Why Group Homes Are No Longer Optimal: A Commentary

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Introduction

The use of group homes as a housing and support option for people with disabilities emerged in the Canadian and other countries context in the early 1970's. It is now almost a half century later and these models have become quite extensive in number throughout Canada and elsewhere. This development occurred in many instances as a way to resettle people with disabilities from large residential institutions that were closing due to the view that these settings were outdated, harmful and inconsistent with the true life potentials, rights of persons and social inclusion of persons with disabilities. Such conclusions had been reached initially reached internationally at that time and over the interim decades the closure of residential institutions has subsequently occurred in many countries.

Though the group home was *at one time* the leading edge option for improving the lives of people with disabilities, it is now no longer considered the best option by leaders in the field. In fact, much as the large residential institutions were eventually viewed as harmful, today group homes have met the same fate and are themselves seen as outdated, harmful and inconsistent with the true life potentials, rights of persons and social inclusion of persons with disabilities. The reason for this is that the disability world has pressed onward since a half century ago with further innovation, leadership and updated concepts and standards of quality. This forward looking and visionary investment has predictably resulted in options that are much superior in terms of the net benefits they provide to people with disabilities. Just as we should not be reliant in 2017 upon technologies that were considered as being at the leading edge in 1970, it is equally prudent that we do the same in how people with disabilities are enabled to live in 2017 and beyond. What will follow is a brief summary of what has been learned and developed in the past half century that offers people with disabilities the best life prospects.

Prior to doing this it is important to address why we still have group homes in 2017, as this has a bearing on the ongoing process of service systems transformation. Much like when we began to introduce group homes as options in 1970, it took a considerable amount of time to construct the supporting financial, operational, policy and safeguarding infrastructure that would enable such options to become more routinely available. That very same group home infrastructure is now unsuitable for this generation of leading edge options and thus stands as a systems impediment at the leading edge. This is because group homes currently consume and divert resources that would be better directed to superior leading edge options, much as in the emergence of groups homes residential institutions similarly took many decades to disassemble such that resources and priority could be directed to better options. In other words, there is normally a lag in time between the demonstration of leading edge models and benefits and eventually bringing them to scale. We are currently in the midst of a similar important systems transformation in many countries as it

relates to both the pioneering of better options and bringing into place the means by which these options can be made available to increasingly larger numbers of people who could benefit from them.

What have been demonstrated to be the leading edge options at this point in time?

In its simplest sense, the leading edge of the disability sector could be summarized as being socially inclusive, self-directed individualised lifestyle and support options. For most people this is captured with terms like "person centred" options, or in some jurisdictions, "personalised" or individualised options. The number and variety of these options have been steadily growing in multiple jurisdictions and have emerged in many areas of support including employment, residential support, education, transport, family support, behavioural support, health support, leisure and so forth. In other words, in all major domains of lifestyle and support. It is also true that options similar to these have emerged in other sectors

There have been many drivers behind this ongoing large scale transformation of practice and support models. Certainly the most significant driver has been at the values or ideological level, where the key premise has been the recognition that people with disabilities are all each unique persons and they quite rightfully want and deserve lifestyle and support options that respect the importance of their distinctiveness as person. This is in contrast to being seen principally in terms of their disability rather than their personhood. Not surprisingly, from such a premise has come the increasing emergence of countless opportunities for people with disabilities to live a life which is much more of their own choosing. Service models and practices have changed to better suit this disentanglement of people with disabilities from stereotypes of people with disabilities to people living a life that better suits them "one person at a time". Obviously, person centred services have followed, as these have become the preferred means by which such individually tailored lives and supports are created.

Another key driver has evolved from what began as the normalization movement in Scandinavia in the 1960's and elsewhere, into the view that people with disabilities are fundamentally people like all other people and ought to have access to the same resources, opportunities, rights and responsibilities of their fellow citizens. This was elevated further into the social role valorisation framework which has emphasized the acquisition of individually meaningful valued social roles. Such a view of people with disabilities as *not being second class citizens* (and thus treated less well than their fellow citizens) has been accompanied by the supportive view that they should be in the heart of community rather than segregated (and involuntarily congregated) at the margins of community life. Or, as many would say, they

should have the same normative *social inclusion* opportunities as anyone else in the community.

