

## **Choice, Equality and Community Homes – NOW.**

### **A Report on The Adequacy of Residential Options for Persons with Developmental Disabilities and Autism Who Are Preparing to Move to the Community.**

Presented by Community Homes Action Group (CHAG) to the Ministry of Community Services Standing Committee, Nova Scotia, October 4, 2016.

***“Housing is one of the most fundamental needs for Nova Scotians. Our homes shape nearly every aspect of our lives, from health, educational achievement, success in the workplace, the security of our retirement, to our dignity in old age”. (1)***

Madam Chair, Standing Committee members and other Nova Scotians present. Thank you for the opportunity to present our concerns about the adequacy of appropriate residential options for our fellow citizens who live with developmental disabilities and Autism Spectrum Disorder.

Developmental disabilities or intellectual disabilities are equivalent terms used to determine “a range of conditions in which lifelong limitations in intellectual functioning and in conceptual, social, and practical skills (i.e. adaptive functioning) are noticeable before age 18 years”. (from “Tools for the Primary Care of People with Developmental Disabilities” by the Developmental Disabilities Primary Care Initiative).

(This ‘tool book’ is under revision and will be republished with the 3<sup>rd</sup> rendition of Guidelines for Primary Care of Adults with Developmental Disabilities in early 2017 and circulated with a special issue of the journal, “Canadian Family Physician” to over 35000 readers in Canada. Three members of CHAG are among the authors of this work.)

“Autism Spectrum Disorder is a neurodevelopmental condition underpinned by recognizable anatomic and functional neurological differences. It is characterized by difficulties in social interaction and communication and by rigid or repetitive behaviours, typically manifested early in development and usually apparent by 3 years of age.” (from “Tools for the Primary Care of People with Developmental Disabilities”, under Health Watch Table - Autism Spectrum Disorder”).

### **Community Homes Action Group**

Community Homes Action Group or “CHAG” is a voluntary group of health care professionals, academics, concerned citizens, parents and advocates formed in 2009 to draw attention to the crisis in residential options for persons with developmental disabilities and to work with the provincial government to find solutions.

We comprise a Bakers Dozen of three successful politicians, two physicians with focused practice on Developmental Disabilities, two PhD scientists in clinical and educational Psychology, a social worker with full-time responsibilities to children and youth with

Developmental Disabilities, a university teacher of Physiotherapy, a university teacher and academic administrator of Business, an evaluation specialist in health services, a senior administrator of a provincial advocacy association for persons and families living with Developmental Disabilities, and an executive director of an advocacy, not-for-profit organization in independent living.

Eight of us have direct experience in having a family member with a Developmental Disability or Autism Spectrum Disorder.

### **Standing Committee & CHAG Meetings**

When we first presented our concerns to this committee in 2011, over 1500 people were living in large care facilities. There were no community-based services for persons with complex health and behavioral needs. A moratorium had been placed on the creation of new small option homes in the 1990s and the waitlists for all residential services had grown to over 1000 people. There was no flexibility in funding to allow for people to engage in self-directed care and to exercise choice and control. The human and financial costs of being housed inappropriately was skyrocketing

We met several times with the Minister of Community Services and with staff within her department to discuss the urgency of the situation for our most vulnerable citizens. We held demonstrations. We wrote op-ed pieces. We met with MLAs and with the Premier.

In 2013, we were pleased to see the Government set up a joint government/community advisory committee - guided by the United Nations Convention on the Rights of Persons with Disabilities - to create a Roadmap to transform services for Nova Scotians with disabilities. The committee, which included government reps, service providers and members of the disability community, set goals, made recommendations and created time lines for action. Two CHAG members took part in the Roadmap process. The committee report *Choice Equality and Good Lives in Inclusive Communities, A Roadmap for Transforming the Nova Scotia Services to Persons with Disabilities Program* was adopted and released by the Department of Community Services, August 29, 2013.

