



**PUBLIC
INTEREST
LAW
CENTRE**



**CENTRE
JURIDIQUE
DE
L'INTÉRÊT
PUBLIC**



**AN INDEPENDENT
SERVICE OF
LEGAL AID
MANITOBA**



**L'AIDE JURIDIQUE
DU MANITOBA**



**SUPPORTED BY
THE
MANITOBA LAW
FOUNDATION
AND MEMBERS
OF THE
MANITOBA
BAR
ASSOCIATION**

**Review of
Social Science Evidence
concerning the
Deinstitutionalization of
Persons living with Mental Disability**

**Daniel Rempel, Articling Student-at-law
Public Interest Law Centre**

**610-294 PORTAGE AVE
WINNIPEG, MANITOBA
R3C 0B9**

TEL: 204.985.8540

FAX: 204.985.8544



E-MAIL: centre@pilc.mb.ca

April 30, 2007

Table of Contents

Introduction.....	1
Historical Trend.....	3
Reasons for the trend.....	4
Studies of Institutional Closure and Self-determination.....	6
The Hypothesis.....	7
“Research shows multiple benefits of community placement.”.....	8
Are Institutions necessary for some individuals?.....	10
“Choice”.....	11
“The Theory of the “Must Stay” Group is Not Supported”.....	18
“Community Support Systems are More Cost Effective than Institutional Systems”.....	26
“Research Findings are Remarkably Consistent”.....	26
“Family Attitudes Change Dramatically”.....	27
“Community Living is not without problems, and requires protections”.....	28
Conclusion.....	30

Introduction

1. The closing of residential institutions for persons living with intellectual disabilities is nothing new. It has been going on in Canada and the USA for decades. Because the closure of institutions is such a significant undertaking both in terms of policy and lives affected, policymakers have been keenly interested in the outcomes of this trend. In consequence, the trend of deinstitutionalization has been the subject of thorough and comprehensive scrutiny.
2. Those decades of experience with the closure of institutions have consequently produced a wealth of research into the outcomes of institutional closures. In broadest terms, researchers have asked, “Was deinstitutionalization a good idea?” Did former institutional residents see an increase in their quality of life, as measured by a dozen or more indicators? What effect did it have on the expenditure of scarce public dollars?
3. Overall, the findings have been “surprisingly consistent” in showing positive outcomes, such that James Conroy, who has studied the phenomenon more than perhaps any other researcher, has observed that “Historically, the movement of people with developmental disabilities from institution to community has been one of the most successful social movements of the baby boomer generation.”¹ Even the government of Serbia has committed to closing all of its institutions and integrating persons with developmental disabilities into the rest of society.²
4. Deinstitutionalization is not a new policy idea in Manitoba either. In 1982, the Manitoba government was provided with “A Report to the Premier on Mental Retardation Services in Manitoba: We have promises to keep.”³ While at that point researchers had 25 fewer years experience with

¹ James W. Conroy, *Outcomes of Community Placement at One Year for the People who Moved from New Castle and Northern Indiana State Developmental Centers*. (Rosemont, PA: Center for Outcome Analysis, 2000) at 2. See also p. 6 where deinstitutionalization is described as “one of the most successful and cost-effective social experiments in the past two decades.”

² Judith Klein and Dragan Lukic, “Out of the asylum”, *Comment is Free* (Guardian UK) December 27, 2006. Online: http://commentisfree.guardian.co.uk/judith_klein_and_dragan_lukic/2006/12/out_of_the_asylum_judith_klein.html

³ Schaefer, Nicola, Nerina Robson and Helen Steinkopf, *A Report to the premier on Mental Retardation Services in Manitoba: We Have Promises To Keep* (Publisher not indicated, 1982)

deinstitutionalization on which to base their recommendations than they do today, it was reported that

The indication to date, however, is that individuals who live with severe and multiple handicaps can be supported to live in the community with dignity, not merely at custodial care levels. Such individuals can be seen across North America working for competitive wages, living at home or in family-like settings, and taking advantage of community resources that support their medical, behavioural, recreational and social needs.⁴

5. This same report also declared that “It is now time that those members of society who have traditionally been isolated and deprived because of segregated systems of service, be brought into the mainstream of community life”, and adopted “Deinstitutionalization” as one of its core principles, stating that

There must be an explicit policy of eliminating new admissions to institutions through the development of individual service responses plus a planned return of institutional residents to competent community based settings. We can point to other jurisdictions where this has occurred on a systematic basis.⁵

6. Unfortunately, since that time, there have been no significant Canadian studies that compare in scope and rigour to the extensive studies that have been conducted in the US and other nations.⁶ However, there is little reason to suppose that Canada's social service system should fail in accommodating people in the community where numerous US states have succeeded.

7. From the experience in the US and other countries, the evidence shows clearly that there are no people who “must” be institutionalized and that all people can be supported in the community. It also shows that persons with disabilities do better and achieve a higher quality of life in the community, with the biggest benefits often being seen in the most severely disabled individuals. Since institutionalization now appears to be unneeded, and life in the community more beneficial, this raises the question of whether we should have any institutions at all. To date, 9 U.S. States and the

⁴ *Ibid.* at 4.

⁵ *Ibid.* at 10.

⁶ Tab 4 in the source materials binder, Affidavit of Michael Bach in *Gray v. Ontario*, 2006 [2006] O.J. No. 266, (2006) 264 D.L.R. (4th) 717, [Bach] at para. 29.

District of Columbia have already answered this question by closing all of their public institutions.⁷

8. In the following pages, the findings of this body of research are reviewed and summarized. In order to better understand the trend, this will be done after setting out the historical and social context within which the trend of deinstitutionalization is occurring.

Historical Trend

9. Although it may seem to many that persons with intellectual disabilities have always been cared for in residential institutions and that this is the natural order of things, such residential institutions are historically a recent innovation. In North America their beginnings can be traced to the middle of the 19th century.

10. The “Institutional model” was introduced to North America by Samuel Gridley Howe, who had observed facilities in Europe. These facilities had been designed as self-sufficient agrarian communities, within which people would be free from the pressures of normal life in a protected, safe and healthy setting.⁸

11. By 1866, a handful of institutions had been built in the U.S., and Howe, who had been a leading and influential figure in introducing the institutional care model, grew concerned that they were failing to achieve his vision and that they were taking on some very undesirable characteristics. In a speech at the laying of a cornerstone of a new institution in 1866, Howe warned:

“Grave errors were incorporated into the very organic principles of our institutions... which make them already too much like asylums; which threaten to cause real asylums to grow out of them, and to engender other evils.”

“... all such institutions are unnatural, undesirable, and very liable to abuse.”

“We should have as few of them as possible, and those few should be kept as small as possible.”

⁷ James W. Conroy, *Deinstitutionalization of People with Mental Retardation and Developmental Disabilities in the United States: Was This Good Social Policy?* (Havertown, PA: Center for Outcome Analysis, 2002) [Deinstitutionalization] at 2.

⁸ James W. Conroy, *Outcomes of the Robert Wood Johnson Foundation's National Initiative on Self-Determination for Persons with Developmental Disabilities. Final Report on 3 years of Research and Analysis* (Narberth, PA: Center for Outcome Analysis, 2002) [Outcomes] at 3.

