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Health Care Utilisation among Older Adults with an Intellectual Disability

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Key Findings

- There was little change between Wave 1 and Wave 2 in the use of health, specialist health and social care services and medications for people with ID as they age. Those rates of usage remained higher than what is being reported for the general ageing population
- Between Wave 1 and Wave 2, 120 participants changed where they lived and those changes were lateral (61) to more restrictive settings (15) and to less restrictive settings (31) with the remainder (13) in more temporary settings.
- Most individuals with ID reported not participating in choosing the new location to live and that they were not part of the decision to move.
- Participants who moved to more restrictive settings were more likely to use occupational therapy and physiotherapy, and access social, psychological/ counselling, dental, neurological, geriatrician and palliative services. It will require further investigation to understand if the need for such services necessitated the move to more restrictive settings.
- On a positive note there is clearly a greater effort for people with ID to prevent influenza with vaccination levels at over 90% compared to 57% found for TILDA participants.

5.1 Introduction

Independent, successful ageing and retirement for the general population is usually supported by pensions, other financial resources, social networks and family supports and by good health and health care (McCallion, *et al.,* 2013). Van Schrojenstein Lantaman-De Valk et al. (2000) previously compared 318 people with ID within a general practice with others and found that people with learning (intellectual) disabilities had 2.5 times the health problems of those without such life-long disabilities. Also, Bhaumik *et al.,* (2008) have highlighted higher psychiatric morbidity among elderly (compared with younger) adults with ID. These same researchers and others (for a review, see Haveman, *et al.,* 2009) also found that such physical and mental health conditions and good health in general are highly influenced by the level of and appropriateness of health care access.

Findings in Wave 1 were of a group of people with ID who were satisfied with the healthcare they received and who accessed healthcare services on a regular basis with levels of health care and utilisation similar to general population reports except for higher rates of hospitalisation. There were also high levels of utilisation of social care services (McCarron *et al.,* 2011). Given austerity issues, during the last few years, there was interest in Wave 2 in exploring the extent to which levels of utilisation may have changed. Also, with increased interest in moving persons with ID out of congregated settings, Wave 2 offers an opportunity to take a first look at how movement to different settings influences utilisation of health and social care services.

5.2 Key methodological considerations

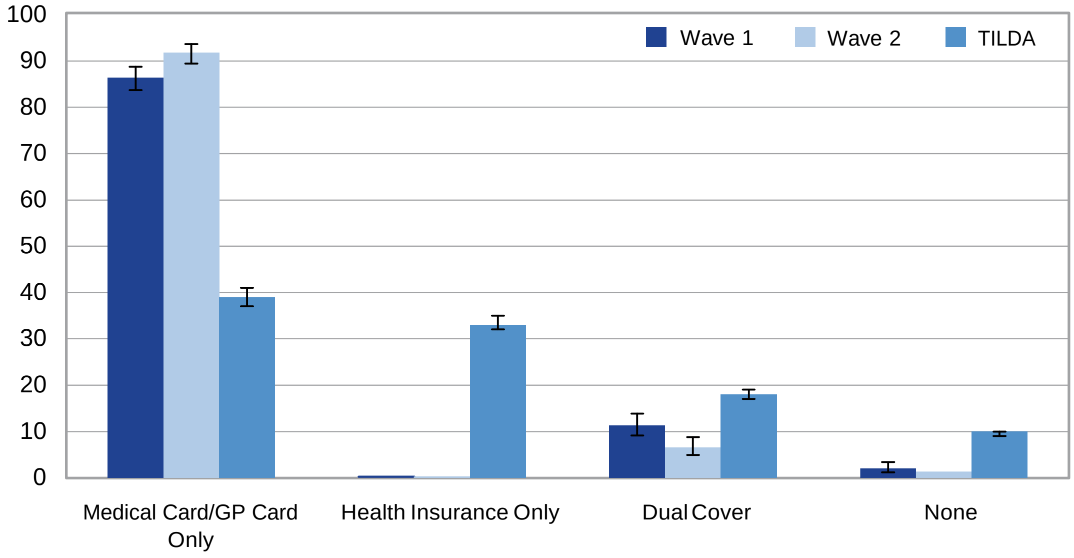
In this chapter data will be initially reported for all persons who completed questions on their use of both health and social care services including availability of medical cards and medical insurance, access to health services such as GP, outpatient, emergency department and hospitalisation services, utilisation of health screening and access to a range of health-related and other professionals and to a range of social care services. In addition, those individuals who moved living situation will be described in terms of those who made a less restrictive, lateral and or more restrictive move and the impact of these moves will be considered in terms of the resulting utilisation differences across settings in terms of health-related and other professionals and social care services.