The Roadmap put forward three key goals:

- greater self-direction, choice and control by people with disabilities and their families
- a modernized delivery system of supports and services to advance social and economic inclusion
- increased capacity and involvement of generic community systems in enabling legislation.

Ten recommendations were laid out to assist in achieving these key goals (see appendix 1).

A five-year plan, with timelines and outcomes, outlined where we all needed to go and how we would get there.

The community was delighted and hopeful that real change was going to happen.

No one was happy when the 5 year plan became a 10 year plan – almost before the ink had dried. However, CHAG was reluctantly prepared to accept the rationale that more internal foundation building was required at the outset.

A year and a half and a change of government later, CHAG presented again to this committee in February 2014 to talk about the importance of the Roadmap and the need to move forward more quickly.

People were again feeling frustrated at the lack of action.

At that meeting, we were heartened by your committee's interest. We heard from your members that you too were dealing with families in your constituency offices desperate for assistance and frustrated by lack of action for their loved ones.

And here we are again three years later. What progress has occurred for people living with developmental disabilities and their loved ones?  
What changes have occurred 'on the ground' for individuals?

We're here to tell you what we are seeing – and not seeing, from the community's perspective. Sadly, we have to report that we have still seen very little change on the ground for individuals.

#### **A Snapshot of where we are.....**

- Still over 1000 people are living in large scale facilities.
- Waitlists continue over 1000.
- Insufficient emergency care for persons with disabilities in most communities.
- Aging parents continue to anguish about the future of their vulnerable offspring still living at home.

#### **Consultations: What we Heard**

Over the last weeks we have met with others from People First, Autism Nova Scotia, the Nova Scotia Residential Agencies Association, and Dalhousie Assessment Clinic for Adults with Developmental Disabilities.

and we heard how things were from their perspectives. We invited suggestions for improving services and comments on the report card survey project.

We heard about a 10 day program led by Michael Kendrick and two colleagues from Ireland and Australia which was attended by 25 senior administrative leaders in Nova Scotia's programs and 5 MCS staff (we are interested in knowing which staff members were selected and how they were chosen). The workshops engaged several client families for discussion and practice learning by participants. His message was reported as "lack of

funding is no excuse”, rather than “thinking outside the box” Kendrick indicated that there was “no box in his world” and he encouraged participants to “aim for supporting one person at a time”.

We heard there was a need for staff development training, particularly for executive level and administrative leaders and for board members.

There were requests for more values-related training for all staff; new hires, existing employees and NSCC program students... particularly mentioned was emphasis on values which several experienced as Social Role Valorization, which hasn’t happened in NS for twenty years.

Core training is needed for providers of services to increasingly complex care clients.

Some wonder whether DCS leaders and the hired consultants for the transformation roadmap plan had sufficient front line experience.

Concerns exist about the lack of succession planning for senior administrative and CEO positions. “there’s a lot of gray hair”.

We were told we, and those directing policy, needed to know that some of the ‘institutionalized” were persons with mental illness or with a disability that was not a developmental disability or Autism.

We heard that nothing would change while the “Homes for Special Care Act” and the “Income Assistance Act”, described as old and inappropriate, remain unchanged. These acts drive the accountability framework for regional agencies. Too often the quality of service is measured by such things as “how many electrical outlets are there?” or “are two clean towels available every day?”, when these are not appropriate service quality measurements.

We were encouraged to be alert to the “aging out” process whereby a youth who reached adulthood only to be moved out from a happy placement in a group home was required to move into a locked unit for adults, and was exposed to unhealthy behaviours, experienced unhappiness, which might take a year or more to turn around.

Many families see a loved one move from cradle to grave without ever having seen a care coordinator. Many haven’t seen a caseworker or had an assessment in over five years.

Information about persons under consideration for a move was frequently outdated and not comprehensive (with “great potential for serious human harm”).

Families afraid of losing resources or waiting list ranking have held back information with great risk to their loved one or his/her residential mates.