*“Such persons [with disabilities] ... should be kept diffused among sound and normal persons.”*⁹

12. Nonetheless, institutions were built at increasing rates until reaching a peak in 1970, when about 280 institutions were operating in the U.S.¹⁰ Institutions became normalized and

Persons with intellectual disabilities [were] placed in institutional facilities based on a pervasive understanding that the needs of individuals, their limited potential for normal development, and the 'burden' that care would impose on families and communities left few or no other options.¹¹

13. When Howe spoke his warning words, the total U.S. population experience of institutional life consisted of one or two thousand people. By 1970, that number reached 187,000 and by the year 2000 it would plummet to 43,000,¹² with 125 institutions closed or slated to close.¹³ Nine U.S. States and the District of Columbia have closed all of their public institutions.¹⁴

14. Judy McLachlin, President, Saskatchewan Association for Community Living, describes the present moment in history as follows:

We stand on the last edge of a receding era. It is the end of a time that, no matter how good the intentions, has taught our society that people with intellectual and other disabilities belong *over there* instead of *with us*. This era of institutionalization is disappearing with a few last gasps from those who fear change, those who feel family members are better off left alone until they die, from those who feel inclusion is fine for some, but not for all. ... We must act quickly and thoughtfully to make sure that, for whatever time people have left, former residents can enjoy their turn as part of our communities, as equal citizens, as our neighbours and friends, as people *with us* and not merely those relegated to remain *over there*.¹⁵

Reasons for the trend

15. James Conroy identifies five major reasons as underlying the trend toward deinstitutionalization.

⁹ *Ibid.* at 5.

¹⁰ *Ibid.*

¹¹ *Bach, supra* note 6 at para. 29.

¹² *Outcomes supra* note 8 at 6.

¹³ Multiple authors, “Trends in institution closure” in *“Community for All” Tool Kit: Resources for Supported Community Living*, online at http://thechp.syr.edu/toolkit/Community_for_All_Toolkit_Version1.1.pdf. (Syracuse: Human Policy Press, 2004) [Tool Kit] at 70.

¹⁴ *Ibid.* See also *Outcomes supra* note 8 at 13.

¹⁵ Judy McLaughlin, “SACL supports human rights complaint” (*Dialect*: Fall/Winter 2006) at 9.

These are: Scandals, Ideology, Litigation, Scientific Evidence on Quality, and Economics.¹⁶

16. According to Conroy, perhaps the most powerful force driving the deinstitutionalization movement was litigation. Lawsuits, sparked by increased public awareness of the conditions that existed in institutions, initially focused on suing governments to better fund institutions to improve the quality of care. However, a major turning point occurred in a lawsuit in Pennsylvania centred on the Pennhurst institution, where plaintiffs arrived at a position that would become the thesis of the entire deinstitutionalization movement.

17. One plaintiff in the Pennhurst litigation, the Pennsylvania Association for Retarded Children, came to the conclusion that no amount of funding would correct the isolation and segregation that were inherent to the institutional model, and that abuse and neglect would inevitably occur when vulnerable persons were placed in a setting of isolation and segregation. Thus, rather than asking the government to throw good money after bad by increasing funding for an institution whose shortcomings were fundamental and essential to its nature, the ARC sought to have the institutions closed and public resources committed instead to serving people's needs in the community.¹⁷

18. This argument succeeded at trial in 1977, and after a decade of appeals and delays, Pennhurst was finally closed in 1987. According to Conroy,

Because the landmark Pennhurst legal decision, and those modeled after it, were made primarily on the basis of expert opinion and principles of human rights, the most urgent question surrounding such lawsuits during the 1980s was: Will the people really be “better off” in community homes? The urgency of this question led to major research efforts which contributed not only to the body of knowledge, but also to the movement away from segregated treatment of people with developmental disabilities.¹⁸

19. Conroy's own extensive research at the Center for Outcome Analysis was part of this trend – governments wanted to know whether deinstitutionalization was *in fact* good social policy, and not just a nice theory. Did the policy prescriptions of “experts” and human rights theorists actually

¹⁶ *Outcomes supra* note 8 at 7-15.

¹⁷ *Ibid* at 10.

¹⁸ *Ibid* at 11.

translate into positive results for people, or was this merely ivory tower hypothesizing that would not hold up in the real world?

20. The transition of hundreds and thousands of people into a new, more independent mode of life is of course not something to be undertaken lightly, and governments were right to want to scrutinize the results very closely. James Conroy and the Center for Outcome Analysis have studied this issue more exhaustively than any other group of researchers in North America. He presents a compelling body of empirical evidence in favour of the conclusions he has arrived at. Moreover, Conroy is not a single voice in the wilderness. As this report and its attachments demonstrate, study after study and expert after expert support his conclusions.

Studies of Institutional Closure and Self-determination

21. The closing of institutions in North America and around the world and the accompanying rise in community support services for persons living with mental disabilities provided rich fodder for researchers as people moved into the community by the thousands. As noted, James Conroy is the leading figure in the research that has been done into the outcomes of this trend. An excellent overview of the lessons that Conroy has drawn from his years of research can be found in *Deinstitutionalization of People with Mental Retardation and Developmental Disabilities in the United States: Was This Good Social Policy?* found at Tab 5 in the source materials binders.

22. This document by Conroy is described as a “Statement” and thus represents his considered opinion of the question asked in the title. However, this 57 page document also reviews a significant number of the studies on which Conroy's opinions are based. It is a concise and accessible overview of his findings regarding decades of research into the outcomes of institutional closures and is highly recommended as an introduction to the literature.

23. Conroy is not coy about his conclusions: directly after the cover page with his electronic signature, he identifies that “the purposes of this Statement are to present, explain and support the following

facts and opinions.”¹⁹

1. Research shows multiple benefits of community placement.
2. Deinstitutionalization in Developmental Disabilities must be Clearly Differentiated from Deinstitutionalization in the Mental Health field
3. Family Attitudes Change Dramatically
4. The Theory of the “Must Stay” Group is Not Supported
5. Community Support Systems are More Cost Effective than Institutional Systems.
6. Research Findings are Remarkably Consistent
7. Community Living is not without problems, and requires protections

24. Along with these statements, Conroy offers both supporting evidence and qualifying statements. For example, while noting that community systems deliver better results at lower costs, he also says that there should not be any cost savings – the lower cost is in large part due to the higher salaries paid to professional institutional staff in comparison to community workers, and he feels that community workers ought to be compensated better for their work. The final point is itself a qualification, an admission that problems will also be found in community living and need to be addressed.

The Hypothesis

25. In 1994, Conroy and the Center for Outcome Analysis formulated this as the central hypothesis underlying the deinstitutionalization movement:

If people gain control, their lives will improve, and costs will decrease.²⁰

26. It must be noted that Conroy actually prefers the positive term “self-determination” over the negative “deinstitutionalization” - this highlights a key aspect of the movement, namely that it is about giving people with developmental disabilities control over their own lives, rather than placing them under the control of an institution. The language chosen closely resembles the original claim made by the ARC plaintiffs in the Pennhurst litigation:

When families decide how to spend the public dollars,

¹⁹ *Deinstitutionalization*, *supra* note 7 at 2-3.

²⁰ *Outcomes*, *supra* note 8 at iii.

They tend to spend more precisely according to their needs,
And perhaps more wisely than professionals.²¹

27. Thus the research can all be understood as a test of this intuitive hypothesis, and Conroy reports that the research is remarkably consistent in affirming it. In his extensive studies, Conroy observed that with deinstitutionalization there was indeed a power shift from paid professionals to freely chosen allies, which enhanced quality of life in more than a dozen dimensions, and decreased public expenditures. This suggests that deinstitutionalization may be a policy-makers dream: it improves services while cutting budget. But more than that, if it truly improves the lives of persons with developmental disabilities and restores to them control over their lives that it now appears did not need to be taken from them in the first place, it is also a matter of liberty and freedom from discrimination on the basis of disability.

