

From Family Alliance Ontario—

AN OPEN MESSAGE TO THE GOVERNMENT OF ONTARIO

Dec. 6, 2006

No to ALL institutions!

Families in Ontario have recently discovered a policy document that reveals that the Ontario government is encouraging and facilitating the placement of people with disabilities, including young adults, in Long Term Care institutions.

Families are outraged. These are the same families that have praised the government in the past for its plans to close all of the remaining institutions for people with developmental disabilities. They are outraged because the government is expanding a practice that families have always opposed.

Long Term Care facilities are unfulfilling environments that are associated with a high incidence of neglect and abuse. They are totally unsuitable as a place for people to live their lives, especially for the most vulnerable people who need disability supports.

This document shares what families think, calls on the government to stop institutional placements, and to offer appropriate options that treat all citizens of Ontario with respect.

Introduction

The policy that we are addressing is called “*Long-Term Care Access Protocol for Adults with a Developmental Disability*”. It is dated July 2006. No self-advocates or families were consulted in the preparation of this document.

The policy claims to promote “*inclusion, independence and choice*”. As informed long-time advocates, we find that the policy and its intended outcomes are contrary to these values.

Indeed, even the notion of “placement”, as exemplified in this policy, is not consistent with these values. The use of the word “placement” reveals a mindset of treating people with disabilities as entities controlled by a system. The problem with “placement” reveals itself clearly in the way that people are forced to stay wherever they happen to be “placed”, and it is virtually impossible to get a change of one’s “placement” in Ontario today. We want a change in language and policy to offer people a range of good options to which they can respond with free and informed choice.

Long-term care (LTC) facilities are very bad and often dangerous environments for people with developmental disabilities. Self-advocates, as well as parents, siblings and friends know very well from experience what it takes to support a person with developmental disabilities. Good support requires circles of friends, personal relationships, respect, full inclusion, freedom, choice, and opportunities to participate in community. It requires consistent adherence to core values and principles. This kind of support and culture cannot be provided in institutional environments.

Even worse, institutional settings have a track record with an appalling incidence of neglect and abuse. To this day, there are no adequate checks and balances to prevent neglect and abuse, and the risks are unacceptable, especially for vulnerable people who may be unable to report their experiences.

We applaud the closing of the old government-operated institutions, but this policy makes no sense when LTC institutions (many of which are operated by for-profit multinational corporations) are equally bad or even worse models.

We oppose any policy that places people with developmental disabilities in LTC facilities. In the rare event that anyone might actually choose such an environment (over other options) with *free* and *informed* consent, *portability* is absolutely necessary. Individuals must be allowed to change their minds, choose another option, and move with their allocated funding, at any time, and to a place of their own choosing.

The Government's Defense Arguments

Here we address the key points in the justification of the policy raised in the policy document itself, as well as in statements from the Ministry of Community and Social Services.

“The protocol further affirms an established interministerial commitment towards inclusion and equal rights of adults with a developmental disability in accessing health services and admission into long-term care homes”.

“The protocol recognizes that older adults with a developmental disability have the same rights as all seniors in the community and should not face additional barriers to accessing a long-term care home placement if that is where they choose to move. This is consistent with the transformation’s commitment to more inclusive communities.”

The numerous emails that we have received express universal reactions of dismay, anger and outrage that institutional placements are being justified on the basis of inclusion and equal rights.

The promotion of institutions with an inclusion argument is inflammatory and not credible. The movement for inclusion is based on welcoming everyone into *valued* environments, promoting participation in *valued* roles, and treating everyone with equal respect.

Advocates for inclusion have asked for inclusion in classrooms, in the community, and in the workplace, but they have never asked for inclusion in institutions! We deplore that the ministries involved do not promote other options that *really* enable inclusion (including self-directed individualized funding) with equal force and equal funding.

The second quote only mentions “older adults” and “seniors”, but we are well aware that adults with disabilities of *all* ages are being forced to accept placement in long-term care facilities. It is very tragic, but true, that as a consequence of this policy, some 18-year-old persons with disabilities will face a lifetime in a nursing home.

“For eligibility into long-term care homes, the applicant would require 24/7 nursing care that is not provided within the community. The protocol supports the transition ... if that placement represents the most appropriate option for their support requirements.”

The key phrases in this argument are “*not provided in the community*” and “*most appropriate option*”. The two ministries concerned do not extend their best efforts to support people who require full-time care in the community and therefore there are no options to pursue. People with disabilities of all ages are forced into a long-term care model designed for frail seniors in their last years and months of life.

Ironically, while the requirement for 24/7 *nursing care* is used as the determinant, people in nursing homes receive a limited amount of time daily for personal care. In the experience of families, the amount of time is usually less than can be available in one’s own home, through attendant care. The Ministry of Health dropped the maximum care level in nursing homes down to 2.5 hours per day. The term “*nursing care*” actually refers to care provided by personal support workers under the direction of a registered nurse. In some cases, registered nurses are not even present on site.

Many people with developmental disabilities happen to require full time care. On becoming aware of the LTC protocol, many families now believe that the ominous possibility of institutionalization is more likely. There are young adults in their late teens, whom Community Care Access Centres are no longer willing to support as they reach adulthood. These young people have been advised that they must consent to being institutionalized in a nursing home when they finish school. There are also families who have experienced the circumstance in which the Ministry of Community and Social Services insisted that the only kind of support it would fund for them was a LTC facility.