A third key driver has arisen from the experience of disempowerment by persons with disability in countless aspects of their lives as others rush in and take control of their lives, often without recognising that they are doing so and not appreciating how harmful it is to take away a person's control of their own life. The antidote to this has been the recognition that people with disabilities ought to be in charge of their own lives, much as most people without a disability take it for granted that their autonomy ought to be respected. This premise is captured by the well known slogan of the independence living movement which is "nothing about me without me". The adoption of this ethic has had many impacts and one of the more notable has been the rise of user directed services in which the person with a disability designs and directs their own individualised lifestyle and support arrangements.

How has leading edge thinking and values been transformed into new models of support?

Again, at its simplest, "one person at a time" person centred lifestyle and support options are now becoming widespread as the infrastructure to support them has gradually been put in place to make these options possible. That infrastructure principally had initially included a gradual expansion of more personalised support arrangements, often at the outset through demonstration projects and other pilots and subsequently by incrementally expanding the availability of these options for greater numbers. This has involved changing attitudes and practices, installing various forms of individualised funding to suit purpose, establishing varieties of self-direction and self-management, the spread of a multitude of individualised planning modalities, creating governmental policy frameworks, adding targeted supports for individuals with specific needs not addressed well enough in more conventional system arrangements, the targeting and installation of more individualised safeguards and so on. As has already been indicated. individualisation has also expanded into all areas of people's lives and needs.

This expansion of individualised options can be seen by simply looking at the extent to which significant jurisdictions internationally and within Canada have unrelentingly moved towards towards increased individualisation. This trend can be observed in many countries as an expanding preference for such options by service users and families, *once these opportunities have been made available*. Similarly, there seems to be no evidence of service users somehow abandoning individualised options once they have accessed them in favour of returning to traditional congregate (group) models such as group homes. Rather, the reverse is true. People with disabilities and their families are increasingly opting for these options once they have a chance to experience some of the benefits that come with their use. It is notable that even those

persons and families that may have been initially wary of these options have been able to transition to their use.

For example, Australia with its new National Disability Insurance Scheme (NDIS) has recently made self-directed individualised funding a right for approximately 460,000 people with disabilities throughout the country. In the United States there are now over 300 individualised funding streams operating across fifty states and territories and more are added each year. The United Kingdom has had *direct payments* (a form of individualised funding) for several decades and Scotland in recent years has passed a law making individualised funding a right if the disabled person wants it for themselves. New Zealand has been expanding its individualised funding every year since it was introduced about a decade ago. Ireland is currently hard at work with a national task force designing its individualised budgets program for the country. Finland has just introduced their national scheme for widespread individualised funding. Holland has had individualised budgets since the 1990's and they are expanding the numbers served. Canada has growing numbers of people in individualised funding in many provinces including British Columbia, Alberta, Manitoba, Saskatchewan, Ontario, Newfoundland and New Brunswick. It is notable that individualised supports, lifestyles and funding are not only for people with disabilities, as parallel movements to create these are and have been underway for some time in aged care, mental health, addictions, children's services, income support, housing and so on.

It is hard to argue that individualised supports are somehow not emerging "best practice", given their growing size and significance in these and other national and more local service systems. This significance is not just in greater numbers and consumer demand, it is also reflected in government policy in support of socially inclusive individualised lifestyles in the community. A key aspect of this is that the use of individualised options increases when these are made available. Similarly, congregate model use declines when individualised alternatives are made available. It is true that small congregate models may be preferred over large congregate models in instances when no other alternative is on offer. So, the key question is whether people who might have experienced individualised options ultimately prefer to return to small congregate support options. The evidence in that regard is that they massively prefer individualised options and are reluctant to lose them once they have them. A similar pattern had preceded this during the group home era where people opted for smaller group homes over larger ones and very small homes (e.g. 2-3 persons in a home) over small group homes. It all depends upon whether the system concerned makes individualised options possible. Obviously, people may have no choice but to go with whatever options are available at a given moment. So, the real test is what people do when they actually have individualised options "in hand".

