

Developmental Services in Ontario

Current Challenges and Recommendations

for a

Way Forward

Introduction

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, 8,000 CUPE members work in the Developmental Services (DS) sector.

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 only 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 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.

Be that as it may, 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 recent developments and continuing impacts of chronic underfunding on persons with developmental disabilities and their families.

A focus on developmental services

Developmental services has been a significant focal point in the past year between a Select Committee on Developmental Services, money in the budget for the sector, a Housing Task Force, coverage in the Auditor General's Report and a continuing investigation by the Ontario Ombudsman, André Marin, into the sector. Despite the attention, few resources have been directed toward the non-profit network of community agencies that provide front-line developmental services and a massive waitlist for residential services continues.

Budget

The 2014 budget included \$810M for developmental services with \$200M over three years going to front-line workers in the community and developmental services sector. Out of the \$200M, \$20.5M was allocated to Intervenor and Interpreter, Violence Against Women and Aboriginal Healing and Wellness Strategy, with just under \$180M remaining for front-line workers. This money will be allocated to employers based on the number of full-time equivalent (FTE) positions. Eighty per cent will go toward wages and associated mandatory benefit costs and twenty per cent will be allocated to precarious work issues, defined as low-wages, pensions

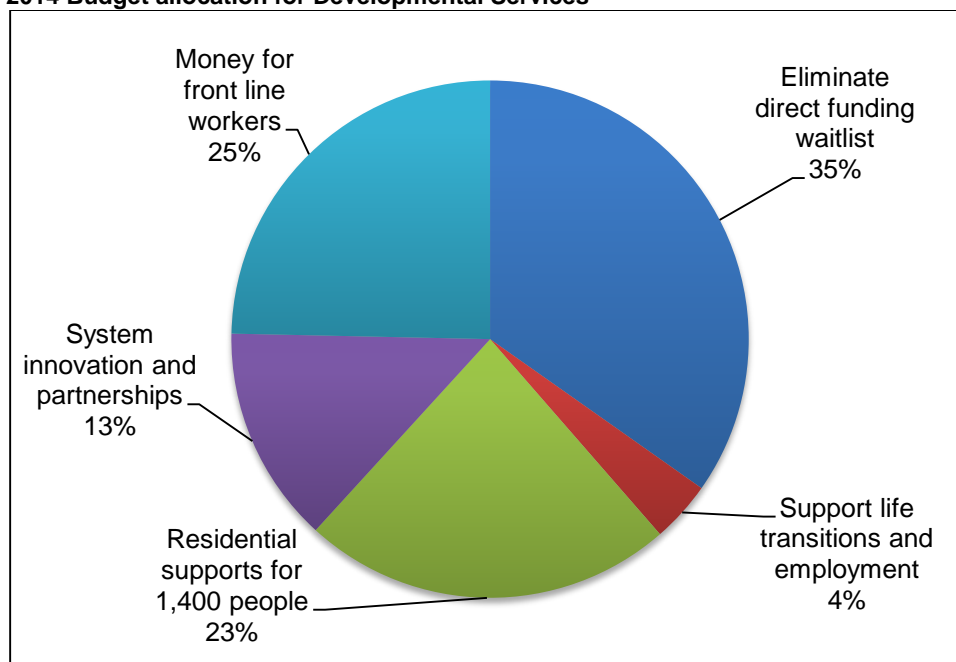
and benefits. Though more money is needed to ensure a stable workforce and continuity of care, CUPE is pleased to see recognition of the important work that CUPE members do in the developmental services sector.

Unfortunately the budget failed to allocate any additional base operating funding to developmental services agencies. With inflation, the cost of heating, electricity, water and transportation have increased leaving agencies in a bind without additional government funds. Many agencies have responded to these increased costs through reduced staffing, services and programs, which affects both workers and clients. This was a significant shortcoming in the 2014 budget.

The budget committed to eliminating the waitlist for direct funding with the largest segment of money directed toward Passport and Special Services at Home direct funding. It did little to address the 14,300 adults on the waitlist for residential services with only 1,400 new residential spaces created. This will leave 12,900 adults waiting for residential spaces.

The \$110M allocated to promoting system innovation and community living partnerships goes toward establishing a Housing Task Force, which had its initial meeting in September 2014 and launching the Employment and Modernization Fund. The Housing Task Force unfortunately has a limited mandate, which includes developing a framework for “capacity-building housing projects” and making recommendations on promising housing proposals. It will not provide any analysis or recommendations on issues linked to waiting lists for adult residential developmental services or the process to access residential supports.

2014 Budget allocation for Developmental Services



Select Committee on Developmental Services Report

Shortly after the budget was released, the Select Committee on Developmental Services tabled their final report on July 23, 2014. The Committee, which was struck in late 2013, made

recommendations on a comprehensive developmental services strategy in its report including that all waitlists for developmental services be eliminated within 12 months.

The report made several constructive recommendations including that:

- Additional funding be put toward the sector,
- An Inter-Ministerial Committee on Developmental Services be created,
- A long-term multi-year funding commitment to services agencies be established,
- A plan be developed to ensure that legal pay equity obligations are met.

At the same time, the report failed to address several key issues including fair compensation for direct support workers, whether individualized funding is meeting the needs of supported individuals and their families, and on staffing ratios, they recommended creating best practices rather than mandated minimum ratios, standards of care and mandated services as CUPE had proposed in its brief.

