

# Putting People First

## What We Heard

Everyone deserves to have a say in where and how they live. Everyone deserves a chance to be included and involved in their community. Yet for people with disabilities, seniors, persons with mental health issues, and their families, this is often a challenge.

Nova Scotians across the province shared their experiences with government to help improve services for those who receive continuing care from the province. More than 650 people responded, either in person or in written submissions. Their feedback is gathered in the report *Putting People First: What We Heard*.

In a nutshell, the current system of programs and supports is too inflexible and impersonal. Many people have a hard time figuring out where to start and spend too long waiting for help. Government needs to do better.

Alongside these consultations, the province sought input from a joint advisory committee, made up of government and community partners, to begin work on a transformation of services for persons with disabilities. In response to the *What We Heard* report, the province is taking three actions right away to help this transformation.

### **A single entry point for programs and services.**

Getting help should be a straightforward, timely, and accessible process. But, many people find the process frustrating from the start. Navigating different departments, programs, and criteria is more confusing than it should be. The province will begin work to use one toll-free number for continuing care and services for persons with disabilities to provide Nova Scotians with easier access to guidance and support.

### **A demonstration project that provides families more flexible housing and funding options.**

Many people with disabilities, seniors, persons with mental health issues, and their families have their own creative, community-based housing solutions in mind. They just need the means to get started. The province will work with families to explore their ideas that could be models for accessible housing options in the future.

### **Modern legislation to support people with disabilities, seniors, and others needing long-term care.**

Nova Scotia needs a better framework to support seniors and people with disabilities. The Homes for Special Care Act, introduced in 1977, is not set up to encourage a flexible, people-based response to needs. Government will immediately begin work, with community input, on new laws and regulations that are community-focused, socially inclusive, and put people and families first.

In the coming months, government will release action plans to respond to the challenges Nova Scotians shared during the Putting People First consultations and through the roadmap for transforming services for persons with disabilities. The actions announced on August 29 are the first steps in a long-term commitment to provide more person-directed, home and community-based supports for people with disabilities, seniors, persons with mental health issues, and their families. It's a transformation that will take time, vision, and cooperation. Nova Scotia can become a leader again in empowering people with disabilities and other continuing care needs to live independently in inclusive communities.

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July 2013



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# Foreword

In March 2013, the Minister of Community Services and the Minister of Health & Wellness released a discussion paper, *Putting People First: Working Together to Support Independence and Dignity*. This document set out how the Department of Community Services and the Department of Health & Wellness could work together to create a major shift in the way Nova Scotians regard disability, aging, and community. It proposed some draft principles and possible actions to put in place the right supports and conditions that will help Nova Scotians to have maximum independence and quality of life, improved social and health outcomes, more choice, and stronger, more socially inclusive communities.

Over three months, more than 600 people participated in facilitated discussions to share their ideas and experiences. Sessions were held in Dartmouth, Truro, Kentville, Amherst, Sydney and Digby, for individuals and families who use our services. Sessions were also held with front line staff, service providers, and other interested groups. An additional 50 people shared their expertise and opinions through written and internet submissions. Although participants had diverse backgrounds, the stories they shared were often extremely similar. Sometimes there were differing opinions and perspectives about the same issue, and we present both in this report.

The input we received from those engagement sessions will be used to inform our plan for the future. The goal is to make the services provided by Continuing Care, Mental Health, Addictions & Children's Services, and Services for Persons with Disabilities, more person-directed, socially inclusive and home and community focused, so that Nova Scotians of all ages and all levels of ability can have options to help them live with maximum independence and dignity.

# Introduction

We know that right now in Nova Scotia, many people are receiving excellent supports and services from the Department of Health and Wellness and the Department of Community Services. We also know that there are many opportunities to do better. Although the people who deliver services do their best to provide person-centred support, the system itself isn't person-centered. In fact, calls to overhaul, modernize and transform the way government provides services to seniors, people with mental illness, and people with disabilities – and to improve the relationship that people and their families have with government programs -- go back twenty years or more.

There has been an awful lot of talk. Many promises. Little action. In the meantime, people have fallen through cracks, spent much of their lives on waiting lists, lost the power of choice and the hope of independence.

In general, government's approach to providing long-term supports to help people of all ages and levels of ability is rooted in a paternalistic, custodial, risk-averse culture. People are diagnosed, classified, cared for, protected and 'developed'. They are required to fit into criteria that are sometimes so rigid, no one can qualify. To be able to access facility-based care, parents must sign their child who has a disability over to the State. A family home can need almost impossible institution-level renovations to be approved as a place of residence for a program client. A person who wants supports to continue to live in her own home may be told that her pet cat constitutes a sufficient hazard to keep service providers from entering her home.

The level of frustration expressed by many people who require support to live independently, their family members and advocates is echoed by many service providers, program staff and administrators. They see first-hand the consequences of policies that are often not person-focused, well-coordinated or based on common-sense. "Red tape" is as much a complaint of people working within the system as it is for people using it. So too is the frustration about not being able to make decisions without layers and layers of bureaucracy. Too often, we expect a person

to fit into the programs that are available, rather than customizing a response to what they actually need.

