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The Inclusion of Adults with Intellectual Disabilities (ID): A Study of Two Community Based Group Home Service Providers in Saskatchewan

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Abstract

A survey was conducted with front line disability service workers in two community-based organizations providing supports to adults with ID in Saskatchewan. The survey consisted of questions regarding the staff member's training, experience and education as well as their perceptions of the resident's experiences in three major areas. The areas of focus are participation in the daily tasks of the home, physical participation in the community, and social inclusion. The results, albeit inconclusive, suggest that adults with ID in group homes participate in a subset of the daily tasks of their homes and enjoy a large degree of physical inclusion in their communities. Unfortunately, these same people are not being socially included in the community outside of the organizations where they receive services. The reasons for this exclusion are outside the scope of the present paper but the current results demand further examination of community supports to determine the social barriers that exist between people with ID and non-disabled peers in their communities.

Keywords

Intellectual disability, group home, community, inclusion, relationships, natural supports.

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Introduction

Since the late 1960s people with intellectual disabilities (ID) in Canada, and many other western nations, have increasingly been afforded greater legal rights. One important result of this trend has been that the number of people with ID living in large congregated institutions has steadily decreased while the number of people living in the general community has increased. Advocates for this change have argued that quality of life (QOL) is better for people living in the community than it is for those living in institutional settings. Most people with ID, advocates, and researchers agree that one important facet of QOL has to do with a person’s inclusion in their community. As the last institutions in Canada are closed, it is important to empirically evaluate existing community living services to determine if people with ID are being fully included in their communities. The aim of this study is to assess the experiences of people with ID living in group homes in a small city in southern Saskatchewan. This research is timely because of the impending 2016 closure of Valley View Centre (VVC), located in southern Saskatchewan, which currently accommodates more than 190 adults with ID.

Method

An online survey was conducted with front-line group home care providers working in a mid-sized Saskatchewan city. The survey consisted of three parts. The first section gathered

basic demographical information about the staff members. Part two consisted of 19 questions about the residents in the group homes where the staff work. The criterion for participation was that the respondent must work in a group home(s) with adults (18 or older) operated by a non-profit community based organization (CBO). The group home had to house no less than one resident and no more than six and the residents had to be receiving services as a person identified as having an intellectual disability (ID). These criteria were chosen because the Transition Steering Committee (TSC) identified this living arrangement as one of the most likely residential options for the 129 VVC residents who identified the surveyed community as their preferred place of residence after the closure of the institution (TSC, 2013, p. 27). The latter portion of part two of the survey asked questions about the staff member's perceptions regarding the resident's daily activities in the home and surrounding communities. The final portion of the survey asked the staff members for information about their training and the expectations of their employers in terms of performance.

Results

Limitation of the study

There are two obvious limitations in this study that need acknowledgement. As noted above, care providers are used as proxies to gather information regarding the lived experience of adults with ID. The validity of this method has been recently criticised (Rabinovitz, 2003, p. 75; Jingree et al., 2006, p. 224). Despite concerns, a proxy method was chosen because the residents in the group homes are impacted by a variety of communication related impairments which would make data collection extremely difficult. Secondly, part of the survey design allowed survey participants to leave a question blank and still complete the survey. The intent of this

design was to avoid respondents answering questions about which they were not certain. An unintended consequence of this method was that several response totals dipped below the 30 responses typically required for statistical viability.

Demographics of the respondents

The sample group consisted of 34 group home staff members. The youngest portion of this group was between 18 and 24 years old and composed 11.8% of the sample. The oldest group members were between 65 and 74 years old and represented only 5.9% of the group. The largest age group was between 25 and 34 years old making up 38.2% of the sample. Half of the respondents were full time employees while the rest were part time or casual. A large percentage of those surveyed had only been in the field for two years or less (35.2%). Only 14.7% had been in the field for more than 20 years and more than half of the respondents had been with their current agency for two years or less (53%). Only 2.9% had been with the same agency more than 20 years.

