

Public Perceptions of the Best Living Arrangements for Most Adults With Intellectual Disabilities

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Abstract

A telephone survey was conducted to determine attitudes towards individuals with intellectual disabilities. This article explores the perceptions of the public regarding the best living arrangements for adults with intellectual disabilities. A majority of the 680 respondents believed that some form of community living would work best, either in a supervised apartment or in a group home. Less than 20% of respondents felt a group home would negatively impact their neighbourhood. Respondents also indicated that they believed that a lack of community services was a major obstacle to inclusion within communities of people with intellectual disabilities.

Public policy on how best to provide residential support to individuals with intellectual disabilities has shifted dramatically since the mid-twentieth century. Over a few decades, the policies and practices in many western countries have moved from a reliance on custodial institutions for people with intellectual disabilities to a preference for integration in the community (Brown & Radford, 2007). Parents, advocacy groups, and the introduction of the principles of normalization (Nirje, 1970) and social role valorization (Wolfensberge & Tullman, 1982; Wolfensberger, 1983), were instrumental in the promotion of this redesign of service models.

The policy shift was apparent in Ontario as early as 1974 when the provincial government made a major commitment to provide community living alternatives for individuals with intellectual disabilities. At that time, 8,000 people with intellectual disabilities resided in 16 facilities. A decade later, following the closure of 5 institutions, the population living in facilities dropped to 5,200. The community living policy adopted in Ontario, further articulated in the 1987 document titled "Challenges and Opportunities" (Ministry of Community and Social Services, 1987), called for the down-sizing and eventual closure of the province's remaining institutions within

25 years. It also included a commitment from the Province to expand community-based accommodation and services for children and adults with intellectual disabilities over a seven-year period. Today, approximately 1,200 adults with intellectual disabilities live in the three residential institutions still operated by the province: Huronia Regional Centre in Orillia, Rideau Regional Centre in Smiths Falls and Southwestern Regional Centre in Chatham-Kent. There had been a no new admission policy in place for several years and recently the government has announced the planned closure of these institutions by 2009 noting:

“The phasing out of the remaining institutions completes Ontario's evolution from an institution-based to a community-based system that promotes greater inclusion, independence and choice.”

(<http://www.cfcs.gov.on.ca/CFCS/en/newsRoom/newsReleases/040909.htm> accessed October 31, 2004)

For individuals with intellectual disabilities, living in the community has not necessarily meant being full participants within it. A four and a half year longitudinal study across Ontario (1994-1999) showed that while people who had moved from institutions to the community tended to make greater use of community resources than when they lived in facilities, there were still challenges. Cost, the ability to get around, and especially being accepted by other citizens were still problematic for some (http://www.utoronto.ca/qol/final_summary.pdf accessed August 29, 2005).

This reality is not unique to Canada. Critiques of deinstitutionalization are noted in such recent research reports as those published by Deborah Metzel in the United States and Edward Hall in Scotland. Metzel (2005) wrote of the negative consequences of service dependency and social poverty recreated by a well-intentioned, community-based, voluntary organization supporting adults with intellectual disabilities in Baltimore, USA, in the early 1990s. Referring to qualitative research in Scotland between 2002 and 2003, Hall (2005) argued that social inclusion policy in that country resulted in the social exclusion of persons with intellectual disabilities.

Perhaps in recognition of some of the past failings of normalization-based policies, advocacy groups in Ontario are now calling for the government to create a new comprehensive framework of policy and funding guided by a principle of ensuring full citizenship to people with intellectual disabilities (<http://www.communitylivingontario.ca/briefs/mcssconsult.html> accessed August 29, 2005). They state: “[i]n a worldview that recognizes the citizenship rights of people with disabilities, it is a proper role of government to enable

the citizen to manage his disability and simultaneously enable the community to include that citizen” (Community Living Ontario, November 2003).

While there is significant agreement on the notion that community response is important to the successful implementation of integration policy, there have been few efforts to explore the relationships between community characteristics and their effects on the social inclusion of individuals with intellectual disabilities. One such characteristic is the prevailing attitude of members of the community regarding inclusion.

Some studies have reported a lack of awareness of the presence of individuals with intellectual disabilities in the community; others have noted a sense of discomfort, even hostility felt by the public to the idea of people with intellectual disabilities living in their communities. Still other research has identified a willingness on the part of the community to engage with people with intellectual disabilities as consumers, neighbours, or as possible friends (Myers et al., 1998; Knapp et al. 1992; Lutfiyya, 1991; Saxby et al., 1986).