“Research shows multiple benefits of community placement.”

28. Conroy's first point is not controversial; the responses to the present complaint acknowledge that there is a need to accelerate movement into the community, and the nationwide trends in Canada and the USA attest to the fact that by and large policymakers have decided in favour of community based care. Conroy's own conclusion is that

Twenty-five years of developmental disabilities research literature on movement from institutional to community settings indicates that, on the average, people experience major enhancements in dozens of quality of life indicators. The research is remarkably consistent in this area. ... Their qualities of life are enhanced, they display less challenging behavior, their homes are more pleasant, and their families believe that they are far “better off” than they were in developmental centers.²²

29. It must be noted that the “major enhancements” are “on average” - thus, there are individuals who in may experience little to no enhancement in some of the many quality of life indicators. While Conroy reports that the “research findings are remarkably consistent” he does report one set of reports he is

²¹ *Ibid.* at 25. This “New Idea/Theory” comes as the conclusion of a story about a man named Sean, told in powerpoint, that illustrates the experiences underlying this suggestion.

²² *Deinstitutionalization, supra* note 7 at 2.

aware of that suggests a negative impact, that people moved to the community may have a higher rate of mortality; however, he says that these results have since been discredited.²³

30. The live question really is not whether community-based care is generally better, but whether institutions should be maintained for the benefit of some for various reasons, which is explored further below.

31. The bulk of Conroy's statement (Tab 5) is organized under this first point, with pages 4 to 40 falling under this heading. However, it is in this section that Conroy broadly reports the findings of the many studies of the past 25 years, and much of this material supports his later points, which receive fewer pages but are supported by this section.

32. In 25 years of studies, researchers have measured a broad range of "quality of life" indicators, including independence, productivity, integration, health care, friendships, physical comfort, privacy, freedom from excessive restraints (physical, chemical, and authoritarian), respect for dignity and human rights by staff and others, and more.²⁴ When such a broad range of "soft" factors are measured, one would expect to see mixed results, but Conroy reports that,

However, the research literature on community versus institutional living has not been "mixed." Through the assessment of all of these quality of life dimensions, my research in 18 states, and the research of other scientists in America, has consistently shown strong benefits associated with community placement. Furthermore, the results have been extremely powerful, in that improvements have been documented in nearly every measurable outcome dimension. Research in other nations (Australia, Canada, Denmark, England, France, Ireland, the Netherlands, New Zealand, Norway, Sweden) has revealed remarkably consistent findings associated with institutional closure (Mansell, J., & Ericsson, K. (Eds.), 1996.²⁵

33. The research on deinstitutionalization thus appears to be remarkable in that the results are consistently favourable in almost all dimensions. Among the many studies he has done over the years, Conroy did find a negative outcome in one dimension in a study of California's experience of deinstitutionalization, where he observed a slight decrease in adaptive behaviour following

²³ *Ibid.*

²⁴ *Ibid.* at 5.

²⁵ *Ibid.*

community placement, which he attributed to California under-funding its community programs to a greater extent than all other states.²⁶

34. Others share in Conroy's conclusions. For a concise review of 33 published studies, see Kim, Larson & Lakin, "Behavioral outcomes of deinstitutionalization for people with intellectual disability: A review of US studies conducted between 1980 and 1999" at Tab 21 in the source materials binders. This review initially identified a set of 250 studies from which it selected 33 for review on the basis of several criteria to determine the usefulness of the studies; the criteria are given at p. 2 of the review. The authors here also identified a consistency in the research showing improvements in adaptive behaviour in individuals who have moved into the community.

35. For the purposes of this brief however the focus will be on outcomes that have been measured in individuals for whom it is argued institutional care is still preferable. These are:

- the severely or profoundly disabled,
- those with complex medical needs,
- those with behavioural issues, and
- those who have grown old in institutions and thus know it as their only home.

Are Institutions necessary for some individuals?

36. For the purposes of the present human rights complaint regarding the Manitoba Development Center in Portage La Prairie, this is the crucial issue. It is not controversial between the parties that community placement is generally preferable, and the placement patterns of recent years indicate that the Province of Manitoba has adopted a policy of community placement for new recipients of public services for persons with mental disabilities. New admissions to the Portage Manitoba Development Centre are rare.

37. However, the replies of the respondents suggest that for many residents of the MDC, continued

²⁶ James Conroy, *Eight Years Later: The Lives of People Who Moved From Institutions to Communities in California*. Center for Outcome Analysis, 2001, 52 pp.

institutionalization may be preferable for various reasons, and that the MDC ought to be maintained to provide institutional care as an option for those individuals who may prefer it or for whom it is allegedly more appropriate. Thus the respondents advocate the continued availability of institutional care delivered via the MDC as a matter of patient choice. See the first two paragraphs of section IV of the Reply of The Minister of Family Services and Housing, and the Executive Director of the Manitoba Development Centre:

The Minister and the Director are committed to the vision of full inclusion of Manitobans with disabilities with community living as a preferred option; however, it recognizes that a range of residential options must be available to meet a wide spectrum of needs and preferences.

The Minister and the Director are very much committed to continue to work with service providers to assist current MDC residents to transition to community settings. However, this is in the context that the MDC is to remain open so current MDC residents have the choice to continue to remain at MDC or to transition to a community setting. ...

38. This brief examines the evidence as it relates to these two arguments: That institutional care should be preserved as a choice for those who prefer it, and that there are some individuals who for a variety of reasons are better cared for in an institutional setting.

“Choice”

39. The word “Choice” is a contentious one when it comes to the rights of persons with mental disabilities. First, “choice” operates on different levels – it is used in relation to the decision of where to live, i.e. in the community or in an institution. Secondly, it is used to describe decisions in day-to-day decisions such as what to eat and what to wear; one of the main arguments advanced by advocates of deinstitutionalization is that community life affords people a much greater degree of choice in the decisions of daily life. Thus it is used by both sides of the debate, with one side saying that persons with disabilities ought to have the choice to continue to live in an institution if they wish, and the other saying that institutional life by its very nature deprives residents of the freedom of choice that would allow them to pursue their own dreams and preferences and simply to live life as

they want to, and further that the continued existence of institutions undermines the right to live in the community and realize those choices.

40. The concept of choice is further complicated by the difficulties associated with determining the true preferences of persons with disabilities. The individual resident may simply lack the capacity to communicate their preferences. With residents who are communicative, further barriers may exist in their ability to fully appreciate the options being presented to them. This difficulty is especially acute when the individual has not experienced anything other than institutional life and is asked, without any experience, to decide if they want to leave their institutional home for something else.

41. Lorri Solomon, former staff at the Valley View Centre in Moose Jaw, says this about choice and institutions, speaking of people who say they like living at Valley View:

Having had some involvement with the foster care system, the thing that always shocked and amazed me is no matter how badly they were treated, there were children who just wanted to go home to what they knew. Even when they knew they weren't safe there, they just wanted to go home. I don't know if that is what people think when they say they want to live at Valley View (when the person says it, and it is not the declaration of someone else) and I wouldn't presume that they all think that way. The point should be considered though. How can a person make an informed choice if they don't know what the other choices are? Isn't the devil you know always safer than the devil you don't know?²⁷

42. It is true that, as reported in one policy research brief, “However, some older adults who have lived for many years in institutions indicate that their preference is to remain in the institution.”²⁸ The authors suggest however that this preference must be understood within its context, as “This preference is often based on lack of experience with other alternatives and fear of something new and different. Individuals may also be reluctant to part with close friends and staff in the institution.”²⁹ They conclude that to ensure that individuals truly understand the options available to them and thus can determine their preferences on the basis of a fuller appreciation, “it is particularly important that such individuals have the opportunity to have community experiences that assist them in learning

²⁷ Lorri Solomon, “I Hope” (*Dialect*, Fall/Winter 2006) [Hope] at 6-7.

