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January 20, 2014

The Select Committee on Developmental Services
90 Wellesley Street West
Room 1405
Whitney Block
Queen's Park,
Toronto, Ontario
M7A 1A2

Dear Members of the Select Committee,

On behalf of CUPE Ontario and our 8,000 members working in developmental services across Ontario, let me express our support for the committee's timely establishment and its mandate to develop 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."

CUPE welcomes the opportunity to appear before the Select Committee and to deliver to you our detailed submission on the state of the sector and our proposals for a way forward.

The analysis and recommendations contained in our submission reflect our broad experience in developmental services across Ontario over many years. Indeed, prior to becoming CUPE Ontario President I personally had the privilege of working in this sector for more than ten years.

The developmental services sector has evolved and changed dramatically over the years and our union's members have been there at every step. CUPE members working in developmental services care passionately about the work they do and the supported individuals and families they work with every day.

We are looking to you, the members of the Select Committee, for leadership in a sector desperately searching for a champion. We look forward to your report and hope that our efforts will have made an important contribution.

Thank you.

Sincerely,

A handwritten signature in black ink that reads "Fred Hahn". The signature is written in a cursive, slightly slanted style.

Fred Hahn
President

:gb/cope491

Fred Hahn
President

ONE STRONG VOICE

Candace Rennick
Secretary-Treasurer



Submission to the Select Committee on Developmental Services in Ontario

Fred Hahn, President, Canadian Union of Public Employees (CUPE) Ontario

January 20, 2014

Executive Summary

The Canadian Union of Public Employees (CUPE) is Canada's largest union. With approximately 627,000 members across Canada, CUPE represents workers in health care, education, municipalities, libraries, universities, social services, public utilities, transportation, emergency services and airlines. CUPE represents 240,000 workers within the province of Ontario alone, and of that number, approximately 8,000 CUPE members work in the Developmental Services (DS) sector or approximately 40% of the entire DS workforce of 21,000 individuals. The vast majority of our members employed in the DS sector, approximately eighty percent (80%), are women.

Our members are employed by fifty-five (55) independent community living agencies located in communities large and small across Ontario providing a range of programs and supports to children, youth and adults with developmental disabilities. Our members are very passionate about their work, and care very deeply about the individuals they support.

According to Government of Ontario data, approximately eighteen thousand (18,000) people with developmental disabilities are in receipt of community residential supports and more than fifteen thousand (15,000) are in receipt of direct funding through the Passport program (MCSS: July 30, 2013).

CUPE and the members we represent in the DS sector have a vision for the delivery of services and supports to persons with developmental disabilities and their families. It is our vision that quality supports for persons with developmental disabilities can best be sustained through public, not-for-profit, mandated services via an adequately funded community agency system, where workers are compensated fairly and provided training and skills enhancement opportunities.

In addition, supports must be tailored to meet the needs of individuals – that is, individualized planning, not individualized or direct funding. Only a properly funded public system, where *all* people with developmental disabilities have the right to access the supports they need, can provide redress to such inequities as long wait lists for programs and services, service cuts, limited capacity to respond to changing needs, deteriorating infrastructure, staff recruitment and retention challenges, and low and disparate wages.

Recent surveys of DS organizations across Ontario conducted by Ontario Agencies Supporting Individuals with Special Needs (OASIS) illustrate the many challenges confronting the sector. OASIS is an employer organization that is the voice of 173 developmental services transfer payment agencies in Ontario. The results of the most recent OASIS *Operating Pressures Survey* (September 2013), reveal that agencies are taking drastic measures to manage increasing operating costs, including the following:

- 62% of respondent organizations are cutting hours of staff;
- 51% are eliminating staff positions;
- 58% are not filling open positions (e.g. maternity leave);
- 18% are reducing program hours of operations;
- 7% are permanently closing programs;
- 16% are shutting down programs for a specified period of time;
- 26% are changing program delivery methods.

According to OASIS, 28,000 staff hours *per week* have been eliminated across the sector, along with 665 program hours *per week*. Forty-two programs have been temporarily closed. And yet at the same time, the demands on the system are increasing with an estimated 10-20% increase in the number of individuals receiving program supports.

Sixty-five percent (65%) of agencies surveyed report negative impacts on the delivery of quality care to supported individuals in the form of:

- Less individualized care being provided;
- Fewer specialized services;
- A decrease in prevention services;
- Dietary concerns are an issue;
- Elimination of recreational activities and community outings;
- Elimination of quality of life activities;
- New user fees for transportation and day programs.