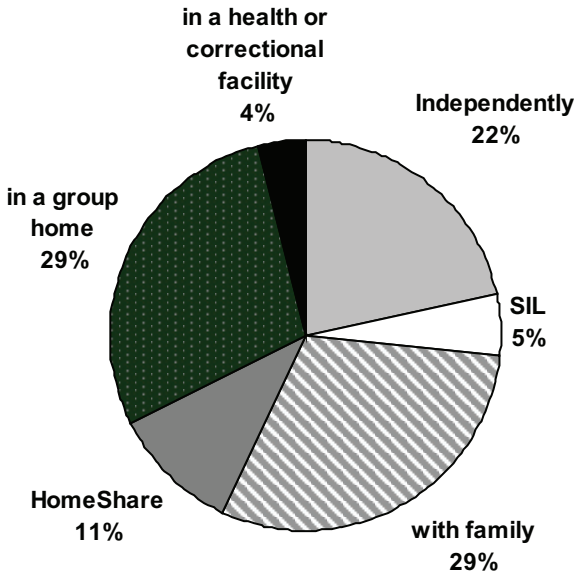
In this paper, we present and discuss results of a community attitudes poll in Southeastern Ontario. The focus is on understanding factors associated with perceptions of the best living arrangement for most adults with intellectual disabilities. A variety of living arrangement options now exist for adults with intellectual disabilities in communities across Ontario including living independently in an apartment, in a supported independent living arrangement, in a group home, with family members (including siblings), and living with another family. In times of crisis, some individuals find themselves needing a level of support previously available in institutions; however, the government has indicated that institutions are no longer seen as a long-term living arrangement option in Ontario. In Southeastern Ontario, most adults with intellectual disabilities can be, and are, supported in relatively independent settings (see Figure 1). We sought to determine if the public recognized this reality, and to increase our understanding of public attitudes and thereby help shape and target public education strategies to foster enhanced inclusion.

Method

Procedures

A telephone survey of a random sample of households across Southeastern Ontario was conducted. The protocol was reviewed and approved by the Queen’s University Health Sciences and Affiliated Teaching Hospitals Research Ethics Board.

Figure 1. Breakdown of living arrangements of 2,095 adults with intellectual disabilities in Southeastern Ontario



The data for this figure are taken from the Southeastern Ontario Geographic Registry in Intellectual Disability –May 2004 (see www.seocura.org).

- Independently includes alone, with spouse/children, in a hostel, room and board, with roommates or housemates (excluding SIL and Group Home).
- SIL stands for Supported Independent Living and includes arrangements where one is living with spouse/children or others.
- With family includes living with parents/siblings as well as other family members (such as grandparents and uncles) but excluding spouse/children.
- Home Share includes associate/host families.
- In a health or correctional facility includes hospitals, nursing homes, homes for the aged, and correctional facilities.

Measures

The Multinational Attitudes Toward Individuals with Intellectual Disabilities Questionnaire, originally developed by researchers at the Center for Social Development and Education at the University of Massachusetts at Boston (Special Olympics, 2002) was modified for use in Ontario. The questionnaire, developed for administration by telephone, measures public perceptions of the abilities of individuals with intellectual disabilities and beliefs about their inclusion in the community, workplace, and schools.

The survey begins by asking the respondent to envision most adults with an intellectual disability and rate the abilities of this group on a total of fourteen adaptive behaviour items. This model, developed by Siperstein and others (Siperstein, Wolraich & Reed, 1994) posits that a respondent's perception of abilities of most adults with intellectual disabilities influences their beliefs about social inclusion and their expectations of its potential impact. The responses were summed giving a capabilities score which was then translated into a level of disability (mild vs. moderate/severe) as per Siperstein (Gary N. Siperstein, personal communication, October 2004).

A measure of social distancing was added to the survey as well as supplemental questions about perceptions related to employment and health of adults with intellectual disabilities. The concept of social distance encompasses a willingness to recognize, live near, or be associated with persons belonging to different groups. An eight-item subscale developed by Harth was used (Harth, 1974). The subscale sought agreement or disagreement on 4-point scales to statements such as "I would be willing to go to a competent barber or hairdresser who has an intellectual disability". An average score was calculated after reverse scoring such that a social distance score could range from '1' indicating low willingness to associate to '4' a high willingness to associate.

The modified survey was pilot tested with five adults and completion required about 16 minutes. This report is the first in a series and as such reflects only the section of the survey concerned with living arrangements.