As previously stated, this research is timely because of the impending closure of a large institution in the region of the agencies surveyed, namely Valley View Centre (VVC). The families of VVC residents have expressed fears about high turnover and undertrained staff in community settings (TSC, 2013, p.25); these same reservations are reflected in the academic literature (Tabatabainia, 2003, p.247, Bostock, Gleeson, McPherson, & Pang, 2004, p. 49, Mansell, 2006, p. 71, Bigby, 2008, p.154, Burrell & Trip, 2011, p. 81). Other studies have suggested that staff deficiencies are observable in some of their actions. Two examples include manipulative interactions between staff and participants (Jingree, Finlay, & Antaki, 2006) and reporting higher levels of participant satisfaction than is warranted (Schwartz, Schwartz &

Rabinovitz, 2003). The responses from the present study confirm that low staff retention and inexperience are current realities in Saskatchewan CBO's. Take as evidence the fact that only 38.3% of the sample group had been working in the field for more than five years and that only 26.4% had been with their present agency for the same length of time. Although group home staff appear to have relatively short career portfolios their levels of education present more positively when compared to the negative predictions in the literature (Shalock & Fredericks, 1990, Tabatabainia, 2003; Bostock, Gleesen, McPherson, & Pang, 2004; Mansell, 2006; Burrell & Trip, 2011). The levels of education reported by the sample group were impressive. Seventy-three point five per cent (73.5%) of the participants had some education beyond high school while 20.6% of the participants had bachelor level or higher education. All of the respondents had completed high school or equivalent and the highest degree obtained was a graduate degree (5.9%). The survey did not require the participants to indicate in what field they studied, which makes it impossible to infer whether their education has had a direct impact on their work. Despite not knowing discipline details, education levels do indicate experience in learning environments, which may translate to better understanding and acquisition of field related knowledge in onsite training.

When asked about "on-the-job training", survey participants consistently listed an impressive array of programs including MANDT (workplace and relational violence prevention) or Professional Assault Response Training (PART), CPR and First Aide, Supported Decision Making, Abuse Policy Training, Transfers Lifts and Repositioning (TLR), and Comprehensive Personal Planning and Support Policy training (CPP and SP). The higher than expected levels of educational experience, coupled with the amount of onsite training offered by agencies, bodes well for community supports in the Province. This is especially encouraging given that several

recent studies have indicated deficiency in staff training and education as barriers to community inclusion for adults with ID (Tabatabainia, 2003, p.247; Bostock, Gleesen, McPherson, & Pang, 2004, p.49; Mansell, 2006, p.71; Burrell & Trip, 2011, p. 81).

New Learning and its implications

The demographic information indicates that Saskatchewan community based group homes have a staff retention issue. Despite this fact, the higher than anticipated levels of staff education and onsite training opportunities are encouraging. More data is required to determine why staff members are not staying with agencies beyond five years. At least one study suggested that the two biggest factors, in high staff turnover, are lack of education and training opportunities and low wages (Tabatabainia, 2003, p.247). Given the positive data regarding training and education demonstrated in this study, it is suggested that future studies begin by examining wage discrepancies between group homes and comparable industries as a potential cause for high staff turnover in community based group homes.

Social Inclusion

Recent studies have suggested that group homes in the community are superior to institutional living arrangements in terms of access and participation in public life (Young, 2000; Young, 2001; Baker 2006, p. 108; Bhaumik, 2009, p. 301). Others have contested these findings saying that group homes are little more than "mini-institutions" (Bostock, Gleeson, McPherson, & Pang, 2004, p.46). Group homes have also been characterised as restrictive and isolating (O'Brien, Thesing, Tuck, & Capie, 2001 p. 68; Burrell & Trip, 2011, p. 81). In addition, the social networks of residents have been shown to consist primarily of other people with

disabilities plus staff members (Forrester-Jones, et al., 2005, p. 289; Bigby, 2008, p.151). Baca and McNair have argued that even the relationships that do exist between staff and residents tend to be unilateral in nature (2013, p.30). The present study affirms both that people with ID enjoy community involvement and that certain institutional elements, including limited social networks, persist in community settings.

A series of questions about participant involvement in recreational/social activities revealed that the typical group home resident enjoys the benefits of physical inclusion but do not develop natural (unpaid) relationships as a result. Table 1 illustrates the pertinent findings.

