



The Ontario Government's Betrayal of People with Developmental Disabilities

**A CRITIQUE OF THE MINISTRY OF COMMUNITY & SOCIAL SERVICES
AND MINISTRY OF HEALTH & LONG-TERM CARE**

***LONG-TERM CARE HOME ACCESS PROTOCOL FOR ADULTS WITH A
DEVELOPMENTAL DISABILITY***

© Patricia Spindel, Ed.D.

Revised - January, 2007

DOUBLESPEAK: The Ontario Government's Betrayal Of People With Developmental Disabilities

© Patricia Spindel, Ed.D.

**A CRITIQUE OF THE MINISTRY OF COMMUNITY &
SOCIAL SERVICES AND MINISTRY OF HEALTH
& LONG-TERM CARE**

**LONG-TERM CARE HOME ACCESS PROTOCOL
FOR ADULTS WITH A DEVELOPMENTAL
DISABILITY**

Revised – January, 2007

Contact: info@spindelconsulting.com

**No part of this document may be copied or redistributed without the
permission of the author.**

DOUBLESPEAK: THE ONTARIO GOVERNMENT'S BETRAYAL OF PEOPLE WITH DEVELOPMENTAL DISABILITIES

© Patricia Spindel, Ed.D.

October, 2006

“Deinstitutionalization can equate with citizenship only if it means freedom. If it means being shuffled around to another segregated place, that has nothing to do with being a citizen.”

(The late Patrick Worth, Self-Advocate Extraordinaire)

Doublespeak: A deliberate, calculated misuse of language.
(Lutz, 1990)

Preamble

“Deinstitutionalization can equate with citizenship only if it means freedom”. Prophetic words from the late Patrick Worth, a distinguished, long time self advocate for people with developmental disabilities. But what does it mean to the Ontario Liberal government?

The Ontario Liberal government, in July, 2006, issued a Long Term Care Access Protocol for placement of people with developmental disabilities in nursing homes and homes for the aged. This document, and the machinations behind it, may well go down in Ontario government history as an attempt at one of the most masterful betrayals of an entire movement and service system in Ontario history, all accomplished through the use of this movement’s own language – terms like inclusion and equal rights. Through this Protocol, the Ontario Liberal government has attempted to justify the institutionalization or re-institutionalization of people with developmental disabilities as a “deinstitutionalization” initiative. This is being justified by referring to nursing home placement of people as young as 18, as an “access” and “inclusion” issue, and redefining nursing homes as community placements¹.

This is exactly the kind of doublespeak that makes citizens distrust their governments. Doublespeak is a calculated misuse of language that “misleads, distorts reality, pretends to communicate, makes the bad seem good, avoids or shifts responsibility, makes the negative appear positive, creates a false verbal map of the world, limits, conceals,

¹ The Ministry of Health and Long Term Care’s own documents show that there are now 4127 people with a variety of disabilities, all under the age of 65, living in long term care facilities. A policy analyst with the MOHLTC confirms that at least 1600 of them are people with developmental disabilities (Age Cohorts of Persons With Disabilities in Long Term Care – Ministry of Health and Long Term Care, 2006).

corrupts and prevents thought, makes the unpleasant appear attractive or tolerable, creates incongruity between reality and what is said or not said.”²

Advocates in the developmental services system could, therefore, be forgiven for failing to see what was occurring before their very eyes³.

The release by the Ministries of Community & Social Services (MCSS) and Health and Long Term Care’s (MOHLC) document Long Term Care Home Access Protocol for Adults With a Developmental Disability (July, 2006) is an utter betrayal of people with developmental disabilities and their families. It completely undermines the community living philosophy and principles of citizenship, community integration and deinstitutionalization that have been the bedrock of developmental disability policy in Ontario for over 30 years.⁴

The History

Since the late 1960’s when exposes of horrendous conditions in Ontario’s institutions, then termed “hospital schools” for people with developmental disabilities, advocates had begun calling for their closure⁵. At the time, these facilities were operated by the Ministry of Health, and many believed that until they were transferred to a Ministry that would support community-based service options, there could never be any change. Dominated by the biomedical model of diagnosis and cure, “incurables” were subject to custodial care, and sometimes not even that. Institutions became dumping grounds for the people who medicine had failed, who doctors could not cure – frail, ill elderly people and people with a range of chronic disabilities.

