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Social Participation for Older People with Intellectual Disability

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Social Participation for Older People with Intellectual Disability

2.1 Key Findings

- Family networks of older people with ID in Ireland looked very different to that of the general population, insofar as older people with ID are generally single/unmarried and without any children or grandchildren. As such, they were far more reliant on siblings and extended family to provide family networks, especially as they age and parents pass away.
- Most family members of older people with ID lived in different neighbourhoods than their relative with ID; this is very different than that reported by TILDA for the general population and highlights the difficulty in maintaining family connections for older people with ID.
- There was a trend of reduced rates of regular contact with family between Wave 1 and Wave 2. In addition, only a little more than half of all respondents (56.6%) said that they had friends outside their own home. For respondents with severe-profound ID the rate was even lower with less than one third having contact with family. Trends here from Wave 1 to Wave 2 were for a reduction in the number of outside friend contacts and for there to be little difference between experiences in community group homes and institutional settings.
- Other social partners appear more critical in the lives of older people with ID, including paid staff which remained the highest (75.4%), friends with whom people live with (53.4%), and family members (32.0%). Paid staff remained the most likely confidant for respondents in Wave 2; but siblings were more likely to be chosen by people living in independent/family residences.
- While self-reported feelings of social exclusion (loneliness, feeling left out, and finding it difficult to make friends) have reduced slightly since Wave 1, women were more likely to feel excluded than men; and people living in institutional settings (on all levels) and in community group homes (in terms of loneliness and difficulty making friends) were more likely to feel excluded than those living in independent/family residences.
- Purposeful contact with neighbours, friends and family was greatly impacted by level of ID, type of residence and age; with those with severe and profound ID, those

living in institutional residences, and the oldest group much less likely to engage in this type of social participation. Again, the experiences of those in community group homes were closer to those in institutional settings than those living in independent/family residences.

- There has been an overall decline in the rate of engagement in social activities between Waves 1 and 2, as well as a decline in participation in voluntary organisations; people with severe/profound ID, those living in institutional environments, those aged 65 years and over, and men were all more likely not to be a member of any voluntary organisation. For the general population, TILDA reported a direct link between such participation and overall quality of life.
- People with severe-profound ID, those aged 65 years and over, and those living in institutional settings were also at much greater risk of being unable to travel around their local communities. However, the experience of those in community group homes was not substantially different, with most participants requiring assistance to get around their community.
- Despite often serving a higher functioning and younger population, community group home experiences in terms of community engagement resembled institutional settings; a renewed effort is needed to ensure that community group homes are organised to support greater levels of genuine integration. These findings raise concerns for the planned movement from congregated settings of often older adults with severe and profound ID and higher levels of ill-health.
- There was very little improvement in employment status for respondents between Wave 1 and Wave 2, with dramatically lower levels of employment compared to those which TILDA has reported for the general population.
- Respondents who were employed spent an average of 3.3 days a week in work, over an average of 15.7 hours a week, for an average wage of €72.66.
- Two thirds (66.3%) of respondents reported having trouble with reading, writing, numeracy and money management; while very few currently benefit from access and use of communication technologies.
- Four out of five people attended a day service at Wave 2. The majority of these said that they choose their day service activities; and the vast majority said they were very satisfied (59%) or satisfied (36.4%) with their day service.

2.2 Context: Social Participation and Intellectual Disability

The TILDA study of the general older population in Ireland found that engagement in each area of social participation measured (intimate social relationships, formal activity outside work, active and social leisure, and passive and solitary leisure) was associated with better quality of life. Similarly, for people aged over 65 years, quality of life was highest for those who were ‘most integrated’ in terms of social networks, and lowest for those ‘most isolated’ (Nolan *et al.*, 2014).

For people with an ID current policy in Ireland addresses social and community participation by emphasising deinstitutionalisation and the movement of people with ID into community group homes and more independent settings (Department of the Environment, Community and Local Government, 2011; HSE, 2011). This follows on similar policy and practice in several other countries including Australia, Canada, Sweden, the UK and USA. A specific aim of current policy in Ireland is to move all of the people with ID that currently reside in congregated settings (i.e. in units of 10 or more people, or in clustered campus arrangements) into ordinary housing dispersed amongst the general population. The ‘vision’ is that people with ID *“will be actively and effectively supported to live full, inclusive lives at the heart of family, community and society”* (HSE, 2011: 25).

In the research literature, Mansell and Beadle Brown (2009) noted general findings that community-based service models achieve better outcomes for people with ID than institutions, with some variation reflective of individual characteristics and range of abilities, characteristics of service design and, most importantly, differences in staff performance; Emerson and Hatton (1994) found that a majority of transition studies in the UK and Ireland showed positive impacts across five of six outcome measures (including community participation); Young *et al.*, (1998) reported that a majority of similar studies in Australia showed positive impacts across six of nine outcome measures (including community participation and contact with family/friends); and in the USA, Heller *et al.*, (1998) found that people moving out of a nursing home found more positive community functioning. Participation increased from close to no activities to activities one to three times per month. Activities usually consisted of talking with family and friends and visiting friends. However, the actual day to day differences in people’s lives were limited. Findings by Emerson and McVilly (2004) raised concerns in that they found that people with ID living in community settings had low levels of friendship activities over a four-week period, with a median of two friendship activities with friends who also had an ID, and a median of zero friendship activities with people who didn’t have an ID.

Similarly, Robertson *et al.*, (2001) reported low levels of social connectedness amongst people with ID living in community residences with an average social network size of just two people (excluding staff). Finally, Cummins and Lau (2003) concluded their review of community participation research by criticising what they saw as a ‘heavily biased’ literature misrepresenting community integration as physical presence when it should be about personal experiences and a sense of belonging to community. Similarly, Verdonschot *et al.*, (2009) noted that, while people with ID living in community settings participated more in the community than those in segregated dwellings, their level of participation remained much lower than for people with other disabilities or for those without an identified disability.

These are important concerns and challenges as Ireland moves an increasing number of people with ID into the community. In Wave 1 of IDS-TILDA community settings were found to offer more opportunities, but overall people with ID still often have low levels of connectedness with family and friends and small social networks outside of staff and the other people with ID with whom they live – relationships whose importance nonetheless also needs to be recognised (Novak Amado *et al.*, 2013). Even where improvements are reported, people with ID appeared to start from such a low baseline that improvements still leave them less connected than the general population and/or people with other types of disabilities. The initial findings presented in this chapter, along with more in-depth analyses of Wave 2 data later on, will add to our understanding of social participation for older people with ID and how it is influenced by where people live.

2.3 Social & Community Engagement. Results & Comparison Wave 1 to Wave 2

Findings from Wave 2 of IDS-TILDA are outlined in this section. These are drawn mainly from the Social Participation and Social Connectedness, Occupation and Lifelong Learning modules of the main questionnaire. Changes over time are outlined by comparing relevant data from Wave 1. Comparisons between older people with ID with the general Irish population are made where possible using data reported from Wave 2 of TILDA and other identified sources. Findings in this section will look at results for social connections, engagement in social life, facilitators and barriers of social participation, and a range of different aspects related to occupation and lifelong learning.

2.3.1 Social Connections for People with Intellectual Disability

As in Wave 1, respondents were asked about the type and frequency of contacts that they had with family and friends who they were not living with. New to Wave 2, respondents were also asked to identify the members in their family network, and their proximity to those family members.

2.3.1.1 Connections with Family

As noted in Wave 1, in contrast to the general population the vast majority of older people with ID were not married and had no children. Without the network provided by partners, children and grandchildren, older people with ID are more reliant on parents, siblings and extended family. This is reflected in table 2.1 below, which shows that sisters (77.0%, $n=538$) and brothers (70.4%, $n=492$) are the most common family members, followed by niece/nephew (53.2%, $n=372$), cousins (25.3%, $n=177$) and mothers (24.6%, $n=172$). Those over 65 are the group most likely to report having no family at all (8.8%).

Table 2.1: Family of Older People with ID

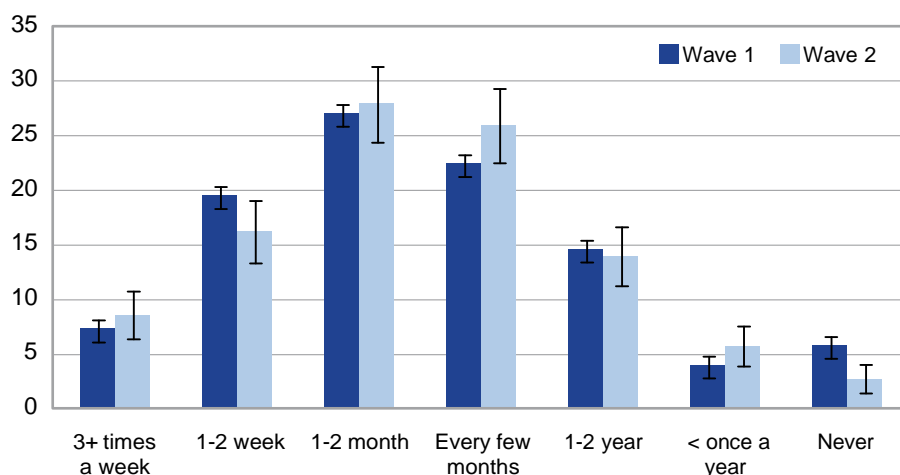
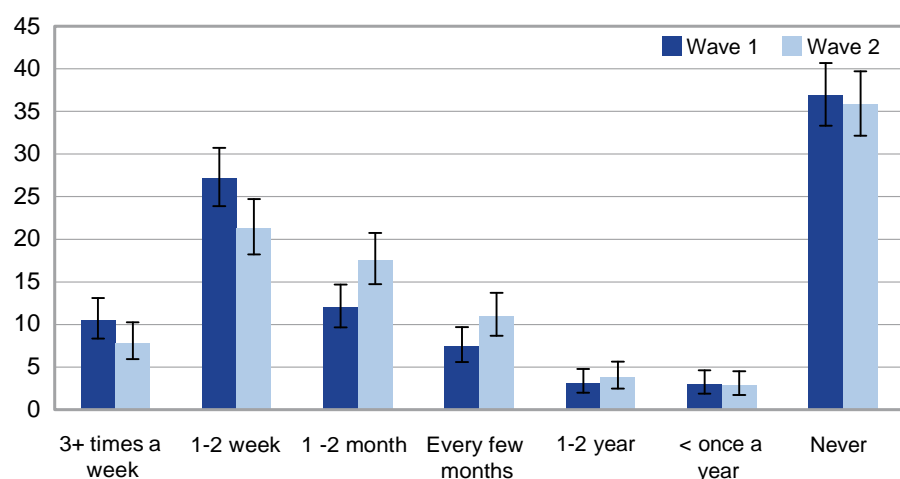
Family Member	Gender		Age			Level of ID			Type of Residence			Total	
	Male	Female	43-49	50-64	65+	Mild	Moderate	Severe- Profound	Independent / Family	Community Group Home	Institution	<i>n</i>	%
Sister	73.1	80.1	84.2	77.2	66.9	68.0	77.0	82.3	86.7	78.2	71.7	538	77.0
Brother	68.5	71.9	75.5	73.5	56.1	73.2	69.0	69.8	81.4	70.3	66.1	492	70.4
Niece/Nephew	51.6	54.5	57.7	52.7	48.6	51.6	61.7	39.6	74.3	54.1	43.8	372	53.2
Cousin	24.4	26.1	29.1	26.5	17.6	33.3	26.3	16.7	38.1	27.1	18.4	177	25.3
Mother	26.0	23.5	47.4	21.1	2.7	24.2	23.0	25.5	39.8	23.1	20.1	172	24.6
Aunt/Uncle	14.6	16.9	24.5	15.2	6.1	24.8	17.0	7.8	32.7	15.5	9.5	111	15.9
Father	9.7	9.0	22.4	5.6	0.7	9.2	7.0	13.5	18.6	7.3	7.8	65	9.3
Spouse/Partner	1.0	0.8	1.0	1.1	0.0	1.3	0.7	0.0	2.7	0.7	0.4	6	0.9
Other	3.6	2.3	2.6	2.8	3.4	3.3	2.0	3.1	7.1	2.0	2.1	20	2.9
No family	3.9	3.6	2.0	2.5	8.8	4.6	4.0	2.6	0.0	3.6	5.3	26	3.7
Total	308	391	196	355	148	153	300	192	113	303	283	699	

Where respondents indicated that they did have family members, they were then asked to identify where those family lived in relation to them. With the exception of cousins (52.6%, $n=91$), the majority of family members lived outside the respondent's own neighbourhood (see table 2.2 below). However, with approximately 40% additionally having family members who live in the same county, there is perhaps the potential to improve the social connectedness for older people with ID by utilising this relatively untapped social resource. As we will see below, less than a third of respondents currently do social activities with family.