All this speaks to the need for us to turn the system on its head, making it a person-directed system of support, not a system-driven approach to care. That means that seniors, people with mental illness, and people with disabilities, who are their own best experts, should be able to obtain services based on what they need rather than on what each program is structured to give them. It means living up to the promise of dignity, respect and inclusion.

When asked how the system is falling short, there was a remarkable and often haunting similarity of lived experience. When asked how the system could be made better, people came forward with no shortage of thoughtful, constructive suggestions. This is what we heard.

*The following section summarizes the input received from hundreds of people who use Continuing Care services or who are clients of the Services for Persons with Disabilities program. It also includes feedback from family members and people who support and advocate for seniors and people with disabilities, as well as staff who work in government programs and publicly funded agencies and organizations.*

# What We Heard

Inclusion driven. Person directed. Community first. That is how programs and services to support seniors, people with mental illness, and people with disabilities should perform.

We heard that sometimes, it seems as though the whole system is upside down. People with disabilities are penalized for success in finding work or otherwise enriching their lives by losing meagre government benefits as their reward. People with disabilities are accountable to program staff for their use of funds. Instead, programs should have accountability to clients for performance and outcomes.

People at the engagement sessions expressed hope that Nova Scotia can be a leader again in how we plan, manage and deliver these services. They want government to take steps toward a system that reflects the principles of the UN Convention on the Rights of Persons with Disabilities. But that means making some very significant changes to how we look at the role of government in the lives of persons with disabilities and people who are aging into disability. It means moving from a custodial, paternalistic and protective system of care to a respectful, person-directed and choice-based system of support for community living. People are not cases. Bureaucrats should not be managing people's lives. Nobody should be defined by a diagnosis or level of care classification.

## **Disability is expensive**

The need for special equipment, to hire extra help, to make a home accessible, to have a family member abandon a career to become a primary care-giver – or being left behind in the workforce - makes having a disability a significant financial burden. For many, it can be a direct route to poverty. People can't live well or get better, with any kind of choice or dignity, if they have to choose between rent and food. This is the harsh economic reality for many disabled people and their families.



Families make sacrifices to care for and support their disabled loved ones willingly, but many have come to their limit and need help if they are to continue in their role. Relaxing or abolishing income testing to be eligible for a program or subsidy was suggested. So too were tax incentives or relief to acknowledge personal contributions to the care of a disabled dependent.

**Personal stories:**

- I don't like the way you have to prove how poor you are to receive any help, it's very degrading. I have a lot of pride and don't like to ask for help.
- Some programs are means tested and I'm just over the cut-off. But I can't afford to pay for the services.

## **Transition planning for leaving home**

Leaving home to move to another place is, for many people, a very significant life event even when it's 'part of growing up' and well planned. For families that are caring for children with disabilities, this is often a far more complicated and stressful process. These families need the assurance that a plan is in place for when caregiver parents can't be there any more for their disabled loved one – a plan that they are part of crafting and that gives them peace of mind for the future. Many families are extremely worried that this planning is already long overdue. They fear that desperate measures will be taken through crisis to activate a placement for their child – a placement that may be traumatic and highly inappropriate. Instead, they want a collaborative process in place to develop and then implement a plan that is supported and understood by a network of program and agency partners.

**Personal story:**

- From the time he was born every effort has been made to make him part of the community. We're not asking for something that's not realistic. We want to be part of the solution. Our dream is to see him living in the community, where he has family and friends and support. I could die in peace. He doesn't want to live in a big institution, he wants to live with two or three other guys his age in a similar situation. We're willing to work together if you'd just give us a chance.

**Facility-based care: small community-based residences**

The role of institution-based care was among the more contentious points of discussion, with deeply held views being expressed by a variety of stakeholders. There can be no doubt that the legacy of an era of residential facilities where occupants were treated more like inmates than residents lingers still. Equally, there are today many examples of facilities in Nova Scotia that are regarded, in every sense of the word, to be home for those who live there – where close social networks and pride of place are the hallmark of the address. Many staff of residential facilities feel tarred by the brush of history and are concerned that the good work they do is not widely understood or valued.

There is strong agreement that any facility-based model which clusters people with disabilities for administrative convenience, or segregates them for lack of inclusive community-based options, is not person-centred and must be rejected. But for those for whom living in small groups is the right choice, facilities that provide a home-like environment and strong social connection are a necessary point on the continuum of supportive living. It was pointed out that social isolation can be the unintended consequence of housing a person with a disability in a private home with no outreach or connection with their broader community. Small, community-based residences where people with disabilities live as members of the broader community is the model overwhelmingly supported by all stakeholders. There is strong

consensus that Nova Scotia needs to minimize its reliance on unnecessary institutional placements for seniors and people with disabilities, and create more options for people to live with maximum independence in the community.

### **Personal stories:**

- I was in an institution since I was eleven. I know how it feels. I had to leave family and friends. I was there till I was 17. No privacy. Can't go shopping, can't do things everyone else can. Imagine eating at certain times...showering once a week, placed for life, not getting a day pass...or parole.
- There are good stories, success stories, but the public doesn't hear them. It's demoralizing for those who work in our sector. As I was leaving work the other night, I heard music and thought it was a CD. I looked in the dining room, and there were a group of our residents jamming together on their instruments and people were singing along. How is that not community? I left work feeling good, for once, about my job.