Ombudsman and Auditor General's Report

Several other investigations are taking place in the sector—a significant report is in progress by the Ontario Ombudsman and the Auditor General's 2014 report covered the sector in one of its chapters.

The Auditor General report's chapter on developmental services recommended that:

- The Ministry establish benchmarks on care standards including staff-to-resident ratios because care standards in the sector are few and open to interpretation
- The Ministry ensure all staff have adequate training because 5-11% of staff in compliance inspections didn't have training in mandatory areas such as first aid, CPR, basic needs, medical support etc.
- Employees undergo regularly updated Canadian Police Information Centre reports
- Funding should be tied to the level of care/support required because a wide variation exists in the cost per bed or level of support

Another major report on the sector is expected in 2015 from the Ontario Ombudsman; many CUPE members in the sector gave testimony about issues such as the lack of supports for clients due to low staffing during this investigation. The Ombudsman's office continues to analyze evidence received, including 1,100 complaints, for adults with developmental disabilities in crisis situations. The Ombudsman's 2014 Annual Report also included some discussion of issues in developmental services. They highlighted the lack of planning and continuity of care for children with special needs when they become adults. The report spoke of long waitlists for appropriate placements, including during crisis situations, where in some cases, people were arrested by police and held in hospitals, often in psychiatric units. It also noted that in some cases, group homes are also unable to care for clients in crisis due to a lack of resources, skills or training.

While much attention is being paid to developmental services, the sector is still in crisis after years of underfunding. In 2014, a survey of developmental services employers in Ontario revealed that many agencies have taken drastic measures in response to the underfunding dilemma and the liberal government's austerity agenda. The survey was conducted by Ontario Agencies Supporting Individuals with Special Needs (OASIS), an umbrella organization that is the voice for 179 developmental services transfer payment agencies in Ontario.

Of the approximately 225 agencies that were asked to complete the survey, 94 agencies responded for a response rate of 42%. The survey findings reveal that many agencies have been forced to make cuts to programs and positions:

- Increased administrative burden
- Less professional development for staff
- Less individual care being provided
- Less specialized service
- Minimal maintenance being done
- Eliminated recreational activities
- Positions remaining vacant longer, if filled at all
- Only able to provide the basics¹

Cuts to staff and services mean that many agencies have fewer resources to meet the demands of vulnerable individuals. At one CUPE organized agency, 300 to 400 support hours have been eliminated to offset the deficit. In fact, 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. Group home closures have occurred in at least two CUPE organized agencies and supported individuals have been moved to other group homes. Group homes 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 also may result in staffing changes that can negatively impact the health of supported individuals.

The Fallout: Waitlists

Citizenship is one of the pillars of the ministry's 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.

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

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. Though the government has committed to eliminate the waitlist for direct funding, there are still 14,300 adults on the waitlist for residential services. Even with funding in the budget for 1,400 additional residential spaces, 12,900 adults will still be languishing on the waitlist for residential supports. 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, and to add insult to injury the liberal government has enshrined wait lists in legislation for people 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.

The Fallout: Low Wages = Recruitment and Retention Challenges

Wages in the sector have increased in recent years but remain far behind those of comparable jobs in other sectors. 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.

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-harming 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

- The addition of 290 new day program spaces.

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 in 2013-14 to assist CBO's with ongoing recruitment and retention challenges of direct support workers.

arrangements. In many agencies, in fact, the number of part-time and casual workers far exceeds the number of full-time workers. Part-time and casual workers often have to rely on one or more jobs to make ends meet. 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.

The Fallout: Direct Funding

In 2008, the liberal government amended the legislation that regulates the province's developmental services sector.¹ For the very first time, a form of funding and service delivery called "direct funding" was enshrined in legislation, a controversial move that impacts supported individuals and their families, community-based agencies, and front-line workers.

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*.² 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 staffs provide a range of quality public services and supports.

Direct funding is ultimately a replacement for public investment in the 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

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

The anticipated cost of the NDIS is \$6.5 billion 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 will eventually outweigh the costs in terms of the following:

- Increased well-being of supported individuals and care-givers;

¹ The *Services and Supports to Promote the Social Inclusion of Persons with Disabilities Act* can be accessed online at E-Laws, <http://www.e-laws.gov.on.ca/navigation?file=home>

² Direct funding is also known as individualized funding.

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,
- Adults with a developmental disability, who are no longer in school, and are seeking transition planning and community participation supports.³

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. It can be used to purchase any of the following services and supports:

- Continuing education;
- Personal skills development;
- Employment preparation and vocational activities;
- Volunteering;
- Daily living activities; and
- Leisure and social skills.

- 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 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.

³ *Ontario Passport Guidelines* (Revised June 2011), Ministry of Community and Social Services.

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.

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. 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 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 caregivers 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.

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 yet another burden. 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.

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.

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 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 will be gradually eliminated; instead, not-for-profit providers will bill the NDIS. Agencies will 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.

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.

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:

- Adequate multi-year provincial funding for community-based services;
- Mandated standards of care, as exists in child welfare;
- A program of action to reduce and eventually eliminate wait lists for agency services;
- Policy development with stakeholders to address the challenges of an aging caregiver population; and
- Fair compensation for direct support workers

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