Table 2.2: Proximity of family members

Proximity	Spouse/ Partner	Mother	Father	Brother	Sister	Aunt/ Uncle	Niece/ Nephew	Cousin	Other
Lives with me	33.3	19.8	21.5	4.5	5.1	0.9	2.5	6.9	26.3
In same building	0.0	0.6	3.1	1.4	0.9	0.0	0.5	0.0	0.0
In same neighbourhood	16.7	7.6	7.7	9.6	7.9	11.0	9.0	45.7	10.5
In same county	16.7	40.1	38.5	43.4	45.6	44.0	46.9	0.0	42.1
In different county	33.3	30.8	29.2	32.6	34.2	38.5	35.1	38.7	15.8
In different country	0.0	1.2	0.0	8.4	6.2	5.5	6.0	8.7	5.3
<i>n</i>	6	172	65	488	531	109	367	173	19

Respondents were asked about the frequency of face-to-face, phone and written contact they had with family members who they were not living with. *Figures 2.1 and 2.2* below show the changes in face-to-face and written contact between Waves 1 and 2. While the number of people who never have contact with their family has fallen slightly, there were also fewer people with regular contact (i.e. at least monthly) at Wave 2 compared to Wave 1. Regular/monthly face-to-face contact has fallen from 53.5% ($n=394$) in Wave 1 to 52.3% ($n=348$) in Wave 2. Whereas regular telephone contact has fallen from 49.7% ($n=336$) in Wave 1 to 46.6% ($n=298$) in Wave 2. Written contact remains very low, with just 4.2% ($n=25$) having such contact at least once a month (down slightly from 4.8%, $n=31$, in Wave 1). For further details see Appendix Tables 2.A.1, 2.A.2, 2.A.3.

Figure 2.1: Face-to-face contact with family**Figure 2.2: Telephone contact with family**

2.3.1.2 Connections with Friends

In Wave 2 respondents were first asked to indicate whether or not they had any friends outside their own home and then to report on the type and frequency of such social contacts. As may be seen in table 2.3 below almost half of respondents (43.4% $n=301$) had no friends outside their own home; the numbers and percentages were lower for respondents with severe-profound ID (34.4%, $n=65$); those living in independent/family residences were more likely to have friends outside their own home (86.7%, $n=98$) compared to those living in community group homes (59.5%, $n=179$) or institutional settings (41.2%, $n=115$). While the importance of friends who participants lived with should not be underestimated, these results are nonetheless indicative of particularly limited social networks for all people with ID. Those with the most severe disabilities and living in institutional settings are at greatest risk, with concerns remaining for those in community group homes.

Table 2.3: Do you have friends outside your home?

	Wave 2		Number in sample
	%	95% CI	
Gender:			
Male	52.5	46.7 – 58.16	305
Female	59.8	54.71 -64.67	388
Age:			
43-49	59.2	51.93 – 66.06	196
50-64	57.8	52.46 – 63.02	351
65+	50.0	41.66-58.34	146
Level of ID:			
Mild	77.1	69.5-83.35	153
Moderate	57.9	52.06-63.55	297
Severe/Profound	34.4	27.74-41.68	189
Type of Residence:			
Independent/Family	86.7	78.74-92.14	113
Community Group Home	59.5	53.67-65.02	301
Institutional	41.2	35.43-47.26	279
Total	56.6	52.78-60.29	693

For respondents who said they had friends outside their own home, the majority (82.3%, $n=320$) had face-to-face contact with those friends at least once a month. Men (84.9%) had slightly more regular/monthly contact than women (80.4%); regular contact decreased with increasing age; and those living in independent/family residences (87.7%) reported more regular contact than those in community group homes (83.0%) or institutional settings (76.5%) (See Appendix Table 2.A.4).

In relation to telephone contact with non-resident friends, the overall rate was much lower than face-to-face contact at 22.1% ($n=82$). Respondents with mild ID (36.9%, $n=42$) had the highest rates of regular/monthly telephone contact; compared to 16.6% ($n=31$) of those with moderate ID, and just 3.6% ($n=2$) of respondents with severe-profound ID (see Appendix Table 2.A.5). Similar to that reported for family contact, overall rates of written contact with friends was also very low with only 4.4% ($n=15$) having regular contact, highlighting the reliance upon and importance of face-to-face contact for people with the most severe disabilities (see Appendix Table 2.A.6).

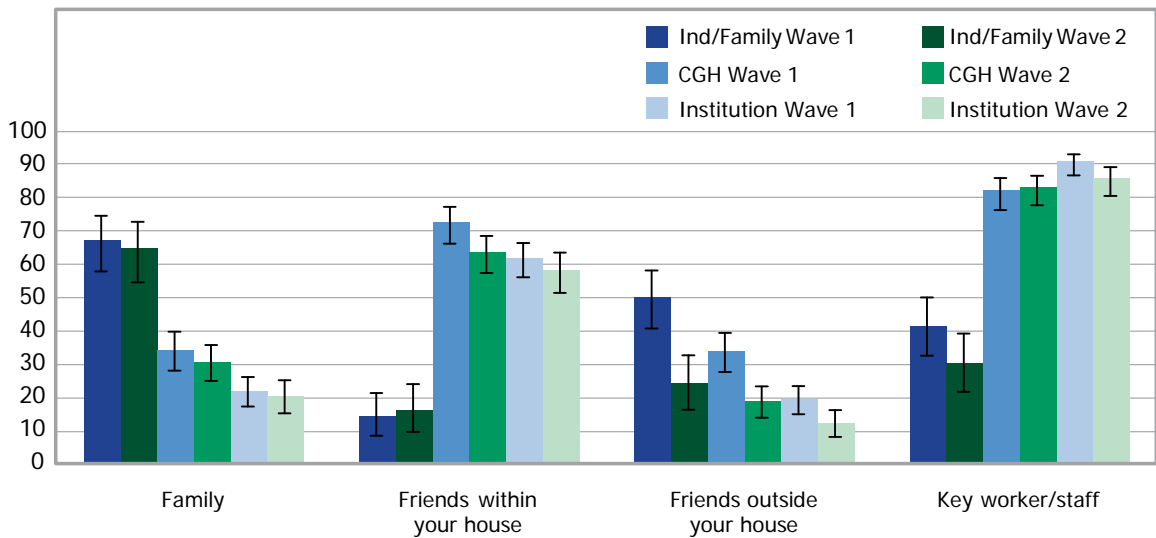
Respondents in Wave 2 were also asked about who participated in their main social activities. As shown in table 2.4, regardless of age over 70% of respondents participated in social activities with staff, with those with moderate to severe ID, regardless of whether they lived in the community or an institutional setting being heavily dependent on paid staff. Movement to a community group home does not appear to change the central social role that staff play in the lives of older adults with ID.

Table 2.4: People who respondents do their main social activities with

Family Member	Gender		Age			Level of ID			Type of Residence			Total
	Male	Female	43-49	50-64	65+	Mild	Moderate	Severe- Profound	Independent / Family	Community Group Home	Institution	
Keyworker/ support staff	76.8	74.2	73.3	75.8	77.1	56.2	74.5	91.1	30.1	83.1	85.9	75.4
Friends within your house	53.7	53.2	46.6	54.8	59.3	52.9	57.1	49.2	15.9	63.5	58.0	53.4
Family	33.6	30.8	44.5	32.3	14.3	37.9	32.7	21.2	64.6	30.4	20.1	32.0
Friends outside your house	13.1	19.7	17.8	17.3	14.3	23.5	17.0	10.1	23.9	18.6	11.9	16.8
Other	2.7	2.4	3.7	2.6	0.7	4.6	2.4	0.0	8.0	2.7	0.0	2.5
Total	298	380	191	347	140	153	294	179	113	296	269	678

Looking at changes in activity participation by type of residence, there is a general decline across settings in respondents socialising with friends outside their own homes, and little difference between community group homes and institutional settings in relation to the numbers who socialise mainly with staff and those who socialise mainly with friends within their home (see *figure 2.3*).

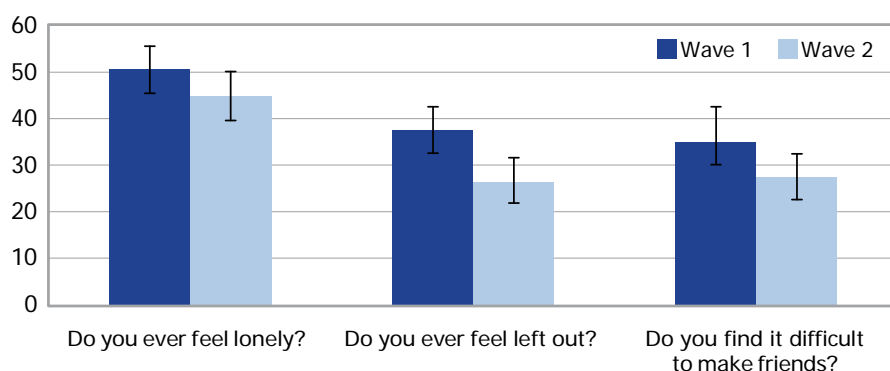
Figure 2.3: People with whom respondents do their main social activities with by type of residence



Note: CGH: Community group home
Ind.: Independent Living

2.3.1.3 Social Inclusion & Exclusion

In Wave 2 respondents were again asked a number of questions about feelings of loneliness and other aspects of social inclusion. *Figure 2.4* below shows that, between Waves 1 and 2, less people reported feeling lonely, feeling left out or finding it difficult to make friends.

Figure 2.4: Self-reported feelings of social inclusion/exclusion

While overall feelings of exclusion have fallen there were notable differences in relation to gender and type of residence. Women were more likely than men to report feeling lonely (52.7%, $n=168$, versus 34.2%, $n=98$), feel left out (28.4%, $n=55$, versus 23.7%, $n=32$) and having difficulty making friends (27.6%, $n=53$, versus 26.8%, $n=36$). Respondents living in institutional residences were much more likely than those living in independent/family residences to report feeling lonely (48.2%, $n=41$, versus 35.9%, $n=33$), feel left out (33.8%, $n=25$, versus 23.1%, $n=21$) and having difficulty making friends (32.9%, $n=24$, versus 18.9%, $n=17$). Those in community group homes reported similar levels to institutional residences in terms of feeling lonely (47.8%, $n=85$) and difficulty making friends (29.3%, $n=49$) but had lower levels for feeling left out (23.1%) (See Appendices, Table 2.A.7 and Table 2.A.8).

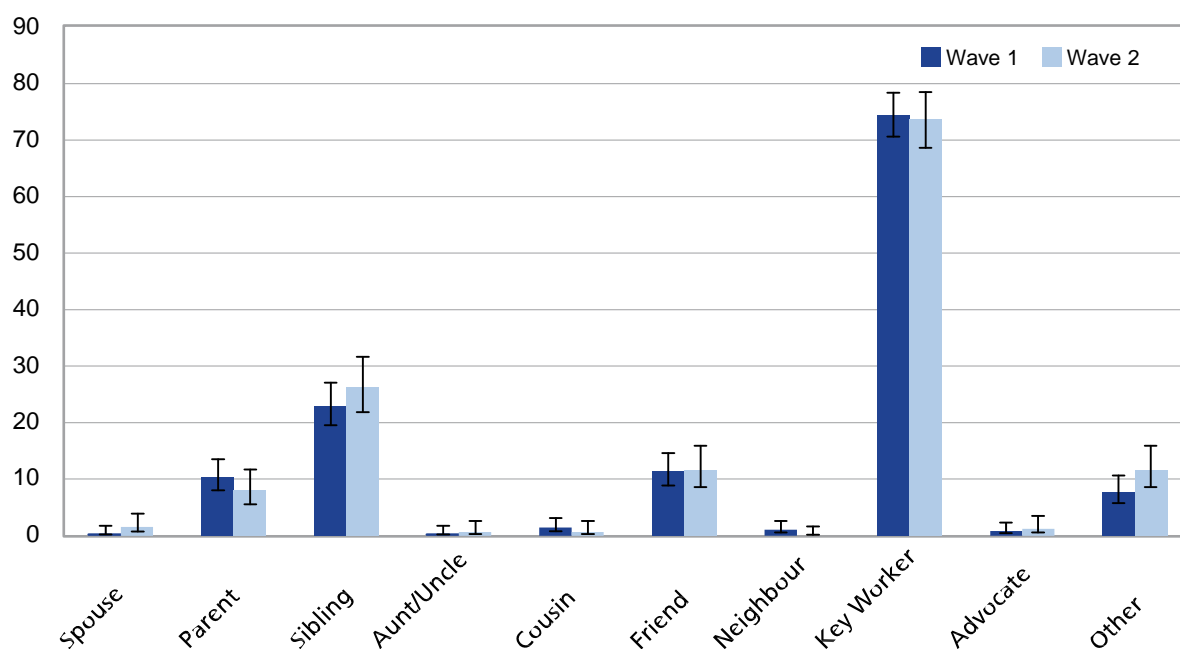
Respondents were again asked in Wave 2 if they had someone in whom they could confide, or talk to about private matters. While a change in the format of the question means a direct comparison of the overall figure is not possible, an analysis of the people who respondents confide in shows that paid staff remain the most likely confidant (73.7%, $n=241$), well ahead of siblings (26.3%, $n=86$) and friends (11.6%, $n=38$) (see table 2.5 below).