Table 1:
Participation in community recreation

Activity	Number of respondents	Daily	Weekly	Monthly	Very Rarely	Never
Playing sports outside of the home	27	0 (0%)	17 (63%)	4 (14.8%)	4 (14.8%)	2 (5.9%)
Attending sporting events as a fan	28	0 (0%)	7 (25%)	15 (53.6%)	3 (8.8%)	3 (8.8%)
Eating at a restaurant	27	0 (0%)	11 (40.7%)	13 (48.1%)	2 (7.4%)	1 (3.7%)
Visiting unpaid friends at their home	28	0 (0%)	2 (7.1%)	7 (25%)	10 (35.7%)	9 (32.1%)
Going for coffee with staff and/or other participants	28	3 (10.7%)	19 (67.9%)	4 (14.3%)	1 (3.6%)	1 (3.6%)
Going for coffee with unpaid friends	28	0 (0%)	2 (7.1%)	5 (17.9%)	9 (32.1%)	12 (42.9%)
Going to the library	27	0	3	10	7	7

		(0%)	(11.1%)	(37%)	(25.9%)	(25.9%)
Attending religious services	27	2 (7.4%)	15 (55.6%)	1 (3.7%)	2 (7.4%)	7 (25.9%)
Attending community events (concerts, art festivals, craft shows, trade fairs, etc.)	28	0 (0%)	8 (28.6%)	17 (60.7%)	2 (7.1%)	1 (3.6%)
Going to the movie theatre with staff and/or other participants	28	0 (0%)	6 (21.4%)	10 (35.7%)	8 (28.6%)	4 (14.3%)
Going to the movie theatre with unpaid friends	27	0 (0%)	0 (0%)	2 (7.4%)	5 (18.5%)	20 (74.1%)
Participating in a league/club with non-disabled peers	28	0 (0%)	4 (14.3%)	1 (3.6%)	5 (17.9%)	18 (64.3%)
Having unpaid friends into the group home to visit	28	0 (0%)	0 (0%)	9 (32.1%)	9 (32.1%)	10 (35.7%)

Table 1 shows that the typical group home resident enjoys at least monthly involvement in several activities including playing sports (77.8%), attending sports as a fan (78.6%), eating out (88.8%), attending religious services (66.7%) and attending community events like art shows, concerts, and festivals (89.3%). Sadly, when presented with the statement that "most of the residents of the group home have unpaid people in their lives, other than family, with whom they regularly interact and who would call the residents their friend" an alarming 58.6% disagreed (17.9% strongly and 35.7% just disagreeing) with an additional 17.9% being unsure. This aligns with current research that suggests limited social networks for people with disabilities in community settings (Forrester-Jones, et al., 2005, p.289; Bigby, 2008, p.151; Baca & McNair,

2013, p.30.) In response to the assertion that "at least one of the people in the group home belong to community groups that are not exclusively for people with disabilities (i.e. clubs, sports teams, book clubs, church clubs, etc.)" a dismal 67.9% of the respondents either disagreed or strongly disagreed. The high levels of physical presence in community activities, coupled with the low level of natural friendships, and participation with non-disabled peers suggests that physical presence does not predict social inclusion. This was born out in other specific areas of social life.

Take for example the fact that 82.2% of respondents said that residents go out for coffee with staff and other residents at least monthly. In contrast 75% said that residents rarely or never go for coffee with unpaid friends. Similarly, 57.1% of those surveyed said that residents go to the cinema with staff and other residents at least monthly while 74.1% said that residents never go to the movies with unpaid friends. Social isolation was reflected in home life as well. Only 35.7% of respondents indicated that residents receive cards or gifts on special occasions and 64.3% of respondents said residents rarely or never speak with their neighbours. Interestingly, when asked if the training the staff had received included information about helping people with disabilities to make friends in the community less than half of the respondents agreed or strongly agreed (45.8%) and an additional 20.8% were unsure. This illustrates that at least 54.2% of those who answered the question believed that they did not receive training from their employer about facilitating social inclusion for their clientele or they were unsure.

