percent of the total ODSP caseload.

The Committee heard that the maximum annual income for a single person on ODSP is about $13,000 – about 40 percent below the current poverty line. The Committee also heard that the current ODSP system may consider two people in shared housing to constitute a “family,” which means that together they would receive approximately $19,000, much less than they would each receive as individuals. Presenters noted that this reduction in ODSP benefits to individuals in a shared living situation is an impediment to developing innovative shared housing arrangements for people with developmental disabilities.

The Committee heard from several witnesses objecting to the suggestion, found in a 2013 document produced by MCSS (*Hiring a Support Worker: A Guide for*

*Ontarians with a Developmental Disability*), that individuals could use a portion of their ODSP funds to employ a personal support worker.[12] These presenters stated that the amount of the ODSP benefit is insufficient to allow individuals to pay another person's wage, and that persons with developmental disabilities should not have to use their sole small source of income to pay for support services.

### *Employment Income*

The Committee heard that ODSP rules for employed individuals are confusing and many people with developmental disabilities find it hard to understand how much ODSP will be clawed back from their paycheques.

Presenters also noted poor coordination between ODSP and EI supports: where working individuals qualify for EI and subsequently lose their employment, they must access and exhaust the EI system of support before returning to an ODSP employment program. Witnesses observed that this route is especially difficult because the EI program does not have the expertise or capacity to support persons with a disability, while the ODSP system does provide this specialized support.

### *Dental Benefits*

Health benefits under the ODSP program, and in particular dental benefits, were singled out as insufficient in covering the needs of individuals with developmental disabilities. Presenters stated that because it is so difficult to recoup costs from people with developmental disabilities, dentists are often reluctant, or altogether refuse, to treat patients on ODSP. The Committee heard that people who require anaesthesia or sedation prior to dental care due to behavioural concerns may wait as long as five years for care, and that some dentists have stopped procedures halfway because a patient's ODSP funds did not cover the cost of the whole procedure.

### *Age 65 cut-off*

Finally, ODSP is cut off for recipients once they reach the age of 65, at which time they are entitled to Old Age Security and the Guaranteed Income Supplement, both federally-funded programs. The Committee heard that once ODSP ends, individuals lose what limited dental, denture, and eye care support they had been receiving, as well as funding for specialized items such as wheelchairs and other medical devices.

## Legal Capacity and Supported Decision-making

The Committee heard of the legal difficulties encountered by individuals with developmental disabilities when they turn 18 and enter adulthood in the eyes of the law. Presenters spoke of confusion about the rules for determining when a person is legally capable of making their own decisions and their frustration in having to apply for legal guardianship to assist with that process. The Office of

---

[12] MCSS, *Hiring a Support Worker: A Guide for Ontarians with a Developmental Disability* (2013).

the Public Guardian and Trustee (OPGT) noted that institutions and governments are more commonly requesting proof of signing authority when documentation needs to be completed, leading more people to question whether they need to obtain guardianship, whereas less intrusive, informal family support has been sufficient in the past. The OPGT noted the importance of having funds available to vulnerable persons while at the same time ensuring that those funds are used properly for their benefit (the Registered Disability Savings Plan or "RDSP" was mentioned as a good example).

The Committee heard praise from community living associations for a model of supported decision-making, whereby an individual is supported by those they trust to assist them in making substantial decisions. This model of supported decision-making is viewed as an alternative mechanism to legal guardianship that recognizes the abilities of adults with developmental disabilities to make their own decisions, with support.

The Committee heard that this model furthers the notions of social inclusion and enhanced citizenship rights, including the right to autonomy and choice, for individuals with intellectual disabilities. These presenters advocated in favour of acknowledging the legal capacity of these individuals and supported mechanisms that would allow them to enter into all types of legal agreements, including direct funding agreements, leases, mortgages, financial loans, and marriage contracts.

The Law Commission of Ontario is currently studying capacity and decision-making, and is specifically addressing decision-making as it relates to opening and managing an RDSP.

## CLOSING COMMENTS

This report outlines the Committee's observations from its hearings across the province and the hundreds of written submissions received. The next stage of the Committee's work is to develop recommendations for a final report.

The Committee is grateful to the many people who shared their personal experiences and suggestions.