## **Two facility lenses: seniors and young people**

Seniors aging into disability and younger people living with disability often view the facility debate through different lenses. Although most seniors want to stay in their own home for as long as possible, some are still concerned about whether Nova Scotia makes enough of an investment in institutional care. Many people with disabilities want less reliance on institutional care and believe that Nova Scotia has invested too much. Facility-based care, once the 'default' option when a person turned 65, is an important part of the continuum of service. Seniors who require support are often accustomed to considering care in a facility instead of at home, perhaps due to an historic lack of supports to remain home safely and comfortably. Some seniors have said they are concerned that there may not be enough nursing home beds available for them to exercise that choice. On the other hand, younger people

with disabilities have expressed fear that facility-based care may be their only option, and are afraid that inappropriate residential solutions will be imposed. Both groups agree that many people also feel compelled to get themselves onto waiting lists before they really need facility-based care. They could live in their own home for longer if they had modest additional supports to extend their independence. When needing a higher level of care than is possible at home, lack of facility-based options for couples who are aging together but with different levels of care needs is a huge gap.

## **More home and community based supports**

People want more options to support them to live in their homes and in the community. They are also concerned that these supports be in place in advance of any 'de-institutionalization' to avoid the mistakes made by the mental health system two decades ago (essentially making people with mental illness homeless because institutions closed before home and community-based supports were in place).

### **Personal story:**

- The worst part of my husband being in a nursing home is the split between husband and wife. We have been together for over 50 years. Before he went in the nursing home I investigated senior living places to see if we could rent an apartment in a seniors' home where we could live together. But there was no place we could live together where he would also receive nursing care. Husbands and wives should not be separated.

## **Staff training to understand the nature of disabilities**

As more disabled people live to reach their senior years, staff working with geriatric clients, patients and residents must be prepared for the needs of this specialized elder population. Many home care staff have expressed concern that they need more training to deal with those living with mental illness and dementia. Providers working in nursing homes also need additional training to know how to support residents with intellectual disabilities. Furthermore, because of long-standing social attitudes, the fellow residents may have gone through life discriminating toward people with disabilities, making inclusion extremely difficult. Specialized training is also required for staff across the support continuum to understand the nature of acquired brain injury and how to support the person with disability and their family through recovery and beyond. Although specialized staff are now available to support children with autism spectrum disorders and their families, adults with autism spectrum disorders also require support to reach their full potential.

## **Assessments & wait lists support the system, not the person**

The Department of Health and Wellness and the Department of Community Services each host a suite of programs that support people with disabilities, but the policies are often misaligned, overlapping or disconnected. There is, for example, the typical client experience of having multiple assessments performed by multiple programs, frequently asking for the same information and often coming to different conclusions. People are assessed against program criteria, not on what they identify as needing to support their independence. There are sometimes gaps in what supports are available to a person simply because of age. Information isn't shared across or within departments for the benefit of the client; staff often aren't aware of other assessments that have been done, or their outcomes. And there are rules that don't allow staff from one department to participate in the support of their client when they seek services delivered through the other department.

Assessment sometimes doesn't lead to action. People described being left on wait lists for years with little or no support. While on a wait list, the system treats the person as a case on file: invisible and static, although their lives are changing. By the time they reach the top of the list, they may not be the person they were when assessed, and their needs may be different. Or, while waiting for service, they (or their caregivers) pass their tipping point and are in crisis. This usually results in the most expensive solutions for the system and poor outcomes for the person with disability and their family. It was noted, however, that some parts of the system are improving how they manage wait lists. Mental Health & Addictions staff from District Health Authorities described various strategies they've been using since the release of the Mental Health & Addictions Strategy in 2012, to provide services to non-urgent people waiting for programs and services in times of higher wait lists.

People assessed with mental health and behavioural problems sometimes require more collaboration between departments and programs to identify safe and appropriate living options. Some people described long waits for government to determine which department would provide funding, and for staff with the appropriate training and education in behavioural issues were found. While the person waits, sometimes for months or even years, their condition often deteriorates, and their lives (as well as their families') are put on hold.

**Personal stories:**

- I don't like the concept of wait list. The assessment should be the beginning of support, not the beginning to wait.
- We are used to telling people what they can have, rather than asking them what they need.
- Government sees it like this: "You're a DCS client, you're a DHW client". But we don't live our lives in silos and our problems don't go in neat packages.

## **Eligibility requirements slot people into programs**

Many people are either “not disabled enough” or “too disabled” to be eligible for support. Some people have great need, but don’t fit into the criteria for existing programs, so end up with little or nothing. Others get ‘over-serviced’, either because there is a rule about how a service must be delivered as a ‘bundle’, or because no less intensive option is available. One woman used to give herself insulin injections, but since moving into a community-based facility she must have a registered nurse come to administer the injections three times a day – even though she’s perfectly capable. The variable timing of the nurse’s visit means the woman is stuck, waiting. The result is a far more expensive service being delivered and the person’s true needs not being addressed. In fact, her independence has been lost. Similarly, people with acquired brain injuries do not fit into the criteria for many support programs because their needs are, by nature, very different than for people with developmental, intellectual and other physical disabilities. To be truly person-directed, we must start with what the person needs, not what the program is structured to provide or what a blanket policy prescribes.