Table 2.5: People who respondents confide in.

Person confides in	Gender		Age			Level of ID			Type of Residence			Total
	Male	Female	43-49	50-64	65+	Mild	Moderate	Severe- Profound	Independent / Family	Community Group Home	Institution	
Keyworker/Staff	76.6	71.6	64.1	75.0	84.1	69.8	77.3	93.3	43.8	87.7	78.7	73.7
Sibling	28.5	24.7	27.2	26.2	25.4	27.8	22.7	33.3	41.6	20.9	20.0	26.3
Friend	7.3	14.7	9.8	12.2	12.7	15.9	8.4	0.0	11.2	11.0	13.3	11.6
Parent	11.7	5.3	15.2	6.4	1.6	6.3	9.1	6.7	15.7	6.1	2.7	8.0
Spouse/partner	1.5	1.6	3.3	1.2	0.0	2.4	1.3	0.0	1.1	2.5	0.0	1.5
Advocate	2.2	0.5	1.1	1.7	0.0	0.8	1.9	0.0	1.1	1.8	0.0	1.2
Cousin	0.7	0.5	0.0	1.2	0.0	1.6	0.0	0.0	1.1	0.0	1.3	0.6
Aunt/uncle	0.0	1.1	1.1	0.6	0.0	0.8	0.6	0.0	1.1	0.0	1.3	0.6
Other	12.4	11.1	12.0	13.4	6.3	13.5	8.4	0.0	19.1	7.4	12.0	11.6
n	137	190	92	172	63	126	154	15	89	163	75	327

As shown in *figure 2.5* the most notable change by Wave 2 was an increase in the rate of siblings as confidants, from 22.9% in Wave 1 to 26.3% in Wave 2. A fall in the rate of parents as confidants, from 10.3% ($n=52$) to 8.0% ($n=26$), might be expected with an ageing sample.

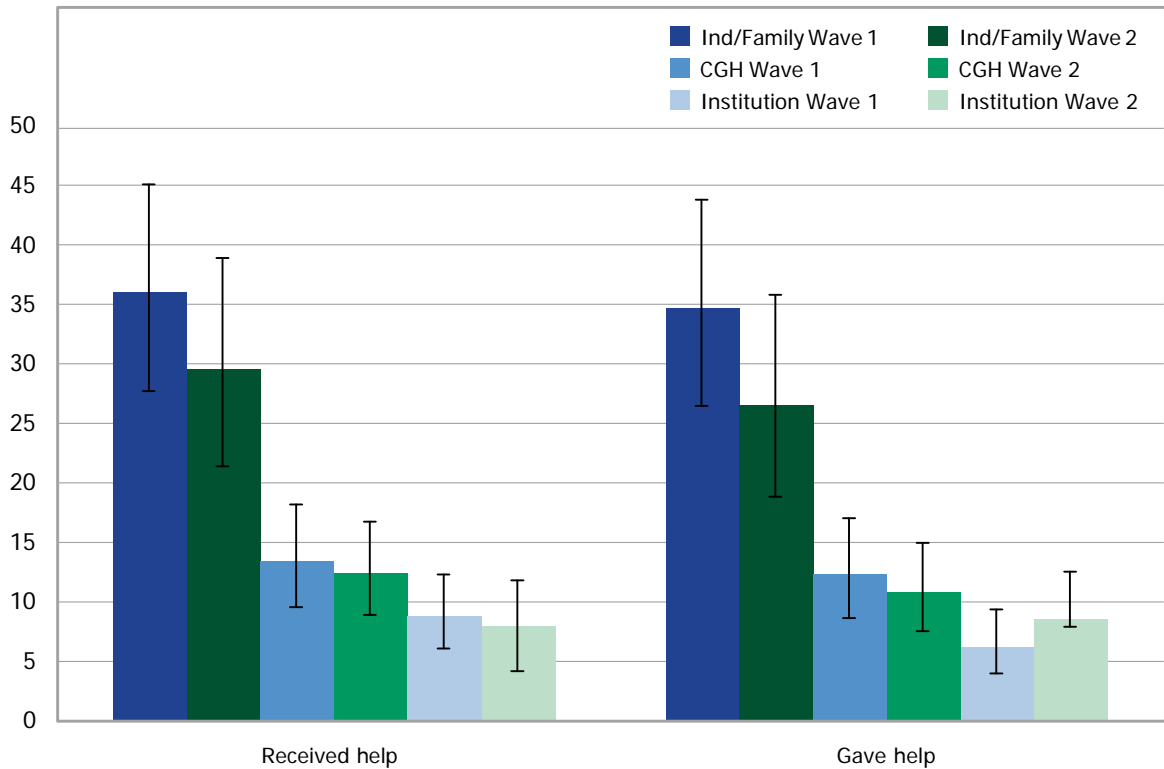
Figure 2.5: People confided in by respondents who said they had confidants.



Purposeful contact with neighbours and friends is another important element of social inclusion and participation in community. As in Wave 1, respondents were asked in Wave 2 if they had given or received any help to/from neighbours or friends in the previous two years. Results show an overall decline in both the level of help given (12.4%, $n=86$) and received (13.3%, $n=92$) since Wave 1.

Within these figures the rates of giving and receiving help has dropped for men (respectively down from 16.3% [$n=54$] to 14.1% [$n=43$]; and from 18.6% [$n=62$] to 13.2% [$n=40$]) while increasing slightly for women (up from 10.5% [$n=43$] to 11.1% [$n=43$]; and from 12.0% [$n=49$] to 13.4% [$n=52$]). Figures for Wave 2 continued to highlight a large gap between rates of giving and receiving help for people with severe-profound ID (2.1% [$n=4$] and 4.2% [$n=8$]) compared to those with mild ID (27.5% [$n=41$] and 29.5% [$n=44$]) (see Appendix Table 2.A.9). There were also significant gaps depending on type of residence, as shown in *figure 2.6* below. While rates declined for people living in independent/family residences, they remain much more likely to give and receive help compared to people living in both community group homes and institutional settings.

Figure 2.6: Help received from/given to neighbours or friends by type of residence



Note: CGH: Community group home
 Ind.: Independent Living

Respondents were also asked if they provided any support/help to family. Table 2.6 shows that, regardless of gender, age, level of ID or type of residence, most support was provided to siblings and parents, with the number helping parents declining with respondent age.

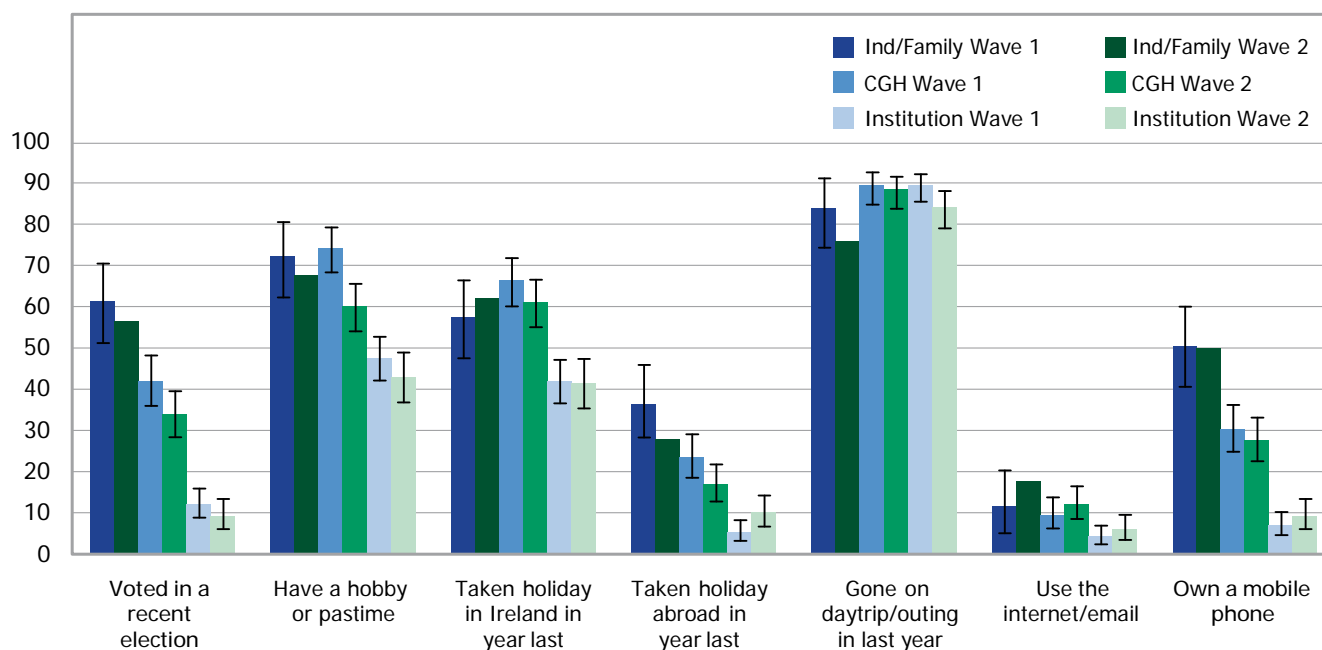
Table 2.6: Family members to whom respondents provide support/help

Person confides in	Gender		Age			Level of ID			Type of Residence			Total
	Male	Female	43-49	50-64	65+	Mild	Moderate	Severe- Profound	Independent /Family	Community Group Home	Institution	
Sibling	67.9	50.8	50.9	61.1	88.9	66.7	51.0	66.7	58.2	64.1	41.7	58.5
Mother	34.0	46.2	50.9	37.0	0.0	39.6	40.8	33.3	47.8	30.8	33.3	40.7
Father	13.2	12.3	21.8	5.6	0.0	8.3	22.4	0.0	17.9	5.1	8.3	12.7
Aunt/Uncle	0.0	1.5	1.8	0.0	0.0	0.0	2.0	0.0	1.5	0.0	0.0	0.8
Cousin	0.0	1.5	0.0	1.9	0.0	0.0	2.0	0.0	0.0	2.6	0.0	0.8
Other	17.0	9.2	5.5	18.5	22.2	12.5	12.2	0.0	13.4	10.3	16.7	12.7
n	53	65	55	54	9	48	49	6	67	39	12	118

The rates of family support/help given were far lower than those for the general population in Ireland. TILDA initially reported that older people in the general population provide a broad range of support to family: 36% provided non-financial support to non-resident children; 47% provided care to grandchildren; and among the 50-64 year-olds 50% provided non-personal care, and 28% provided personal care to parents (Barrett *et al.*, 2011). TILDA's Wave 2 quality of life analysis also identified that those who were 'most integrated' socially had significantly higher quality of life scores than those who were 'least integrated' (McCrory *et al.*, 2014). That this is an important area in social participation in which most older people with ID are losing out is reinforced by the findings that 100% of IDS-TILDA respondents in Wave 2 who said they provided support/help to a family member also spoke of the satisfaction they experienced from providing such support and help.

2.3.2 Engagement in Social Life

At Wave 2 respondents were again asked a range of questions regarding their participation in general and social activities. The small decline noted in the level of social activity and in engagement in voluntary organisations may reflect the impact on services to support social participation, resulting from the economic recession experienced in Ireland. As may be seen in *Figure 2.7* by Wave 2 people in independent/family settings remained far more likely to vote and own a mobile phone compared to those in community group homes and institutions, with people in community settings were more likely to have a hobby or pastime and to go on a holiday.

Figure 2.7: Participation in general activities by type of residence – Wave 1 and 2

Note: CGH: Community group home
Ind.: Independent Living

Overall the number of voters dropped between waves from 30.9% ($n=233$) to (27.5%, $n=184$) and remained significantly lower than the 80% voting rate found amongst the general older population (Barrett *et al.*, 2011).