And sadly, we heard again, “decisions are frequently made according to what services/resources are available as opposed to what the client needs.

Very recently we learned of the “National Housing Strategy”, a collaboration of federal, provincial and territorial partners, receiving an invitation from the President and CEO of Housing Nova Scotia, Dan McDougall, to participate in a survey on October 21, 2016. His letter provided the quote beginning this report.

“Housing is one of the most fundamental needs for Nova Scotians. Our homes shape nearly every aspect of our lives, from health, educational achievement, success in the workplace, the security of our retirement, to our dignity in old age.”

Let us incorporate this fundamental value into our discussion today.

We would compliment the Province on some things: of course there are lots of committees struck (an expected necessity in new administrative initiatives). There has been a lot of internal work accomplished. There are more streamlined waitlists; improved communications with a newsletter and effective public presentations across the province. DCS has been conducting first voice consultations in their efforts to ‘drill down’ on what community means and how its needs are determined. We commend the Department for their efforts at building these steps toward a foundation for action.

However, our message is... We need to start building the structure, and increasing the number of real community living choices for our fellow citizens and family members with disabilities.

## **CHAG Report Card 2015**

Last fall, Community Homes Action Group (CHAG) sent out a province-wide survey asking folks - families, self advocates, social services professionals, service deliverers to try to assess what progress had been made on the Roadmap recommendations. What did it really look like for people living with developmental disabilities, their loved ones and service deliverers - 2 years later? We asked five questions to gauge what progress had been made on **five key areas** called for in the Roadmap; self-directed planning, community-based housing options, reduction of reliance on institutions as housing options for persons with disabilities, community employment and reduction of waitlists and gridlock.

The survey sampling was conducted during September and October of 2015. The results were very discouraging. The Report Card, derived from the information collected, indicated dissatisfaction with the pace of change. The respondents gave the government failing grades in all five areas.

1. 79% said the government had shown poor progress on person-directed planning.

*"We don't see where people have choices that are not Gov't forced or mandated. If people had choices, they would not live in institutions."*

2. 90% said the government had shown poor progress on providing community-based housing.

*"There are not enough supports for families to create flexible solutions that meet their adult dependents' needs. The system needs to be changed more efficiently and with a shorter timeline...there are too many people in crisis."*

3. 85% said the government had shown poor progress on reducing reliance on Institutions.

*"...it is fine to write reports but it is not matched with DCS walking the road and taking real action towards achieving the end of this model in Nova Scotia. As long as these institutions are seen as being the main provider of good, well-paying jobs in certain areas it will be very difficult to eliminate them without clear will of government."*

4. 82% said the government had shown poor progress on increasing employment opportunities.

*"I am deeply disappointed that the government seems to have decided to abandon the roadmap. It is very concerning that they now speak of only providing help in finding jobs in the community for people who are 'employable'. Who decides who is employable? The starting point should be that every individual is employable and has something to contribute."*

5. 86% said the government had shown poor progress on decreasing waitlists

*"To my knowledge nothing has been done to decrease waitlists. My son has been on the waitlist for 20 years. How can this be?"*

*"My son attempted to kill himself last night and I am so frustrated and angry and sad. I feel like we are disposable."*

*"My son died while waiting for appropriate care."*

The sense of hope about the Roadmap in 2013 had dissipated and the despair had become palpable.

*"It is sad indeed, when NS was actually a leader in the area of closing children's institutions in our province to where we are today even after DCS spending has increased so dramatically. We are fighting the same battle as parents 20 & 30 years ago. We know the harm, neglect and abuse that individuals have endured living in institutions--this is no longer an argument. It is not difficult to support an individual to live a good life in their community. The fact that*

*we have not moved forward with the Roadmap, in this day & age, with the UN Convention and the Charter of Rights and Freedom, is simply beyond comprehension.”*

CHAG is conducting the survey and Report Card again this fall and hopes to reach many more people. But the message is clear – we need to see real actions – more community capacity, person-directed planning and support – now.