The funding crisis is so dire some agencies have had to take out loans in an effort to maintain operations.

There are more than 23,000 individuals across the province languishing on waitlists – approximately 12,000 of those are waiting for residential supports; an additional four thousand individuals are waiting for Passport funding (Community Living Ontario). Waitlists have an enormous impact on the families of people with developmental disabilities. Families need community supports to provide the best care and support to their loved ones.

The shocking truth is that some persons with a developmental disability may never receive the care they need in their lifetime. Wait lists have become so commonplace that they are even now acknowledged in legislation and a fact of life for persons with developmental disabilities.

There is a way forward to the challenges that exist in the sector. All it takes is the political will to implement positive change for some of the most vulnerable people in Ontario. Positive change for persons with development disabilities and their families is possible and is evidenced by recent funding and legislative changes in two jurisdictions: the Province of Saskatchewan and the Commonwealth of Australia. Details on the Saskatchewan and Australian solutions to underfunding and wait lists are provided later in the paper. First, however, we offer a discussion of the negative impacts of chronic underfunding on persons with developmental disabilities and their families.

Deinstitutionalization and the Shift to Custodial Care

By the mid-1970s there were sixteen institutions in Ontario designed to house individuals with developmental and physical disabilities. The process of deinstitutionalization began in the 1980's and ended in 2009 with the closure of the last three facilities: the Rideau Regional Centre in Smiths Falls, the Southwestern Regional Centre in Chatham-Kent, and the Huronia Regional Centre in Orillia.

The estimated cost to the government for institutional care was \$100 thousand per individual (SSAHPC, 2012). However, the average cost of residential care in Ontario is considerably less at approximately \$62 thousand per individual (*Deputy Ministers' Review of Community Living British Columbia*, December 2011). Furthermore, recipients of direct funding under the Passport Program receive on average \$11,500.00 per year to purchase services and supports. Advocates of direct funding, such as the Special Services at Home / Passport Coalition point out that “amounts available for direct funding are woefully inadequate” (SSAHPC, 2012: 15). Deinstitutionalization has resulted in a huge cost savings for the government as funding has not entirely followed supported individuals into the community.

Deinstitutionalization held the promise for a fuller participation in society for persons with developmental disabilities; but the possibility of a brighter future is being undermined as community agencies strive to provide quality supports under tremendous financial pressures. Reductions in staffing positions and hours, increased workloads, an increased number of supported individuals in programs (with fewer staff), less time devoted to one-on-one care, and a reduction in community and recreational outings and activities for supported individuals signals the shift to what many have called a custodial care arrangement where supported individuals are increasingly segregated and isolated in residential care due to the lack of services and supports.

One of our member's works in a residential home that provides care to five supported individuals: three of the five are in wheelchairs, four of the five are in briefs that need to be changed throughout the day, two individuals require assistance to eat, and all need assistance in dressing and bathing. There are times when this residential home is single staffed. To take a supported individual on a community outing (e.g. for groceries, for a visit with family and/or friends, for a recreational or leisure activity) would require one-on-one staffing. It becomes impossible to go on a community outing when a residential home is single staffed. There is also less one-on-one time for such in-home activities as colouring or simply talking – these are the moments that make supported individuals feel special; these are the moments that are eliminated when a residential home is short-staffed.

This shift to custodial care is undermining the objectives set out in the *Services and Supports to Promote the Social Inclusion of Persons with Developmental Disabilities Act, 2008* including the objectives such as citizenship, social inclusion, fairness and equity, accessibility, safety and security.

And whereas the shift from institutions to community based agencies produced a significant cost savings for government, Ontario is yet again saving money at a cost to people with developmental disabilities by underfunding the community agency sector and with the introduction of direct funding.

A Sector in Turmoil: Chronic Underfunding

Ontario experienced its fair share of hard knocks during and after the near economic collapse of 2008-09, but we remain a prosperous province in one of the richest countries in the world. And yet, many thousands of individuals with developmental disabilities are receiving insufficient services and supports to facilitate the quality of life they're entitled to. Thousands are languishing on wait lists or receiving the wrong kind of care, or worse.