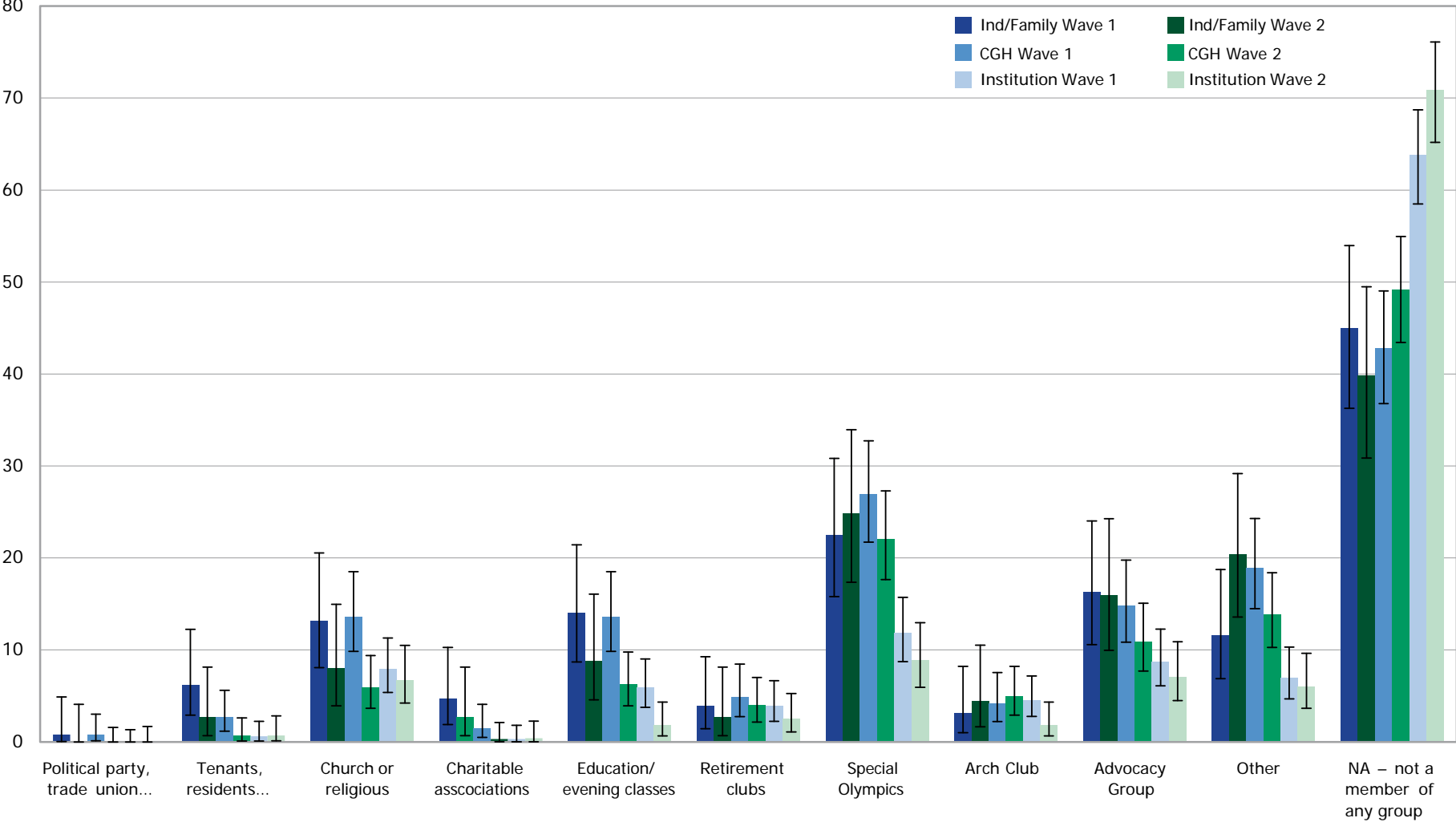
2.3.2.1 Internet and Mobile Phone

There was a small increase with internet use from 7.3% ($n=55$) to 10.5% ($n=70$). However, this remains far below the usage rates among the general population of 77% (CSO, 2012). Ownership of mobile phones remained essentially the same (23.8% as compared to 22.8% and continues to compare poorly with mobile phone ownership nationally of 120% (Central Bank of Ireland, 2013).

2.3.2.2 Membership of Clubs, Organisations and Societies

Involvement in voluntary clubs, organisations and societies declined from 47% to 43%. Men (58.8%, $n=181$) were a little more likely not to be a member of any voluntary organisation than women (54.6%, $n=213$) and membership levels were lower for people with severe-profound ID (75.0%, $n=144$), people living in institutional settings (70.9%, $n=200$), and people aged 65 years and over (65.5%, $n=97$). For those who were members, Special Olympics remained the most popular organisation, followed by Advocacy and Church/Religious Groups. As may be seen in *figure 2.8* there was little difference between independent/family residences and community group homes, but those in institutional settings had substantially lower membership of voluntary organisations. Regardless of setting, level of ID or age, membership in organizations by people with ID were substantially less than the 64.1% reported by TILDA for the general population (Nolan *et al.*, 2014: 171) (see Appendix Table 2.A.10).

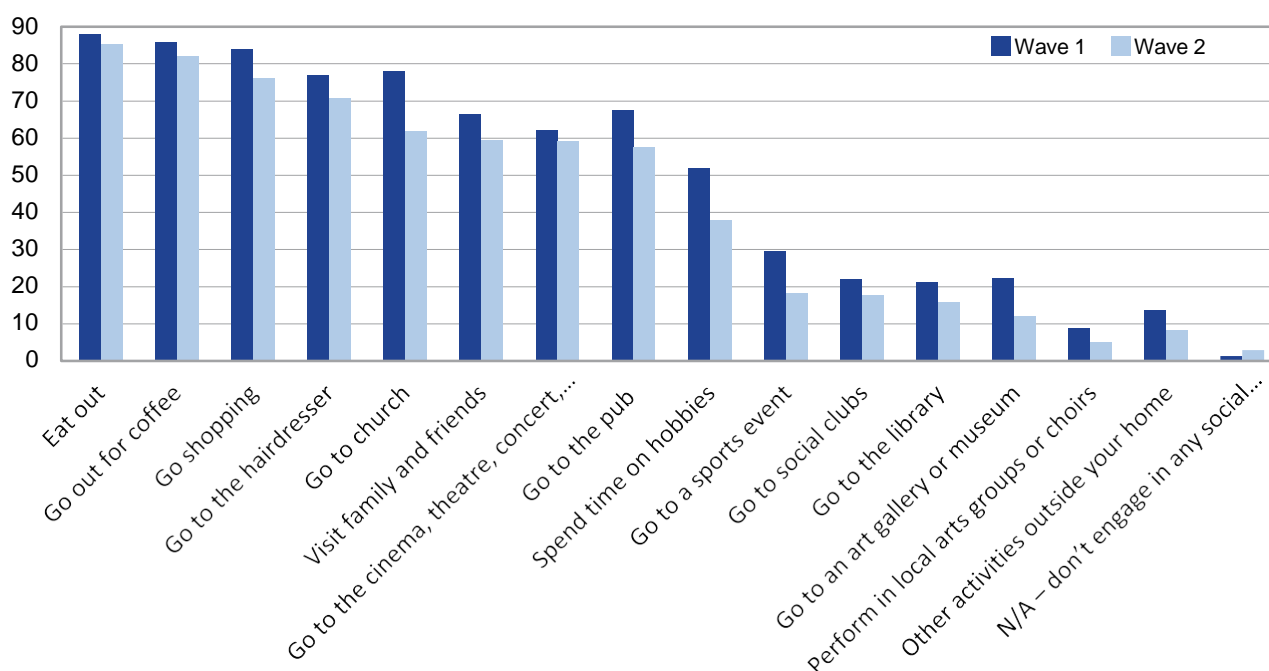
Figure 2.8: Membership of clubs, organisations and societies by type of residence



2.3.2.3 Social Activities

Although there were some declines it is still impressive the number of activities in which people with ID are involved as are the very high number participating in activities like eating out/going for coffee; shopping and going to the hairdresser; and going to church, visiting friends and going to the cinema (*figure 2.9*).

Figure 2.9: Social activities in Wave 1 and Wave 2



Respondents aged 65 years and over had lower activity rates than other age groups; people with mild disabilities had the highest participation rates across all activities while those with severe-profound had the lowest; and with regard to type of residence, people living in institutional settings had the lowest participation rates across the majority of social activities (see Appendices, Table 2.A.11 and Table 2.A.12).

2.3.3 Facilitators & barriers of social participation

In Wave 2 respondents were asked about the difficulties they experienced in getting out of their home to engage in social activities. People were also asked about difficulties experienced getting around their community, about transport options available and any transportation difficulties experienced.

2.3.3.1 Difficulties participating in social activities outside the Home

Just over half (52.4%, $n=356$) of respondents in Wave 2 said they experienced difficulties participating in social activities outside their homes, which is similar to the rate reported in Wave 1 (51.6%, $n=382$) (see Appendix Table 2.A.13). More women (55.4%, $n=211$) experienced these difficulties than men (48.5%, $n=145$). The over-65 age group (59.4%, $n=85$) also experienced these difficulties more than either the under-50 group (50.3%, $n=98$) or the 50-64 group (50.6%, $n=173$). However, the biggest differences related to level of ID and type of residence. More than three-quarters of people with severe-profound ID (78.3%, $n=148$) experienced such difficulties, compared to 30.7% ($n=46$) of people with mild ID, and 47.7% ($n=137$) of people with moderate ID. Just over a quarter of people living in independent/family homes (26.5%, $n=30$) experienced these difficulties, compared with almost half (48.3%, $n=144$) of people living in community group homes, and more than two-thirds (67.7%, $n=182$) of people living in institutional settings. *Figure 2.10* below also highlights that difficulties for community group home and institutional respondents have increased compared to those in independent/family residences.

Figure 2.10: Difficulties participating in social activities outside the home by type of residence – Waves 1 and 2

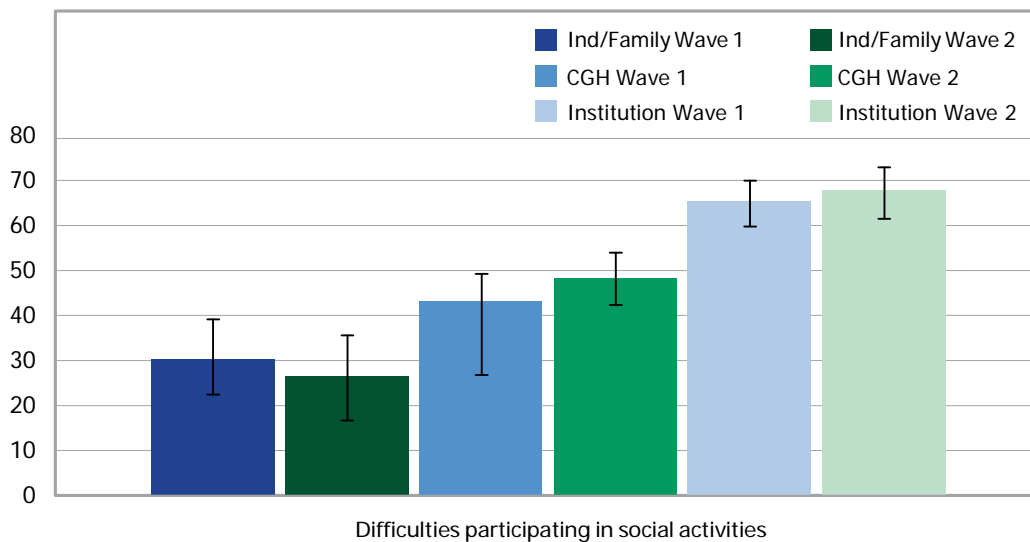
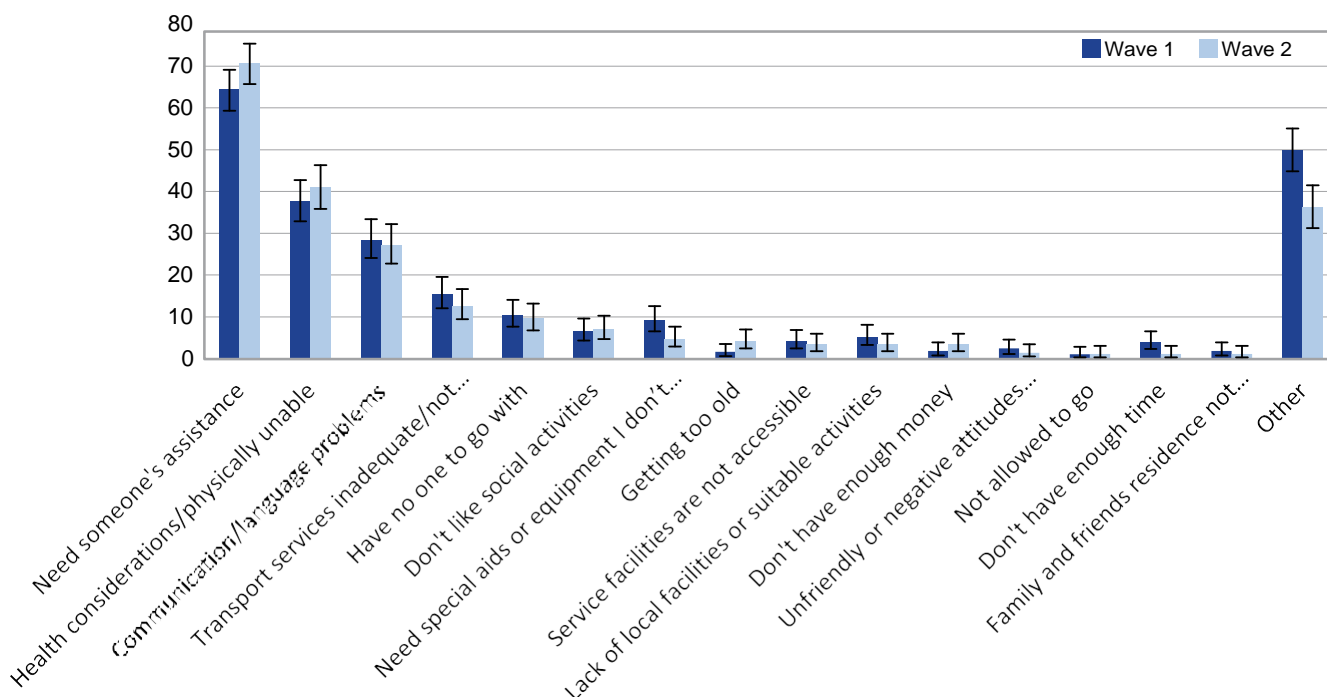


Figure 2.11 highlights that needing someone's assistance not only continued to be the most frequently reported difficulty (70.8%, $n=252$), followed by *health considerations or physically unable* (41.0%, $n=146$), but the percentage experiencing these two difficulties increased.