# APPENDIX A

## Private Member's Motion re Select Committee on Developmental Services

Select Committee on Developmental Services

That a Select Committee on Developmental Services be appointed to consider and report to the House its observations and recommendations with respect to the urgent need for a comprehensive developmental services strategy to address the needs of children, youth and adults in Ontario with an intellectual disability or who are dually diagnosed with an intellectual disability and a mental illness, and to coordinate the delivery of developmental programs and services across many provincial ministries in addition to the Ministry of Community and Social Services; and

That in developing its strategy and recommendations, the committee shall focus on the following issues:

—the elementary and secondary school educational needs of children and youth;

—the educational and workplace needs of youth upon completion of secondary school;

—the need to provide social, recreational and inclusionary opportunities for children, youth and adults;

—the need for a range of available and affordable housing options for youth and adults;

—the respite and support needs of families;

—how government should most appropriately support these needs and provide these opportunities.

That the committee have the authority to meet on Wednesdays following routine proceedings when the House is in session, and Wednesdays from 9 a.m. to 12 p.m. and 1 p.m. to 5 p.m. when the House is not in session; and

That the committee shall have the authority to call for persons, papers and things, to employ counsel and staff and, as the committee deems relevant to its terms of reference, to commission reports and adjourn from place to place, subject to the normal budget approval from the Board of Internal Economy; and

That the committee shall present an interim report to the House no later than February 26, 2014, and a final report no later than May 15, 2014; and

That in the event of and notwithstanding any prorogation of the House before the presentation of the committee’s final report, the committee shall be deemed to be continued to the subsequent session or sessions and may continue to meet during any such prorogation; and

That the committee shall be comprised of: four members from the government caucus, one of whom shall be the Chair, three members from the caucus of the official opposition and two members from the caucus of the third party; and

That the chief whip of each of the recognized parties shall indicate in writing to the Clerk of the House, within five sessional days of the passage of this motion, their party’s membership on the committee.

# APPENDIX B

## Schedule of Public Hearings

Public hearings were held in Toronto and various other locations on the dates listed below.

| | |
|---|---|
| **Toronto** | October 30; November 13, 20, and 27;<br>December 4, 11, and 18, 2013;<br>January 20 and 21, 2014 |
| **London** | January 13 |
| **Thunder Bay** | January 14 and 15 |
| **Ottawa** | January 17 |

The *Hansard* transcripts of the proceedings for each Committee meeting are public documents available through the Legislative Assembly.

# APPENDIX C

## List of Developmental Service Ontario Offices

DSO Hamilton-Niagara Region

*Administered by Contact Hamilton*

DSO South West Region

*Administered by Community Services Coordination Network*

DSO South East Region

*Administered by Extend-A-Family*

DSO North East Region

*Administered by Hands – TheFamilyHelpNetwork.ca*

DSO North Region

*Administered by Lutheran Community Care Centre*

DSO Eastern Region

*Administered by Service Coordination services*

DSO Central West Region

*Administered by Sunbeam Residential Development Centre*

DSO Toronto Region

*Administered by Surrey Place*

DSO Central East Region

*Administered by York Support Services Network*

# APPENDIX D

## List of Witnesses and Written Submissions

| Organization/Individual | Date of Appearance / Written Submission |
|---|---|
| Abilities Centre | January 20, 2014 and written submission |
| Adult Protective Service Association of Ontario | January 21, 2014 and written submission |
| Ali, Eliza | Written submission |
| Alves, Diana | Written submission |
| Amenta, Salvatore | Written submission |
| Anderson, Faith | Written submission |
| Anita | Written submission |
| Anonymous | Written submission |
| ARCH Disability Law Centre | January 21, 2014 and written submission |
| Arthurs, Wilma | December 11, 2013 |
| Autism Ontario | December 4, 2013 and written submission |
| Bach, Angela | January 21, 2014 |
| Baillargeon, Giselle | Written submission |
| Baker, Lee Ann | Written submission |
| Balaz, Joyce; Hiltz, Bill; Row, Arn | January 13, 2014 and written submission |
| Barker, John | Written submission |
| Beal, Teresa | Written submission |
| Benoit, Patricia | Written submission |
| Bensen, Karen | Written submission |
| Bermingham, Nancy M. | Written submission |
| Bond, Deryle | January 15, 2014 and written submission |
| Bonnah, Greg | January 14, 2014 |
| Bowen and Associates Inc. | Written submission |
| Bowles, Susan | Written submission |
| Boyes, Sandra | January 15, 2014 and written submission |
| Boylan, Brenda | Written submission |
| Brammall, Diana | January 14, 2014 and written submission |
| Brennan, Harold; Brennan, Debbie | January 21, 2014 and written submission |
| Brock, Helen | Written submission |