## **Ontario’s Experience**

We are constantly aware of how other provinces face the same challenges as our own. Ontario, our largest sister province, has made substantial investment in revising its programs directed at persons with developmental disabilities. Earlier this year an international visitor commended its HealthCare Assessment Research in Developmental Disabilities (HCARDD) project in which health care utilization data have profiled, more accurately than ever before, the use of health care resources by persons with developmental disabilities. The expert opined that it was a world leader. The leader of the HCARDD project, Dr. Yona Lunskey, visited here three years ago and spoke about the use of emergency rooms by persons with developmental disabilities.

However, apparently having a good data retrieval is not enough. We want to draw your attention to the latest Ontario Ombudsman Report because it is germane to the situation we face here as well.

The Ontario Ombudsman, Paul Dubé, released his disturbing report, Nowhere to Turn, this past August. In his report, the Ombudsman called for sweeping overhaul of Ontario’s systems for supporting adults with developmental disabilities.

He stated, “Ontario’s systemic failure to help desperate families who are unable to care for loved ones with developmental disabilities has left vulnerable people in dire and often dangerous circumstances.”

The Ombudsman’s office reviewed over 1,400 complaints it had received (now over 1,500), conducted 221 interviews, and made 60 recommendations about abuse and abandonment of persons with developmental disabilities; inappropriate placements in hospitals, homeless shelters, nursing homes and jails; people with medically-complex cases; vacancies in residential facilities; and the need for consistent case management and prompt response to crises.

The Ombudsman’s office also reviewed the egregious reports from two inquests: one into the death of a 38-year-old man who drowned in a cistern while placed with an alternate family; and the other into the death of a 41-year-old man found weighing 57 pounds, and suffering from pneumonia, starvation and infected bedsores while in the “care” of his brother, now serving 20 years for manslaughter.

The report highlights 18 other stories including...

- Tommy from Toronto Region, who had been in hospital repeatedly, not for medical reasons, including a 73-day stint at \$2,000/day;
- Patrick, from Eastern Ontario, placed in a nursing home at 24, using a wheelchair because of Cerebral Palsy, whose chair was taken from him because he accidentally broke the ankle of a frail woman and who was himself sexually assaulted by his 75-year-old room-mate with a history of sexual abuse.
- Cindy, 41, also from Eastern Ontario, who was close to homeless when her elderly aunt could not care for her and who had “inherited” her from Cindy’s mother and uncle when they died.

These stories could have happened here. We have heard stories like them from our own media. Our Ombudsman’s office would find the same results should it undertake an investigation like Paul Dubé’s in Ontario. We hope that doesn’t have to happen in Nova Scotia.

The Ontario government has made a commitment to implement all of the Ombudsman’s 60 recommendations, including the 60<sup>th</sup> which requires the government report back on its progress every six months.

Already, through the direct intervention of the Ombudsman, a number of the most-urgent cases have been resolved through appropriate community placements and resources, and some new programs, with long waitlists, are offering flexibility in supports for individuals and their families.

The Ontario Ombudsmen Report brings home the importance of one of the key Recommendations in our Roadmap –the need for a Comprehensive Community-based Network of Specialized Supports. To make living in community an option for some people, we need to develop 24 hour teams in community to deal with folks BEFORE they have problems.

To date, this Recommendation has not been acted upon.

### **Health Sector Experiences**

Dr. Karen McNeil, the senior Physician at the Dalhousie Family Medicine Clinic for Adults with Development Disabilities sees daily the hardships families are facing caring for their loved ones.

“Parents of adult children with behaviors that challenge are tired; tired of advocating, coping and seeking solutions for problems that even the most experienced clinicians find daunting. There is an urgent need for behavioral supports in the community for these families in a seamless program that spans the life cycle.”