Participants

A stratified random sample was obtained of adults (i.e., age over 17) residing in the six county region of Southeastern Ontario (Population = 519,200, Minister of Finance, 2005). In keeping with practices in the application of this multinational survey, a target of 900 survey respondents was adopted and these were selected from amongst households with listed telephone numbers. Following stratification of the region into 27 geographic areas of interest, a telephone contact list of households to be called was created using InfoCanada's electronic databank of telephone white pages residential phone numbers (i.e., Select Phone Canada). To ensure representation from each grouping, sampling across strata was based on the following quota rule: 1 in 440 households or a minimum of 25 households per grouping. The first available, eligible and willing household member was interviewed.

In all, 2949 households were reached and invited to participate in the survey; 680 agreed (23%). Research on the decline in response rates to telephone surveys has found that participation rates of this order do not necessarily invalidate the results (Keeter, Miller, Kohut, Groves & Presser, 2000). In fact, our sample characteristics very closely approximated those of the underlying population. A profile of respondents can be found in Table 1.

Table 1. Profile of respondents compared to census population

Characteristics	Sample (N=680)		Population (N= 409,520)	
	n	%	n	%
<i>County</i>				
Lennox & Addington	62	9	32,899	8
Frontenac	167	25	117,892	29
Hastings	144	21	104,730	26
Prince Edward	41	6	21,236	5
Lanark	114	17	52,120	13
Leeds & Grenville	151	22	80,643	20
<i>Gender</i>				
Men	229	34	200,604	49
Women	444	65	208,916	51
<i>Age</i>				
18-24	39	6	48,003	12
25-34	75	11	59,376	14
35-44	133	20	81,170	20
45-54	130	19	77,637	19
55-64	132	19	62,014	15
65-74	96	14	44,049	11
75+	52	8	37,271	9

Analysis

Responses were tabulated to reflect the public's perception of (a) the type of living arrangement that is best for most adults with intellectual disabilities, (b) the impacts of a group home on a neighbourhood, and (c) barriers to community inclusion. The relationship between perception of best place to live and respondent characteristics was examined using multivariate analyses (cross tabulations and logistic regression). Proportions, odds ratios and confidence intervals are presented. A significance level of 0.05 was set a priori for all analyses conducted. For the logistic regression, all variables of interest were entered into the model and a backwards deletion process was used to remove variables that changed the estimate of effect by less than 10%. All statistical analyses were carried out using SPSS.

The following independent variables were included in the multivariate analyses: respondent gender; age (18-24, 25-44, 45-64, 65+); level of education (low=public school or less and some high school, medium=high school diploma up to trades school or other non university certificate or diploma, high=university certificate or diploma); geographic area (FLA=counties of Frontenac, Lennox & Addington, HPE=Hastings & Prince Edward counties, LLG=counties of Lanark and Leeds & Grenville); level of contact with people with intellectual disabilities (from 1= having a close family member with an intellectual disability to 5=having no contact at all); perception of level of disability of most adults with intellectual disabilities (low=score above 8 on capabilities scale); and reported social distance (low=maximum score on Social Distance subscale).

Results

Based on the ratings to the abilities items, we note that 52% of respondents perceive most adults with intellectual disabilities to have a mild level of disability, 36% view most as having a moderate to severe disability, and 12% chose not to answer or felt unable to answer. This primary perception is key to the attitudes expressed as the questions refer to ‘most adults with intellectual disabilities’.

Of the five living arrangement options presented to the respondents, “a supervised apartment” was most often identified as the best place for most adults with intellectual disabilities to live (45.7%). Less than 2% viewed institutions as the best option (see Table 2).

Table 2. Views on best place to live for most adults with intellectual disabilities (n=633)

Setting type	n	% of sample
In a supervised apartment	289	45.7
In a group home for people with intellectual disabilities	165	26.1
With their family	94	14.8
Independently in their own apartment or house	73	11.5
In an institution	12	1.9

Note: Excludes 47 individuals out of 680 respondents who did not know how to respond (42) or refused to answer (6).

Respondents, who were most likely to consider independent living or living in a supervised apartment as best for most adults with intellectual disabilities, tended to be between 25 and 44 years old, women, those who perceived most adults with intellectual disabilities to have a mild level of disability, or those who reported low social distance. As well, respondents from Frontenac and Lennox & Addington counties were more likely than those from Lanark, Leeds & Grenville counties to favour independent living. The final logistic regression model revealed that female gender, reported low social distance and the perception that most adults with intellectual disability are mildly affected were independently associated with a view that independent living was best for most adults with ID (see Table 3).