Figure 2.11: Difficulties experienced participating in social activities outside the home – change since

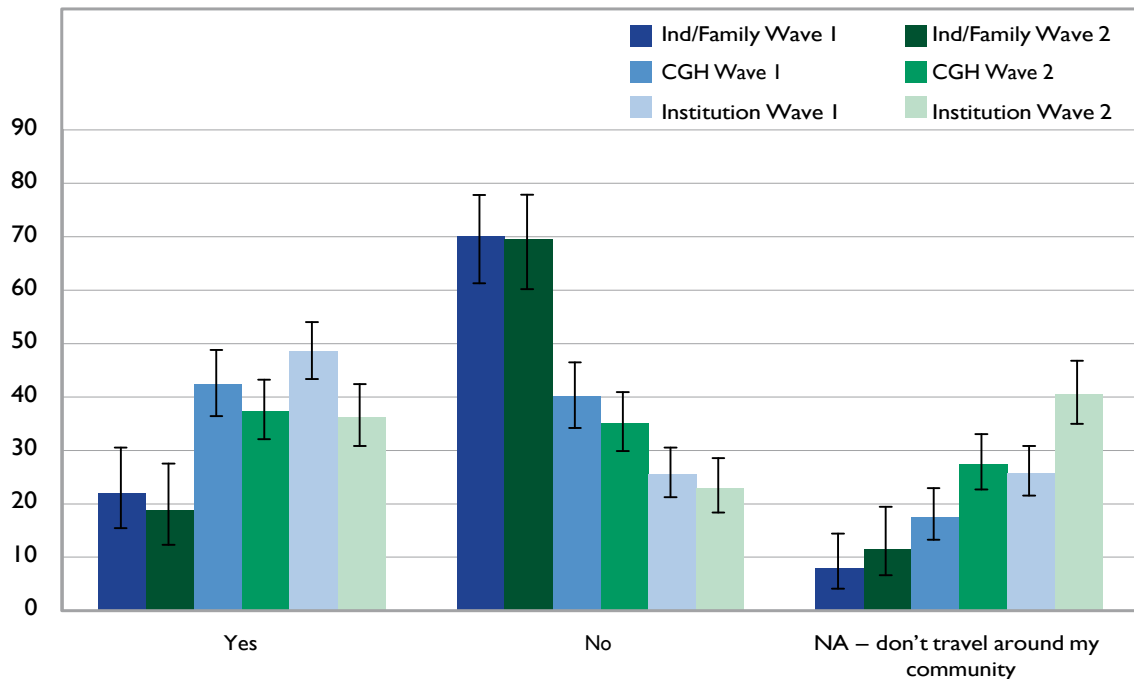


2.3.3.2 Difficulties getting around the community

An initial appearance that there was a reduction between Waves from 42% to 34% in people experiencing any difficulties getting around their community, must be balanced with a larger increase in the number of people who said that they don't travel around their community at all, from 19.8% in Wave 1 to 30% in Wave 2. Taken together, this means that almost two-thirds (64.2%, $n=444$) either experience difficulty or else do not travel around their community at all, an increase of 2.3% since Wave 1.

While more men (35.7%, $n=109$) than women (32.6%, $n=126$) reported difficulties getting around their community, more women (31.3%, $n=121$) than men (28.9%, $n=82$), people aged 65 years and older (42.5%, $n=62$), and people living in institutional residences (40.6%, $n=113$) were much more likely than others to report that they didn't travel around their community at all (see Appendix Table 2.A.14). Figure 2.12 below shows that, while there has been little change for people living in independent / family settings, those living in community group homes and institutional settings had higher rates of difficulties.

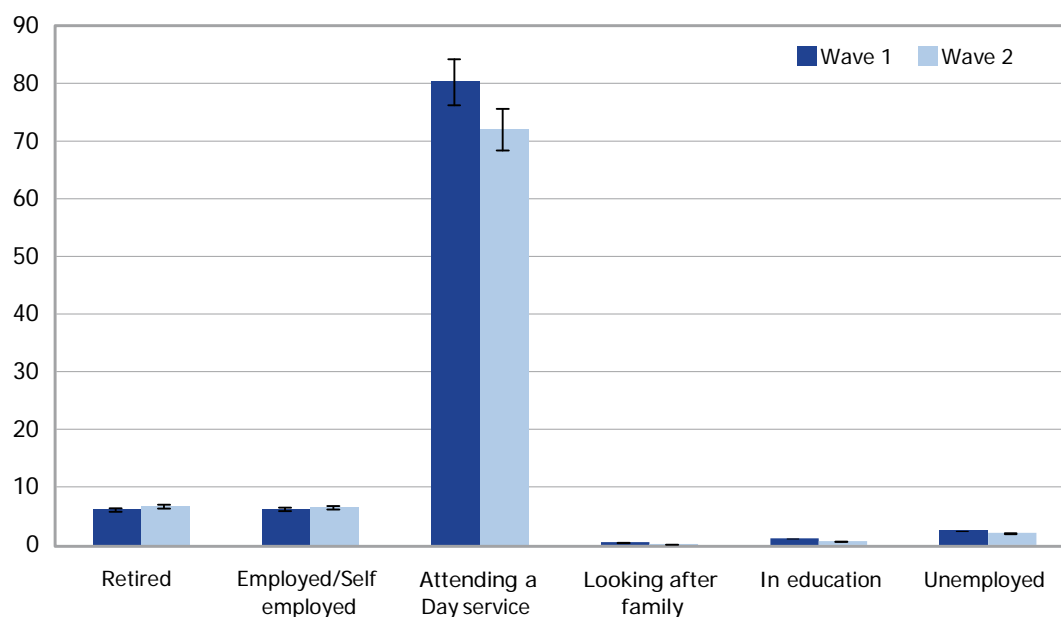
Figure 2.12: Difficulties experienced getting around your community by type of residence – Wave 1 and 2



Note: CGH: Community group home
Ind.: Independent Living

2.3.4 Employment Changes from Wave 1

As may be seen in *figure 2.13*, in Wave 2 6.5% were in regular paid employment/self-employed, 11.6% were attending a sheltered workshop, and a further 80.3% were attending a day service. These findings are very similar to the employment status identified in Wave 1 IDS-TILDA but were significantly different from the picture for TILDA, where 33% were employed (Hudson *et al.*, 2014). There was a small increase in retirees from 6.1% to 6.7%. This compares to 40% of TILDA participants being retired. Less than 1% of IDS-TILDA participants looked after the home whereas this was true of 16% of TILDA participants (Hudson *et al.*, 2014).

Figure 2.13 Occupational status comparisons between Wave 1 and Wave 2

2.3.4.1 Labour Market Movement between Wave 1 and Wave 2

There was very little movement observed in the labour market between Wave 1 and Wave 2. Of the 44 who were employed in Wave 1, 65.9% were still in employment in Wave 2. Of the 14 respondents who no longer indicated that they were employed, 8 moved to a day service, two moved to sheltered employment and two indicated that they were unable to work due to being permanently sick or disabled.

The small number of individuals in open paid employment spent an average of 3.3 days a week in work, over an average of 15.7 hours a week, for an average wage of €72.66. The industries in which people were most commonly involved were the food and drink industry (28.9%, $n=11$), retail (26.3%, $n=10$), cleaning/maintenance industry (15.8% $n=6$), office work ($n=3$), banking ($n=1$) and other services ($n=2$).

2.3.5 Day Services

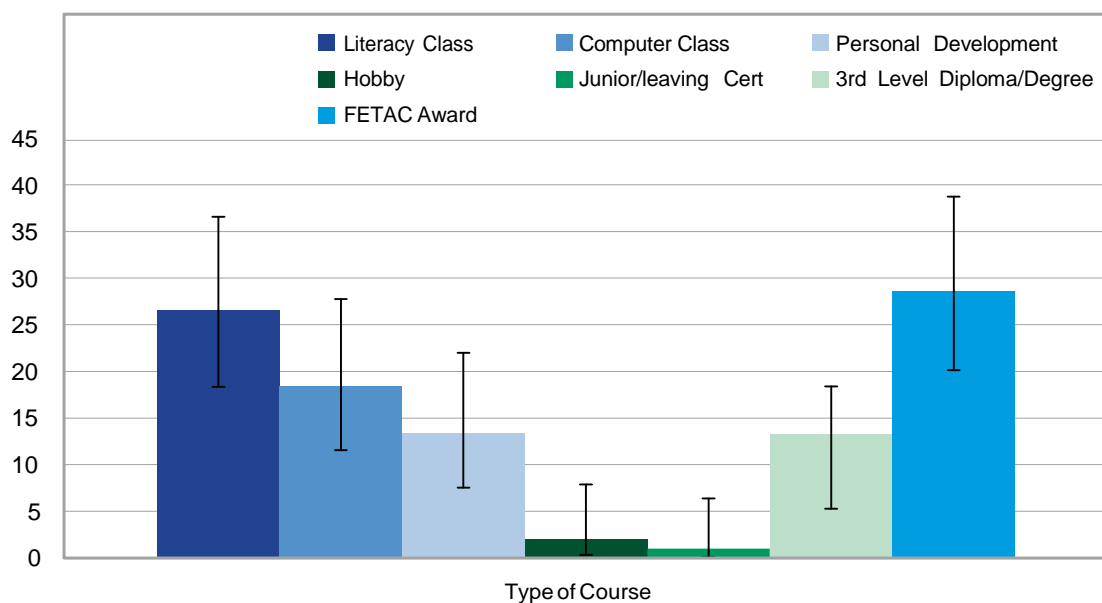
Just over 80% of people were attending a day service in Wave 2. Similar to findings in Wave 1, arts & crafts (72.9%), and music (69.3%) were the most frequent activities. The majority (51.4%, $n = 228$) chose their activities most of the time, while 18.6% ($n=83$) said that they rarely or never chose their activities. Individuals attended the day service on average 4.3 days a week, for 21.8 hours a week. Fifty nine percent of those attending a day service were very satisfied and a further 36.4% were satisfied. Four percent indicated that they were dissatisfied with the day service.

2.3.6 Education and Life Long learning

There is a clear link between educational level and employment, spending power, health and well-being and further education has been linked to better health behaviours, improved cognitive ability and engagement in preventative healthcare (Lochner, 2011; Grundy & Holt 2001). However as was seen in Wave 1 of IDS-TILDA, educational levels were low with 32% noting they had never attended an education programme (McCarron *et al.*, 2011).

In Wave 2 we further explored educational experiences by asking people to identify if they had engaged in any further education. The majority (85.7%) of adults with an ID were not currently engaged in further education. The 14.3% who did attend represents a slight decline from Wave 1 (15.4%). Of this 14.3%, the majority (28.6%) were attending a FETAC level course, with 26.5% engaging in literacy classes (see *figure 2.14*). Of the courses attended, 21.6% reported was organised by a training centre, 11.3% by a local community programme, and 9.3% by and Institute of Technology.

Figure 2.14 Types of engagement in further education

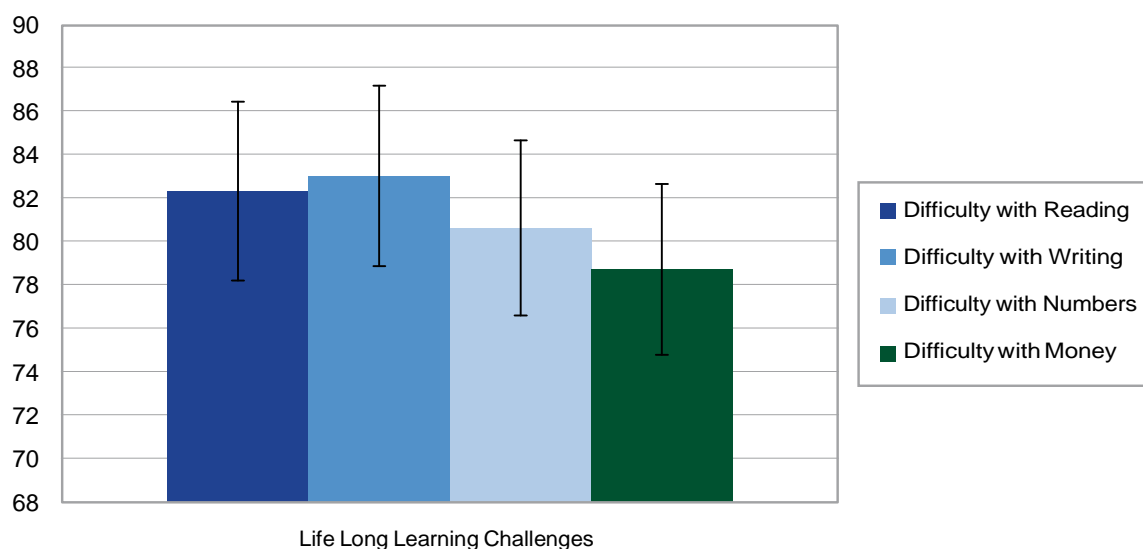


Of the 85.7% who were not engaged in further education, 83 (11.9%) expressed interest in attending courses, with the most preferred courses being reading/writing and computers. This level of interest declined from Wave 1, when 32.2% of respondents reported a desire to attend courses.