People with psychiatric disabilities were placed, in large numbers, often directly out of mental institutions, or asylums as they were then called, in residential and nursing homes for special care or in domiciliary hostels. Frail or chronically ill older adults were forced

² Doublespeak is a word first coined by George Orwell in his book, *1984*. Please see: <http://www.damronplanet.com/doublespeak/whatisdoublespeak.htm>

³ Most advocates in the developmental disabilities movement had been invited to sit at “Partnership Tables” in order to provide input into the redesign or “transformation” of developmental services in Ontario, according to the Ministry of Community and Social Services. Most of these advocates were completely taken by surprise by the appearance of the Long Term Care Protocol and said that MCSS had never raised the issue with them, nor did they have any input into the creation of the document. Had they had the opportunity, all, including the Family Alliance Ontario and the Adult Protective Services Association of Ontario, would have objected, and have since objected. The Ontario Association for Community Living, the provincial representative of community service providers in this sector has called on the Ministry to withdraw the document.

⁴ The Hon. Madeleine Meilleur, Minister of Community & Social Services, appears to be the first MCSS Minister in 30 years to be unaware of this longstanding policy. She has told the Ontario legislature that this Protocol does not represent a change in policy.

⁵ At the time, 11,300 individuals with developmental disabilities were living in these “hospital schools”.

to accept chronic care hospital or nursing home placement in the absence of community-based residential and in-home supports. In some cases, they ended up in unregulated retirement homes.

People with developmental disabilities or dual diagnosis (psychiatric and developmental disability) were placed in hospital schools, later to become regional centers.

People with physical disabilities, like cerebral palsy, were also often institutionalized in these kinds of facilities. The result, in homes for special care and some institutions, was often a bad mix of people with mental health challenges, older chronically ill people, and younger people with physical and/or developmental disabilities living together. The tragedy was that in most cases none of these devalued groups of people were receiving the care, comfort, or support that they needed and deserved. Many were abandoned by their government and their society into what Baum termed “warehouses for death” (Baum, 1977).

Unfortunately, not much has changed for many of these groups in the past thirty years. The one bright light was in the developmental services system, where advocates fought hard for progressive changes. They achieved wave after wave of deinstitutionalization initiatives, and were instrumental in helping to create a range of community-based, nonprofit residential and support services. There was seldom enough funding, but in general, support and services continued to move in a progressive direction. Community living options became commonplace. Whether it was early learning, integration of the school system, community-based residential or employment services, or in-home support, the push was on for full community integration and inclusion. Fueled by Wolf Wolfensberger’s⁶ new, in 1972, philosophy of normalization, there was widespread recognition that segregation was a dehumanizing, isolating, and often cruel alternative to inclusion.

For many years, until the mental health system began to embrace the notion of psychosocial rehabilitation in the late 1980’s, developmental disability rights advocates and their counterparts in the independent living movement for people with physical disabilities were the only ones leading the charge for more humane, community-based alternatives and full citizenship rights.

The only group left behind was older adults. Suffering from the absence of a grounding philosophy that supported their dignity and human rights, and taken hostage by the medical model that viewed aging as a disease, older adults continued to be forced into institutions in large numbers because of an absence of community-based options. The push for something better for them was simply not there, until Concerned Friends of Ontario Citizens in Care Facilities first raised the issue in 1984. Criticizing the

⁶ For more on Dr. Wolfensberger’s theories of normalization and social role valorization, go to Lemay (1995)
http://www.seapr.ca/doc_pdf/Social%20Role%20Valorization%20Theory%20and%20the%20Principle%20of.pdf

substandard care in nursing homes, and challenging operators' rights to make a profit at the expense of care to older adults, they were met with significant resistance, and in some cases threats by the biomedical establishment, and those who benefited from the medical-industrial complex – doctors, nurses, commercial nursing home operators and their associations and lobby groups.⁷ All that Concerned Friends was able to achieve was changes to legislation, including a Resident's Bill of Rights⁸ enshrined in the Nursing Homes Act; mandatory reporting of abuse and neglect; public inspection reports; some degree of financial accountability; and the establishment of resident and family councils. None of these helped improve conditions in these facilities very much⁹, as subsequent newspaper exposes of conditions there showed (Welsh, M. (2003) Toronto Star; McKay, P. (2003) Ottawa Citizen - <http://www.healthcoalition.ca/mckay.pdf>).