Dr. McNeil goes on to say “If we calculated the costs of such programs and compared them with the accumulated costs of: two- in- one support in group homes and institutions, one-



on-one support in schools, medications, replacement of property, inappropriate use of Emergency Rooms, the use of police and justice services, managing injuries to family and support workers, removing parents from the workforce to provide necessary care and never facilitating persons with disabilities to work for pay, then we could show that a community based behavior program over a lifespan would prove to be cost effective and likely cost-saving.”

Dr. McNeil is currently on study leave in Lima Peru, visiting R. Liliana Mayo at the Centro Ann Sullivan Del Peru clinic and school. Their philosophy is that every child and adult with different abilities can learn. Their clientele comprise persons aged 2-62 and there is no age limit. They have an outreach program that trains families to teach their children and to teach other mothers.

### **Institutions Prevail**

Another key recommendation in the Roadmap is the reduced reliance on larger residential facilities (i.e. Adult Rehabilitation Centres (ARCS), Regional Rehabilitation Centres (RRCS) and Residential Care Facilities (RCFS) in concurrence with the development of necessary community-based alternatives.

What has Nova Scotia done? The government has put a moratorium on new entries to ARCS and RRCS as of June 2015. This is a start, although the use of a placement time limit of three years does not promise a quick moving process.

Work has been done on accessing the readiness of clients to move into the community. So far, it appears as many as 300 folks are ready to move. Again, a start. If there were only 300 appropriate places for them to call home!

The 25 individual placements for which the \$2.2 M granted this year was to be spent, have not yet happened although we understand that the individuals have been selected. In meeting recently with over twenty six executives and senior administrators of group homes and small option homes, we heard questions about these assignments, most particularly about how the formula of \$2.2m for 25 places came about, because most of them felt it was insufficient. With over 1000 people living in large scale facilities, “25” is a very small proportion, it is one out of forty. At this rate, there will be many folks who will not get out into the community, ever.

And there was no guarantee within this year’s budget that that level of investment would be ongoing. We have yet to hear any assurance there will be any more.

We sometimes hear the argument that some people don’t want to move out of these facilities – that that’s their home. Certainly, families who cared for a loved one for many years in home and after years of waiting for a place, finally had a place made available, will experience a reduced stress. We have also heard parents express a hope that their loved one with a disability doesn’t outlive them... because they would not know how they’d be looked after.

## **No Real Choices... Yet**

The Roadmap is predicated on creating community alternatives that can be seen and visited in order to give people choices... but if the capacity for real alternatives in the community doesn't exist, there is no real choice being offered.

"Government needs to make a commitment to long term sustainable funding for a variety of community based residential options."

"Until we start seeing real community living alternatives being offered to persons with disabilities on Briar Island, in Cape Breton, Rawdon, Dartmouth, when we start seeing people being able to live in the community and see the community involved in making it work, that's when progress can be said to be taking place!"

There are a series of more provincial consultations planned by DSP staff. It is important that the Department is asking for such input, continuously,

But until we start creating community, really rolling up our sleeves, bringing service deliverers with great track records into creating good community options; talking with and listening to individuals and parents who want to try their own options; continuing to engage the extensive expertise of service deliverers and the administrative know-how of department administrators; and receive real and continuing government financial commitment on the table, the frustration will continue.

The Roadmap Document and the United Nations Convention on the Rights of Persons with Disabilities (NCRPD) will be just more empty verbiage... left in an unopened file in a government office.

In summary, the Roadmap recognized the challenges ahead. It acknowledged that transformation of the DSP program would take visionary leadership, steadfast commitment and resolute determination over a four-to-five year period (pg. 51).

It called for using the fiscal year 2013-2014 to develop shared government-community commitment and leadership and detailed implementation plans, time-frames, and actionable steps that would begin major roll-out in 2014-15. It is now nearly 2017 and no major roll-out is evident.