## **Funding should follow the person, not the program**

Changing the model, and accountability, for how funding is assigned was a dominant theme. Many people said that this is the first step to transforming the system. For example, it was suggested that instead of a ‘bed’ being funded in a residential facility, the money should be assigned to the person needing a place to live. This would shift control and accountability, and put the person using the service in a position to exercise choice in how funding for their support should be directed. People with disabilities and people aging into disability should be able to decide how to invest resources to design their own support plan, because they are most expert in what they need. This would be a huge philosophical shift for government and the disabilities community alike. Many people would be ready to take on a more direct role in directing and developing their own support plan. Others will need help to build

those skills. And some will not choose or be able to do this for themselves. People want a full range of choices, from fully self-managed care to fully-supported care. This continuum should support the ability to 'dial up and down' the level of support as a person's need changes, and should be based on a person's choices, not the worker's. Getting people to their greatest possible level of independence must be the goal.

**Personal stories:**

- Have the money follow the person. This helps with the quality piece too, because people will vote with their feet. Programs that aren't working or aren't giving people what they need won't be used; more emphasis can be placed on investing in what is working.
- I like the idea of the money following the person, but it would take a lot of capacity building and time to get many of our clients there. It would be important to build that foundation before diving into big changes.

**Program staff need more authority, flexibility and tools**

Front-line staff feel they lack the authority to make common-sense decisions that could benefit the people they work with. Decisions that should be made about programs on the front-line are often passed 'up the chain' until they are made by Head Office, particularly in matters of 'complex care'. This undermines the relationship between case workers, program staff and their clients. The decisions made can set precedents that are difficult to sustain. This contributes to a perception that there is a lack of fairness, and encourages people to escalate issues to get what they need. Front-line staff, who are in the position to have the best understanding of how to help the client's situation, want the authority to make decisions and the flexibility to move money out of 'protected pots' to where it's most needed. It makes no sense for some budgets to go unspent because no one met the eligibility criteria, while other



programs have people waiting for service because there is no money to fund them. It also makes no sense to spend more money on the process of making a decision (because of the number of people and time involved) than the amount being approved. Front line staff also need access to technology to do their work efficiently (such as laptops and cell phones), and the time to spend with clients on their case loads to ensure the greatest possible success of support plans as they evolve.

### **Personal stories:**

- There are too many layers of red tape to make a simple decision. I know what my client needs, but I have no authority.
- Our staff should not be spending time going through a client's receipts to check on how they spend their money. We should be helping them to navigate the system and get the fullest value from the services they have available to them.
- I worked with a young woman who didn't fit our guidelines – a so-called 'complex case'. I got Justice, Health, DCS, Education, all together to talk about what we could each do. Unfortunately, this was five years ago and it hasn't happened since. I still think about it because it was the one time I was really able to do the job I wanted to do, not the paperwork I'm doing now. These examples shouldn't be so memorable or special stories. They should just be the way we the work. Clients don't care which department we're from. We're just the government.
- I'm sure it cost the system at least \$5000 in staff time over several months to make a decision to spend \$200. No one even considers the value of the client's time that we wasted making them wait.

## Stop pushing people to crisis

The system seems far better at mobilizing to respond to a crisis than it is at stepping up before things unravel, even though the build-up to the crisis may have been coming for months (or years) and with plenty of warning signs. When a support system does come un-glued, there is usually no going back. If we could put as much energy into sustaining home and community-based supports, with help to care-givers, respite services that give people the help they really need and commitment to address the situation as needs change, most crises would never happen – and significant cost (both personal and financial) would be avoided.

## Single entry, and ‘coaches’ rather than ‘case managers’

When people have entered the system, they often feel lost about what to do next or where to look for support. And once people are in the system, there are critical ‘hand-off’ points where transition is rough or non-existent based on age (child to adult, becoming a senior) or jurisdiction (going from a DCS facility to a hospital, for example). Some people suggested that a navigation function or advocate would be useful to help people understand where to go, what’s available, and to ensure coordination of support. Others pointed out that if we need navigators, the system is too complicated – or isn’t working at all.

There are a growing number of people who are coming to us in old age with no supports, and therefore have no one to advocate on their behalf. They might be estranged from family, isolated from neighbours, have lived in isolation for many years, or have family in other countries. They could return to the community if there was a navigator or advocate to check in on them, make sure they have groceries, are clean, etc. Otherwise, they spend their last years in hospital because that is their only option.

Another approach could be to have ‘coaches’ who work with the team that includes the person with a disability and their family, support workers and the community, by giving direction, creating linkages, building capacity and forging long-term relationships. The coach would

identify opportunities to adapt the support plan over time as circumstances ebb and flow and needs change. For this to work, 'case managers' need to have a reasonable workload so that they are able to spend the time to come to know and understand each person's circumstances and deal with issues in a proactive, timely way. They also need to be confident (and supported) in their role as advocate for their clients.