2.3.7 Prevalence of difficulties engaging in further education

Additional questions in the Wave 2 interview examined issues of numeracy and literacy. As shown in *figure 2.15*, 82.3% identified difficulties with reading, 83% with writing, 80.6% with number identification and 78.7% with understanding money and monetary transactions.

Figure 2.15 Challenges engaging with lifelong learning.



Overall, only 8.5% of the participants reported that they had no trouble with any of the described tasks; both males and females noted high levels of difficulty with approximately 5% more females reporting concerns; difficulties increased with age and by level of ID with those within the severe-profound category presenting with the greatest difficulties (see Appendix Table 2.A.15).

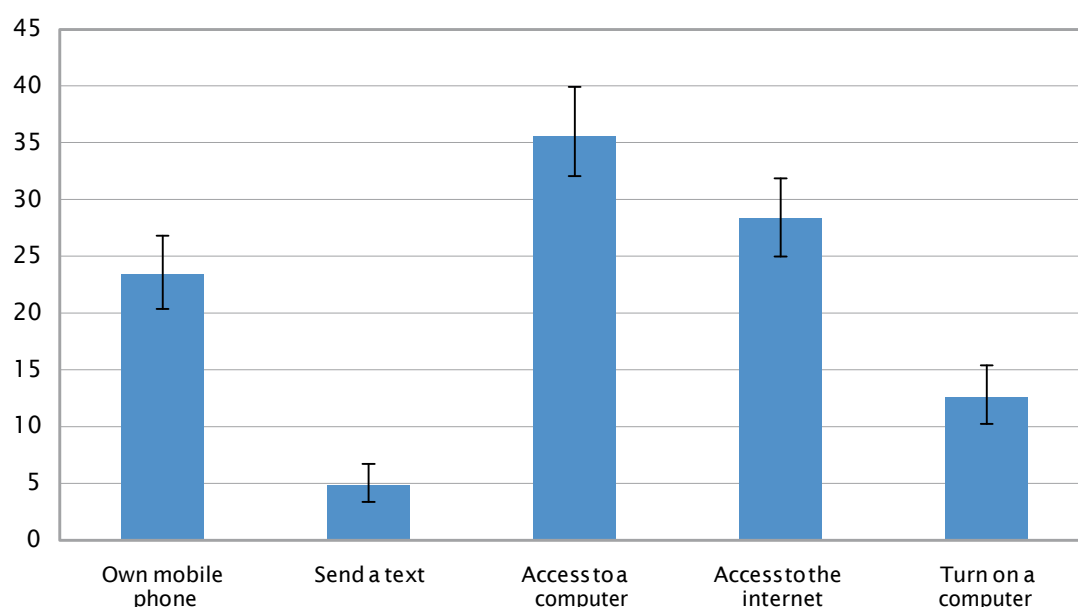
Among community survival knowledge, often identified as in signing one's own name, recognising numbers and being able to know what change you get from purchases, there were additional concerns. Just 29.4% of people reported they could read their own name without assistance with a further 7.9% indicating they would require assistance however the majority, 62.7% reported they were unable to read their own name. The majority of people (93.9%) reported being unable to complete forms such as a bank deposit slip and just 1.1% reported being able to use a calculator. Approximately 15% reported they could identify the differences between currency notes however 89.9% said they would not be able to recognise if change was due when making a purchase (see Appendices, Table 2.A.16a, Table 2.A.16b).

Considering the policy changes that have occurred in recent years within the field of ID in Ireland with greater emphasis on engaging in the community lack of education and basic literacy skills among a group of people with ID who are now ageing represents a major barrier to successful community participation. To some extent greater educational efforts will be helpful but of more concern is the need for concentrated efforts using technology and other aides to compensate for these literacy barriers so that day to day participation in community life becomes more feasible.

2.3.8 Access and engagement with technology

The growth in technologies and social media in recent years has the potential to offer older people with ID greater opportunities for social engagement. However, findings from Wave 2 show this population continues to be behind the general population with regard to having access to and being able to use information and communication technology (ICT). *Figure 2.16* below shows that less than a quarter of respondents owned a mobile phone, while less than one in 20 could send a text message. Just over a third of respondents (35.6%) said that they had access to a computer, and only 28.3% had internet access. However, just 12.6% said that they were able to turn on a computer (7.9% with assistance only). As such, we can see that currently in Ireland ICTs are not being utilised to anywhere near their potential for this already marginalised group of people (see Appendix Table 2.A.17).

Figure 2.16: Access and Engagement with Technology



2.4 Conclusion

Concern that placement in the community does not necessarily mean living in the community on the same terms as other community members continue to be well founded for older people with ID. On the one hand there is the reality of more limited social networks because so few people with ID have spouses and children. On the other hand low levels of social activities, reliance on staff, low levels of employment and survival literacy challenges make successful community engagement more difficult. There are additional concerns that the IDS-TILDA group of respondents have at best sustained a low level of community engagement and in some areas have seen declines in access and participation. Of most concern is that a primary mechanism of community integration and engagement, movement to community group homes, in many areas more resembles experiences in institutional settings rather than other community-based living situations such as family care and independent living. To some extent lower levels of community participation noted are attributable to differences in levels of intellectual disability. However, family and independent living situations already represent substantially less community engagement than experienced by the general population. It is of concern that community group homes are not yet matching family/independent settings when this represents just a first step in offering people with ID community experiences similar to the general population.

That those living in community group homes tend to be younger, higher functioning and experience less health problems than those currently living in institutional settings heightens the concern that physical location in the community does not appear to be translating to the espoused community living benefits in terms of friendships, employment, and engagement in neighbourhoods. A renewed effort is needed to ensure that community group homes are organised to support greater levels of genuine integration; it is also a responsibility for day and employment programmes to see as a critical role the facilitation of opportunities for friendships and community engagement. Finally, there remain questions that if, for the highest functioning and supported persons with ID, community group homes are not yet fully supporting the transition to community life, what additional steps will be needed to support the movement from congregated settings of those with greater needs and barriers to integration. As others have noted movement must not simply be about a change of address.

Also of concern is the continuing low level of employment opportunities for people with ID, coupled with low levels of reading, writing, numeracy and money management capacity which, individually and collectively, further disadvantage the community integration of people with ID. Again, community placement alone is not sufficient; there is a need for interventions and wider use of technology to compensate for these disadvantages, increase the likelihood of employment and offer tools for greater community involvement.

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Appendix 2A: Tables on Social Participation of Older Adults with an Intellectual Disability

Table 2.A.1. Frequency of contact with family with whom respondents do not live: meeting up

Meet up	Spouse/ Partner	Mother	Father	Brother	Sister	Aunt/Uncle	Niece/ Nephew	Cousin	Other
3+ times a week	75.0	3.6	5.9	6.0	5.5	3.7	4.5	1.2	6.7
Once or twice a week	0.0	24.6	29.4	9.2	13.1	0.9	6.7	3.5	6.7
Once or twice a month	0.0	30.4	11.8	22.5	25.7	13.1	19.4	5.8	26.7
Every few months	0.0	16.7	17.6	23.8	26.1	18.7	28.9	22.7	40.0
Once or twice a year	0.0	12.3	15.7	18.5	15.5	26.2	19.7	22.1	20.0
Less than once a year	0.0	6.5	7.8	12.7	9.2	17.8	11.0	20.3	0.0
Never	25.0	5.8	11.8	7.3	4.9	19.6	9.8	24.4	0.0
<i>n</i>	4	138	51	466	510	107	356	172	15



Table2.A.2: Frequency of contact with family with whom respondents do not live: telephone

Meet up	Spouse/ Partner	Mother	Father	Brother	Sister	Aunt/Uncle	Niece/ Nephew	Cousin	Other
3+ times a week	50.0	7.6	8.5	4.7	6.1	1.9	2.1	0.6	7.7
Once or twice a week	25.0	23.5	17.0	11.0	17.7	3.9	3.8	1.2	23.1
Once or twice a month	0.0	11.4	6.4	14.5	16.9	5.8	7.1	4.7	15.4
Every few months	0.0	9.8	6.4	10.5	12.7	10.7	12.6	8.3	0.0
Once or twice a year	0.0	1.5	4.3	5.6	4.2	4.9	3.8	8.9	0.0
Less than once a year	0.0	2.3	2.1	4.0	3.1	4.9	3.5	2.4	0.0
Never	25.0	43.9	55.3	49.7	39.2	68.0	67.1	74.0	53.8
n	4	132	47	447	479	103	340	169	13

Table 2.A.3. Frequency of contact with family with whom respondents do not live: written contact

Meet up	Spouse/ Partner	Mother	Father	Brother	Sister	Aunt/Uncle	Niece/ Nephew	Cousin	Other
3+ times a week	0.0	0.0	0.0	0.0	0.5	0.0	1.0	1.3	0.0
Once or twice a week	0.0	1.7	4.4	0.5	0.5	0.0	0.0	0.7	8.3
Once or twice a month	25.0	0.8	2.2	1.0	2.6	0.0	0.0	0.7	8.3
Every few months	0.0	5.8	2.2	4.3	6.5	0.0	3.6	0.7	8.3
Once or twice a year	0.0	8.3	2.2	10.3	11.1	5.4	4.9	5.3	0.0
Less than once a year	0.0	0.8	2.2	3.8	3.0	4.3	1.9	2.7	8.3
Never	75.0	82.5	86.7	80.2	75.9	90.2	88.6	88.7	66.7
n	4	120	51	398	431	92	308	150	12

Table 2.A.4. Frequency of contact with friends with whom respondents do not live: meeting up

Meet up	Gender		Age			Level of ID			Type of Residence			Total
	Male	Female	43-49	50-64	65+	Mild	Moderate	Severe- Profound	Independent /Family	Community Group Home	Institution	
3+ times a week	50.3	44.3	56.9	43.3	40.3	46.1	48.3	47.7	62.2	43.2	39.1	46.8
Once or twice a week	23.3	24.8	27.6	24.4	18.1	28.7	22.7	18.5	20.4	27.3	22.6	24.2
Once or twice a month	11.3	11.3	8.6	12.4	12.5	10.4	11.6	13.8	5.1	12.5	14.8	11.3
Every few months	7.5	8.3	5.2	9.5	8.3	7.0	7.6	9.2	8.2	6.3	10.4	8.0
Once or twice a year	3.1	4.3	0.0	4.0	9.7	3.5	3.5	3.1	0.0	4.0	7.0	3.9
Less than once a year	3.1	1.3	0.9	1.0	6.9	0.9	3.5	0.0	1.0	2.8	1.7	2.1
Never	1.3	5.7	0.9	5.5	4.2	3.5	2.9	7.7	3.1	4.0	4.3	3.9
n	159	230	116	201	72	115	172	65	98	176	115	389

Table 2.5 Frequency of contact with friends with whom respondents do not live: telephone

Meet up	Gender		Age			Level of ID			Type of Residence			Total
	Male	Female	43-49	50-64	65+	Mild	Moderate	Severe- Profound	Independent /Family	Community Group Home	Institution	
3+ times a week	3.4	4.9	2.8	6.2	1.4	7.9	1.8	1.8	8.4	3.0	2.8	4.3
Once or twice a week	8.7	13.5	15.6	12.4	2.9	20.2	9.6	1.8	14.7	13.1	6.4	11.6
Once or twice a month	5.4	6.7	6.4	5.7	7.2	8.8	7.2	0.0	7.4	6.5	4.6	6.2
Every few months	6.0	4.0	6.4	4.1	4.3	7.9	3.6	1.8	8.4	4.2	2.8	4.8
Once or twice a year	2.0	3.1	0.9	2.6	5.8	1.8	2.4	0.0	2.1	4.2	0.9	2.7
Less than once a year	1.3	2.7	0.9	2.6	2.9	3.5	2.4	0.0	2.1	3.6	0.0	2.2
Never	73.2	65.0	67.0	66.5	75.4	50.0	73.1	94.5	56.8	65.5	82.6	68.3
n	149	223	109	194	69	114	167	55	95	168	109	372