Table 3. Association between respondent characteristics and views on living arrangements for adults with intellectual disabilities (ID)

Respondent Characteristics	Best Place for Most Adults With ID to Live		Unadjusted Odds Ratios (95% CI)	Multivariate Adjusted Odds Ratios (95% CI)
	Independent n (%)	Other n (%)		
<i>Gender (n=626)</i>				
Female	257 (71%)	151 (57%)	1.87 (1.34-2.60)	1.69 (1.15-2.49)
Male	104 (29%)	14 (43%)	1	
<i>Age Category (n=613)</i>				
18-24 years	15 (4%)	23 (9%)	0.61 (0.30-1.28)	—
25-44 years	127 (36%)	66 (25%)	1.82 (1.16-2.86)	—
45-64 years	139 (40%)	107 (41%)	1.22 (0.81-1.85)	—
65+ years	70 (20%)	66 (25%)	1	
<i>Level of Education (n=631)</i>				
Low	137 (38%)	109 (41%)	1	
Medium	137 (38%)	100 (38%)	1.09 (0.76-1.56)	—
High	85 (24%)	55 (21%)	1.23 (0.80-1.88)	—
<i>Level of Income (n=529)</i>				
<\$20,000	31 (10%)	22 (10%)	1	
\$20,000 - <\$60,000	150 (49%)	113 (50%)	0.94 (0.52-1.71)	—
\$60,000 - <\$100,000	88 (29%)	66 (29%)	0.95 (0.50-1.78)	—
\$100,000 plus	35 (12%)	24 (11%)	1.03 (0.49-2.20)	—
<i>Geographic Area (n=633)</i>				
FLA Counties	134 (37%)	79 (29%)	1.55 (1.06-2.27)	—
HPE Counties	100 (28%)	75 (28%)	1.22 (0.83-1.79)	—
LLG Counties	128 (35%)	117 (43%)	1	

continued

Table 3. (cont'd)

Respondent Characteristics	Best Place for Most Adults With ID to Live		Unadjusted Odds Ratios (95% CI)	Multivariate Adjusted Odds Ratios (95% CI)
	Independent n (%)	Other n (%)		
<i>Has a Family Member with ID (n=626)</i>				
Yes	119 (33%)	79 (30%)	1.16 (0.82-1.63)	—
No	242 (67%)	186 (70%)	1	
<i>Level of Disability Perceived to affect Most Adults with ID (n=596)</i>				
Mild	225 (67%)	129 (49%)	2.13 (1.52-2.97)	2.18 (1.49-3.20)
Moderate/Severe	109 (33%)	133 (51%)	1	
<i>Social Distance (n=627)</i>				
Low	91 (25%)	41 (15%)	1.85 (1.23-2.79)	1.70 (1.06-2.75)
Moderate/High	270 (75%)	225 (85%)	1	

When presented with a hypothetical question about a situation in which a group home for individuals with intellectual disabilities is established in their neighbourhood, less than 20% of respondents felt that such a development would very likely or likely negatively affect the image of their neighbourhood, decrease property values or disrupt safety and public order (see Table 4).

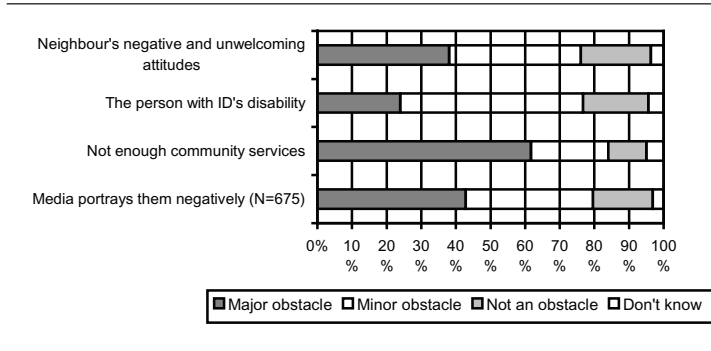
Table 4: Views on the likely impacts of a new group home on the neighbourhood by proportion of respondents

	Disrupt safety and public order (n=679)	Decrease property values (n=678)	Negatively affect the image (n=678)
Don't know	1.8%	4.7%	2.2%
Very likely	1.5%	4.1%	3.7%
Likely	5.4%	11.9%	9.3%
Not too likely	40.4%	28.4%	26.9%
Not at all likely	51.0%	50.7%	57.8%

Finally, when presented with a list of four potential obstacles or barriers to the integration of people with an intellectual disability into the community, over 60% of respondents identified insufficient community services as a major

obstacle. The actual disability was viewed as a major obstacle to inclusion by the smallest proportion of respondents, about 24% (see Figure 2).