## **Partnerships and innovation for housing solutions**

Whether it's in a nursing home, a group home, or an individual dwelling, there is little more important to a person's well-being than having a place to live that they can happily call home. There are many examples of people with disabilities being stuck in inappropriate 'placements' rather than being in 'their home' – including being warehoused in an acute care bed for lack of a community-based alternative, being assigned to a bed in a nursing home because it was an available solution, not the right one; or not being able to move out of the parent's home because no independent living arrangement has been organized. When housing needs become a crisis, invariably the solution is very expensive for government, and very poor for a person's quality of life. Innovative, creative solutions are lacking. Government needs to learn to trust the client and welcome new ideas about housing options and how to develop them. Families often have great ideas about what would work -- government needs the flexibility and trust to try new approaches. Families don't expect government to do it all. They want to be involved in creating solutions, and see government policy and inflexibility as roadblocks to creating the solutions they need.

## **Acknowledge differences & include everyone**

People with disabilities, and people aging into disabilities, are not homogenous groups. They come from different cultures, different ethnicities. They speak different languages. They have differing sexual orientations. Some have secure financial and social supports; others spend much of their time living on the streets. Some were born with

their disability; some acquired it later in life. They live in all parts of the province, and some communities may have fewer options (home, community and facility-based) than others.

There are many factors to consider in understanding potential barriers to service access and social inclusion by people with disabilities. Cultural attitudes and beliefs about disability, aging, and caregiving may prevent people from seeking support. Francophone and Acadian people sometimes are placed in predominantly English facilities, and the resulting language barrier can lead to social isolation. Aboriginal people may experience social disconnection or cultural trauma due to well-documented historical policy injustices. African Nova Scotians and other visible minorities have experienced racism and discrimination in long term care facilities and group homes. Seniors who are lesbian, gay, bisexual or transgender (LGBT) may not feel safe being 'out' in a long term care facility.

**Personal stories:**

- My father and my aunt are hearing and speech impaired and we're an immigrant family. They also lack English skills. The dynamic in our culture is that disability is equated with shameful things. So, my father and aunt try to hide their disabilities. My father doesn't wear hearing aids, so he can't connect with this boss and others on the job, he gets frustrated even though he's a talented chef. He loses jobs, has to go back in front of IA/EI folks and they think he just can't keep a job. It's sometimes tough with an invisible disability. Cultural piece can complicate the disability.
- We don't have a group home in our community, it's a French area. So we take people out of their homes and communities and put them in a totally different place where they have to adapt to new people and culture. It's sad.
- We need more workers who can work here, in their own community, in their own language. This could also help us to keep our young people in our communities, with good jobs.

We're going to need so much support for all these seniors, and wouldn't be great if we could get our young people to see that these are good careers that will help them stay in their own communities.

## **Acquired Brain Injury requires tailored approach to programs and treatment**

There is a general lack of understanding about acquired brain injury and too few supports for the unique needs of that group. Too often, they are offered supports meant for people with intellectual disabilities or mental health issues, which do not reflect their realities and are a poor fit. In fact, the whole approach, philosophy and goals of programs for people with acquired brain injuries is fundamentally different than for those with other types of disability. This must be reflected in how programs are planned, how services are delivered and how care providers are trained and prepared for their roles. Typically, the health care system is highly responsive in treating the patient for the trauma that caused their brain injury, but once the acute phase of treatment is over, sometimes extending through to the beginning of rehabilitation, the individual and their family are largely left to fend for themselves to find the services they need.

### **Personal Stories:**

- They need competent people who understand brain injuries. Need your home care worker to support how you need it to be, not how they want it to be. In order to get services, I had to bring up other issues. I have a brain injury, and physical issues, but home care only seems to focus on the physical.

## **Aboriginal People face additional issues**

First Nations people living on-reserve can be additionally challenged by often complicated policies about which level of government (federal or provincial) is responsible for paying for a service. This has led to significant gaps in program coverage, and different levels of support being available to these residents of Nova Scotia. It has sometimes shifted the burden of caring for the elderly and people with disabilities to the Band level, which is neither appropriate nor sustainable.

There are examples of what can work well. Significant improvement has been seen with regard to access to provincial Continuing Care services through the work of the Aboriginal Continuing Care Policy Forum, where representatives from First Nations communities, health policy organizations, and the provincial and federal governments, meet to identify and resolve policy issues.

## **The further from Halifax, the fewer the supports**

Although there are gaps in service in the large urban centres for people with and aging into disability, there are even fewer options (home, community and facility-based) for people who live in rural areas. This is made worse by a lack of transportation services.

## **Support the whole family**

In almost all cases, it isn't just the person with a disability who needs support. The whole family will be affected, either directly or indirectly. Some families feel getting supports from the SPD program leaves them vulnerable to judgment and unnecessary interference in their lives. When there are other children in a family, parents feel vulnerable with Child Protection. They need to protect their other children from aggression, and feel they end up living in a fishbowl. They risk losing one child in order to protect the others. Child protection workers need a better understanding of the challenges of special needs parenting.

Parents with intellectual disabilities could potentially successfully parent their kids if they had life-long support. Without such support, many of these parents feel that their only option is to surrender their children to care.