The Roadmap stated "we are fully aware that our proposed Roadmap for change will require substantial investment beginning in 2014-15. We see this as a transformative investment that will lead to the creation of a sustainable cost-effective system of supports." (p. 51)

## **Call to Action**

We, Community Homes Action Group, are here to urge the provincial government to honor the Rights of Persons with disabilities as outlined in the UN Convention on the Rights of Persons with Disabilities and determine that the recommendations in our 2016 report card are fulfilled. Most fundamental is the assurance of a continued, substantive investment necessary to increase community living capacity and fulfill the promises made to Nova Scotians with disabilities and their families.

Thank you for your attention.

Community Homes Action Group

This report card reflects that there has been little to no change to date in these areas:

- Providing person-directed planning and decision-making
- Providing community-based housing options
- Reducing reliance on institutions
- Increasing employment opportunities
- Decreasing waitlists.

Persons with developmental disabilities require appropriate housing and supports. With them stand family members and service providers with expectations of the Transformation process.

**CHAG, on behalf of those responding to this survey, asks the provincial government to honour the Rights of persons with disabilities as outlined in the UN Convention on the Rights of Persons with Disabilities. We ask the provincial government to:**

- Commit to person-directed planning and support, create community based living options, close institutions, increase employment and reduce waitlists.
- Work with families and service providers across the province to create small community-based housing options.
- Commit to stopping new placements to ARCs or RRCs as of June, 2016 as outlined in Community Services' 10-year Plan for Transformation.
- Begin work to reform all disability-related legislation in accordance with the UN Convention on the Rights of Persons with Disabilities.
- Report regularly to the community on the number of people with developmental disabilities on waitlists for housing options and provide updates on the progress in creating new housing opportunities.
- Provide substantive investment to fulfill the promises made to Nova Scotians with Disabilities and those involved in their lives.

For a full report of this study, please go to [nsacl.wordpress.com](http://nsacl.wordpress.com)

CHAG encourages you to send your comments to Minister Joanne Bernard:  
Department of Community Services, 8th Floor, Nelson Place,  
5675 Spring Garden Road, P.O. Box 696,  
Halifax, Nova Scotia, B3J 2T7

Phone: 1-877-424-1177 ; Fax: (902) 424-3287, [DCSMIN@novascotia.ca](mailto:DCSMIN@novascotia.ca)

# REPORT CARD 2015

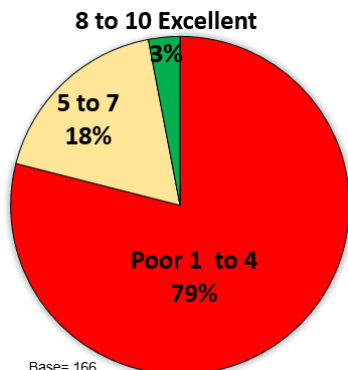
## Evaluation Results on the Government of Nova Scotia “Transforming Services for Nova Scotians With Disabilities”

Prepared by  
Community Homes  
Action Group (CHAG)

In 2013, the government of Nova Scotia, through a joint government-community advisory committee, created a Roadmap to transform services for Nova Scotians with disabilities. The committee, which included government representatives, service providers and members of the disability community, set goals and made recommendations. The resulting Roadmap has informed the Disability Support Program transformation currently underway.

CHAG has carefully monitored the Roadmap's implementation, and this year conducted a province-wide survey to find out what other Nova Scotians think; 168 people from across the province responded and provided close to 1,000 comments. The survey gave people in the community the opportunity to evaluate the provincial government's progress in meeting the key goals of the Roadmap. The key findings are:

### 79 % said Poor Progress on Person-Directed Planning

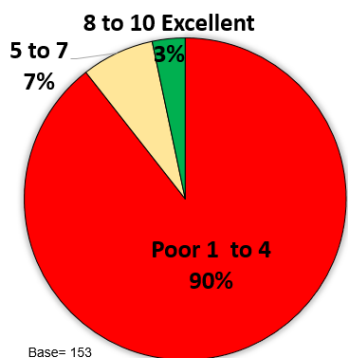


"We don't see where people have choices that are not government-forced or mandated. If people had choices they would not live in institutions."