²⁸ Bonnie Shultz *et al.*, *Policy Research Brief: Status of Institutional Closure Efforts in 2005* (Minneapolis: University of Minnesota, 2005) [Closure Efforts] at 3.

²⁹ *Ibid.*

about life in the community and various support options.”³⁰

43. The Saskatchewan Association for Community Living gives this response to the question “Are people with disabilities having their choices taken away by closing institutions?”:

No. In fact it is just the opposite. Choice is a word that is thrown around and misused a lot. Ask people with intellectual disabilities how many choices they have had in where, with whom and how they live. The answer is very few. If people with disabilities could experience a more independent way of living, with their own home and with staff that take direction from them, they would choose it over anything else. It is hard to really choose when your options have been limited. Presently, there are almost no choices.

Institutionalization is the only option that many people are offered. SACL believes in real choice. We believe that people with intellectual disabilities deserve to be authors of their own lives with support they need. Telling them that SACL is threatening their homes is not true and it is irresponsible. It scares people into accepting and being thankful for any support they are given. Real choice means being able to make choices with your own support money and have the service system respond to your needs and dreams.³¹

44. Another organization, the Maryland Developmental Disabilities Coalition, puts it more bluntly in a document called “Shattering Myths about Choice”: in response to “Should a continuum of services include institutions, the answer is given as “No. Society has no responsibility to subsidize segregation.”³² This reflects again the view of community living proponents that institutions by their very nature are places of segregation and isolation, features that cannot be alleviated by any level of increased spending, renovations, quality control, policies or staff training. The response of the MDDC is further elaborated as follows:

Society's values change as civil rights, contemporary technology, and new medical and health approaches are incorporated into mainstream society. Outdated technologies and treatment approaches are then replaced by more advanced practice. Institutions are no longer the contemporary approach for the way individuals with disabilities seek to live and receive treatment and supports.³³

45. Proponents of community-based care argue that by their very nature, institutions deprive residents of

³⁰ *Ibid.*

³¹ Saskatchewan Association for Community Living, *Putting Deinstitutionalization in Focus: Questions and Answers*. [SACL] Online: <http://www.sacl.org/webapp/images/gallery/fact%20sheet.pdf>

³² Maryland Developmental Disabilities Association, *Shattering Myths about Choice* (2004) at 1

³³ *Ibid.*

“choice” in many areas of their life. As Solomon describes it, the reality of institutional life is simply that residents do not get to make many of the decisions that those of us who live in community take for granted:

The meals come on steam tables and you don't have a choice of menu or meal times. The staff who strips your clothing off and cleans you *everywhere* might be someone you never met. The television programs that you watch are chosen by somebody else. The clothes you wear come up from the laundry in a large hamper; who knows who wore them last. Everyone in the place you live has probably seen you naked. You live with others you did not choose to live with. You cannot lie down for a nap without specific permission and you can't stay up late watching infomercials when you can't sleep. You can't sit and read the newspaper while you do your business in the bathroom. You can't sit and do your business *alone*. Outings involve more people than you, and they take you to places you didn't say you wanted to go to, you cannot have a pet, you cannot drink a beer, you cannot have sex and any outcry against this way of living is treated as a behaviour problem and dealt with accordingly.³⁴

46. The words of former residents themselves also cast some light on the question of choice. In one reported study, the last word is given to the people who moved from the institutional setting into the community. These individuals are happy with the change, but more tellingly, their happiness with the change appears to be linked to the greater degree of choice and opportunities they now enjoy in the community:

“Community is not as bad as (name of hospital). There is more environment, more space to move around in. Life has changed.”

“Yeah, hum, yeah I'm very happy. Yeah have a nice house, being able to go to the shops, nice clothes, yeah, yeah, yeah. All those things, yeah.”

“(Outside the hospital) there's lots of places, like the rose garden. It is good, no problems really. Sometimes we go to the pictures and sometimes we go to the beach for a barbecue.”

“My life is better, it's changed a lot because I have more freedom. I go anywhere I like that's not too far for the staff to take me there. I've got friends that I've had since I left hospital and places to go. I've got much more freedom. I can get away from the others but at the hospital I couldn't get away. I could only go to the side room. Here I can go out with the staff and I behave myself.”³⁵

³⁴ Hope, *supra* note 25 at 7.

³⁵ Patricia O'Brien, Avril Thesing and Bryan Tuck, “Perceptions of change, advantage and quality of life for people with

47.As seen here, “Choice” is used in different ways in the debate around deinstitutionalization, and is a very complex subject in the context of adults living with intellectual disabilities, individuals who may require the assistance of others in making choices. For a fuller treatment of this issue, Michael Smull's brief essay “Revisiting Choice” is highly recommended and can be found at Tab 15 of the source materials binders.³⁶

48.It should be noted that Smull has little sympathy for the use of “Choice” to justify the continued existence of institutions. Rather dramatically, he suggests that “the same argument could be made to retain “bleeding” as a treatment option for the flu”. Smull writes,

Choice is the most powerful word and the most abused work in the current lexicon of the disabilities services system. ... Perhaps because choice is the word du jour, it has been used to argue that congregate facilities are needed in order to ensure residential “choice”. An even more egregious example is justifying the use of pain to control behavior to allow “choice among a full range of treatment options”. ... Other abuses are more subtle. When you look behind the rhetoric of agencies which say “we offer and teach choice”, you find places that ask people what they want to wear but not who they want to live with.³⁷

49.Smull argues that such agencies are operating with an overly simplistic, impoverished notion of choice that sees it as a question of power; either the resident has it, or the agency has it. In some areas the resident is viewed as being competent to make their own choices, as in what to wear, but in more important areas, the professional staff of the institution reserve decision-making power, for the protection of the resident. Tia Nelis, a self advocate, reports from her experience that

People who live in institutions or other large facilities have fewer choices to make because many decisions are made for them, including simple decisions that are made for staff convenience or cost savings. ... When you are “placed” (my friends and I like to say “incarcerated”) many decisions are taken away, like where you will live and with whom, how you will spend your day, and when you want to eat, sleep, and work. Institutional advocates like to say we can't make choices, don't know how to make good decisions, and are not responsible, or that it is easier for us to have them make our choices.

intellectual disability who left a long stay institution to live in the community” (2001) 26 *Journal of Intellectual & Developmental Disability* 1 at 79.

³⁶ Michael W. Smull, “Revisiting Choice”, in *Tool Kit*, *supra* note 13 at 120. [Revisiting Choice] (Tab 15 in source materials binder)

³⁷ *Ibid.*

The bottom line about choices is that in the institution you get to make very few choices and the ones you do make are not the big ones. Living in the community you have opportunities to make choices about all parts of your life, from what comforter you may choose to where and with whom you will live.³⁸

50. As one example that is closer to home, it was reported in the inquest into the death of Dennis Robinson at the MDC that residents were given donuts while they were passengers in a moving van, contrary to institutional policy. This illustrates how the nature of institutions can result in loss of choices: While many residents might safely be able to eat while driving, the realities of care in a congregate setting require that, “to be on the safe side”, a blanket policy must be created denying all residents the choice to enjoy a snack while in a vehicle outing.