Figure 2. Views on possible barriers to community integration by proportion of respondents (N=678 unless stated)



Discussion

The attitude poll results provide valuable information to the researchers and their partners about societal perceptions toward community integration especially as it relates to living arrangements for people with intellectual disabilities. Our poll shows that only a small majority (52%) of respondents recognize that most adults with intellectual disabilities have mild impairments and can or often choose to live independently, few perceive the establishment of a group home as having a negative impact on the neighbourhood (<20%), and a significant proportion consider insufficient community services as a major obstacle (>60%). Taken as a whole, these statistics suggest a rather positive attitude towards community living.

In interpreting these findings however, it is important to recognize that biases may be reflected in these statistics. Our decision to use the living arrangements questions already administered internationally via the multinational survey for Special Olympics meant that we could not reasonably ask a more opened ended question about the best place to live for most adults with intellectual disabilities. One very informed reader of our draft study results expressed a preference for such an open-ended question. He suggested that such a question might have obtained responses more indicative of respondents' values toward self-determination for people with intellectual disabilities. In particular, it was hoped that respondents

might say that “the best place for most adults with intellectual disabilities to live is wherever they want to live”. This simple comment actually reflects a complex reality. In order to provide choice for individuals, options must be developed with the support of the community. Municipal by-laws must not be discriminatory and funds must be made available. These are examples of actions affected by public attitudes.

Social desirability, the bias that occurs when respondents are motivated to present themselves in a way that society regards as positive, may account for the lack of NIMBY (‘Not in my back yard’) type responses to the questions of impacts of group homes. In addition, when respondents were asked about how a new group home would impact their neighbourhood some respondents living in very rural areas remarked that they had no close neighbours and indeed did not consider themselves as residing in a traditional neighbourhood and therefore could not imagine any impact whatsoever. It is not clear how many respondents residing in rural settings may have treated this question similarly and so interpretations of responses to this question should be viewed cautiously. Furthermore, responses to a hypothetical situation are limited in their ability to predict reactions to real situations.

Finally, we recognize that our sample is biased in that it includes disproportionately more women than men, and our findings may be impacted by a reported tendency for women to hold more pro social views on similar issues (Hampton & Crystal, 1999; Cross & Madson, 1997). The latter being confirmed by our analysis (Table 2). This limits our ability to generalize our findings across our region.

Our study reveals a number of variables that warrant further study. Our analysis shows the impact of age on attitudes with those between 25-44 and 45-64 more likely to identify independent living or living in a supervised apartment as best for most adults with intellectual disabilities compared to the very young (18-24) and the very old (65+). A generational influence is suspected here but our design does not allow us to explore this further.

Respondents from Frontenac and Lennox & Addington counties were more likely than those from Lanark, Leeds & Grenville counties to favour independent living. We speculate that the proximity of the latter to the only remaining residential institution for adults with intellectual disabilities in our region may explain this difference. Variations in awareness of more segregated approaches to support and their benefits may have influenced such perceptions.

Two other variables associated with support for more independent living: respondents perceiving most adults with intellectual disabilities to have a mild level of disability, and reporting low social distance. This suggests that increasing awareness and contact might lead to more pro-social attitudes towards community living. While in the case of our poll, it is not possible to determine if more pro-social attitudes led to more contact and hence awareness, research on public reactions to the siting of group homes indicates that a majority of community members learn to accept these homes and their inhabitants suggesting that people's initially negative conceptions of difference can be challenged by proximity (Wilton, 1998; Robertson et al., 2005). It has been said that proximity can and does promote acceptance because it forces a reconceptualization of the self/social to incorporate a more nuanced understanding of 'difference' (Wilton, 1998).

Conclusion

The poll results present a hopeful picture. As the closure of the last remaining institutions for adults with intellectual disabilities in Ontario is undertaken, it is heartening to find that our communities recognize the need for community services to enhance inclusion by improving the supports available to those with intellectual disabilities. While public education serves to increase awareness, increased contact between real people with intellectual disabilities and their fellow citizens is likely to be the best teacher toward changing attitudes and breaking down barriers to integration.

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