"Government must stop funding buildings where people are put and start investing in people."

"When a personal development plan has been developed by a person with a disability, DCS will challenge it."

### 90% said Poor Progress on Providing Community-Based Housing



"I have a son, 28yrs old, still living at home. He has been on a waiting list for seven years but they tell us that there are too many others worse off on the list so it will be many more years. My son is depressed."

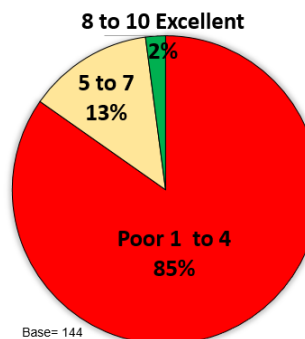
"There has been some movement with funding made available for the independent living support program. Otherwise new housing options have primarily been developed to address critical issues where the media/politics have been engaged."

"As a service provider, we submitted a cost-neutral proposal to the DCS to open a new 4-bed home with blended levels of support. All of the individuals wanted to live together despite their different need...in fact they would be each other's "natural support" in their own communities where they grew up and work. This proposal was rejected."

All questions were asked on a 10 point scale:  
1= Poor to 10= Excellent

The Community Homes Action Group (CHAG) consists of concerned citizens, health care professionals, parents and advocates who have come together to draw attention to the crisis in residential options for persons with developmental disabilities and to work with the provincial government to find solutions.

### 85% said Poor Progress on Reducing Reliance on Institutions

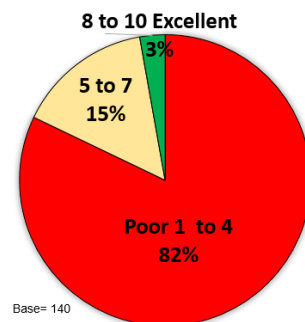


"One has only one choice by the time one comes to the end of their rope, so to speak. Put your young adult in an institution or suck it up, grinding both yourself and your child into the life of despair."

"The very few who manage to get out of institutions do so by embarrassing the government in media or taking them to court."

"There is no real reduction in the reliance on institutions. There is a lot of rhetoric, but no real progress."

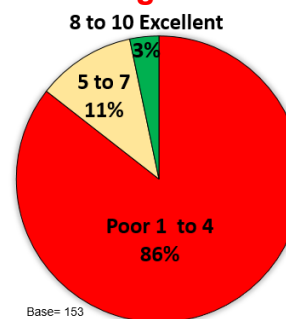
### 82% Poor Progress on Increasing Employment Opportunities



"I am deeply disappointed that the government seems to have decided to abandon the roadmap. It is very concerning that they now speak of only providing help in finding jobs in the community for people who are "employable". Who decides who is employable? The starting point should be that every individual is employable and has something to contribute."

"Parents have to create jobs. Beg for services."

### 86% said Poor Progress on Decreasing Waitlists



"My own son has been on the waitlist for 20 years. How can this be?"

"My son attempted to kill himself last night and I am so frustrated and angry and sad. I feel like we are disposable."

"Son died while waiting for appropriate care."

## Ten Recommendations of “Choice, Equality and good Lives in Inclusive Communities”

Page iv, v of the Roadmap, June 2013

1. Person-Directed Planning/Navigation
2. Individualized Personal Disability and Family Supports
3. Individualized Funding Mechanism
4. Equal recognition of Legal Capacity and Supported Decision Making
5. Reduced Reliance of ARCs, RRCs, and RCFs
6. Transformed community-Based residential Service System
7. Increased Access to Competitive Employment
8. Equal Access to Housing
9. Comprehensive Community-Based Networks of Specialized Supports
10. Coordinated and integrated Disability-Specific and Mainstream Community Services