Some individuals are placed in unsuitable, long-term care institutions. There are approximately 4,500 persons with disabilities in long-term care, which represents approximately 6% of the entire long-term care population (Hansard, November 20, 2013). A recent study conducted by the Institute for Clinical Evaluative Services (ICES) and the Centre for Addiction and Mental Health (CAMH) found that persons with developmental disabilities are less likely to receive the care they need when compared to other adults and the care received often does not meet health care guidelines. The study findings also indicate that persons with developmental disabilities experience larger gaps in services and often end up in hospital emergency rooms in crisis (Mississauga News, November 2013). Individuals with the dual diagnosis of a developmental disability coupled with a mental health issue run the risk of ending up in prison due to the lack of appropriate resources. There are approximately 23,000 adults with a developmental disability in Ontario with a mental health issue (Hansard, November 20, 2013).

Billions of taxpayer's dollars have been wasted in the e-health Ontario and ORNGE scandals and the cancellation of gas power plants in Oakville and Mississauga; and then there are the billions more in corporate tax cuts. The creation of Developmental Services Ontario (DSO), the government entity tasked with determining eligibility for services and supports and for determining service and support needs, represents an additional layer of bureaucracy that individuals and their families must navigate. The DSO was established as a single point of access for services and supports but many families say nothing has improved and the money spent allocated to DSO's might be better spent if reinvested in the network of community based agencies.

Under successive governments in Ontario many families and support workers have a sense of feeling devalued. This is creating a situation in which financial pressures are likely to force potential disruptions in services as employers are forced to pay for the costs of delivering services through cuts to staffing levels and services and stagnating wages, benefits and working conditions.

The most major significant funding announcement for the DS sector occurred six years ago. Following many years of chronic underfunding, in 2007 the liberal government took positive steps to address the underfunding dilemma by injecting \$220 million into the sector over four years. The intent of the funding was to improve front-line wages to stem high rates of staff turnover to allow for more consistency in the provision of services and supports and thereby enhance service quality; however, in reality, the four year funding commitment turned out to be for two years only. Not all of the announced funding was directed to addressing retention challenges.

For example in 2009, the ministry announced the *Innovative Community Capacity Initiative* (ICCI). Under ICCI, agencies were directed to provide 2.0% more in services with the same amount of funding to address the ongoing waitlist dilemma. As a result of the ministry's directive, the year three funding commitment was all but lost and agencies were no farther ahead.

Then in 2010, the ministry broke its fourth year funding commitment. The \$20 million targeted to agency base budgets was instead directed to the ministry's transformation agenda¹. The move left agencies scrambling to find the funding to pay for compensation increases already bargained. Transfer payment agencies and locals bargained compensation increases with the expectation that funding to base budgets would increase, as the ministry had committed. However, agencies were put in the position of having to pay for negotiated wage increases from within existing budgets. Many agencies incurred operating deficits to meet their contractual obligations to workers as a direct result of government's broken funding commitment.

The developmental services network of community based transfer-payment agencies has struggled to provide quality services and supports to meet the complex needs of supported individuals within a discretionary, fixed funding envelope. The developmental services sector in Ontario has never enjoyed the public investment needed to meet the demand for services, and to ensure a high quality of supports for those in need.

CUPE members working in the sector report that their ability to provide a quality public service to a highly vulnerable population is being compromised due to ongoing financial pressures, which has forced many community agencies to cut staff and staff hours. For example, members of CUPE Local 4392 report that last year Community Living Guelph-Wellington eliminated ninety (90) direct support hours.

CUPE members also report that many agencies are not filling vacant positions due to ongoing financial pressures, which means fewer staff to provide consistent levels of care. At the same time, the number of individuals supported in programs has increased while the staff complement has either stayed the same or decreased. When staffing positions are cut or hours reduced, agencies are essentially changing the ratios of direct support staff to supported individuals, which can have a negative impact on individuals' overall physical and emotional well-being.

Staffing reductions and funding cuts have a negative impact on quality service delivery. Our members are keenly aware of that fact. According to our members, financial pressures are affecting service delivery in four key areas:

- Reduced outings for supported individuals;
- Reduced staff hours;
- Increased number of supported individuals served in programs;
- Not filling open positions (e.g. leaves of absence).