5.3 Changes in Service Use

5.3.1 Medical Cover

As may be seen in *figure 5.*1 there were few changes in medical cover from Wave 1 to Wave 2 for IDS-TILDA respondents although there was a small increase in medical card/GP card coverage (almost everyone held both) and a reduction in the numbers with dual (medical card and insurance) coverage. The only difference of note was that there was a small increase (from 4.3% to 5.9%) in the numbers of individuals aged 50-64 with private health insurance. Rates of availability of medical cards/GP cards by respondents remained higher and health insurance availability was lower for IDS-TILDA respondents as compared to TILDA reports.

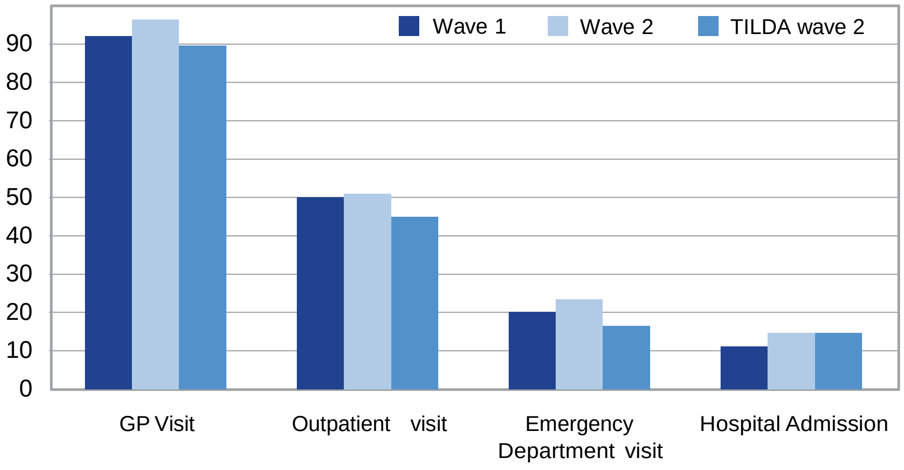
Figure 5.1: Comparison of prevalence of medical cover between IDS-TILDA Wave 1, Wave 2 and TILDA Wave 2.



5.3.2 Use of health services

Use of GP, outpatient, emergency department, and hospital services remained similar across Waves; utilisation rates were a little higher than for the general population as reported by TILDA, but not markedly so (see *figure 5.2* below).

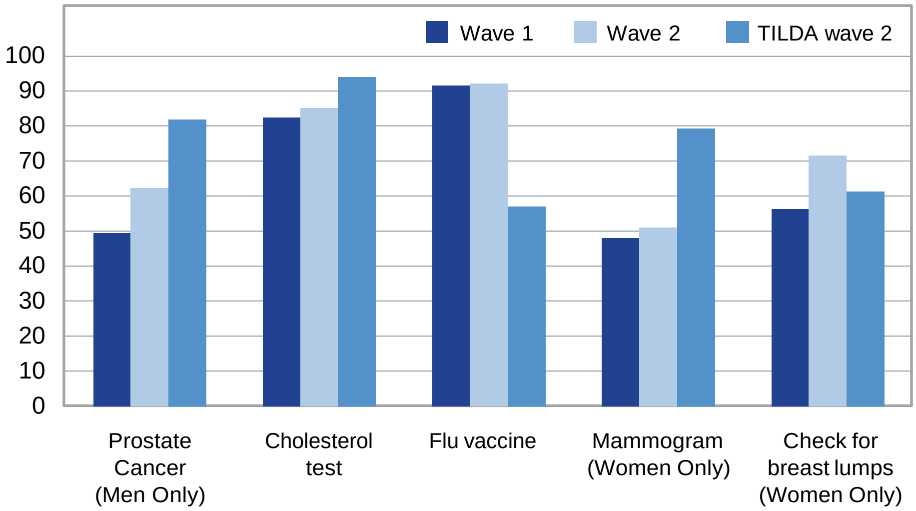
Figure 5.2: Comparison of the use of health services between IDS-TILDA Wave 1, Wave 2 and TILDA Wave 2.