51. Another point Nelis makes is in relation to social choices: “People with disabilities want to be friends and neighbours and coworkers with lots of different kinds of people, not just other people with disabilities,” suggesting that when individuals are congregated in a large institution, they are denied choices of who their friends are by virtue of being congregated with each other and by the same token segregated from others.

52. Nelis says that the choices afforded to institutional residents are few, and “not the big ones.”

According to Smull,

What appears to be absent is depth of understanding and a sense of balance. A single word is being used for complex concepts. Too often, there is no recognition of the need for an individual balance between honoring choice and ensuring safety.³⁹

53. Smull divides the concept of choice into three related concepts: preferences, opportunities and control. Regardless of one's position on the role of institutions, Smull's analysis of the concept of choice in mental disabilities services is thoughtful and well worth reading. One final point that may be highlighted here is Smull's view of the consideration that should be given to safety. Smull says that

³⁸ Nelis, Tia, “The Realities of Institutions”, *Impact* Feature Issue on Institution Closures, Vol 9(1) Winter 1995/96 [Realities] at 27. Also in *Tool Kit supra* note 8 at 129.

³⁹ *Revisiting Choice, supra* note 36 at 120.

One of the traps of the current system of planning is that we determine how people can be safe before we look at what they require to be happy. We forget that there is no such thing as a risk free life, that risk is relative and has a context. What we need is to begin with an understanding of what is required for the “pursuit of happiness” and then seek to reduce or avoid risk within that context.⁴⁰

54. Smull notes that for most of us, choice is not a solitary activity, but is rather something that we frequently ask others to help us with. Similarly, choice is inherently a “risky” activity. In the final analysis however, individual dignity is closely tied to the right to make choices, even bad ones. Nelis notes that

Making choices about our lives gives all of us pride about who we are and what we have done with our lives. ... Well, I have a Mickey Mouse comforter and purple walls and I love it because it's mine. It says something about me. It may not be your choice. In fact, you may think it was a bad choice, but it's not your decision to make. It's mine.⁴¹

55. Nelis feels that ultimately, “Everyone should be allowed to make mistakes and learn from these mistakes. I'm not talking about putting people's lives at danger, but about mistakes like spending all your money so you can't afford to buy snacks for a week.”⁴² Because of institutional life however Nelis reports that many individuals have not learned to make choices, or been able to learn from mistakes. However, because of the importance of choice, she feels that those individuals need to be given that opportunity, because even though “Community living is not always easy, perfect or safe, but at least the people who live in the community are free.”⁴³ With respect to choice, the first thing that Tia Nelis says she is sure of is that “I've never met anyone who would choose to live in an institution once they have moved out.”

56. Choices may look different for persons with a mental disability, and they may be made with a great deal more intentional assistance from others, but in the end, deinstitutionalization / self-determination advocates argue that choice must be respected whenever and wherever possible, not just where it is convenient within an institutional care model, where the individual is from the start

⁴⁰ *Ibid.* at 123.

⁴¹ *Realities*, *supra* note 38 at 130.

⁴² *Ibid.*

⁴³ *Ibid.*

denied the fundamental choices of where and with whom they want to live.

“The Theory of the “Must Stay” Group is Not Supported”

57. This point is central to the question of whether institutions need to be preserved to meet the needs of certain groups of residents. Conroy alleges that what he calls the “classic four reasons given for keeping people in large segregated settings” have been discredited. These reasons are severe retardation, challenging behaviour, medical fragility, and advanced age. On the basis of the experience of 25 years of deinstitutionalization, Conroy and others report that persons who might have been kept in institutions for these reasons have all been shown to be able to successfully adapt to life in the community. This evidence actually received judicial recognition in *Gray v. Ontario* [2006] O.J. No. 266, (2006) 264 D.L.R. (4th) 717, where the court found as follows:

I accept that these residents are severely developmentally delayed and are no doubt very vulnerable individuals. However, it does not follow and the evidence does not establish that their needs cannot be met in community placements. On the contrary, the evidence establishes that individuals with this level of developmental disability have been placed successfully in community settings since the mid-1980's. There have been no new admissions to the three remaining institutions for nearly 20 years.⁴⁴

58. Some of this evidence was entered in the *Gray* case via an affidavit by Michael Bach. It is worth repeating here a significant portion, to indicate precisely what the court was relying on in its decision in *Gray*, at paragraphs 25-28:

This study's conclusions are consistent with the experience of community living facilities throughout Canada and the US indicating that, given adherence to certain variables, community living facilities using differing methodologies are capable of supporting even those individuals with the most challenging behavioural support needs.

...

One of the leading experts in Canada, Cam Dore, provides services and consulting out of British Columbia. His experience of supporting individuals who leave institutions and have challenging behaviours shows dramatic success and demonstrates that it is possible to provide needed supports in ways that enable all individuals to take advantage of the benefits of living in the community.

...

Regardless of the level of disability, people with intellectual disabilities who move from institutional facilities to live in the community benefit substantially. [Research] ... points

⁴⁴ *Gray v Ontario* [2006] O.J. No. 266, ¶ 7.

to positive outcomes for individuals in five main areas:

- a) Self-determination
- b) Personal relationships
- c) Access to needed supports
- d) Educational and economic integration
- e) Community access and participation

In general this research supports the findings of extensive research on deinstitutionalization in the US that finds that the four main reasons given for keeping individuals in institutional facilities (severe intellectual disability, medical fragility and complex needs, challenging behaviour, and advanced age) are not based on evidence.⁴⁵

59. In citing the US studies, Bach refers specifically to Conroy as “an internationally renowned researcher on deinstitutionalization”, and reports that the research of Conroy and others also indicates “that individuals identified as 'severely' or 'profoundly' disabled show the greatest gains in “adaptive behaviour” (conceptual, communication, social, and practical life skills) after moving from institutions to the community.”⁴⁶ Conroy's summary of this point can be found on pages 44 to 46 of his Statement.

60. The Pennhurst institution was ordered to close in 1978, with all 1,154 residents to be transferred to the community. Of the 1,154 residents, 40% had aggressive behaviours, and 87% were labelled “severely” or “profoundly” retarded.⁴⁷

61. Conroy and his associates were commissioned to do a longitudinal study to determine whether the people transferred to the community were really “better off” as a result of the change. He reports that this is the most thoroughly studied group of people with disabilities in history, with each one individually still being tracked annually today, nearly 30 years later. The aggregate data showed improvements in “Developments toward increased independence” and in “Challenging behaviour” as well as other factors.⁴⁸ While the data is aggregate, it is significant that 87% of the individuals were labelled “severely” or “profoundly” disabled, and all were moved to the community, which suggests that it was not only the 13% who were considered higher-functioning who thrived in the community.

⁴⁵ *Bach, supra* note 6 at paras. 25-28.

⁴⁶ *Ibid.* at para. 29.

⁴⁷ *Deinstitutionalization, supra* note 7 at 7.

⁴⁸ *Ibid.* at 7-9.