As members of Concerned Friends' former Executive have freely admitted, without systemic changes, including the deinstitutionalization of nursing homes, and the establishment of a comprehensive range of staffed residential and in-home support services, there can never be any real change for frail or ill older adults in this province. Today, Ontario still has one of the highest rates of institutionalization of older adults in the industrialized world, and this may be the direct result of undue influence by the wealthy and powerful nursing home industry on provincial politicians and the Ministry of Health and Long Term Care bureaucracy¹⁰. (CTV Marketplace, March 20, 2001).

The Developmental Disabilities Movement Leads the Charge

Two reports, ordered by the Premier in the early 1970's in response to the increasing public outcry about the treatment of people with developmental disabilities¹¹ introduced

⁷ Arnold Relman, a Harvard professor, coined the term "medical industrial complex" to describe a "huge new industry that supplies health care services for profit" (Relman, October 23, 1980) <http://content.nejm.org/cgi/content/abstract/303/17/963>

⁸ Interestingly, the current Minister of Health, George Smitherman, is attempting to take credit for introducing a residents' Bill of Rights in current changes to long term care legislation, even though the Nursing Homes Act has contained a Residents' Bill of Rights since 1986.

⁹ Some long term advocates now believe that true long term care reform will not occur until there is election finance reform which would end the ability of the for-profit nursing home industry to make political campaign contributions and hold fundraisers for politicians. Since non-profits are unable to engage in this kind of activity by law, the for-profit industry has a distinct advantage when attempting to influence public policy. This has long been considered to create an uneven playing field in policy formation and may be the reason why one government after another has funded long term care institutions over more progressive and humane residential alternatives like supportive housing and group homes operated by non-profit organizations, or in-home care options or direct funding to families.

¹⁰ It has been documented over many years that nursing home officials and Ministry officials from Astrida Plorins formerly with the Nursing Home Inspection Branch of the Ministry and now VP Operations of Leisure World, to Vida Vaitonis, former Executive Director of the Ontario Nursing Home Association, and now a member of the Ministry of Health bureaucracy, that the nursing home industry and Ministry bureaucracy have had close associations.

¹¹ On March 5, 1971, Frederick Sanderson, a resident of the Rideau Regional Hospital in Smiths Falls, hanged himself. Walter Williston found the conditions in which this man had lived to be "deplorable",

systemic change. The first, known as the Williston Report, presented to the Hon. A.B.R. Lawrence, Minister of Health in 1971, “forever altered the custodial mode of caring for individuals with developmental disabilities in large, impersonal, and often inhumane institutions” (Spindel, 1989:3). The Williston Report recommended phasing down, as quickly as possible, the large hospital institutions.

In March of 1973, the Hon. Robert Welch, Provincial Secretary for Social Development, issued his report entitled Community Living for the Mentally Retarded in Ontario: A New Policy Focus. It outlined, in detail, the new policy direction of the provincial government, which would facilitate the transfer of individuals with developmental disabilities to the community. It included four recommendations:

“A special program of guardianship and protection should be provided for all mentally retarded adults in the community.

Economic incentives that discourage the employment of mentally retarded persons and that encourage the development and use of institutional programs rather than community services should be eliminated.

Appropriate residential facilities should be provided in the community to accommodate mentally retarded persons according to their individual needs.

Coordinating mechanisms should be established at both the local and the provincial levels to ensure that a wide range of services is available”. (Welch, March, 1973).

The Welch Report set the stage for the transfer, in 1974, of the hospital schools to the newly minted Ministry of Community and Social Services, and the beginning of an era of deinstitutionalization and movement towards community based services¹² that would span three decades.

Meanwhile, the Ministry of Health, which continues to be dominated by the medical model, and is seemingly oblivious to the newer, more humane social model, and policy of community living for people with disabilities, continues to build and financially support institutions, termed “nursing homes”¹³ that have been the subject of constant criticism by

saying that he “suffered from a lack of human support”. That same year, in February, Jean Marie Martel, who had been discharged from the same facility, was found walking along a road. He had gangrenous fingers and a frostbitten nose, ears, and toes. He had been attempting to leave his foster home.