In 2013, the Ontario Agencies Supporting Individuals with Special Needs (OASIS), an employer organization that is the voice of 173 developmental services transfer payment agencies in Ontario, conducted a survey of DS organizations. The results of the *OASIS Operating Pressures Survey* (September 2013) revealed that agencies are taking drastic measures to manage increased costs with insufficient funding, including the following:

¹ According to the Ministry of Community and Social Services' website, "the transformation agenda for developmental services is broad and covers many areas of Ontario's system of services and supports such as eligibility, making access easier, and providing more choice and flexibility."

- 62% of respondent organizations are cutting hours of staff;
- 51% are eliminating staff positions;
- 58% are not filling open positions (e.g. maternity leave);
- 18% are reducing program hours of operations;
- 7% are permanently closing programs;
- 16% are shutting down programs for a specified period of time;
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According to OASIS, 28,000 staff hours per week have been eliminated across the sector, along with 665 program hours per week. Forty-two programs have been temporarily closed. And yet at the same time, the demands on the system are increasing with an estimated 10-20% increase in the number of individuals receiving program supports.

Sixty-five percent (65%) of agencies surveyed report negative impacts on the delivery of quality care to supported individuals in the form of:

- Less individualized care being provided;
- Fewer specialized services;
- A decrease in prevention services;
- Dietary concerns are an issue;
- Elimination of recreational activities and community outings;
- Elimination of quality of life activities;
- New user fees for transportation and day programs.

The funding crisis is so dire some agencies have had to take out loans in an effort to maintain operations.

Cuts to staff and services mean that many agencies have fewer resources to meet the demands of vulnerable individuals. Reduced hours of work are happening across the sector which has resulted in fewer community outings for supported individuals due to a lack of staff. Supported individuals often have difficulties coping with change such as reduced community outings and sometimes act out in harmful ways including exhibiting self-injurious behaviours and aggression toward other supported individuals and staff.

Layoffs have occurred and more are anticipated as the sector struggles to provide quality services with strained resources. Residential services closures have occurred in at least two CUPE organized agencies and supported individuals have been moved to other residential homes. Residential services have limited space and overcrowding presents its own unique challenges in terms of increased stress and workload. Supported individuals are denied the right to choose where they want to live when group home closures occur. Sometimes supported individuals are moved further from their families who care for them, which may also result in staffing changes that can negatively impact the health of supported individuals.

Understaffing and increased workloads are factors that may lead to experiences of violence at work. 65% of CUPE members report an increase in workload. The top five reasons for the increase in workloads are:

- Additional job duties;
- Increased paperwork expectations;
- Cutbacks to funding;
- Staff reductions / layoffs;
- More individuals in care.

CUPE members report that increase in workloads has negatively affected their health and/or safety at work. The Top 4 stress-related health symptoms reported by CUPE members are:

- Feeling run down;
- Headaches/migraines;
- Sleeping difficulties;
- Anxiety.

The experience and ramifications of increased workloads are perhaps best illustrated in the words of our members:

“The people we support are aging; with their age the workload becomes significantly heavier.”

“The needs of the people that I help support has (sic) dramatically increased but the staffing levels haven't. We often work single staffed and don't have many relief staff to cover sick/vacation time.”

“Due to a change in how ‘paperwork and daily logs’ are filled out it has added extra time and effort to complete. It seems we are more and more forced to fill out paperwork taking precious time away from actually providing support to people.”

A Made-In Saskatchewan Solution:

The government of Saskatchewan has developed a public solution to the wait list dilemma for developmental services in the province. In 2008, the government which is led by the right-of-centre Saskatchewan Party, embarked on a multi-year plan known as the *Community Living Waitlist Initiative*. The goal was to eliminate wait lists for services and supports for persons with developmental disabilities.

In 2008, 440 individuals requiring residential care and/or day programs were on wait lists for services and supports; that number grew by an additional 215 individuals to reach 655 individuals in recent years. In the spring of 2013 the government announced the elimination of wait lists for individuals looking for residential group home placements and day programs.

The wait lists were eliminated through an infusion of \$62.5 million in government funding. Here's how the money was spent:

- Construction of 75 new residential group homes in 41 communities and the subsequent creation of 244 new spaces;
- An additional 1,064 weekly hours of supported independent living for 100 individuals; and
- The addition of 290 new day program spaces.

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The Fallout: Waitlists

Citizenship is one of the pillars of the Ministry of Community and Social Services' transformation agenda. In this context, citizenship means the freedom to choose. It is argued that persons with developmental disabilities want the right to be the primary decision-makers over matters that affect them directly such as the provision of personal services and supports. However, it is difficult to have the freedom to choose in a system that by its very nature constrains choice due to underfunding.