Table 2.A.6. Frequency of contact with friends with whom respondents do not live: written contact

Meet up	Gender		Age			Level of ID			Type of Residence			Total
	Male	Female	43-49	50-64	65+	Mild	Moderate	Severe- Profound	Independent /Family	Community Group Home	Institution	
3+ times a week	1.4	0.0	0.9	0.6	0.0	1.9	0.0	0.0	1.1	0.0	1.0	0.6
Once or twice a week	0.7	3.5	3.8	1.8	1.5	4.6	2.0	0.0	3.3	2.6	1.0	2.3
Once or twice a month	0.7	2.0	1.9	1.2	1.5	2.8	1.4	0.0	1.1	1.3	2.0	1.5
Every few months	0.7	1.0	1.9	0.0	1.5	0.0	2.0	0.0	0.0	1.3	1.0	0.9
Once or twice a year	1.4	4.5	2.8	3.5	3.1	2.8	2.7	7.8	0.0	3.3	6.1	3.2
Less than once a year	1.4	2.0	0.9	2.9	0.0	3.7	1.4	0.0	0.0	2.6	2.0	1.8
Never	93.6	87.0	87.7	90.0	92.3	84.3	90.5	92.2	94.6	88.7	86.7	89.7
Total	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0	100.0
n	141	200	106	170	65	108	148	51	92	151	98	341

Table 2.A.7. Self-reported feelings of social exclusion

		Do you ever feel lonely?						Do you ever feel left out?					
		Wave 1			Wave 2			Wave 1			Wave 2		
		%	95% CI	n	%	95% CI	n	%	95% CI	n	%	95% CI	n
Gender	Male	44.4	36.91-52.22	171	34.2	26.84-42.4	152	36.2	28.93-44.14	163	23.7	16.99-31.93	135
	Female	55.3	48.4-61.91	219	52.7	45.61-59.7	203	38.4	31.87-45.35	211	28.4	22.24-35.33	194
Age	43-49	51.3	43.12-59.45	152	41.7	31.83-52.18	96	38.7	30.94-46.99	150	30.8	21.75-41.44	91
	50-64	52.7	45.28-59.93	188	48.1	40.82-55.52	187	38.5	31.47-46.13	179	26.4	20.22-33.62	178
	65+	40.0	26.73-54.8	50	40.3	29.09-52.51	71	28.9	16.84-44.52	45	20.0	11.19-32.7	60
ID Level	Mild	53.1	44.66-61.37	145	50.4	41.3-59.49	123	34.3	26.61-42.85	140	28.1	20.49-37.12	121
	Moderate	50.5	43.15-57.9	186	40.4	33.25-48.07	178	38.3	31.28-45.86	180	24.5	18.22-32.1	159
	Severe- Profound	50.0	26.77-73.23	18	52.6	29.49-74.79	19	29.4	11.38-55.95	17	33.3	20.14-79.86	15
Residence	Independent /Family	47.7	38.13-57.45	109	35.9	26.33-46.61	92	42.6	33.24-52.47	108	23.1	15.16-33.31	91
	Community Group Home	50.5	43.15-57.9	186	47.8	40.26-55.33	178	35.6	28.68-43.07	180	25.0	18.72-32.47	164
	Institution	53.8	43.16-64.05	93	48.2	37.37-59.27	85	33.3	23.65-44.55	84	33.8	23.45-45.81	74
Total		50.5	45.44-55.57	390	44.8	39.56-50.13	355	37.4	32.55-42.57	374	26.4	21.82-31.62	329

Table 2.A.8. Self-reported feelings of social inclusion

		Do you find it difficult to make friends?						Do you have someone to confide in?					
		Wave 1			Wave 2			Wave 1			Wave 2		
		%	95% CI	n	%	95% CI	n	%	95% CI	n	%	95% CI	n
Gender	Male	34.6	27.39-42.49	162	26.8	19.8-35.14	138	65.9	60.4-70.92	328	81.1	74.18-86.52	169
	Female	35.0	28.77-41.81	217	27.6	21.53-34.59	192	70.2	65.51-74.54	413	86.0	80.52-90.13	221
Age	43-49	37.0	29.27-45.41	146	20.2	12.73-30.33	89	67.3	61.41-72.61	284	85.2	76.76-91.04	108
	50-64	34.9	28.21-42.32	186	31.8	25.2-39.27	179	70.0	64.78-74.76	340	85.1	79.32-89.61	202
	65+	27.7	16.09-42.87	47	24.2	14.6-37.02	62	65.8	56.4-74.17	117	78.8	67.89-86.79	80
ID Level	Mild	30.7	23.35-39.15	140	28.1	20.49-37.12	121	93.2	87.8-96.37	161	97.7	92.83-99.4	129
	Moderate	37.2	30.23-44.64	183	27.8	21.18-35.46	162	78.8	73.79-83.09	316	83.2	76.9-88.16	185
	Severe- Profound	43.8	20.75-69.45	16	21.4	5.71-51.59	14	31.1	24.92-37.94	206	38.5	23.81-55.34	39
Residence	Independent/ Family	27.1	19.17-36.7	107	18.9	11.7-28.8	90	90.5	83.62-94.77	126	97.8	91.53-99.62	91
	Community Group Home	35.9	29.02-43.41	181	29.3	22.69-36.96	167	80.5	75.06-85.09	257	82.3	76.13-87.22	198
	Institution	41.1	31-51.99	90	32.9	22.6-44.98	73	51.4	46.08-56.71	354	74.3	64.43-82.21	101
	Total	34.8	30.08-39.89	379	27.3	22.61-32.47	330	68.3	64.78-71.6	741	83.8	79.73-87.28	390

Table 2.A.9: Help received from/given to neighbours or friends in the last 2 years

		Help received from neighbours/friends						Help given to neighbours/friends					
		Wave 1			Wave 2			Wave 1			Wave 2		
		%	95% CI	n	%	95% CI	n	%	95% CI	n	%	95% CI	n
Gender	Male	18.6	14.62-23.24	334	13.2	9.7-17.66	303	16.3	12.59-20.84	331	14.1	10.5-18.63	305
	Female	12.0	9.05-15.58	410	13.4	10.28-17.34	387	10.5	7.78-13.94	410	11.1	8.38-14.81	386
Age	43-49	16.5	12.48-21.43	285	9.3	5.75-14.49	194	17	12.88-21.96	283	11.9	7.82-17.46	194
	50-64	14.4	10.94-18.7	340	16.9	13.17-21.29	350	12.4	9.14-16.44	340	14.6	11.13-18.84	350
	65+	12.6	7.47-20.25	119	10.3	6.06-16.66	146	5.9	2.62-12.27	118	8.2	4.48-14.13	147
ID Level	Mild	27.7	21.19-35.28	166	29.5	22.49-37.64	149	28.9	22.29-36.55	166	27.5	20.68-35.54	149
	Moderate	12.9	9.48-17.14	319	10.8	7.62-15.05	296	10.4	7.38-14.44	317	10.5	7.33-14.67	296
	Severe- Profound	6.9	3.97-11.54	203	4.2	01.96-8.38	191	3.9	1.84-7.9	203	2.1	0.67-5.59	192
Residence	Independent /Family	36	27.75-45.12	125	29.5	21.42-38.94	112	34.7	26.51-43.82	124	26.5	18.89-35.83	113
	Community Group Home	13.4	9.6-18.23	262	12.4	8.96-16.77	299	12.3	8.69-17.08	260	10.8	7.59-15	297
	Institution	8.8	6.14-12.35	322	7.9	5.12-11.86	279	6.2	4.04-9.42	353	8.5	5.66-12.0	281
Total		14.9	12.48-17.73	744	13.3	10.93-16.15	690	13.1	10.79-15.78	741	12.4	10.13-15.2	691

Table 2.A.10: Membership of organisations, clubs and societies by gender, age and level of ID

Club, Organisation or Society	Gender		Age			Level of ID			Type of Residence			Total
	Male	Female	43-49	50-64	65+	Mild	Moderate	Severe- Profound	Independent /Family	Community Group Home	Institution	
Special Olympics	16.9	17.4	19.4	19.5	8.8	21.6	19.7	9.4	24.8	22.1	8.9	17.2
Advocacy Group	10.4	10.0	11.2	11.0	6.8	6.5	14.0	5.2	15.9	10.9	7.1	10.2
Church/ Religious	3.6	9.0	6.1	6.8	6.8	7.2	6.7	7.3	8.0	5.9	6.7	6.6
Education, Arts, Music or Evening Class	6.2	3.8	4.6	5.6	3.4	7.8	6.4	0.5	8.8	6.3	1.8	4.9
Arch Club	4.9	2.6	5.6	3.1	2.0	5.2	3.7	2.6	4.4	5.0	1.8	3.6
Retirement Club	3.2	3.1	0.0	2.5	8.8	6.5	2.7	1.0	2.7	4.0	2.5	3.2
Tenants, Residents, Neighbourhood Watch	1.0	1.0	0.5	1.7	0.0	1.3	1.3	0.0	2.7	0.7	0.7	1.0
Charitable Association	0.3	1.0	1.0	0.8	0.0	2.0	0.0	0.0	2.7	0.3	0.4	0.7
Political, Trade Union, Environmental	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0	0.0
Other Group	10.4	12.8	12.8	13.0	7.4	19.6	12.4	4.7	20.4	13.9	6.0	11.7
Not a member of any group	58.8	54.6	55.6	53.1	65.5	43.1	51.5	75.0	39.8	49.2	70.9	56.4
n	308	390	196	354	148	153	299	192	113	303	282	698

Table 2.A.11: Social activities in Wave 1 and Wave 2

Social Activity	Wave 1			Wave 2			Change
	n	%	95% CI	n	%	95% CI	%
Eat out	753	87.8	85.18-89.99	698	85.2	82.42-87.74	-2.6
Go out for coffee	753	85.8	83.04-88.16	697	81.9	78.81-84.67	-3.9
Go shopping	753	83.9	81.07-86.44	698	76.1	72.69-79.16	-7.8
Go to the hairdresser	753	77.0	73.82-79.96	698	70.6	67.07-73.96	-6.4
Go to church/place of worship	753	78.0	74.78-80.83	698	61.7	58.02-65.35	-16.3
Visit family and friends in their home	753	66.3	62.75-69.62	698	59.5	55.7-63.11	-6.8
Go to the cinema, theatre, concert, opera	753	72.2	68.87-75.38	698	59.2	55.41-62.83	-3.0
Go to the pub for a drink	753	67.5	63.96-70.77	698	57.4	53.68-61.14	-10.1
Talk to family or friends on the phone	n/a	n/a	n/a	698	46.6	42.82-50.34	n/a
Spend time on hobbies/creative activities	753	51.7	48.03-55.28	698	38	34.37-41.70	-13.7
Go to a sports event	753	29.5	26.27-32.9	698	18.1	15.31-21.14	-11.4
Participate in sports activities/events	n/a	n/a	n/a	698	17.5	14.78-20.55	n/a
Go to social clubs (e.g. bingo, cards)	753	21.9	19.04-25.07	698	17.6	14.91-20.7	-4.3
Go to the library	753	21.1	18.29-24.25	698	15.8	13.18-18.73	-5.3
Go to an art gallery or museum	753	22.4	19.54-25.62	698	11.9	9.63-14.58	-10.5
Perform in local arts groups or choirs	753	8.8	6.89-11.07	698	4.9	3.45-6.81	-3.9
Other activities outside your home	753	13.5	11.23-16.25	698	8.2	6.3-10.52	-5.3
N/A – don't engage in any social activities	753	1.3	0.68-2.51	698	2.9	1.81-4.48	+1.6

Table 2.A.12: Social activities by gender, age, level of ID and type of residence