## **Home care & respite don't always give what people need**

Family and other caregivers often make huge personal, social and financial sacrifices to care for a loved one at home. Home Care and Respite services are critical supports. We heard that Home Care is often intrusive and is restricted by many policies, some of which seem to be inconsistently applied. Multiple workers coming into a home can be disruptive and unsettling for the client and family, who would be far more reassured by an established relationship with a small number of familiar providers.

Respite is a critical part of social inclusion; it means the parents can have their lives and the person with disability can have his/her life, too. But both Home Care and Respite workers can be difficult to find, train, and retain. The work can be challenging and doesn't pay well, so positions are often used as stepping stones to more appealing careers. A respite worker becomes an extension of the family, so finding a good match is difficult, and high turnover is disruptive and disheartening. Some families are frustrated that DCS can authorize the money for them to hire respite care, but can't help them find a worker. People don't know where or how to look. Families are tired, (which is why many ask for respite in the first place), but find the process of looking for help is more exhausting than the care they are providing to their family member. There is also a strong opinion that families should be able to decide what they will use their respite dollars for. It might be for quality recreation, someone to cook meals, someone to provide house cleaning...whatever it is, the families should be trusted to make the choice on how the dollars get spent, because they know best what they need.

We also heard that there should also be attention given to ensuring that recreation programming is inclusive for people with disabilities. If parents know their kids are involved in quality programming and that it is inclusive, then they will be able to relax and get the full value from their respite.

**Personal story:**

- Once high school's over, it's terrifying. There's nothing. They're graduating into nothing right now. It's one thing to have the quantity of years, but they need quality of life.

## **DCS and DHW staff need to work more closely together**

The two most significant government departments in providing services and supports for people with disabilities function as two solitudes, rarely collaborating unless over a matter of budget-driven debate. People are frustrated by the lack of collaboration which can result in unmet need, duplication of effort and long waits to figure out what services may be available. Program staff are also frustrated by the lack of mechanism to work effectively together, or even to understand the services offered by another area of government. There are also examples of a DCS client going to hospital for care and their worker not being allowed to accompany them because they are in the DHW jurisdiction. Some staff feel a lack of respect (and trust) in their dealings with other professions or the other department. Many staff have developed work-arounds, which are largely based on strong personal relationships with colleagues from the other department, but this is not always the case. Where informal mechanisms have been established to support collaboration, it is always to the benefit of client services and professional satisfaction. This way of working is a culture shift. People who deliver government services told us that collaboration needs to be a stated expectation from the highest levels, and will require commitment and change throughout the system.



### **Personal story:**

- Don't underestimate the upfront work that needs to be done. This is a big change in culture, if the bureaucracy doesn't buy it, it won't work. So much work to do to change attitudes.

## **Legislation needs a very big overhaul**

For all of us, making choices means taking risks in everyday life. But fear of liability and a desire to protect people from harm has led to layers of rules that result in the opposite of person-centred support. This, matched with a bias that professionals are more qualified than the person with a disability to make the right decisions about many aspects of daily living, has created the most debilitating handicap any person could have: it has taken away people's ability to make choices about how to live their own life.

Key pieces of legislation are the foundation to our outdated system and they need to be overhauled. The pieces of legislation most frequently mentioned by people in this process include the Homes for Special Care Act, the Occupational Health and Safety Act and the Fire Safety Act. Until they are addressed, real transformation of the system of support and care is impossible. Examples of how legislation entrenches the custodial, paternalistic approach to program offerings and service delivery are many, and were shared with exasperation from people with disabilities, family members, program staff and advocates alike. They combine to reflect a system that is managing and interfering in people's lives in ways in which other people would never tolerate.

Not all change has to wait for new legislation. Some people suggested that at times, all that is needed is an update to a policy, or a clarification about how a policy should be interpreted. It was also pointed out that two different staff people might interpret the same policy in different ways, resulting in different ways of responding to a client's needs. Sometimes, staff are reluctant to be too 'creative' because they are afraid that an audit of their program will look unfavourably on their actions. Support from management in defining policy boundaries so that there is maximum flexibility and consistency in interpretation is very important. So, too, is support from management for staff to work together, across departments, to find the best solutions and options.

**Personal story:**

- Government doesn't have these rules for everyone else. Clients in these settings can't leave toasters plugged in because of Fire Marshal regulations. They can't drive in a car with a coffee.

## **Invest limited public funds creatively – be transparent and honest**

There is widespread acknowledgement that Nova Scotia is not in a strong financial position, and that new money for programs and services will be scarce. Equally, there is general agreement that many opportunities exist to extend the reach of money already in the system – by being more innovative, less crisis oriented and investing upstream – before support systems fall apart. Having a person languish in a hospital bed because there is no community-based alternative is extraordinarily expensive and means poor quality of life for the individual. Increasing choice and giving more control to program clients and their families does not mean limitless spending and unchecked expectation. It does mean new accountabilities (for outcomes) and new ways of measuring success – with the quality of life of the person with disabilities at the fore.

**Personal stories:**

- Choice implies no limits. "Informed choice" is a better term. Informed choice requires transparency of policies and programs so that people understand what the choices are, and are confident that there is fairness and equity in how decisions are made.
- We invest obscene amounts of money keeping someone in a hospital while anguishing over the lack of money for affordable and appropriate housing. You could build several group homes for the price of a couple of years in a hospital bed, and the person would actually have quality of life.