Take wait lists as an example: having the freedom to choose amongst service and support options is constrained by the fact that the demand for services and supports exceeds the current supply. Waitlists are at an all time high. There are more than 23,000 individuals across the province languishing on waitlists – approximately 12,000 of those are waiting for residential supports. Approximately four thousand individuals are on the waitlist for Passport funding. Based on the wait list statistics, we can say with confidence that the majority of supported individuals and their families in the province prefer a residential support option rather than a direct funding arrangement through the Passport program.

Saskatchewan example con't from pg. 7

Included in the funding is \$23.9 million in capital investments. In addition, 500 new staffing positions have been created to provide supported independent living at Community Based Organizations (CBO's) around the province. CBO's are publicly funded, non-profit organizations that are akin to Developmental Service Agencies or Associations for Community Living in Ontario. Funding was also made available in the amount of \$8.94 million 13-14 to assist CBO's with ongoing recruitment and retention challenges of direct support workers.

Waitlists have an enormous impact on the families of people with developmental disabilities. Families need community supports to provide the best care and support to their loved ones.

The shocking truth is that some persons with a developmental disability may never receive the care they need in their lifetime. Wait lists have become so commonplace that they are even now acknowledged in legislation and a fact of life for persons with developmental disabilities. Contrast this with child protection where legislation *requires* access to services and supports for children and youth in need of care and protection – there are no wait lists in child protection.

There are no readily accessible Ontario government data on the costs of providing residential care to persons with developmental disabilities in Ontario, outside of a Freedom of Information request. But, according to the Deputy Ministers' Review of Community Living British Columbia (December 2011), the average cost of residential supports for Ontario in 2010-11 was approximately \$62,000.00 per annum; however, in some circumstances, the cost may be as high as \$100 thousand per annum, especially for individuals with multiple and complex needs. Community Living Ontario estimates there are 12,000 individuals on the wait list for residential supports. Therefore, we can estimate that the cost of eliminating the waitlist for residential supports is in the range of \$744 million to \$1.2 billion per annum.

The Fallout: Low Wages = Recruitment and Retention Challenges

While there were nominal wage increases in the sector in the period 2007-08 due largely to funding specifically allocated to wage increases, wages in the DS sector still lag behind those of comparable jobs in other sectors. A compensation survey conducted by the consulting firm KPMG revealed that “employees in this sector receive compensation that is 25-30% lower than comparable positions in broader public sector agencies, in Health, Education, Universities and Municipalities” (Alliance of Associations Serving Children and Youth, December 2000). The KPMG study is the most recent survey of wages in the DS sector to date. However, given the pattern of comparatively low wage increases that have occurred since the year 2000, including at least two years of zero net compensation increases, we have every reason to believe that wages in the sector remain comparatively low.

Our members don’t expect to get rich but they do expect to be fairly compensated. They choose to work in the DS sector because they truly love the work they do, and have a close connection with the individuals they support. Unfortunately, government doesn’t place a high value on the very important work performed by our members. A CUPE direct support worker earns on average \$20.69 an hour; that works out to \$40,345.50 a year *before* taxes, based on a 37.5 hour work week. However, we know that the majority of workers in the sector are part-time and cannot count on the security of permanent full-time employment which means that many have to work multiple jobs to make ends meet.

There is a critical need to standardize wage rates across the sector. An examination of wage rates across the DS sector reveals that wages vary widely from agency to agency. The maximum wage for a CUPE direct support worker in the DS sector is \$28.69 per hour and the lowest wage is the minimum wage, \$10.25 per hour. In several agencies, part-time workers are being paid less for doing the same job as a full-time worker.

This discrepancy in wages across the sector has resulted in a revolving door of staff at many agencies, which works against the sector’s, including the ministry’s desire to make developmental services a career of choice, and which impacts negatively on the ability of agencies to provide consistent supports to individuals

Decent and fair compensation play a pivotal role in the ability to recruit and retain qualified front-line workers. Quality services are enhanced by the presence of qualified and consistent staffing. High rates of staff turnover may have significant impacts on supported individuals. The psychological and physical well-being of supported individuals may be jeopardized resulting in self-injurious behaviours or other behavioural challenges, which are symptoms of distress as a result of change in the staffing relationship.