For example, for 50 years, Jane (not her real name) was supported by her family to live and to participate in her community. Jane always required full-time supports. When her parents were no longer able to cope because of their health, the Ministry refused to grant funding that would have enabled Jane to continue living her life at home with her sister in the most natural and fulfilling environment. The parents were given no other option but to “consent” to the nursing home, despite the sister’s willingness to offer Jane a home given some funding to support Jane’s needs. Jane’s life is now bleak and isolated as she deteriorates in a government paid bed in a for-profit nursing home. But she never required 24/7 nursing care. The Ministry of Community and Social Services must review this case and offer the family good options and an opportunity to reverse the placement.

“The provision of long-term care supports such as 24/7 nursing care is not part of the Ministry of Community and Social Services mandate.”

Again, 24/7 nursing care is not the real issue. But more to the point, nursing homes cannot meet the more extensive needs of people with disabilities. The appropriate

response is not to place those people totally in the care of the Ministry of Health, but for the Ministry of Health to offer flexible care supports that would complement the supports provided by the Ministry of Community and Social Services. We call on the government to offer seamless access to supports to meet each individual's needs.

We don't approve the practice of forcing people into inappropriate settings because of shortcomings in a poorly designed system.

The protocol states that the transition of people into the LTC system “*will create Developmental Services capacity to accommodate residents moving from the DS facilities*”. This reveals that the Ministry of Community and Social Services intends to move residents away from their existing community group homes to free up spaces, passing the financial responsibility from itself to the Ministry of Health with a few top-up dollars. This illustrates clearly the way in which supports are compromised by inadequate fund transfers and collaboration between the two ministries.

All of the resources come from the same government (from the same taxpayers' pockets), so there should not be any benefit for either Ministry to unload people on the other. Silos with artificially conflicting interests are detrimental to everyone.

Ministry of Health services are based on the medical model (focused on ailments and treatments in isolation), whereas the evolving culture in the Ministry of Community and Social Services is based on more holistic supports that address people's broader needs. Given the extensive needs and vulnerability of people with developmental disabilities, we expect the Ministry of Health to collaborate in supporting people with developmental disabilities by transferring funds to the Ministry of Community and Social Services, rather than the other way around, to enable beneficial options. We also expect the Ministry of Community and Social Services not to unload its responsibilities onto the Ministry of Health.

“Client consent is a critical component...

If an individual/family/substitute does not consent to admission into a long-term care home, the planning process will continue and other options will be explored.”

This statement does not reflect the actual experience of most families. The typical experience is more like Jane's case above, i.e. a “take it or leave it” decision. Many families are coerced into accepting what they are told is the one and only possible option for supports.

Adults with disabilities must have access to supports that are consistent with the values of inclusion and citizenship. Everyone should have the option of having support resources applied to modes of support that have proven to be most effective in enabling people to have the most fulfilling lives. This requires that people be offered good options, including the option of self-directed individualized funding.

The notion of freedom of choice and informed consent also requires portability. People must be free to move. Often, people become truly informed about their support arrangements only after they've actually tried them out. They can change their minds. The resources for peoples' supports must follow their choice. The resources must not be tied to agencies or corporations.

Further remarks

The issues around inclusion, citizenship, choice, informed consent, etc. are obviously complicated. We have tried to draw attention to key aspects in true and concise statements.

Many details found in the protocol document and in the Ministry defense arguments, could have been addressed in this message, but that would take focus away from the main issues. The bottom line is simply that we will never accept institutions, and we call on the government of Ontario to listen to people with disabilities and their families.

Our concerns, arguments, and expectations also apply to the for-profit group homes in Ontario, as their service model shares most of the faults of the LTC institutional model.

It is clear to us that the Ministry of Community and Social Services must work more closely with self-advocates and families to adapt all of its policies and practices, in all the regions, to conform to the values and principles that it has announced in its blueprint for transformation.

As well, the Ministry of Health must work with us to transform some of its services into more flexible modes of support that are responsive to people with disabilities. We call on the Ministry of Community and Social Services to collaborate with us in this endeavour.

Required Actions

1. The Protocol:

The Ministry of Community and Social Services and the Ministry of Health and Long-Term Care must abolish their LTC Access Protocol because it encourages and facilitates the “placement” of people with disabilities in institutions, an outcome that we totally oppose.

2. Choice:

The Ministry of Community and Social Services must implement a practice of allowing people to choose the form of supports that they prefer. It must stop the practice of allocating funds preferentially to institutional or traditional models of service. It must stop passing responsibility to another ministry and instead work together with the Ministry of Health and Long Term Care to enable creative options in the community for all adults with high care needs.

3. Transformation:

The Ministry of Community and Social Services must start immediately to move in the direction that is defined in its blueprint for transformation. It must start taking immediate significant steps to change attitudes, policies and practices in its regional offices to promote effective support options consistent with inclusion, citizenship, free choice, and informed consent.

4. Corrective Action:

The Ministry of Community and Social Services, in response to requests from anyone currently placed in a LTC facility or for-profit group home, must review their case and arrange a transfer of funds to enable better options if a change is requested.

5. For-Profit Contracts:

The Ministry of Community and Social Services must collaborate with families and self-advocates in addressing serious concerns about LTC and for-profit group home “placements”. It must openly share statistical information about the number of people affected, the allocated funds, and other related data.

6. LTC Policy Review:

The Ministry of Health and Long-Term Care must invite the participation of people with disabilities and their families to review its policies relating to adapting health services and supports for people with disabilities.

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