New Learning and its implications

The fact that people with ID are being afforded regular access to community resources deserves positive recognition but one is confronted with the question of why these same people are not developing natural friendships with the people in these same environments. Some studies

suggest that inhibitive policies and procedures within CBO's contribute to social isolation (Forrester-Jones, et. al., 2005, p.289; Bigby, 2008, p.151; Van Alphen, 2010, p. 359). Future studies should examine the nature of CBO policies and procedures with emphasis on their impact on the social lives of people living in group homes. It would also be beneficial to survey community members to ascertain why they do not engage, in their environments, in natural relationships with people who have disabilities.

Participant engagement in meaningful activity at home

Several academic studies have indicated that participants who move from large institutions to smaller community based group homes experience an increase in participation in meaningful daily activity. For example O'Brien stated that families reported their relocated loved ones had "a varied life, a normal life, people in their life that now cared for them, as well as the opportunity to live in their own home" (O'Brien, Thesing, Tuck & Capie 2001). Researchers in Wales reported that "there [was] sufficient indication that participants had greater involvement in household activity after moving, and spent more time engaged in social interaction and in constructive activity generally" (Perry, Felce & Meek, 2010, p. 13). Other researchers have affirmed the positive impact that this involvement has on participant self-perception (Grunewald, 2003, p. 4). The current research only partially affirmed these results. Table 2 details survey responses concerning participant involvement in meaningful activities in their home.

Table 2:
Participation in personal care and home based activities

Activity	Number of respondents	Does not participate	Some participate -on	Unsure	Very involved	Does activity independently (total participation)
Personal laundry	27	5 (18.5%)	17 (63%)	0 (0%)	4 (14.8%)	1 (3.7%)
Making a grocery list	27	17 (63%)	5 (18.5)	2 (7.4%)	3 (11.1%)	0 (0%)
Grocery shopping	27	5 (18.5%)	19 (70.4%)	1 (3.7%)	2 (7.4%)	0 (0%)
Bathing	27	1 (3.7%)	14 (51.9%)	0 (0%)	10 (37%)	2 (7.4%)
Cleaning the home	27	2 (7.4%)	21 (77.8%)	1 (3.7%)	3 (11.1%)	0 (0%)
Deciding what to wear	27	0 (0%)	12 (44.4%)	0 (0%)	11 (40.7%)	4 (14.8%)
Choosing recreational activities outside of the home	27	3 (11.1%)	15 (55.6%)	1 (3.7%)	7 (25.9%)	1 (3.7%)
Choosing recreational activities inside the home	27	2 (7.4%)	14 (51.9%)	0 (0%)	8 (29.6%)	3 (11.1%)
Setting the table	27	5 (18.5%)	14 (51.9%)	1 (3.7%)	5 (18.5%)	2 (7.4%)
Cleaning their room	27	5 (18.5%)	17 (63%)	1 (3.7%)	3 (11.1%)	1 (3.7%)
Choosing furniture	27	9	13	2	3	0

and decorations for the home		(33.3%)	(48.1%)	(7.4%)	(11.1%)	(0%)
Planning the house schedule (i.e. eating times, bedtimes, etc.)	27	8 (29.6%)	10 (37%)	1 (3.7%)	8 (29.6%)	0 (0%)
Cooking meals	27	12 (44.4%)	14 (51.9%)	0 (0%)	1 (3.7%)	0 (0%)
Taking the garbage out		10 (37%)	13 (48.1%)	0 (0%)	3 (11.1%)	1 (3.7%)

Table 2 illustrates that that the group home residents enjoy some degree of participation in a variety of household activities including laundry (81.5%), grocery shopping (77.8%), house cleaning (96.3%), deciding what to wear (99.9%), and choosing recreational activities inside the home (92.6%). However, in other areas the responses showed less resident involvement. For example, 33.3% of respondents indicated that residents do not choose the furniture or decorations in the home while an additional 7.4% were unsure. Concerning the planning of daily routines (i.e. eating times, bedtimes, etc.) 29.6% of those surveyed said that residents are not involved with an additional 3.7% being unsure. Forty-four (44%) of the respondents indicated that the residents are not involved in meal preparation, and a surprising 37% said that residents do not take out their own garbage.