| Organization/Individual | Date of Appearance / Written Submission |
|---|---|
| Broomes, Orlena; Broomes, Jefferson | January 20, 2014 and written submission |
| Brown, Mari | Written submission |
| Buczek, Christina | January 21, 2014 and written submission |
| Burnett, Stephanie | Written submission |
| Butler, Colleen; Butler, Michael | December 18, 2013 and written submission |
| Bycok, Carmen | Written submission |
| Cacciatore, Silvana; Jacques, Brian; Maclam, Ken | January 14, 2014 |
| Cain, Carol | Written submission |
| Calligan, Catherine | Written submission |
| Campbell, Kaycee | Written submission |
| Canada Fetal Alcohol Spectrum Disorder Research Network (CanFASD) | Written submission |
| Canadian Association of Muslims with Disabilities | January 21, 2014 and written submission |
| Canadian Mental Health Association Waterloo Wellington Dufferin | January 13, 2014 |
| Canadian Union of Public Employees (CUPE) Ontario | November 13, 2013 and January 20, 2014 and written submission |
| Card, Cheryl | Written submission |
| Career Services of Brockville | Written submission |
| Casa de Angelae | Written submission |
| Caslick, Robin | Written submission |
| Catulpa Community Support Services | Written submission |
| Centre for Addiction and Mental Health (CAMH) | November 27, 2013 and written submission |
| Champlain Local Health Integration Network | Written submission |
| Charlton, Dee | Written submission |
| Children's Aid Society of Toronto | Written submission |
| Christian Horizons | December 18, 2013 and written submission |
| Citizens with Disabilities Ontario | Written submission |
| Claeys, Erin | Written submission |
| Clare, Mary-Ellen | Written submission |
| Clyne, Nancy | Written submission |
| CNIB | Written submission |
| Coalition des familles francophones d'Ottawa (CFFO) | Written submission |
| Collins, Sherri | Written submission |

| **Organization/Individual** | **Date of Appearance / Written Submission** |
|---|---|
| Community Living Brampton Caledon | Written submission |
| Community Living Essex County | December 4, 2013 and written submission |
| Community Living Kawartha Lakes | Written submission |
| Community Living London | January 13, 2014 |
| Community Living Middlesex | Written submission |
| Community Living Mississauga | Written submission |
| Community Living Norfolk | Written submission |
| Community Living Ontario | November 13, 2013 and written submission |
| Community Living Owen Sound and District/Walkerton and District | January 13, 2014 |
| Community Living St Mary's and Area | January 13, 2014 |
| Community Living Thunder Bay | January 15, 2014 |
| Community Living Tillsonburg | January 13, 2014 and written submission |
| Community Living Toronto | December 4, 2013 and written submission |
| Community Living Toronto Central Regional Council | Written submission |
| Community Living Welland Pelham | Written submission |
| Community Networks of Specialized Care | Written submission |
| Coons, Kelly; Watson, Shelley; Pepper, Jenna; Clement, Alexandra | Written submission |
| Cornelius, Betty | Written submission |
| Cotter, Maggie | Written submission |
| Coyle, Leisha | Written submission |
| Cranstone, Irene | Written submission |
| Crossing All Bridges Learning Centre | January 13, 2014 and written submission |
| Crowder, Adrienne | Written submission |
| Cunningham, Mary K.; Watson, Shiona | Written submission |
| Dawdy-Curley, Nancy | Written submission |
| de la Penotiere, Ethel; de la Penotiere, Percey | Written submission |
| DeafBlind Ontario Services | Written submission |
| Deline, Patricia | Written submission |
| Delorey, Brian; Delorey, Shelley | Written submission |
| Deohaeko Support Network | January 20, 2014 and written submission |
| Developing and Nurturing Independence (DANI) | January 20, 2014 and written submission |
| Developmental Services Ontario (DSO) Provincial Network | Written submission |
| Developmental Services Ontario Provincial Network | Written submission |