¹² Chappell (2006) defines community-based agencies as “nonprofit, open to the public at large, non-discriminative and have objectives that are in the best interest of the community (p.129)”. Chappell cites the goals of community-based agencies as “promoting independence and self-sufficiency [while] trying to maximize an individual’s chances of reaching his or her full potential” (Ibid). They are meant to “maintain the ties with friends, family and other informal support networks – ties that are considered essential for healthy human development and functioning (p 130)”.

¹³ Most recently the MOHLTC has added long term care beds to Sudbury (http://www.health.gov.on.ca/english/media/news_releases/archives/nr_06/aug/nr_082506.html) This is in

long term care advocates, older adults organizations, and the press since they were first regulated in the early 1970's¹⁴.

The Ontario Liberal Government: Regression In Motion

Reading this now, one cannot escape the irony – that the policy makers of yesteryear in the newly created Ministry of Community & Social Services were far more progressive than the policy makers of today. Today, thirty three years after the Welch report was issued, the Ontario Liberal government has decided that the institutionalization of people with developmental disabilities in Ministry of Health funded for-profit institutions is just fine. Ignoring the foresight of Premier Leslie Frost and his Ministers, today's Liberal government claims that there has been no change in policy, in spite of the large numbers of younger people with disabilities being forced into nursing homes because of a lack of other options. Families, desperate for any kind of support or assistance, have agreed to these placements under duress in the absence of these more humane community-based alternatives. This practice is what the Liberal government is now calling “consent to placement”.

The government is justifying this reprehensible regression to the darker days of institutionalization of people with developmental disabilities by suggesting that they are simply promoting “an interministerial commitment towards the inclusion and equal rights of adults with developmental disability in accessing health services and admission into long-term care homes” (MCSS, MOHLTC, July, 2006).

This “inclusion” that the ministries are speaking of is the right for people with developmental disabilities with “health needs” to be segregated and institutionalized alongside thousands of older adults in nursing homes that have been roundly criticized in one press expose after another as providing substandard living conditions for their residents. This government's idea of progress appears to be a return to the conditions of thirty three years ago, and equal opportunity discrimination, ageism, and ableism..

What Does The Protocol Document Really Say?

The ministries' report requires a translation if the ordinary person is to understand what is behind the doublespeak that it contains.

addition to the 3760 additional long term care beds announced in its 2004/05 budget
<http://www.fin.gov.on.ca/english/budget/bud04/statement.html>

¹⁴ Canada has one of the higher rates of institutionalization of older adults in the world, and it is continuing to rise with the addition of long term care beds by the Liberal government in Ontario. In 2001, 4.9% of senior men, and 9.2% of senior women, were living in health care institutions (Statistics Canada, 2002). This amounts to a 6.2 – 7.5% rate of institutionalization of people 65 and over (Jacobzone, 2000), compared to Austria's rate of 4.9%, and the United Kingdom's rate of 5.1%. Even the United States with its heavy reliance on for-profit institutional care has only 5.7% of its adults over 65 living in institutions (Ibid).

“For some individuals supported by developmental services agencies in the community or leaving the three DS facilities, a long-term care (LTC) home may be the most suitable setting to meet their health care needs”. (pg1)

Translation: As a government, we are not prepared to properly fund developmental services agencies so that they can assist older people with health problems to age in place. Instead we will funnel funding, not to non-profit, community-based organizations, but to for-profit institutions, some of which are operated by multi-national corporations. We will justify this by pointing to the fact that there is no “suitable” placement in the community, neglecting to mention that it was our own funding priorities (or lack thereof)¹⁵ that created this situation.

“As part of the planning for these individuals, full assessments and transition plans will be completed to assure the placement to a LTC home is appropriate, and the transition is safe, secure, and comfortable for the individual and for the residents already living in long-term care homes.” (pg 1)

Translation: Government plans to seek justification of this reprehensible conduct in institutionalizing people with developmental disabilities by having it written up in an assessment format, in some cases prepared by the biomedically dominated Community Care Access Centres. This way, should something bad happen to the person being transferred, or to others in a particular facility, because of the transfer, they can blame it on the front line professionals who completed the assessment, and on the long term care workers in the facility where the person was improperly placed.