Perhaps the most extensive data base on trends in residential support models is the University of Minnesota Institute on Community Integration, National (USA) Residential Information Systems Project (RISP), and the Supporting Individuals and Families Systems Project (FISP). These are long term US data sets and quite massive and thus are very useful for detecting trends. Without unduly oversimplifying the data, the trend is repeatedly over time clearly away from large options to increasingly smaller and individualised options. It should be noted that there is considerable variance from state to state with some US states at the leading edge of the trends and others more at the tail end of these trends.

Another important aspect of the overall move towards socially inclusive and self-directed individualised options have been the challenges involved in closing and downsizing outdated models. This showed itself initially with both the large institutional models resisting downsizing and elimination and the challenge faced by proponents of community living options to obtain the necessary resources to expand these options. This same pattern was repeated when it came time to reduce and eliminate smaller institutions. Now, it is repeating itself again in the effort to eliminate and replace “mini institutions” i.e. group homes, with individualised options. It is instructive that in each of these phases, the smaller and more socially inclusive options have eventually prevailed. The US data are typical of the fact that eventual system transformation to smaller and individualised options is routinely incremental, but is often delayed by economic, political and attitudinal constraints like governmental austerity budgets, mobilisation against change by interest groups trying to preserve the status quo, a lack of leadership and resolve politically and other quite normal pressures involved in changing systems over the long term.

Why would building new group homes at this point in time be regressive and misguided?

As indicated earlier, group homes have had their day and are now at least a generation out of date and that fact will simply deepen in significance and consequence as the disability world progresses forward. There is absolutely no evidence that the future leading edge of best practice shows any support for group homes in comparison to person centred options. If you like, group homes are “behind the curve” rather than in front of the curve. Consequently, from an actuarial point of view, any proponent of group homes will be locking its resources into what will undoubtedly become a wasted fifty year investment into buildings that will ultimately prove to be a “white elephant”. After all, why would one invest in an option that is in decline rather than one on the leading edge? Such a judgement call to build new group homes may deal with immediate pressures to stay with status quo thinking and models, but in relatively short order it will be revealed to be damaging and regressive in terms of forward and enlightened practice in relation to people with disabilities. The

difficulty with starting with buildings is that their *raison d'etre* gets locked into the architecture and if that reasoning proves to be invalid, it is very expensive to fundamentally redesign and rebuild individualised options. Consequently, the more prudent strategy is to use options that have a very strong likelihood of being viable for a long period of time into the future.

This raises the question of whether better options than group homes have been properly explored such that a proper assessment of the comparative merits can be done. In other words, on the basis of what specific multi-dimensional programmatic evidence has it been concluded that group homes excel over other options? Thus far, no such exhaustive study has been done or presented by those involved that provides justification for a singular uncritical reliance on group homes as the only option being considered. Such an approach is negligent given that if the conclusion turns out to be wrong, it largely creates an option that is irreversible and not modifiable since it essentially creates a "bricks and mortar" dead end. If one upholds the precautionary principle of "do no harm". It is better to err at this point in history on an exclusive use of socially inclusive individualised approaches.

Group homes have been repeatedly evaluated as being essentially "mini-institutions", particularly by service users themselves. Further, they are often built alongside other groups homes on a segregated campus, thereby creating an involuntary encampment of people with disabilities set apart from the many other normative living arrangements possible in the community. Strikingly, when only this option is presented to people with disabilities, it means that the wide range of community options they might otherwise have been conceivably offered is entirely jettisoned by pre-emptive and arbitrary administrative fiat. This is in contrast to taking into account what the potentially diverse housing and support options of people with disabilities might be if they were enabled to make their own decisions on the subject "one person at a time". The imposed "take it or leave it" approach summarily and without justification, unilaterally dictates to the people with disabilities affected that they should all settle for only one housing and support option i.e. group homes congregated on a former institutional site. Such a high handed, patronizing and unwelcome imposition upon their lives and future life possibilities could hardly be taken as being consistent with the ethic of "nothing about us without us".