| Organization/Individual | Date of Appearance / Written Submission |
|---|---|
| Developmental Services Toronto Council | January 20, 2014 and written submission |
| Dolmage, Marilyn; Slark, Marie; Seth, Patricia; Dolmage, Jim | November 27, 2013 and written submission |
| Dominato, Janis | Written submission |
| Doughty, John | Written submission |
| Down Syndrome Association of Ontario | December 18, 2013 and written submission |
| Dundas Living Centre | January 14, 2014 |
| Eastabrook, Wayne | Written submission |
| Easter Seals Ontario | Written submission |
| Edmondson, Lynda | Written submission |
| Elementary Teachers’ Federation of Ontario | Written submission |
| Eyraud, Debbie | Written submission |
| Faith and Culture Inclusion Network | January 21, 2014 |
| Families for a Secure Future | January 21, 2014 and written submission |
| Families from St. Marys and Area | Written submission |
| Families Matter Co-operative | January 17, 2014 and written submission |
| Family Alliance Ontario | January 17, 2014 and written submission |
| Family and Children's Services of Frontenac, Lennox and Addington | Written submission |
| Family Directed Alternative Support Services | Written submission |
| Family Service Toronto | January 20, 2014 and written submission |
| Fawcett, Heather | Written submission |
| Feinman, Mitchell | January 21, 2014 and written submission |
| Fetal Alcohol Spectrum Disorder Group of Ottawa | January 17, 2014 and written submission |
| Fetal Alcohol Spectrum Disorder Network of Elgin, London, Middlesex, Oxford (FASD-ELMO) | January 13, 2014 and written submission |
| Fetal Alcohol Spectrum Disorder Ontario Network of Expertise (FASD ONE) | January 21, 2014and written submission |
| Fiala, Yvette; Midgley, Betty | January 21, 2014 and written submission |
| Finlay, Barry | Written submission |
| Flynn, Duane | Written submission |
| Flynn, Julie | Written submission |
| Flynn, Nicole | January 20, 2014 |

| Organization/Individual | Date of Appearance / Written Submission |
|---|---|
| Forte, Nick; Forte, Elia | Written submission |
| Foster, Leona | Written submission |
| Franks, Patricia | Written submission |
| Fuchs, Tracy | Written submission |
| Fulton, Margery; Fulton, David | Written submission |
| Galley, Alison | December 18, 2013 |
| Gallin, Patricia; Lowry, Dana; Richardson, Wendy | January 13, 2014 |
| Ghebrekidan, Taddese | Written submission |
| Gifford, Kathleen | January 13, 2014 and written submission |
| Goldberg, Ben | Written submission |
| Goldthorpe, Janice Lynne | Written submission |
| Gowing, Nancy | Written submission |
| Graham, Karen | Written submission |
| Great Lakes Society for Developmental Services of Ontario | Written submission |
| Grey Bruce Family Network | Written submission |
| Griffith, Linda; Cowan, Doug | Written submission |
| Groulx, Carrie | January 14, 2014 and written submission |
| Hacio, Lois | January 14, 2014 and written submission |
| Hainer, Lynn | January 13, 2014 |
| Hall, Gregory; Hall, Joanne | Written submission |
| Halton Special Needs Family Network | January 20, 2014 and written submission |
| Hamill, Brian | Written submission |
| Hamm, Susan Buro | January 13, 2014 and written submission |
| Harrison, Connie | January 14, 2014 |
| Heald, Colleen | Written submission |
| Health Care Access Research and Developmental Disabilities Program (H-CARDD) | December 18, 2013 and written submission |
| Helwig, Maggie | January 14, 2014 |
| Highland Shores Children's Aid | Written submission |
| Holloway House | Written submission |
| Holmes, Ted | Written submission |
| Hub for Beyond 21 Foundation | January 17, 2014 |
| Hucal, Ann | Written submission |
| Humes, Michael F. | Written submission |
| Hunter, Brenda | Written submission |
| Imagine Respite Services | Written submission |

| **Organization/Individual** | **Date of Appearance / Written Submission** |
|---|---|
| Inclusion Initiatives Corp. | January 21, 2014 |
| Individualized Funding Coalition for Ontario | Written submission |
| Irving, Jim; Irving, Sue | December 18, 2013 and written submission |
| Jacobson, Suzanne | Written submission |
| James, Franke | January 21, 2014 and written submission |
| Jensen, Linda | Written submission |
| John Howard Society of Sudbury | Written submission |
| Johnsen, Debra | January 15, 2014 and written submission |
| Johnston, Sandi | Written submission |
| Jovanović, Anne; Jovanović, Dušan | Written submission |
| Joyce, Susannah | Written submission |
| Justice for Children and Youth | January 21, 2014 |
| Kavallappa, Bharathy | Written submission |
| Kazmierski, Urszula | Written submission |
| Kerry's Place Autism Services; Autism Ontario | December 18, 2013 and written submission |
| King, Chris | Written submission |
| Kitor, Mick | January 14, 2014 and written submission |
| Lamont, Gava | Written submission |
| Latty, Jeff; Latty, Patti | Written submission |
| Leask, Helen | January 14, 2014 |
| Lee, Laura | Written submission |
| Leiterman, Marilyn | January 14, 2014 |
| Leyshon, Judith | Written submission |
| Leyshon-Doughty, Sian | Written submission |
| LIGHTS | December 18, 2013 and written submission |
| LiveWorkPlay.ca | Written submission |
| Lougheed, Donna | Written submission |
| Lowrie, Jody | Written submission |
| Lutheran Community Care Centre | January 15, 2014 |
| Masters, Michele | Written submission |
| McGowan, Susan | Written submission |
| McGowan, Wendy | Written submission |
| McLaughlin, Coleen | Written submission |
| McLellan, Brian | Written submission |