## Moving forward, together

While our work focused on how the Department of Health and the Department of Community Services can work more effectively together in addressing the needs of people aging into disability, people with long-term mental health and addictions issues, and people with disabilities across the life-span, a wide range of issues that need attention were raised outside of this scope. The need for more safe and affordable housing clearly falls within the mandate of the Nova Scotia Housing Strategy. Many people stressed the need to address poverty for Nova Scotians in general, and for seniors and people with disabilities and their families in particular. In part, this is being addressed by the current realignment of income assistance programs. Vocational training and employment opportunities for people with disabilities is obviously linked closely with the hope for economic self-reliance and ultimate prosperity – and these issues are intertwined with government’s efforts to develop and nurture communities that are welcoming, supportive, prosperous and inclusive.

Through its SPD Transformation Initiative, DCS is currently developing a long-term strategic roadmap for transformation of its services for persons with disabilities, guided by the United Nations *Convention on the Rights of Persons with Disabilities (CRPD)*. Reducing reliance on institutions for the care of people with disabilities, and strengthening Nova Scotia’s commitment to social inclusion, are key focus points of that work. The input received on all of these areas during the *Putting People First* engagement sessions (APPENDIX A) will inform that transformative work.

What we heard is that a transformation of the way Nova Scotia supports seniors and people with disabilities, and people aging into disability, is urgent and very long overdue. Making this shift will require long-term vision, courage and commitment. It will demand collaboration within government and involving all community stakeholders. And it will take trust. The directions proposed in *Putting People First: Working Together to Support Independence and Dignity* – strengthened by what stakeholders told us are the areas to focus on – can lay a solid foundation for that work.

# Appendix A

Many people at the Putting People First engagement sessions shared concerns about issues outside the mandate of Putting People first – issues like affordable housing, transportation, poverty reduction, education, and income and employment support. These issues are no less important than the issues discussed in the main body of this report; indeed, addressing them is critical to the success of further transformation, particularly of services for persons with disabilities. Some of what we heard about those issues is shared in this Appendix. This information is being shared with the departments and programs responsible for them, to ensure the concerns are heard and addressed.

## Employment & Skills Training

### What We Heard:

- *I see a roadblock – what if we create some really effective programs to help people develop job skills, but because of the economy there aren't any jobs out there for people to go to? Are there some contracts or programs that could help with job creation for these skills, creating jobs for our kids and other people who don't have PhDs?*
- *It's not just about creating work placement opportunities, it's about creating a better more supportive and prosperous community for everyone.*
- *I have two adopted children, both mildly challenged, 17 and 24. There's a hole in the system for kids with minor challenges. My daughter and son can do work, but if an employer has so many to choose from with so many people looking for work, and they can pick someone who is well-trained and not disabled, they'll take them. Used to be better when they could do farm labour, things like that. Those opportunities aren't there anymore. Technology has shot us in the foot, taken away many opportunities. I too lie awake at night wondering what will happen to them. My goal is that my daughter can support herself and be happy. My son is 24, hasn't had much to do, has lost his motivation, employers can see that.*

*I wish I or someone who knows him, like a job coach, could go on interviews with him to help explain his strengths and skills, because a lot of our kids aren't good at doing that. I know these kids are very valuable parts of the community, but have to be given extra time. In this economy, people don't want to do that.*

- *There are some places like McDonalds and Subway that are crying for employees. The government gives money to train and employ immigrants, why don't we invest in our own children? Just a modest investment to give us a boost.*
- *We've attended quite a few employment conferences; most employers who do take on someone with a disability find they get an employee who is loyal and serious and will stay on much longer than other employees. It does take support, sometimes two or three months.*
- *We should be our own advocates. We know what we need. Check in with us every few months to give us feedback and advice. Follow-up is key. Anyone on assistance just gets cut off instead of giving them time to develop skills and independence.*
- *Maybe have jobs for those who can work or want to try and work full or part time or as available, like me. I can only work between 8:30 and 2:00 because that's when she is at school, but the school might call and I have to go and she might be sick for 2-3 weeks and off for the summer. With little or no help, I can't work in a situation like this because there are no jobs out there that are that flexible. So I get no retirement built up, and I don't want to have to collect bottles and cans like a lot of people I see. That is truly a sad sight that people have to live like that to make ends meet.*
- *If I do find a job, then I have to worry about parking, transportation, door openers, and bathroom obstacles. Always have to ask, "What obstacles will I face today?" It's demeaning. Can't do even the simplest thing, everything becomes so much more difficult. Able-bodied people don't get it.*
- *Some disabilities are invisible, employers don't understand.*

## Income Security/ESIA

### What We Heard:

- *If someone loses a job, they can go to DCS and apply for income support. Their kids can play sports for free. Why is the same not true for people with disabilities?*
- *We live on social assistance and don't have any paid staff helping us. So we get \$1215 a month for both of us, not each of us. Our rent is \$675 and we have a 1-bedroom apartment and heat and lights are included. We pay about \$45 for cable and about \$50 for phone. That leaves us \$45 for groceries and taxis to get our groceries and for the co-pay for our medications and other personal things like toothpaste and deodorant, shampoo, razors, and so on. We've never been to the dentist. Social Services would pay half if we had to get a tooth out. Where would the other half come from? I have diabetes and high blood pressure. I can't possibly buy the healthy food I need like apples and oranges and grapes....*