Setting aside the question of the failure of some increasingly rare current planning processes that have resulted in a proposal for a forced shoehorning of people with disabilities into a single housing and support option, it is important to recognise what has been happening in terms of leading edge practices and options for even the most significantly disabled persons. The most crucial is the fact that it is quite possible today to create a wide range of individualised housing and support options in as many locations in the community as there are people with disabilities. The needs and individual requirements for lifestyle, housing and supports for people with disabilities are routinely quite varied in

many dimensions of people's lives. This diversity of personal requirements ought to be respected and responded to and effective and beneficial person centred practices have proven to be able to do just that.

Some of these "one person at a time" dimensions should be considered at this juncture, as these will help make the questions involved much more tangible. It is not typical for people without disabilities to be restricted to living only in one location in a neighbourhood, community, city, region or province. Ordinary people typically have distinct neighbourhoods and communities that they might prefer over others. For instance, one person might like a community that is near to friends and family. Another might seek a location that has features they value such as access to parks, easy shopping or good public transport. The ability to find locations to live that suit individual preferences and priorities is lost entirely when people are offered only one "take it or leave it" living option.

Another illustrative dimension would be the question of whom to live with and whether the person with the disability is making that decision or whether they are forced to live with or nearby people that they do not want to live close to. In instances that force the person with a disability to share a home with others not of their choosing in a single location with a sizable number of people with disabilities similarly coerced into households not of their choosing, denies the person the right to choose whom to share their home with should they even want to share their home. They also could lose the right to live alone if that is their preference. They could also experiment with living arrangements over time, should their current arrangement not be working for them. In other words, they could have the same choices available to them that most people in the community have.

A further illustrative dimension is that of the specific nature of the supports they might need to live as independently as possible. Though individual people with disabilities may often have some needs in common with those of other people with disabilities, it is also true that they equally may differ extensively in what they might need by way of supports. It should be noted that "supports" go well beyond questions of physical and health supports, as what they are attempting to do with their lives may create the needs for many other varieties of individually targeted supports. For instance, if one individual is studying for a degree, that may require supports that are quite different from a person who wants to participate extensively in community artistic pursuits. In other words, lifestyle supports are as vital to personal wellbeing as might be "in home" functioning supports. Similarly, living in the community rather than being segregated apart from it enables people with disabilities to access and benefit from the myriad resources of a community. However, if they are not supported to be in community and to participate in aspects of community that appeal to them they will inevitably have lives of lost opportunities and avoidable deprivation.

Another dimension that is also illustrative of the needs of various people with disabilities would be whether they would have access both to living within the community in normative homes and locations and access to adaptive features in their home that enable them to live as independently as possible. We are fortunate at this point in history to have an abundance of “smart home” and other technology that can be largely invisibly present in a person’s home that makes them much more highly self-sufficient and that does not require them to be in a designated disability service setting. In other words, they can live as their fellow citizens and yet be otherwise well supported. In reality, such options are very advanced at the technical level, but their availability is still much too limited. Investing in such advanced but feasible technology *in ordinary living arrangements in the community* would be a massively significant advance, as it would put to an end to the justification of the involuntary segregation and exile of people with disabilities from the ordinary life options of community that they seek and need.

Conclusion

The argument made here in this brief commentary is that people with disabilities would not be well served in the limited life options available within group homes, particularly those gathered together in institutional sites. This is because they will be deprived of a wide variety of everyday, but rich and diverse life options, that are freely available to ordinary citizens of our communities but denied to people with disabilities in the name of abstractions like “care” and “service”, but which provide largely only custodial existences compared to what is possible when people with disabilities have authentic access to the fullness of community life. If such custodial settings as group homes were in the least bit life enriching, then one could expect widespread desertion of ordinary citizens to them.

That has obviously not happened, nor will it ever occur, as group homes are not even considered credible options for themselves by most citizens. So, consequently, why should these highly undesirable options be promoted as being somehow at the top of the list for people with disabilities, particularly in the context of them not being offered even a modicum of the options that are massively chosen for themselves by Canadians. It is time to recognize that what is being advanced as a replacement for Pearson is tragically inadequate, harmful to the wellbeing of people with disabilities and that fall short of what could be offered to them while there is now still time to do so.

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