“The planning process will also identify and address an individual’s support needs specific to their developmental disability that may not be typically met in a long-term care home, and will also determine what additional resources may be required to support their placement”(pg1)

Translation: Government knows that what it is doing is unconscionable because no one with a developmental disability should be segregated and re-institutionalized in a for-profit facility. It is trying to make this all right by throwing a bit of money at the situation, and keeping its fingers crossed that no one in the developmental services system or families will twig that perhaps if government had thrown the money at them instead, they might never have had to move the person to a long term care facility in the first place. A bonus is that this is one more way to pay off the nursing home industry so that they won’t lobby for more money from the government in an election year as they often do. Government assumes that no one will actually notice that the money they are giving to support nursing homes is also a way of transferring even more limited resources

¹⁵ This refers to the Ontario Ministry of Health and Long Term Care’s continual additions of long term care beds in institutions, rather than building capacity in the community through 24 hour staffed, supportive housing programs, non-profit community group homes, and significant enough levels of in-home assistance to allow older adults and persons with disabilities to continue to live at home (aging in place). Disability rights advocates have called for “individualized funding” to allow families to purchase only those services that their sons and daughters require. This request has been repeatedly ignored by the Ministry of Community & Social Services.

to the for-profit sector by stealth instead of investing it in the non-profit sector. The phrase “needs specific to their developmental disability that may not typically be met in a long term care facility home” is a brazen admission on the part of the government of the inappropriateness of this kind of placement. But the infusion of additional resources is intended to mitigate possible criticism by individuals, their families, and advocates.

“The protocol provides expectations by the ministries of Community and Social Services and Health and Long Term Care to relevant transfer payment agencies and service sectors in support of transitioning adults with developmental disability in the community and in DS facilities to the long term care home sector”.(pg 1)

Translation: Government’s intent here is to force people with developmental disabilities and their families into accepting institutionalization in largely for-profit facilities or at least in other institutions. Furthermore, they expect the developmental services sector to go along with this, no questions asked – or else. In other words, if agencies refuse to collaborate in the institutionalization of their clients, it will be assumed that they are being insubordinate and not fulfilling the requirements of this protocol. Government will not give them more money to do the job. The Ministries want to give this money to the for-profit system instead so that they can backfill many of the vacant beds that were created when the previous Conservative government seriously overbedded the long term care system and spent 1.1 billion dollars of taxpayers’ money to do it. Nursing home operators need 97% capacity in order not to have their funding cut. Government’s aim is to help them reach that magic number so they will not suffer financial hardship. Government apparently has no similar concerns for the non-profit sector. Besides, forcing people into nursing homes will free up residential spaces for younger people in the community and for those returning from DS institutions, and take the pressure off of them to create more spaces. This strategy will also help the Liberal government, in an election year, to ward off criticism for not providing adequate community-based services for people with developmental disabilities. It will allow them to say that they can go into long term care facilities instead in “care and comfort” no less. The public is likely thought to be gullible enough to accept this rewriting of reality.

Readers of this critique will notice that we are still on only page 1 of the ministries’ document.

“The protocol further affirms an established interministerial commitment towards the inclusion and equal rights of adults with a developmental disability in accessing health services and admission into long-term care homes”. (pg 2)

Translation: We, the government, will teach those advocates who called for interministerial cooperation to create community alternatives, to mess with us! The powerful stakeholders in the medical-industrial complex in Ontario resent the suggestion that they should have to share their considerable resources with community-based agencies. Therefore, in their defense, government is taking the community advocates’ own language and throwing it back at them, not quite the way that the advocates intended. The government’s new definition of “inclusion” and “equal rights” will mean

equal rights to be institutionalized and segregated in large, dehumanizing facilities, in the absence of any other community alternatives - similar to what is currently happening to older adults. Government almost always aims for the lowest common denominator, something it has certainly done in this case. Older adults' advocates have been routinely ignored by this government when they said again and again that they do not want to be institutionalized, but prefer to age in place. Government now apparently plans to ignore the objections of disability rights advocates as well.