In fact, Conroy argues that very often the most disabled people experience the largest benefits from moving into the community:

When people who are labeled severely or profoundly retarded move into family-like community settings, they show even greater gains, proportionally, in adaptive behavior than persons labeled mildly and moderately retarded. No support exists for the proposition that some people are "too low functioning" to succeed in the community. Empirical evidence is directly to the contrary (Conroy & Bradley, 1985; Stull, Conroy, & Lemanowicz, 1990). In fact, the gains made by persons with severe and profound disabilities upon moving to small community homes from large institutions are initially rapid and immediate and continue over time.⁴⁹

62. The Mansfield Longitudinal study in Connecticut tracked 1,350 people who were moved into the community as the result of a 1985 consent decree in the class action suit *CARC v. Thorne*. Sixty-nine percent of this group were labelled "severe" or "profound" and the group's average "challenging behavior" rating was 79/100, but in 1988-89 only 29 persons had "experienced even a short-term placement in a psychiatric facility." On this basis, Conroy concludes that there was no need to maintain the institution as a "back-up" since the need for such specialized care as needed could easily be handled by other resources.⁵⁰

63. Another study that according to Conroy speaks strongly in favour of the success with which even very challenging individuals can be placed in the community is that of the 1,200 "Thomas S." class in North Carolina. This class is unique in that all of its members have both mental retardation as well as a psychiatric diagnosis or "a brush with the law that resulted in placement into a psychiatric facility." Conroy reports that

Hundreds of the Thomas S. class members have moved to new community homes. Despite widespread misgivings about their potential behavior problems, they are doing extremely well in their new community homes, with no evidence of criminal activity or "recidivism." In fact, they have made such progress that I am now working with the state to suggest that the Court's supervision might be relaxed. The Thomas S. class members are more integrated, more satisfied, better served, more independent, receiving less medications, and much more likely to be working and earning money. This project has strongly suggested that serious behavior "problems," even criminal histories, need not prevent people from flourishing in well supervised community homes. The placement

⁴⁹ *Ibid* at 44.

⁵⁰ *Ibid* at 17.

process was so successful that the judge recently dismissed his own Order, concluding that all the original goals of the Thomas S. action had been achieved.⁵¹

64. New Hampshire, with the closure of the “Laconia State School and Training Center”, became the first U.S. state to close all of its institutions. As the last institution to close, Laconia housed many of the most “high-needs” individuals who had been deemed unsuitable for community placement in earlier institutional closures in the state. Per Conroy,

Most of the last remaining group of people had serious behavioral or medical/health challenges. Up until the final year, many state officials appeared to believe that the institution would always be necessary for some people. In the end, New Hampshire elected to demonstrate the opposite. Even the most “medically fragile” people are now living and thriving in small, homelike settings. This achievement has an important place in the history of developmental disabilities. New Hampshire was the first state to show that communities can support all people, regardless of the severity of their disabilities.

I am continuing to perform studies and evaluations in New Hampshire to the present day. I see compelling evidence that even the most “difficult” people have been afforded the necessary supports in community settings. The overall evaluation of my 16 years of research in New Hampshire can only be that all people can, and do, live in the community, and that their lives are indisputably far better on the average.⁵²

65. That is not to say that all cases are easy; one recent Canadian survey of research projects does report that suggest that deinstitutionalization for people with severe developmental disabilities has not been problem-free:

According to Mansell et al. (2001), individuals with challenging behaviour are more likely to be institutionalized, less likely to be offered residential services until the end of the deinstitutionalization process, and are more likely to be reinstitutionalized or sent to other institutions. Furthermore, they are at increased risk of abuse, live in restricted and bleak environments, receive very little staff contact, remain isolated from the community and personal support networks, and receive little help addressing challenging behaviour (Felce et al., 1998, Mansell et al., 2001)⁵³

66. It appears therefore that the problems experienced in the deinstitutionalization of challenging cases stem in large part from the treatment, or lack thereof, that those individuals have received. It must

⁵¹ *Ibid* at 22.

⁵² *Ibid* at 19.

⁵³ Stainton et. al. *Residential Options for Adults with Developmental Disabilities: Quality and Cost Outcomes. Literature and Initial Program Review*. UBC School of Social Work and Family Studies, Community Living Research Project. October 2006, 60 pp., see especially pp. 24-29.

also be noted that the researchers reporting these difficulties are nonetheless committed to the goal of community living for all despite difficulties experienced, perhaps because they feel that the people they have worked with and studied ought not to be punished with institutionalization merely because they will need more support in the community. The studies reported also show that with proper supports, the problems can be addressed and more challenging individuals can also realize benefits in the community, such as increased level of participation in meaningful activity.⁵⁴ While the costs for supporting such higher-needs individuals reach a similar level as for institutional care, the study suggested that people were receiving better service in the community for the same dollars:

Mansell and colleagues (2001) suggest interpreting the results of this study in terms of added value. Staffed houses in this study had double the staff in institutions but were providing 3.4 times the staff contact and 4.5 times the assistance to the individuals served. Overall, Mansell et al. found that It was possible to establish residential alternatives in place of hospitals for people with severe disability and extremely challenging behaviour. Community-based placements offered a much richer social and physical environment, and involvement in meaningful activities and level of competence increased as a result. "The evidence of this project suggests that even specialist institutional provision, including hospital-based housing, provides a very poor quality of life for clients, despite the resources which have been invested in it" (p. 284).⁵⁵

67. Thus, while acknowledging that high-needs individuals were more costly to support in the community such that no dollar savings may actually be achieved, it must be noted that more importantly, high-needs people receive better care in the community for the same level of public expenditure; deinstitutionalization advocates appear to be motivated by human rights concerns, not budget considerations, so they do not regard the absence of dollar savings in some cases as fatal to their argument.

68. Conroy recognizes that in extreme cases there may be a safety risk in the community, but finds that even such cases have been successfully accommodated and he concludes that

... it is possible to place all residents of a state institution into small, integrated residential settings within the community... My opinion is therefore that the four classic reasons for keeping people in large, segregated, isolated, institutional settings cannot be supported by

⁵⁴ *Ibid.* at 27

⁵⁵ *Ibid.* at 27-28.

the facts.⁵⁶

69. Larson and Lakin also reported, after reviewing 18 studies involving 1,350 individuals, that “smaller residential settings had a positive impact on the ability of people with mental retardation, regardless of the level of disability,” that these may in fact be especially beneficial for severe/profound individuals because they promote greater growth in independence, and finally also that one should not overlook the simple benefit of getting to live in community with access to the same options and opportunities that others also get to enjoy.⁵⁷

70. In an article called “The Final Stages: Community Services for People Considered the Most Difficult to Serve”, Fitzpatrick and Lakin report that

States that are successful in final stages of closing state institutions have developed ways to virtually eliminate admissions to those institutions. Such states admit individuals to state institutions only in extreme situations, if at all.⁵⁸

71. This is interesting because this is the present situation in Manitoba, with new admissions to the MDC being a rare occurrence. The success of states that have achieved this probably lies in the fact that in eliminating new admissions, those states have had to find ways to support those potential new residents in the community instead. Once a system has learned how to accommodate new patients in the community, it can presumably apply the same resources and skills to place long-time institutional residents in the community. Lakin & Fitzpatrick also report that

As public institutions are closed, states have been successful in serving persons with developmental disabilities and serious challenging behaviors in a variety of community programs. In doing so, they often face ethical and fiscal questions in deciding how and where to serve individuals with developmental disabilities and behavioral concerns that impact on public safety. But none of these states that have faced these challenges and made these commitments expresses any regrets that they are now operating the residential services without state institutions.⁵⁹

⁵⁶ *Deinstitutionalization*, *supra* note 7 at 46.

⁵⁷ From Larson, S.A. & Lakin, K.C., “Deinstitutionalization of persons with mental retardation: Behavioral Outcomes,” *Journal of the Association for Persons with Severe Handicaps*, 14(4), 324-332, as cited in Lakin & Prouty, “Trends in Institution Closure”, *Tool Kit* at 75.