| Organization/Individual | Date of Appearance / Written Submission |
|---|---|
| Miceli, Rita | Written submission |
| Ministry of Aboriginal Affairs | November 20, 2013 and written submission |
| Ministry of Children and Youth Services | October 30, 2013 and written submission |
| Ministry of Community and Social Services | October 30, 2013 and written submission |
| Ministry of Community and Social Services Partnership Table Housing Study Group | January 20, 2014 and written submission |
| Ministry of Community Safety and Correctional Services | November 13, 2013 and written submission |
| Ministry of Economic Development, Trade and Employment | November 27, 2013 and written submission |
| Ministry of Education | November 13, 2013 and written submission |
| Ministry of Health and Long-Term Care | November 20, 2013 and written submission |
| Ministry of Municipal Affairs and Housing | November 13, 2013 and written submission |
| Ministry of the Attorney General, Office of the Public Guardian and Trustee | November 13, 2013 and written submission |
| Ministry of Training, Colleges and Universities | November 13, 2013 and written submission |
| Mitchell, Cindy | January 21, 2014 |
| Moose Cree Education Authority | Written submission |
| Moose Cree First Nation | Written submission |
| Morse, Alison; Morse, Bob | Written submission |
| Mothersell, Sandra; Mothersell, Jillian | January 13, 2014 and written submission |
| Muir, Steve | Written submission |
| Mulima, Michelle | Written submission |
| Multidimensional Assessment of Providers and Systems (MAPS) | January 17, 2014 and written submission |
| National Association of Dual Diagnosis (NADD) Ontario | Written submission |
| New Vision Advocates | Written submission |
| New Visions Toronto | Written submission |
| Nilson-Rogers, Linda | January 17, 2014 and written submission |
| Nishnawbe Aski Nation | January 15, 2014 |
| Nolan, Cora | January 17, 2014 and written submission |
| Northcott, Tanya | Written submission |
| Ogston, Karen M. | Written submission |
| Ontario Agencies Supporting Individuals with Special Needs | January 20, 2014 and |

| Organization/Individual | Date of Appearance / Written Submission |
|---|---|
| (OASIS) | written submission |
| Ontario Association of Children's Rehabilitation Services (OACRS) | January 21, 2014 and written submission |
| Ontario Association of Residences Treating Youth (OARTY) and Partners in Parenting | January 14, 2014 |
| Ontario Community Services Coalition | Written submission |
| Ontario Public Service Employees Union (OPSEU) | November 13, 2013 and written submission |
| Ontario Residential Care Association | January 17, 2014 and written submission |
| Ontario Shores Centre for Mental Health Sciences | Written submission |
| Opportunities for Mississauga 21 Plus | January 21, 2014 and written submission |
| Options Northwest Thunder Bay | Written submission |
| Ottawa-Carleton Association for Persons with Developmental Disabilities (OCAPDD) | January 17, 2014 and written submission |
| Pakozdy, Judy | January 20, 2014 |
| Palumbo, Giovanni | Written submission |
| Pare, Barb | Written submission |
| Parlor, Margaret | Written submission |
| Parris, Brenda | January 14, 2014 |
| Participation House Project (Durham Region) | January 13, 2014 and written submission |
| Participation House Support Services London and Area | Written submission |
| Partners for Mental Health | January 17, 2014 and written submission |
| Party for People with Special Needs of Ontario | Written submission |
| Peel Children's Aid Society | December 18, 2013 |
| Peel Planning Group | January 20, 2014 and written submission |
| Penning, Heidi | Written submission |
| People First of Ontario | January 17, 2014 and written submission |
| Peters, Elaine M. | Written submission |
| Poisson, LeeAnn | Written submission |
| Popovici, Monica | Written submission |
| Power, Doris | Written submission |
| Provincial Advocate for Children and Youth | December 4, 2013 |
| Provincial Executive Directors Group, Community Living Ontario | December 18, 2013 |
| Provincial Network on Developmental Services | Written submission |