Social Activity	Gender		Age			Level of ID				Type of Residence		Total
	Male	Female	43-49	50-64	65+	Mild	Moderate	Severe- Profound	Independent /Family	Community Group Home	Institution	
Eat out	85.1	85.4	88.3	87.3	76.4	91.5	88.3	77.6	83.2	89.4	81.6	85.2
Go out for coffee	77.9	85.1	85.2	82.4	76.4	85.0	82.6	81.8	79.6	84.1	80.5	81.9
Go shopping	70.5	80.5	78.1	78.8	66.9	87.6	76.9	67.7	77.0	81.5	69.9	76.1
Go to the hairdresser	59.7	79.2	67.3	74.6	65.5	82.4	71.2	62.5	74.3	75.6	63.8	70.6
Go to church/place of worship	60.7	62.6	62.8	63.0	57.4	68.6	61.2	57.8	68.1	61.7	59.2	61.7
Visit family and friends in their home	60.7	58.5	74.0	59.6	39.9	75.2	63.9	39.6	83.2	67.3	41.5	59.5
Go to the cinema/theatre/concert/opera	56.8	61.0	65.3	61.9	44.6	66.0	61.9	49.5	61.9	61.1	56.0	59.2
Go to the pub for a drink	66.6	50.3	61.7	61.0	43.2	64.7	59.9	47.4	60.2	64.7	48.6	57.4
Talk to family or friends on the phone	46.4	46.7	53.6	49.2	31.1	71.9	54.2	13.5	68.1	53.8	30.1	46.6
Spend time on hobbies/creative activities	37.3	38.5	41.3	36.7	36.5	52.3	36.1	28.1	41.6	41.3	33.0	38.0
Go to a sports event	26.6	11.3	21.4	19.2	10.8	22.2	17.7	13.0	27.4	19.5	12.8	18.1
Participate in sports activities/events	20.8	14.9	21.4	18.9	8.8	24.2	17.7	10.4	23.0	18.5	14.2	17.5
Go to social clubs (e.g. bingo, cards)	15.3	19.5	17.3	18.9	14.9	22.9	18.7	12.0	20.4	18.5	15.6	17.6
Go to the library	15.3	16.2	17.9	17.8	8.1	24.8	14.4	10.9	22.1	17.8	11.0	15.8
Go to an art gallery or museum	12.0	11.8	13.8	13.3	6.1	11.8	10.4	12.5	8.0	13.5	11.7	11.9
Perform in local arts groups or choirs	4.9	4.9	7.7	4.5	2.0	6.5	5.4	3.1	9.7	4.3	3.5	4.9
Other activities outside your home	10.4	6.4	9.7	7.9	6.8	5.2	9.4	8.3	13.3	8.3	6.0	8.2
N/A – don't engage in any social activities	3.2	2.6	2.6	2.0	5.4	0.0	1.7	6.8	0.0	2.3	4.6	2.9
n	308	390	196	354	148	153	299	192	113	303	282	698

Table 2.A.13. Difficulties experienced participating in social activities outside the home – change since Wave 1

Difficulty experienced	Wave 1 (n=382)		Wave 2 (n=356)		Change
	%	95% CI	%	95% CI	%
Need someone's assistance	64.4	59.34-69.16	70.8	65.72-75.40	+6.4
Health considerations or physically unable	37.7	32.86-42.79	41.0	35.89-46.33	+3.3
Communication/language problems	28.5	24.11-33.39	27.2	22.75-32.25	-1.3
Not able to read signs and timetables	n/a	n/a	19.7	15.74-24.25	n/a
Transport services inadequate/not accessible	15.4	12.05-19.56	12.6	9.46-16.65	-2.8
Have no one to go with	10.5	7.67-14.09	9.6	6.8-13.21	-0.9
Don't like social activities	6.5	4.36-9.63	7.0	4.68-10.32	+0.5
Need special aids or equipment I don't have	9.2	6.55-12.62	4.8	2.9-7.69	-4.4
Getting too old	1.6	0.64-3.56	4.2	2.46-7.0	+2.6
Service facilities are not accessible	4.2	2.5-6.85	3.4	1.84-5.97	-0.8
Lack of local facilities or suitable activities	5.2	3.31-8.11	3.4	1.84-5.97	-1.8
Don't have enough money	1.8	0.8-3.9	3.4	1.84-5.97	1.6
Unfriendly or negative attitudes towards you	2.4	1.16-4.59	1.4	0.52-3.43	-1.0
Not allowed to go	1.0	0.34-2.85	1.1	0.36-3.05	+0.1
Don't have enough time	3.9	2.3-6.54	1.1	0.36-3.05	-2.8
Family and friends residence not accessible	1.8	0.8-3.9	1.1	0.36-3.05	-0.7
You are self-conscious of your ID	n/a	n/a	0.6	0.1-2.24	n/a
Other	50.0	44.88-55.12	36.2	31.28-41.5	-13.8

Table 2.A.14 Difficulties experienced getting around your community – change since Wave 1

	Wave 1							Wave 2						
	Yes		No		NA			Yes		No		NA		
	%	95% CI	%	95% CI	%	95% CI	n	%	95% CI	%	95% CI	%	95% CI	n
Gender:														
Male	41.7	36.42-47.25	40.2	34.97-45.74	18.0	14.13-22.67	333	35.7	30.41-41.43	35.4	30.1-41.1	28.9	23.9-34.34	305
Female	42.3	37.54-47.29	36.5	31.87-41.38	21.2	17.38-25.51	411	32.6	27.96-37.51	36.2	31.43-41.21	31.3	26.73-36.19	387
Age:														
43-49	41.1	35.37-47.13	39.4	33.67-45.35	19.5	15.41-24.71	282	32.7	26.24-39.76	40.3	33.45-47.56	27.0	21.08-33.92	196
50-64	41.1	35.90-46.52	41.1	35.90-46.52	17.9	13.07-22.22	242	36.2	31.20-41.6	36.0	31.94-42.19	26.0	22.25-31.90	250
65+	47.1	37.92-56.39	26.9	19.37-35.93	26.1	18.63-35.04	119	30.1	22.97-38.37	27.4	20.51-35.5	42.5	34.42-50.92	146
Level of ID:														
Mild	26.2	19.91-32.76	65.2	57.27-72.20	8.5	4.02-14.19	164	27.2	20.29-35.09	62.2	52.97-69.9	10.6	6.27-16.01	151
Moderate	46.7	41.12-52.35	36.0	30.72-41.54	17.4	13.44-22.07	317	37.8	32.34-43.66	29.1	24.01-34.64	33.1	27.84-38.83	296
Type of Residence:														
Independent/ Family	22.0	15.38-30.45	70.1	61.21-77.71	7.9	4.05-14.36	127	18.8	12.23-27.46	69.6	60.13-77.78	11.6	6.57-19.38	112
Community Group Home	42.4	36.34-48.72	40.1	34.09-46.37	17.5	13.18-22.84	257	37.4	31.99-43.17	35.1	29.78-40.81	27.5	22.6-32.95	302
Institutional	48.6	43.31-53.92	25.6	21.18-30.48	25.8	21.44-30.78	356	36.3	30.73-42.32	23.0	18.3-28.51	40.6	34.87-46.69	278
Total	42.1	38.51-45.72	38.2	34.68-41.78	19.8	16.99-22.84	744	34.0	30.46-37.64	35.8	32.28-39.56	30.2	26.83-33.8	692

Table 2.A.15: Prevalence of level of difficulty in reading, writing, numeracy and money recognition by gender age and level of ID.

	Difficulty Reading			Difficulty Writing			Difficulty with number			Difficulty with money		
	%	95% CI	Number in sample	%	95% CI	Number in sample	%	95% CI	Number in sample	%	95% CI	Number in sample
Gender:												
Male	84.6	79.93-88.35	305	85.9	81.37-89.5	305	83.2	78.43-87.15	304	81.6	76.73-85.73	305
Female	80.4	76.01-84.2	383	80.8	76.41-84.52	385	78.5	74-82.47	382	76.3	71.66-80.4	384
Age:												
43-49	80.5	74.11-85.68	195	82.1	75.78-87.02	195	79.8	73.29-85.08	193	78.5	71.89-83.88	195
50-64	80.5	75.89-84.46	349	80.9	76.32-84.81	351	77	72.16-81.25	348	76	71.11-80.31	350
65+	88.9	82.31-93.32	144	89.6	83.11-93.85	144	90.3	84.03-94.42	145	85.4	78.35-90.55	144
Level of ID:												
Mild	61.6	53.3-69.28	151	59.2	49.78-68.61	152	56.4	48.02-64.4	149	50.7	42.47-58.81	152
Moderate	87.8	83.17-92.53	237	88.9	84.59-93.21	237	89.8	85.97-93.63	238	89.7	85.81-93.57	238
Severe/Profound	98.9	95.78-99.81	187	97.9	94.29-99.31	188	97.3	93.57-99.02	188	96.3	92.22-98.37	189
Residence:												
Indep/Family	65.2	55.53-73.77	112	69	59.54-77.21	113	60.2	50.52-69.14	113	58	48.34-67.18	112
CGH*	81.8	76.87-85.88	302	82.1	77.22-86.18	302	80.1	75.01-84.34	301	76.5	71.22-81.07	302
Residential	89.8	85.42-92.99	274	89.8	85.47-93.01	275	89.7	85.32-92.94	272	89.5	85.05-92.71	275
Total	82.3	79.16-85.01	688	83	79.98-85.72	690	80.6	77.41-83.46	686	78.7	75.37-81.62	689

Table 2.A.16a: Participant's ability to engage in foundational skills of education – reading and writing ability

Reading Skills	Yes, without assistance	95% CI	Yes, with assistance	95% CI	No	95% CI	No. in sample
I can read my own name	29.4	25.63-33.26	7.9	5.87-10.49	62.7	58.68-66.76	570
I can identify most letters of the alphabet	16.6	13.59-19.85	10.9	8.5-13.8	72.5	68.74-76.21	570
I can read name of own street or town	11.6	8.97-14.37	4.6	3.06-6.7	83.9	80.71-86.9	570
I can read easy to read material	8.4	6.18-10.9	7.5	5.57-10.1	84.1	80.89-87.05	570
I can read common environmental words in context	14.4	11.67-17.6	5.6	3.93-7.91	80.0	76.43-83.16	570
I can read basic large print book	5.3	3.67-7.53	6.7	4.8-9.14	88.0	85.03-90.54	569
I can read instructions, such as those on a medicine bottle	1.4	0.66-2.87	4.6	3.07-6.71	94.0	91.66-95.76	596
I can read instructions on packaged goods in shops or supermarkets	1.4	0.66-2.87	4.6	3.07-6.71	94.0	91.66-95.76	596
I can read information from government agencies, businesses, or other institutions	0.7	0.22-1.91	3.7	2.36-5.68	95.6	93.5-97.08	596
I can read newspaper articles	1.8	0.9-3.32	4.0	2.64-6.09	94.2	91.87-95.91	569
Writing Skills							
I can write most of the letters of the alphabet	13.2	10.62-16.33	13.7	11.09-16.89	73.0	69.18-76.59	575
I can write my own name	26.4	22.91-30.27	8.7	6.59-11.38	64.9	60.79-68.75	575
I can write notes and letters (e.g. birthday or Christmas cards)	5.2	3.61-7.45	14.4	11.71-17.63	80.3	76.81-83.47	575
I can fill out forms such as applications or bank deposit slips	0.7	0.23-1.9	5.2	3.61-7.45	94.1	91.75-95.81	575

Table 2.A.16b: Participant's ability to engage in foundational skills of education – numeracy and money ability

Numeracy Skills	Yes, without assistance	95% CI	Yes, with assistance	95% CI	No	95% CI	No. in sample
I can recognise numbers 1-10	24.7	21.21-28.52	10.6	8.19-13.47	64.8	60.62-68.69	559
I can recognize and locate numbers on phone or ATM or Post office machine	9.8	7.56-12.69	7.9	5.84-10.5	82.3	78.81-85.31	559
I can dial numbers on phone	10.9	8.51-13.86	8.6	6.46-11.3	80.5	76.92-83.65	559
I understand more-less relationships e.g. If I have 10 apples I have less than someone who has 20 apples	7.0	5.07-9.5	5.9	4.16-8.27	87.1	83.99-89.73	559
I can do simple sums – that is add and subtract	4.1	2.68-6.2	5.0	3.42-7.25	90.9	88.11-93.07	559
I can tell time on a clock or watch	16.1	13.2-19.47	3.4	2.12-5.36	80.5	76.92-83.65	559
I can use a calculator of simple sums	1.1	0.43-2.44	3.2	1.98-5.14	95.7	93.59-97.17	559
Money Skills							
I can identify €5, €10, and €20 notes	15.0	12.21-18.39	7.7	5.68-10.36	77.2	73.45-80.66	545
I can identify coins: 1c, 2c, 5c, 10c, 20c, 50c	11.7	9.22-14.81	9.2	6.94-11.99	79.1	75.37-82.37	545
I can arrange coins in order of value	5.7	3.96-8.07	7.0	5.04-9.53	87.3	84.18-89.96	545
I can arrange notes in order of value	5.5	3.8-7.85	7.5	5.51-10.15	87.0	83.78-89.62	545
I can understand more or less applied to money: can attempt to identify from price of an item whether change is due from note or coin handed in	4.6	3.05-6.79	5.5	3.8-7.85	89.9	86.99-92.25	545

Table 2.A.17: Prevalence of computer skills and social networking

Computer skills and Social Networking	Yes, without assistance	95% CI	Yes, with assistance	95% CI	No	95% CI	No. in sample
I can type my own name on a keyboard	10.5	8.27-13.33	9.2	7.1-11.89	80.2	76.79-83.28	607
I can type a letter	4.8	3.28-6.88	6.8	4.94-9.12	88.5	85.59-90.85	607
I can turn on a computer	6.8	4.91-9.12	7.9	5.95-10.42	85.3	82.22-88.01	607
I can send an email	0.5	0.13-1.56	5.4	3.83-7.63	94.1	91.81-95.76	607
I can look up topics of interest on Google	1.2	0.5-2.47	5.9	4.24-8.19	92.9	90.51-94.77	607
I can use social media sites such as Facebook, Twitter, etc	0.3	0.06-1.32	2.5	1.44-4.14	97.2	95.46-98.31	607