⁵⁸ Tom Fitzpatrick and K. Charlie Lakin, “The Final Stages: Community Services for People Considered the Most Difficult to Serve”, *IMPACT: Feature Issue on Institution Closures*, 9(1), 24-25. See *Tool Kit* at 55.

⁵⁹ *Ibid.*

72. Another group of researchers also agrees with the above conclusions. In “Policy Research Brief: Status of Institutional Closure Efforts”, the issues of challenging behaviour, complex medical needs and elderly residents are all addressed – see Tab 10 in the source materials binders.⁶⁰ With respect to challenging behaviour, the writers rely on a 2001 survey by Kim, Larson & Lakin.⁶¹ This survey of other research reports that 31 of 33 studies of deinstitutionalization reported either improvements (or no significant change) in adaptive and challenging behaviour. This suggests that challenging behaviour is not a barrier to deinstitutionalization and that individuals with challenging behaviour can be supported in the community.

73. On the topic of persons with complex medical needs, it is reported that

People who have medical conditions requiring sophisticated medical expertise and technology are living in the community in most states. For every person with such needs in institutions, others with the same or more complex needs live in the community.⁶²

74. However, it is noted that for individuals on their own or living with family, complex medical needs can create difficulties – appropriate staffing and supports are required, as in an institution.

75. Finally, on the topic of residents who have grown old in the institution:

A good old age is a universal aspiration...at its core is respect for the aging person's human rights, dignity, choices and desire for a decent quality of life. Older people with developmental disabilities require – and deserve – no less (Dybwad, 1999, p. xv)⁶³

76. Nancy Rosenau, in a thought-provoking article called “But aren't there some people... ? Dispelling the myth” (Tab 22) takes a fresh approach to the question, with a particular focus on the question of complex medical needs and the specialized care required.⁶⁴ She breaks down the institution into its basic components: people and buildings, and steps back to question some assumptions that are made.

⁶⁰ *Closure Efforts*, *supra* note 26.

⁶¹ Shannon Kim, Sheryl Larson and K Charlie Lakin, “Behavioural outcomes of deinstitutionalization for people with intellectual disability: a review of US studies conducted between 1980 and 1999” (2001) *Journal of Intellectual and Developmental Disability* 26 No. 1 at 33-50. [Behavioural outcomes]

⁶² *Supra* note 60 at 3.

⁶³ *Ibid.*

⁶⁴ Nancy Rosenau, “But aren't there some people...?’ Dispelling the Myth”, *Tash Connections* 30(3/4) 8-10, 30, reprinted in *Tool Kit* at 63.

She concludes:

The fact is there are people who have significant health issues that are complex, need a trained eye to evaluate, require specialized intervention, are sometimes chronic, and sometimes critical. The fiction is the leap to the conclusion that they need a special kind of building to live in and to share with others with similarly complex needs.⁶⁵

77.Perhaps prompted by the wealth of “functional twin evidence”, that “For every person for whom an institution is suggested, there is a “functional twin” with exactly the same needs who lives successfully in a home in a community”, Rosenau suggests that “Rather than asking “Doesn't A have to live where B is available?”, we can instead ask, “Can B be available where A lives?””, with B referring to specialized medical care.⁶⁶

78.From her own assessment, Rosenau concludes that

If we look at any single individual it is hard to conclude that This Person *needs* cafeteria dining arrangements; or This person *needs* to share a residence with 5, 25, or 300 other people; or This Person *needs* a roommate with equally complex needs.

When we closely examine what This Person does need, we find it is oxygen, not the fact that it is piped in from a line in the wall; or medications, not the fact that they are stored in the pharmacy downstairs; or nursing, not the fact that they park in the employees lot.

...

What we find when we break down the peopled environment is that the need for institutional care is not located in This Person, but is located in the way we've organized needed assistance into a limited number of settings. We find This Person does not need an institution, but, rather, we have configured the delivery of services so that the only place that offers people with the needed time, energy, expertise, and proximity are congregated in a building that is not the person's home. These logistics are alterable.

...

So the question, “Do some people need institutional care?” can be reframed as, “Have we organized our care arrangements in such a way as to provide them in a person's home?” When push comes to shove, these decisions are less often about what individuals *need* and are more often about economics.⁶⁷

79.The unfortunate reality of course is that sometimes human services are not all they should be because of economic necessities. However, as other research has suggested, community care is often in fact more economical, as will be discussed below.

⁶⁵ *Ibid.*

⁶⁶ *Ibid.*

⁶⁷ *Ibid.* at 64-66.

80. For more resources on the question of whether all individuals can be supported in the community, see pages 49 to 69 in the PDF version of the *Community for All Toolkit*⁶⁸ and also pp. 44-46 of *Conroy's Statement*.⁶⁹

“Community Support Systems are More Cost Effective than Institutional Systems”

81. While costs may be similar in the community for high-needs individuals, on the whole the experience has been that community placement is consistently less costly than institutional care. However, Conroy points out that this is largely because community support workers are paid less than their professional institutional counterparts, and that community support should be funded at a higher level.⁷⁰ Nonetheless, individuals placed in community reportedly experience significant benefits in numerous dimensions despite the lower cost of care. One argument to justify large institutions is that they achieve an economy of scale, to which Conroy replies that there are also diseconomies of scale when an organization is too large; in Conroy's opinion, “when we are in the business of creating homes for people, those diseconomies begin to set in at about size 4.”⁷¹

82. Nancy Rosenau speaks on this issue as well; she says that

Defense of institutions invokes “economy of scale” arguments that say we need to put individuals with like needs together in physical spaces to be able to afford the caregivers that are needed. This argument reveals that it's not that individuals need institutions but that institutions need multiple residents to share the helper-people in order to make the economics work. If we can't figure out how to reconfigure our service arrangements, let's at least stop saying people need institutions—let's say institutions need people.⁷²

“Research Findings are Remarkably Consistent”

83. This aspect of the research has already been remarked on above; James Conroy condenses his assessment of this consistency in his *Statement* at pp. 48-49, citing the meta-analysis of Larson &

⁶⁸ *Tool Kit*, *supra* note 13. Available online at http://thechp.syr.edu/toolkit/Community_for_All_Toolkit_Version1.1.pdf

⁶⁹ *Deinstitutionalization*, *supra* note 7.

⁷⁰ *Ibid.* at 47.

⁷¹ *Ibid.*

⁷² *Some People*, *supra* note 63 at 66.

Lakin, who he says “found complete consistency in the literature.”⁷³

84. It is indeed difficult to find contrary evidence, as the consistency is dramatic. According to Conroy,

No researchers have yet found that people become more dependent when they move to the community. One report found no change, and all the others found significant improvement. Similarly, no researchers have found families to be less satisfied with community homes than with the institution, even though families tended to be very satisfied with institutional care as long as their relatives were in institutions.⁷⁴

85. Nevertheless, there continues to be resistance to deinstitutionalization in some sectors. Families believe that their relatives are doing as well as they could in their current institutional home. The institutions believe that it knows what is best for its residents and has the best of intentions. It is often only after seeing the benefits of community living first hand that families become convinced.

“Family Attitudes Change Dramatically”

86. It is not uncommon for families of persons in institutions to support the continued existence of institutions and their relatives' continued placement in institutions. This has been one of the strongest forces opposing the deinstitutionalization movement. Conroy has found however that after seeing their relative move into the community, families' attitudes change dramatically in support of deinstitutionalization.⁷⁵

87. As one representative example, Conroy found that in California, “Large majority of families were pleased with community supports, wanted them to continue, and *would not think of returning their relatives to Developmental Centers.*”⁷⁶ In another study specifically dealing with the question of family satisfaction following the closure of the Hissom Memorial Center, Conroy reports that 38.7% Family opposition to deinstitutionalization was transformed into 90% support after seven years experience of community-based care⁷⁷

⁷³ *Deinstitutionalization, supra* note 7 at 48-49.