“The protocol recognizes two distinct planning processes – one for individuals residing in the DS facilities, and one for individuals residing in the community who are supported by a developmental services agency residentially and/or non-residentially..... The DS Facilities Initiative presents an opportunity for DS service providers to consider the transition of individuals with increasing health care needs that they are currently supporting residentially into an appropriate LTC setting This will create DS community-based capacity to accommodate residents moving from the DS facilities”. (pg 2)

Translation: Government has decided to exploit the divide between DS facilities and DS community service providers because divide and conquer seldom fails. Not only that, but the Huronia families managed to hire a good lawyer who beat the government in court, in a decision forcing it to get informed consent from individuals and their families before it could dump anyone into another facility. Government knew that families would probably not consent to reinstitutionalization in a worse place, so, instead, it decided to target DS service providers who could be more easily coerced with threats concerning the rest of their funding. Facility parents are more likely to accept a group home than a nursing home. So this means that those who currently have sons and daughters living in group homes are going to have to give up their spaces, since, unlike the Huronia parents they have not yet hired a lawyer from the private bar to protect their childrens' rights. Government is also counting on families' ignorance of the Nursing Homes Act which requires an individuals' or their guardian's consent prior to placement. The assumption is that government will be able to dump people into facilities before their families understand their rights. This strategy will open up a whole other “market share” for government's friends in the nursing home industry, whereby people from community group homes can be moved into institutions, citing their “health care needs” as the reason. This same strategy can be expected to be used with parents who are lobbying for group homes or staffed apartment programs for their adult children with developmental disabilities, or for individualized funding. Now, if they try to say that their children have “high needs” government can simply say “no deal”, we will offer placement in a nursing home – take it or leave it. If they take it, government will likely top up the funding a bit to “sweeten the deal”. This is similar to what government did with other parents, forcing them to give their children up to the CAS¹⁶ in order to get funding to care for them. Government likes to be consistent with its regressive policies. Here it is taking a calculated risk with the Ombudsman's Office, assuming it will be some time before the

¹⁶ Please see the report by the Ontario Ombudsman “Between a Rock and a Hard Place”
<http://www.ombudsman.on.ca/UploadFiles/File/PDF/FINALSPECIALNEEDSREPORT.pdf>

staff there realize that what government is doing is the same as its earlier policy of forcing CAS placement, but with a different group. By then, it hopes, it will be too late.

By now, readers are probably getting the picture, and we are only on page 2 of the report.

Analysis

What the above essentially represents is the re-medicalization of developmental disability. It is intended to justify institutionalization, and the migration from non-profit community based MCSS group homes, or parental homes, to for-profit Health funded facilities. This is intended to solve the government's legal, monetary, and political problem created by the deinstitutionalization of DS facilities, lobbying by families for better community services and individualized funding, and nursing home operators' demands for assistance to fill their surplus beds. It is a strategy intended to kill several birds with one stone by also attempting to hide the transfer of funding to the for-profit sector. It also now places many people with developmental disabilities squarely under the jurisdiction of the newly created Local Health Integration Networks (LHIN's)¹⁷, thereby solving two other government problems – Freedom of Information and public accountability. With the LHIN's there is unlikely to be access to information through the Freedom of Information Act because they are at arm's length from the government, and no blame attached to the government, because the LHIN's will be blamed if something goes horribly wrong with these grossly inappropriate transfers.

The plan is Machiavellian in the extreme, fraught with doublespeak intended to mislead and mollify possible critics. One wonders who thought it up.

The Protocol Principles

The rest of this report includes “Protocol Principles”, many of which are either unrealistic, unfair, potentially violate the law¹⁸, or predictably ignore the rights of individuals and their families.