| Organization/Individual | Date of Appearance / Written Submission |
|---|---|
| Queen's University Department of Psychiatry | January 17, 2014 and written submission |
| Rahming, Anne | January 17, 2014 |
| Ranieri, Christina | Written submission |
| Redins, John | Written submission |
| Registered Nurses' Association of Ontario (RNAO) | January 13, 2014 and written submission |
| Renzetti, Rosanne | January 21, 2014 |
| Rivington, Joyce | January 17, 2014 and written submission |
| Rose, Heather | Written submission |
| Russell, Linda | December 18, 2013 |
| Ryerson University: Reimagining Parenting | January 15, 2014 |
| Rygiel Supports for Community Living | January 20, 2014 and written submission |
| Saarinen, George; Duce, Cheryl | January 15, 2014 and written submission |
| Sayles, Lynda; Sayles, Dean | Written submission |
| Scarborough Residential Alternatives | Written submission |
| Schunk, Yvonne | Written submission |
| Seberras, Nancy Tew | Written submission |
| Seifeldin, Iman | January 17, 2014 and written submission |
| Shea, Elaine | Written submission |
| Shea, Geoffrey | January 14, 2014 |
| Shepard, Dawn | Written submission |
| Simcoe County Children's Aid Society | Written submission |
| Sioux Lookout First Nations Health Authority | January 14, 2014 |
| Small-Greenall, Joanne | Written submission |
| Smith, Beth | Written submission |
| Smith, Darlene | January 13, 2014 |
| Smithers, Joanne | January 13, 2014 and written submission |
| Snider, Kyle | Written submission |
| Sobkowich, Shelley | Written submission |
| Solano, Ivan | January 14, 2014 |
| Special Needs Advocacy Group (Moose Factory) | Written submission |
| Special Services at Home and Passport Coalition | January 13, 2014 and written submission |
| Spindel and Associates | Written submission |
| Stadhard, Andrea | January 17, 2014 and written submission |

| Organization/Individual | Date of Appearance / Written Submission |
|---|---|
| Stanczak, Linda; Stanczak, Ray | Written submission |
| Stanley, Barry | January 21, 2014 and written submission |
| Steiner, Karin G. | January 17, 2014 and written submission |
| Storm | Written submission |
| Stuber, Shanti | Written submission |
| Surrey Place Centre, Medical Services | December 18, 2013 and written submission |
| TAMIR | Written submission |
| Tate, Peggy Ann | Written submission |
| Taylor, Margaret V. | Written submission |
| Telford, Philippe Etienne | Written submission |
| The Ottawa Rotary Home | December 11, 2013 |
| Thinking in Pictures Educational Services (TIPES) | January 14, 2014 and written submission |
| Thinking in Pictures Educational Services (TIPES) and Collective Autism Service Providers Association (CASPA) | January 17, 2014 |
| Thoms, Susan | January 15, 2014 and written submission |
| Thomson, Donna | January 17, 2014 and written submission |
| Thunder Bay Family Network | January 15, 2014 and written submission |
| Toronto Developmental Services Alliance | January 21, 2014 and written submission |
| Trulsen, Krista | Written submission |
| Turner, Shirley | Written submission |
| United Families of Eastern Ontario | January 17, 2014 and written submission |
| Van Dorp, Kathryn | Written submission |
| Vandriel, Henrietta | Written submission |
| Walker, Cindy | January 14, 2014 and written submission |
| Walker, Ryan; Walker, Sue | January 20, 2014 |
| Walking In My Shoes Parent Group | Written submission |
| Watt, Laurie | January 20, 2014 and written submission |
| Wentworth, Barb | January 14, 2014 and written submission |
| White, Diane L. | January 13, 2014 and written submission |

| Organization/Individual | Date of Appearance / Written Submission |
|---|---|
| Windsor Essex Family Network | Written submission |
| Winkler-Callighen, Mary Jo | January 13, 2014 |
| Wojewnik, Maria | Written submission |
| Woodview Mental Health and Autism Services | January 21, 2014 and written submission |
| Yorksie, Ron; Yorksie, Val | Written submission |
| Zimmermann, Patty; Hudyma, Jan | January 14, 2014 and written submission |