The Fallout: Increased Part-Time and Casual Work

Many people who want to work prefer a full-time job that provides fair compensation. But the underfunding dilemma in developmental services has seen the rise of part-time and casual work arrangements. The majority of workers in the DS sector are working part-time, which is no accident. Precarious employment in the form of part-time and casual work represents a cheaper supply of labour for cash-strapped agencies. Part-time and casual workers are often paid a lower wage than

their full-time counterparts and provided few, if any, employment benefits (e.g. dental, extended health).

The majority of part-time and casual workers have to rely on multiple jobs to make ends meet. More often than not, our members work at a job outside the DS sector to supplement their income. Consequently, through no fault of their own, they're often unable to make the same commitment to a single employer as a full time worker, which may have an impact on service quality to supported individuals and their families.

Many of our members want to work full-time but are unable to find full-time employment in the DS sector. 63% of part-time CUPE members are looking for full-time work in the DS sector. There is simply a lack of full-time job opportunities: many CUPE members report that they have been looking for full-time hours in the sector for more than 5 years, with no success.

Fewer permanent, full-time staff to provide supports translates into less continuity of care for supported individuals. Support workers and family members emphasize the importance of stability and consistency in support for individuals with developmental disabilities to optimize individuals' emotional and physical well-being.

The Fallout: Direct Funding

In 2008, the liberal government amended the legislation that regulates the province's developmental services sector². For the very first time, a form of funding and service delivery called "direct funding"³ was enshrined in legislation, a controversial move that impacts supported individuals and their families, community-based agencies, and front-line workers.

Australia's New National Disability Insurance Program

The Australian government has launched a new national disability insurance program that provides coverage to all of its 22.5 million citizens, including the 330,000 individuals with developmental, physical, sensory, or psychiatric disabilities. We don't agree with the significant expansion of direct funding under the program. But, the program does contain elements that mirror our vision for developmental services in Ontario; for example, the insurance program is publicly financed, funding is mandated, and coverage is universal.

The National Disability Insurance Scheme (NDIS) is similar to the model of health care in Canada in that it is an entitlement-based system that provides coverage to *all* Australians. Australians with a disability, including a developmental disability, are entitled to receive long-term care and support; however, income support is provided by the government's income support system and private insurance. The insurance program will be phased-in commencing in 2014 with full implementation scheduled for 2018-19.

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² *The Services and Supports to Promote the Social Inclusion of Persons with Developmental Disabilities Act, 2008.*

³ Direct funding is also known as individualized funding.

The entrenchment of direct funding in legislation came about after intense lobbying by some agencies, parents, and advocates of direct funding including the *Individualized Funding Coalition of Ontario*. Disability rights advocates have long argued that persons with developmental disabilities should have the right to be the primary decision-makers over matters that affect them directly, such as the provision of personal services and supports. The right to access direct funding is viewed by some as a basic human right, a citizenship issue that is based on the principles of self-determination and autonomy.

CUPE supports the concept of person directed planning whereby persons with developmental disabilities are provided the necessary supports to prepare life plans that support their distinct needs and goals. But, we also believe that person directed planning is best accomplished within the context of the not-for-profit, community agency system where trained and qualified staff provide a range of quality public services and supports.

Direct funding is ultimately a replacement for public investment in the non-profit community based provision of developmental disability-related services and supports; it is a mechanism by which the government can continue to underfund the sector. One of the effects of direct funding is that it downloads the responsibility for the provision of services to supported individuals and their families. Under direct funding arrangements, the supported individual and his/her family is the employer, a burden that many individuals and families either do not want or are unable to carry; often, they have no recourse when things go wrong.

What is Direct Funding? The Passport Program

The Ministry of Community and Social Services provides direct funding to persons with a developmental disability over 18 years of age through the Passport program. Passport funding is available to:

- Students with a developmental disability who are preparing to transition to adult services and supports, and,

Australia example con't from pg. 10

The NDIS is funded solely by government and funding is mandated. Funding is tied to the government's revenue-raising capacity in an effort to address underfunding and the problem of long wait lists. Under the new system, block funding would be gradually eliminated; instead, service providers (e.g. non-government agencies; private, for-profit firms; paid individuals (neighbours); specialist disability service providers; and state and local government providers) would bill the NDIS and recipients of direct funding directly. Agencies would no longer have to reapply for funding each year. Funding is secure as long as the agency is compliant with national standards and provides a high quality service.