Principle 1 says that once someone's health care needs exceed what can be supported in the community (with inadequately funded community support programs) they can be considered for placement in a nursing home. No mention is made of individuals and/or

¹⁷ For those unfamiliar with LHIN's, please go to:

http://www.health.gov.on.ca/transformation/lhin/lhin_mn.html For critiques of the LHIN's, go to: http://www.cupe.ca/www/p3_alert_november_20/a438cbb3d237b0 and <http://www.web.net/~ohc/lhins/LHINS06January11.htm#Analysis>

¹⁸ The Constitution of Canada affords citizens the right to “security of the person”, as well as equality rights. It will be interesting to see what an enterprising lawyer from the private bar might do in considering a possible response to the government's current plan. (See Canadian Charter of Rights - http://lois.justice.gc.ca/en/const/annex_e.html#I)

their families' rights to refuse this under the Nursing Homes Act¹⁹. Of course if they do refuse, the resident could be dumped into the street, or sent home, so families will probably have very little choice in reality. Service providers, with Ministry guns held to their heads, will likely have to agree as well.

Principle 2 suggests that there will be an individualized plan for every person. Not likely. The Ministry of Health and Long Term Care has not even been able to enforce the most basic care provisions of long term care legislation, as evidenced by nursing home inspection reports²⁰. How likely is it that they will now be able to enforce the notion of "individualized plans" in these facilities? Critics have argued that the "revolution in long term care" promised by the Minister after a Toronto Star expose has failed to materialize in actions that will make much difference in the care provided in nursing homes (CBC, October 4, 2005). Besides, individual plans are what older nursing home residents are supposed to have now. Take a walk into almost any nursing home in Ontario, and listen to residents calling "nurse, nurse", sometimes for hours at a time, or left in their beds with their breakfast trays at their sides when they are unable to feed themselves, or look at the many overmedicated people sitting with their heads down in hallways, and ask yourself, is this where anyone should be placed much less a vulnerable person? If this is "individualized planning" as redefined by government, then people with developmental disabilities are in for the same overmedication, lack of care and neglect currently endured by older adults in these facilities (see Natalie's Story, Moira Welsh, Toronto Star, December, 2003).

Principle 3 sets out the funding top up option whereby funding to long term care institutions instead of community-based services is legitimized. Funding is to come from the "developmental services sector" meaning less money for non-profit developmental services and more for for-profit institutions. This legitimizes for the first time, the transfer of MCSS dollars that would normally be earmarked for non-profit developmental services, to support Ministry of Health funded for-profit institutions. This represents a full reversal of the directions established in the Welch Report of 1973.

Principle 4 celebrates the "equity" in all of this.

Principle 5 legitimizes people being dumped into these homes through the Community Care Access process found in the Nursing Homes Act referring to the "legislated requirements of MOHLTC". All those families and service providers who were forced to accept creeping medicalization through use of home care, when their sons and daughters or clients were denied Special Services At Home or Individualized Funding, may now be shocked to learn of the next steps. Because the Health system now has their sons and daughters' or clients' medical information, it will be able to make the case, through the

¹⁹ Please see Section 20 (7)(8)(10) of the Nursing Homes Act - http://www.e-laws.gov.on.ca/DBLaws/Statutes/English/90n07_e.htm#BK20

²⁰ To view at least some information on nursing homes, see the Ministry's online inspection reports - <http://publicreporting.ltchomes.net/english/index.htm>

CCAC's that these individuals need to be in a long term care home because of their "health needs"— especially if the family or service provider pressures for more funding because of the grossly underfunded community system. This may well even open the door for children to be placed in nursing homes again – a regression to 1985 when the Ontario Association for Community Living successfully fought to have approximately 400 children removed from these homes because of the extreme levels of abuse and neglect they were suffering there (see Inquest into the death of Yves Soumelidis²¹, Ark Eden Nursing Home, Stroud, Ontario).

Principle 6 alludes to the winning of the court case by the lawyer for the Huronia families. It states that facility residents can only be placed in a nursing home with the consent of their guardians thereby reflecting "the judicial consent requirements of MCSS". Unfortunately individuals currently living in community group homes or their family homes have no such court protection, and it appears that MCSS and MOHLTC plan to take full advantage of that fact.

The rest of this report, sets out, in intricate detail, how the individual planning and access processes for individuals moving from DS facilities will work, and how individual planning and placement processes for individuals supported by community-based agencies will work. Both reflect the serious issues that have been discussed previously in this critique.

It is now up to legislators and community advocates to do the right thing and call for the withdrawal of this regressive document and the procedures being used to institutionalize people with disabilities in nursing homes. In this way, future tragedies can be averted.