## Inclusion Shouldn't End When High School Does

### What We Heard:

- *Why put children in school at all if there is nothing for them when they leave? School is a glorified babysitter. All the social skills are lost after age 21 – they are forced to leave their friends and live in isolation.*
- *Such a huge gap when children become adults.*
- *No funding to help people go to university, live independently. They see their friends go off and begin their lives, and they are stuck at home with nothing.*
- *People are required to manage all their funds, manage all the remittance to CRA, in addition to going to school.*

- *The right programs aren't in schools for our kids, anyway. Why are we spending the money on sending them to school, having TAs etc for them, if we leave them to waste when they leave?*
- *Need some kind of school, training, for kids after high school.*
- *Couldn't get an aide at school who was trained to understand how to work with a non-communicative child. Felt like he was being babysat – was capable of so much more. That's not inclusion.*
- *After graduation – need something meaningful for people to do. The school system knows how many people are coming through who will need support after graduation. Need to ensure we plan ahead for more spaces, more activities in community.*
- *This is the first generation to grow up with inclusion in schools. Then they graduate, and have to go on a wait list for ten years before they can find anything meaningful to do.*
- *Heard from parents going through school system...after graduation....there's nothing for that child....loses all social skills, everything invested and moves into isolation. That's tragic.*
- *For some, we transition them into a day program....in grades ten and eleven....by graduation, they're coming five days a week. Met a young lady who is thrilled to be part of that program. But these programs are not offered in all areas. We have to do more of this. Build capacity.*
- *Young disabled persons need to know their options. Just like the student going to university.*
- *Young people with disabilities in their homes, we do everything to ensure they are part of the community. It's sad to see parents working so hard, yet, when they turn 21, the choice is gone. You can't take care of your child at home, here's what you have to do. The choice is gone. If we are person focused, we need to focus on them before they turn 20....all of a sudden the focus changes. It's not what's best for the person or the family.*



## Affordable, Safe Housing

### What We Heard:

- *As a care provider, I see some heart-wrenching situations. Shacks in our community.....people living in unbelievable circumstances. People on Income Assistance forced to live in these situations. I see so many special needs people supporting deadbeat landlords, living in unsightly conditions. Need to interact in a social way. Housing and affordable housing is desperately needed. It's sad. This work lines up with the housing strategy consultations.*
- *We need low rent, wheelchair accessible housing right now in good clean neighbourhoods.*
- *Housing supports are crucial. I am a person living with a mental illness. I lived for several years in a small options home then in a supported apartment program. Gradually I found my way into the world of work and writing and make my living that way now, but I couldn't have thought of doing that if I was struggling along in an apartment that I couldn't afford. Appropriate housing for people with mental illness is crucial to their health and ability to move toward greater independence, as it is for all people. I am greatly appreciative of the support I was given during a very difficult time in my life, with something as basic as shelter and food, as well as the emotional and professional support of the live in roommate and counsellors.*
- *Opening up the vacant units under your housing portfolio to people with disabilities and for emergency housing would help your department greatly. With the current school closures pending there is an opportunity to develop these schools into long term care facilities, these buildings are in great shape and would require little modifications to turn into much needed beds. To sum this part up stop bailing out other housing departments and fix what you have that needs desperate repairs.*
- *Most people would prefer to age at home. Homes are not designed, or constructed with the idea of providing care to elderly. Changes to new construction, such as planning for possible grab bars, ceiling lifts..etc, is one avenue. Also retrofitting current homes.*



*Adequate infrastructure will facilitate optimal care and the ability to stay home longer.*

- *People with severe mental health issues have very limited access to suitable rental. Yes they are given a supplement to the rent from Community Services but it is almost impossible to find a rental for \$575 a month with all utilities included. They therefore have to live in dumps and with landlords that have no idea of the challenges faced by the consumer. This needs to change.*
- *We have some of the oldest housing stock in the province. Hope there is something in the Housing Strategy that helps us modify homes earlier, before people really need them, so that when someone does need to go in hospital they have a house ready for them to return to.*
- *Apartments with elevators are too expensive. ESIA doesn't pay enough to live adequately with what we need.*

## **Transportation**

### **What We Heard:**

- *The lack of transportation is key for anyone with a disability. There was mention in the Continuing Care Strategy that a transportation strategy would be developed. Where is that?*
- *There needs to be Community Transit solutions as, no matter what services are being offered in communities, access is key. Community Transit solutions offer independence longer.*
- *There is an accessible van, two of them, for the whole (Cumberland) county. Drivers are trained to take people with disabilities, we take seniors to medical appointments, the drivers are very capable. We'll soon have three vans, one bus. Call 24 or 48 hours ahead to reserve, we'll be there. It's a success story, the community did this, it's been around five years. This is an example of what the community is able to do together. That's why we're frustrated; we think we should be able to solve these other problems by working together with DCS. We've got good people and can pull it off, but we need support from DCS to pull it off.*

- *Transportation funds are available through DCS to help someone living at home to travel to work.*
- *If you don't have services in the community, you don't have choice.*