The following supports are provided under the NDIS:

- personal care to help with the activities of daily living;
- community access supports (self-help, social skills, numeracy and literacy, leisure and social interaction);
- respite;
- support for residential living;
- domestic assistance to allow individuals to live independently in the community (meal preparation, banking and shopping, attending appointments);

con't on pg. 12

- Adults with a developmental disability, who are no longer in school, and are seeking transition planning and community participation supports.⁴

In the past, some adults with a developmental disability received funding under the Special Services at Home (SSAH) program, but as of April 1, 2012, the SSAH program is for children alone, and adults with a developmental disability or their families are directed to funding through the Passport program.

Passport funding recipients may live at home with their families, live on their own with room-mates or with a family home provider; however, priority is given to supported individuals who live at home with their families. Supported individuals and/or their families can choose between two direct funding options: they can choose to receive funding directly so they can purchase community services and supports themselves, or they can choose to access services and supports through the community agency system. The level of funding does not differ between the two options. Passport funding is portable and moves with the individual wherever they choose to live in the province. Two types of services are funded:

- Respite, including Personal Development and Growth (formerly SSAH); and
- Community Participation Supports.

Under current legislation, Passport funding cannot be used to access residential programming.

Supported individuals and/or their families may use up to 10% of approved Passport funding to purchase planning and/or brokerage and administrative supports to assist in the development and coordination of services and supports, and to manage direct funding allocations; otherwise, individuals and/or families can choose to manage their own funding. Supported individuals and/or families are responsible for submitting invoices for services purchased to the local designated passport agency.

Australia example con't from pg. 11

- transportation assistance;
- supported employment services that prepare people for the labour market; and
- therapies (occupational, physiotherapy, counselling, behavioural).

An independent office at arm's length from government would process complaints from service providers and supported individuals and/or their families. The office would have the authority to reassess contested decisions.

The anticipated cost of the NDIS is \$6.5 billion (Aus.) above the current budget of \$7.1 billion, or about \$295.00 per person. Total expenditures would approximate \$13.5 billion per year. But the benefits of the new system would eventually outweigh the costs in terms of the following:

- Increased well-being of supported individuals and care-givers;
- Early intervention that would produce better outcomes for individuals and reduce future costs;
- Aging parents would no longer have to worry about what happens to their loved one when they die;
- Savings to government services (e.g. health and social programs); and
- Increased labour force participation rates of persons with mild and moderate disabilities, and the resulting economic gains.

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⁴ Ontario Passport Guidelines (Revised June 2011), Ministry of Community and Social Services.

Approximately 15,000 individuals are in receipt of Passport funding. Unfortunately, the ministry does not collect data on whether the amount of funding received is equal to or less than the amount of funding requested. Four thousand individuals are on the waitlist for Passport funding (Community Living Ontario). Some people have been on the waitlist for years, and the list is growing.

Expansion of Direct Funding

The *Commission on the Reform of Ontario's Public Services*, also known as the *Drummond Commission*, recommended the expansion of direct funding in Ontario's developmental services sector. Direct funding is a core component of the Ministry of Community and Social Service's transformation agenda. In fact, the ministry has placed a "significant priority" on direct funding and is working to expand the program (October 30, 2013). Advocates claim that cost savings can be realized through direct funding, a claim that is often put forward by supporters of such privatization schemes but for which there is very little, if any, hard evidence. In fact, often the opposite is true: privatization initiatives result in cost-overruns that are paid for by taxpayer dollars.

Although direct funding arrangements may work for a small number of families, it is an inadequate funding support mechanism for the growing numbers of elderly parents who are not in a position to hire, train and direct workers. Many parents turn to direct funding because they have no other options available. The parents of supported individuals are an aging population. Many parents and families can no longer care for their loved ones due to failing health. At the same time, many people with developmental disabilities are living longer and have complex health needs. As our population continues to age, there will be an increasing demand by families of supported individuals for timely access to residential supports for their loved ones.