The only questions left to ask at this time are: "If not now, when? If not us, who?"

²¹ Yves Soumelidis' younger brother, John Jr., passed away on January 13, 2007 at the age of 39, after he was rescued by his father from the same nursing home. MCSS ordered and funded in-home support in perpetuity for John Jr. after the tragic death of his older brother. John lived successfully in the community from 1982 to 2007 with in-home support to his family, in spite of his significant physical and developmental disabilities. At the time of his "deinstitutionalization" from the Ark Eden nursing home, many said that he would not last a year in the community, yet he lived well for 25 years. Today, individuals with disabilities far less severe than John Jr.'s are being placed in nursing homes in the absence of this kind of in-home support. An inquest jury examining the circumstances surrounding the death of Yves Soumelidis found that he had died of complicating factors in the nursing home – malnutrition, dehydration, and hypothermia.

Dr. Patricia Spindel is a long time disability rights and long term care reform advocate. She is a Past President of Concerned Friends of Ontario Citizens in Care Facilities, a former Chair of the Ontario Coalition for Long Term Care Reform, and a former policy advisor and systemic advocate with the Ontario Association for Community Living. She developed and taught the Advocacy in Aging course at Ryerson University, and has been awarded a Government of Canada medal for her work on behalf of her compatriots and the community. She was also honored by the Ontario Coalition of Senior Citizens Organizations for her work on behalf of nursing home residents in Ontario.

Dr. Spindel currently teaches Social Welfare, Political Process, and High Risk Populations in the B.Sc. (Hons) Program in Family & Community Social Services at the University of Guelph-Humber in Toronto.

REFERENCES

Baum, D.J. (1977) *Warehouses for Death: The Nursing Home Industry*. Toronto: Burns and MacEachern.

CBC. (October 4, 2006) *Nursing Home Reforms Fail to Measure Up: Critics*.
<http://www.cbc.ca/health/story/2006/10/04/nursing-health.html>

Chappell, R. (2006) *Social Welfare in Canadian Society*. Canada: Thomson Nelson.

CTV Marketplace. (March 20, 2001) *Analyzing Political Contributions and Nursing Home Development*.
<http://www.cbc.ca/consumers/market/files/health/nursinghomes/index2.html>

Jacobzone, S. (Autumn, 2000) *Health Care and Aging: International Perspectives on Long Term Care*. Isuma 1. ISSN 1492-0611.
http://www.isuma.net/v01n02/jacobzone/jacobzone_e.shtml

Lutz, W. (1997) *The New Doublespeak: Why No One Knows What Anyone Is Saying Anymore*. N.Y.: Perennial

Lutz, W. (1990) *Doublespeak: From Revenue Enhancement to Terminal Living. How Government, Business, Advertisers, and Others Use Language to Deceive You*. N.Y.: HarperCollins.

Ministry of Community & Social Services/Ministry of Health and Long Term Care. (July, 2006) *Long-term Care Home Access Protocol for Adults With A Developmental Disability*.

Spindel, P. (November, 1989) *Protection for Whom? A Brief to the Ontario Cabinet by the Adult Protective Services Association of Ontario*.

Statistics Canada. (November 6, 2002). *2001 Census: Families and Households Profile: Canada*.

www12.statcan.ca/english/census01/products/analytic/companion/fam/Canada.cfm

Welch, Robert. (1973) *Community Living for the Mentally Retarded: A New Policy Focus*. Ontario government: Queen's Printer.

Welsh, Moira. (December, 2003) *Natalie's Story*. Toronto Star
<http://www.healthcoalition.ca/natalie.pdf>

Williston, W. (1971) *Present Arrangements for the Care and Supervision of Mentally Retarded Persons In Ontario: A Report to the Hon. A.B.R. Lawrence, Minister of Health*. Toronto: Queen's Printer.

Wolfensberger, W. (1972) *The Principle of Normalization in Human Services*. Toronto: National Institute on Mental Retardation.

Worth, Patrick. (October 15, 2004). *Deinstitutionalization Can Equate With Citizenship If It Means Freedom*. Online interview -
http://www.communitylivingontario.ca/Daily_News/2004/October/Oct15.htm