⁷⁴ *Ibid.* at 48.

⁷⁵ See *Ibid.* at 43 for Conroy's summary of this evidence, though it is also reported in his summaries of past studies in the first section, pp. 4-40.

⁷⁶ *Ibid.* at 31.

⁷⁷ James Conroy, *Seven Years Later: A Satisfaction Survey of the Families of the Former Residents of Hissom Memorial Center*. Center for Outcome Analysis, 1999, 32 pp.

88. Thus, according to the research, it appears that not only academics and policymakers are becoming convinced of the benefits of community placement, but also those who know the disabled persons best and who initially strongly oppose deinstitutionalization.

“Community Living is not without problems, and requires protections”

89. Finally, however, Conroy does acknowledge that community placement is not perfect, and will not always bring improvements in all cases. In his words,

It is clear that the overwhelming majority of people can be expected to have very positive experiences with community living. Yet it must be recognized that a small proportion of people will have serious difficulties in the community. The evidence must be examined carefully to see what proportion of people will have difficulties, what kinds of difficulties, whether we can predict which people will have difficulties, and therefore whether it is possible to prevent even those relatively infrequent difficulties.⁷⁸

90. Based on his research in the Pennhurst closure, Conroy concludes that certain safeguards have been shown to be effective in minimizing problems in community. These safeguards are: support coordination, person-centered planning, and quality assurance.⁷⁹

91. One issue that Conroy identifies is the risk of abuse. It has been claimed that in the closely monitored context of a large institution, abuse will be more quickly detected and dealt with. Conroy responds that

I have never seen a shred of evidence for this contention. In contrast, I have seen dozens of investigations, both sociological and criminal, in which Developmental Centers have been accused of generating a "culture of immunity and/or silence" in which staff can do whatever they like without fear of reprisal.⁸⁰

92. Conroy also points to the iconic “prison” experiment conducted at Stanford in 1971 by Zimbardo, which demonstrated how mentally healthy adult males fell into abusive and psychologically unhealthy patterns as a result of merely acting out the institutional roles of prisoners and guards, knowing full well that it was an experiment. Zimbardo concluded that the abuse was facilitated by

⁷⁸ *Deinstitutionalization, supra* note 7 at 50.

⁷⁹ *Ibid.*

⁸⁰ *Ibid.*

the “guards” ability to depersonalize the “inmates”, a phenomenon which is intensified with the size of the institutional setting.⁸¹

93. While it is acknowledged that abuse will also occur in the community, the important question, according to Conroy, is “In which type of setting is there less abuse and neglect?” which unfortunately has never been satisfactorily answered in research largely because of the tendency of abuse to be covered up in either the institutional or the community setting.⁸²

94. Conroy argues that “in a very small setting, care “givers” simply cannot perceive care “receivers” as faceless non-individuals in a group”⁸³ and that consequently smaller community homes are less susceptible to abuse and neglect. Conroy also relies on other organizational and economic literature which he says “are completely clear on the conclusion that small group size for daily work and functioning produces higher satisfaction, productivity and efficiency.”⁸⁴

95. This theorizing is shared by others in the field. The writers of the *Community for All Toolkit* outline some of the inherent problems with the institutional model as follows:

Abuse and Neglect - People with intellectual and developmental disabilities are vulnerable to abuse and neglect. These can occur in institutions as well as in the community. However, because of the large numbers of people in institutions and the depersonalization that occurs in large settings, abuse is more common and harder to detect in institutional settings. Experienced advocates talk of a "wall of silence" among institutional staff. Due to inadequate staff and lack of other resources, institutions became places of widespread abuse and neglect. Dick Sobsey, a leading expert on abuse of people with disabilities, says that people who have the best chance of not being abused are those who are fully integrated into the community and surrounded by people who care about them.

Dehumanization - Within institutions, people have been treated in ways that disregard all human dignity and respect. In many ways, people are thought of more like numbers than as humans. As one example, in the past, many people who were buried in institutional cemeteries had markers with numbers rather than their names.

Segregation and Isolation from the Community - Institutions cut people off from the mainstream of neighborhood and community life. Many institutions have been geographically located in rural areas. Even in urban areas, though, institutions have

⁸¹ *Ibid.*

⁸² *Ibid.*

⁸³ *Ibid. at 51.*

⁸⁴ *Ibid.*

operated on a very self-sufficient basis, with the idea that the institution itself is the "community" for those who live there. Thus, individuals living in institutions have often had little or no opportunity to participate in the life of the community beyond the institution.

Lack of Human and Civil Rights - People have been confined to institutions for years without any legal reason, only because of the label of "mental retardation." They have been denied privacy, choice, and control in their lives.⁸⁵

96. In the end, perhaps it comes back to what the ARC plaintiffs in the Pennhurst case first claimed – that institutions by their nature segregate and isolate, and that this cannot be corrected with any amount of additional funding or “quality control”, or improvements to infrastructure. An institution is an institution.

Conclusion

97. Deinstitutionalization of persons with intellectual disability has been a significant social policy trend in the past decades, more closely studied than perhaps any other. The studies done speak overwhelmingly in favour of this trend, and appear to be both motivated by and provide support for a view that people with all levels of disability can and should live in small homes in community settings, to both honour their human right of self-determination and to deliver the best possible care and promote their full development as individuals.

98. None of the classic reasons for maintaining large institutions appear to be supported on the evidence, as all people, regardless of level of disability, complexity of medical needs, severity of behavioural problems, and history of living in institutions have been successfully integrated into community settings.

99. Based on the current state of the literature on care for persons with intellectual disability, it appears that the institutional model is obsolete and discredited, its last remnants preserved purely by political

⁸⁵ *Tool Kit*, *supra* note 13 at 83-84. For more on this, see *Realities*, *supra* note 38. Also, see John O'Brien et. al “What can we count on to make and keep people safe?”, *Tool Kit* at 138, particularly p. 13 of that article where the section called “What makes people with disabilities vulnerable” lists lack of power, isolation and institutionalization as three leading causes of vulnerability.

and social inertia in the face of broad policy consensus among advocates, governments and international bodies. Manitoba itself has committed itself to a vision of community inclusion for all. Finally, both residents and their families wholeheartedly support community living once they experience it, often despite strong initial opposition.

100. Community-based care appears to deliver better results that are more respectful of individual liberty for comparable or lower cost than institutional care. Both residents and their families and friends overwhelmingly favour community living for their loved ones once they have a chance to experience it after years of institutionalization.

101. The key concerns driving the deinstitutionalization movement are the isolation, segregation, and the denial of self-determination of persons with disabilities; these appear to be inherent to the institutional care model, fulfilling the early concerns of Samuel Gridley Howe about the model that he introduced to North America. Institutionalization subjects people to all three of these not because they have violated the Criminal Code, but merely because they are living with an intellectual disability and because of the practical necessities of trying to deliver human care for vulnerable persons in a large institutional setting.

102. This suggests that the deinstitutionalization movement is not about disability issues as much as it is about human rights. As the research shows that institutional care is simply not necessary, even for the most challenging cases, one must conclude that the continued institutionalization, segregation and isolation of persons with disabilities is unjustifiable in light of the wealth of available social science evidence.