CUPE's Concerns: Supported Individual as Employer

Parents and families caring for a loved one with a developmental disability already carry overwhelming responsibilities. Maintaining and monitoring services purchased through direct funding is a challenge for families. Many families report that the stress of managing direct funding programs and services, coupled with the social isolation that can accompany such arrangements has forced them to abandon direct funding in favor of agency provided supports and services. For example, the government of British Columbia has been actively moving its developmental services sector to a model of direct funding. However, the Deputy Ministers' Review of Community Living British Columbia (2011) fully admits "there has also been a reluctance among families to assume the role of employer" (p.16). Likewise, the executive director of Community Living Essex County, Nancy Wallace-Gero told the Select Committee on December 4th 2013 that "many families cannot manage direct funding. They need support from agencies. We've got to have a strong community support system for those families." We agree.

Australia example con't from pg. 12

- Increased labour force participation rates of persons with mild and moderate disabilities, and the resulting economic gains.

It is estimated that by the year 2050, employment growth for persons with disabilities would increase by an additional 220,000 persons. At the same time, it is anticipated that GDP would increase by 1.0%, which equates to a net gain of \$32 billion to the economy.

Participants of direct funding programs must recruit, hire, train, supervise, discipline, make payroll deductions, and pay their workers. Supported individuals could be left vulnerable if their attendant becomes ill or resigns. Finding a suitable replacement worker poses an additional challenge and jeopardizes the continuity of care.

There are also huge liability issues for consumers of direct funding arrangements. For example, in case of injury the worker may have no recourse but to sue their employer, namely the person with the developmental disability and/or their family. Employers have many obligations and are potentially liable for a great many risks, obligations and liabilities which would be wrongfully placed upon society's most vulnerable citizens.

Australia example can't from pg. 13

The NDIS is funded solely by government and funding is mandated. Funding is tied to the government's revenue-raising capacity in an effort to address underfunding and the problem of long wait lists. Under the new system, block funding would be gradually eliminated; instead, service providers (e.g. non-government agencies; private, for-profit firms; paid individuals (neighbours); specialist disability service providers; and state and local government providers) would bill the NDIS and recipients of direct funding directly. Agencies would no longer have to reapply for funding each year. Funding is secure as long as the agency is compliant with national standards and provides a high quality service.

The following supports are provided under the NDIS:

- personal care to help with the activities of daily living;
- community access supports (self-help, social skills, numeracy and literacy, leisure and social interaction);
- respite;
- support for residential living;
- domestic assistance to allow individuals to live independently in the community (meal preparation, banking and shopping, attending appointments).

CUPE's Concerns: Sector Fragmentation

Direct funding arrangements funnel scarce government funding away from community based agencies thereby diminishing their capacity to enhance services and supports. Direct funding hampers efforts to build a cohesive network of community-based services. It increases the fragmentation of services, diminishes standards of care, and erodes the quality of supports for persons with developmental disabilities and their families.

CUPE's Concerns: Erosion of Wages and Working Conditions

The expansion of direct funding could potentially exert a downward pressure on wages and working conditions and negatively affect the provision of quality public services. It could also undermine efforts by organized labour and employer groups to work toward the development of a Human Resources Strategy for the sector to portray the DSW profession as a career of choice while at the same time providing redress to years of systemic and chronic underfunding of wages.

What the Sector Needs

CUPE is calling on the liberal government to immediately implement the following measures to address the underfunding dilemma and other systemic challenges confronting the Developmental Services sector:

- An immediate injection of between \$744 million to \$1.2 billion per annum to eliminate the growing waitlist for residential supports and multi-year funding commitments for community-based agencies to allow for long-term planning;
- Mandated standards of care;
- Minimum staffing ratios to ensure quality services and supports (as exists in the provision of regulated child care under the DNA);
- A comprehensive review of services and supports to ensure that services are appropriate. Such a review should consider the complex needs of supported individuals, and the need for age appropriate services that meet the needs of elderly people with developmental disabilities, and younger- and middle-aged adults;
- A program of action to reduce and eventually eliminate wait lists for all supports, including waitlists for children who “age out” of the school system and find themselves back on waitlists again;
- Policy development and planning with stakeholders to address the challenges of an aging population of families and parents;
- Fair compensation for direct support workers to recruit and retain qualified staff and create stable support arrangements, including full-time support work;
- Investigate and make public the extent to which the SSAH and Passport programs are meeting the needs of supported individuals and their families;
- Investigate and make public the extent to which individuals with developmental disabilities are living in inappropriate settings including long-term care facilities, mental health facilities and prisons;
- Redirect the \$12 million spent annually on Developmental Services Ontario to reducing the wait list for services and supports.

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