New Learning and its implications

It appears that the typical group home resident, in this Saskatchewan community, participates in a subset of the daily living activities around their home. Table 2 illustrates that the majority of residents were involved in making grocery lists, cleaning the home, yard work, and choosing what to wear. While this evidence suggests partial participation in daily living tasks,

the same table exposes deficiencies in resident involvement in some areas. Four activities in particular reveal higher than expected levels of non-participation. The tasks were choosing furniture and decorations for the home (33.3% reported no participation), planning the house schedule (29.6% reported no participation), cooking meals (44.4% reported no participation), and taking the garbage out (37% reported no participation). These results are troubling in light of the fact that 83.3% of respondents either agreed or strongly agreed that they were expected to include the participants in the daily activities of the home. Additionally, these four activities are associated with institutional conditions.

In institutions furniture and decorations are purchased and provided, routines are regimented and designed by managers, meals are often prepared by food service staff, and garbage is removed by custodial workers. Taking food preparation as one example the TSC report (2013, p. 32) says that,

Institutions tend to be scheduled based on the operational needs of the facility, the required tasks of the staff, and how to minimize costs rather than on the choice, preferences, and self-determination of the residents. Activities of daily living are scheduled and timed based on the need for efficiencies in time management and the delivery of supports. A typical example of this would be meal schedules – where a specific meal occurs at a specific time within a set time period in order to allow the next activity to proceed.

The levels of non-participation in these particular areas may indicate a level of mini-institutionalization (Bostock, Gleeson, McPherson & Pang, 2004) in the community; this need not be the case as involving the residents would not be difficult. The results certainly indicate a contradiction between the expectations the staff believe their managers have of them regarding participant involvement and the realities within the daily rhythms of the homes. The present study contradicts many of the assertions of other authors who claim that group homes suffer from identically deficient levels of meaningful activity to those reported in institutions (O'Brien,

Thesing, Tuck a& Capie, 2001; Burrell & Trip, 2011; Rah & Dymond, 2012). However, it is evident that some institutional practices persist around the daily activities of the home. Future studies should seek to identify the approximate cause of these similarities with a goal of improving resident participation in all aspects of their lives.

Discussion and concluding remarks

The residents of the groups homes involved in this study enjoy high levels of physical inclusion in their communities. They also participate in many of the daily living tasks within their homes. These two observations are to be celebrated but they are not the whole story. While residents enjoy partial participation in their homes there are still several key tasks (meal preparation, daily planning, waste removal, and decorating and furnishing the home) which they are not participating in to the same degree. These areas are significant on two levels. Firstly, they represent a disconnection between the expectations of agencies that staff would maximally include residents in the daily activities of the home. Secondly, they are symbolic of major areas in institutional life to which residents have historically been denied access.

In terms of physical inclusion the residents are utilizing public spaces but their physical presence is not resulting in the development of unpaid relationships. Likewise, the physical presence of group homes in regular residential areas does not result in residents interacting with other members of their immediate communities. The problems of deficient participation in daily living tasks and lack of social inclusion demand more research to determine solutions.

The issue of daily living task participation appears to be internal to the agencies. The staff members largely agree that they are expected to include the residents in the operation of the homes and to some extent they are doing so. It is worthy of note that the categories in which this

is not happening as consistently correspond with traditional areas of institutional control. More research is required to determine the cause of this. However, it would not be surprising if such pressures around efficiency exist in homes that have traditionally existed in institutions. In other words, staff members may feel that they need to control the schedules and meal preparation in order to move efficiently from task to task in the home.

The lack of social inclusion is a more complicated issue. There appears to be confusion about the nature and extent of training received by the staff about supporting natural friendships. Based on this research it is imperative that agencies evaluate their training and procedures regarding social inclusion. Future investigation could also include querying community members about why they do not establish relationships with the people with ID who are in the same social spaces that they are. It would also be an interesting future study to identify agencies that are having greater success with facilitating social inclusion and to determine the differences in their service models compared to less successful groups.

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