5.3.3 Health screenings

Rates of health screening remained largely the same although there were some increase in prostate checks and check for breast lump screening for respondents with ID and receipt of flu vaccine remained higher for respondents with ID than what TILDA reported for the general population. As may be seen in *figure 5.3*, the most notable deficit is the level of mammography completed for people with ID which remained below rates for general population.

Figure 5.3: Prevalence of health screening: Comparison between IDS-TILDA Wave 1, Wave 2 and TILDA Wave 2.



On a positive note there is clearly a greater effort for people with ID to prevent influenza with vaccination levels at over 90% compared to 57% found for TILDA participants.

5.3.4 Use of specialist health and social care services

Across the Waves as may be seen in *figure 5.4,* there was little change in percentages of persons with ID using a range of specialist health and social care services. One area noted of significant increase was in personal care which increased from 12.1% in Wave 1 to 19.2% in Wave 2. This compares with personal care support in the general population of 1.3%. When compared to TILDA responses, use of services by persons with ID was high in all areas but was dramatically higher for psychiatry, chiropody, dental, optician, residential and day centre services.

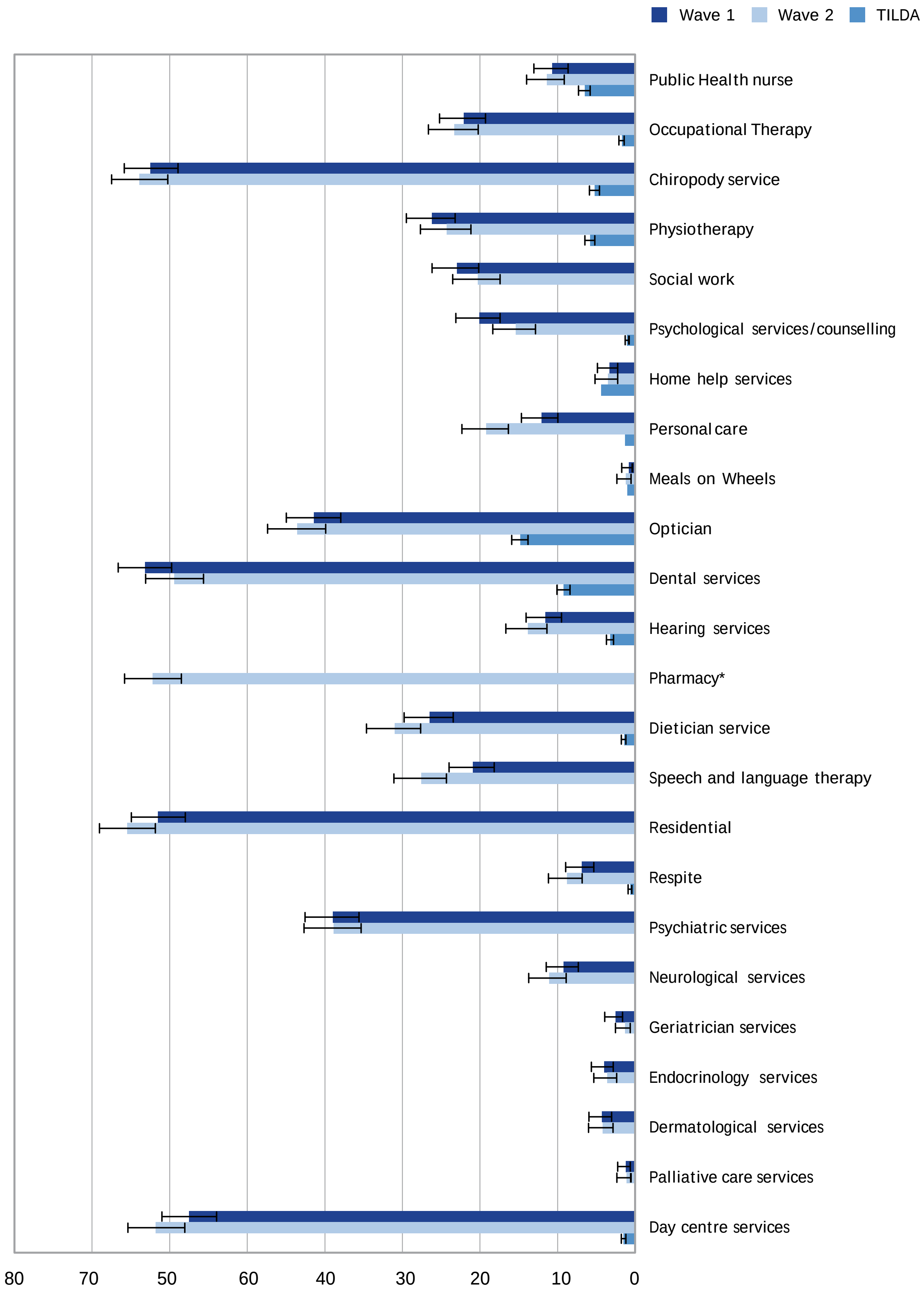


Figure 5.4: Specialist health and social care services.

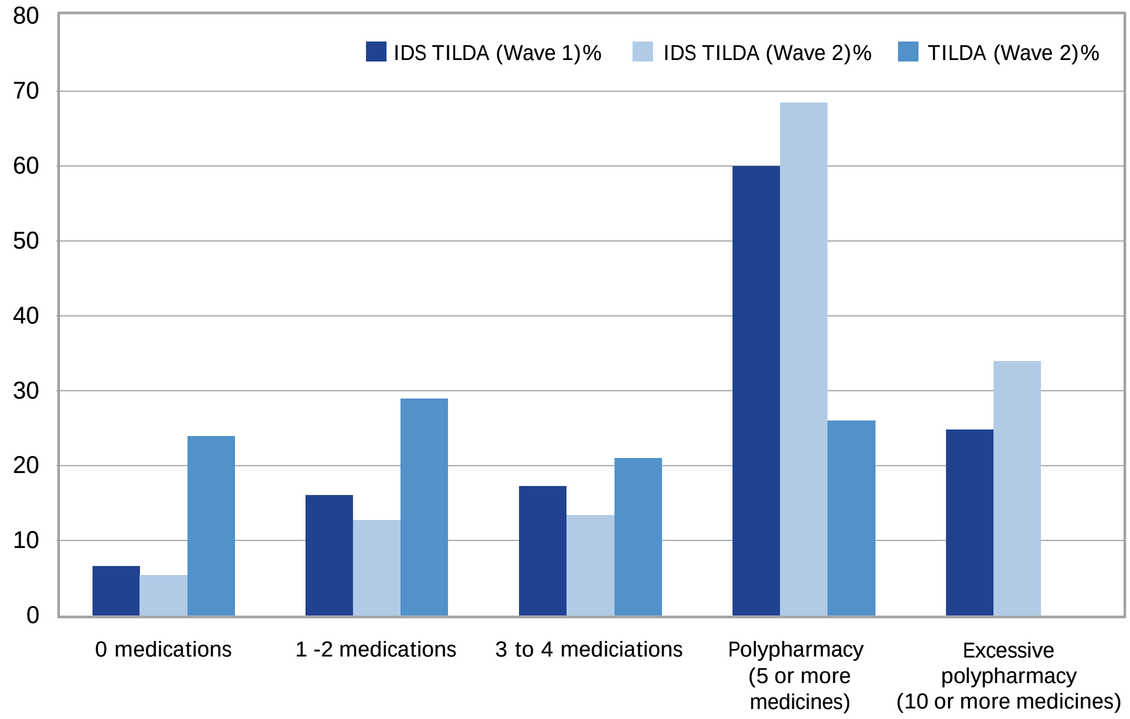
Note: Where there are no TILDA comparison this implies this question was not available from the TILDA report.

*The Pharmacy question was only asked in Wave 2 IDS-TILDA

5.3.5 Use of medications

As may be seen in figure 5.5, at Wave 2 not only do levels of medication use remain much higher overall than for TILDA participants but the percentage of IDS-TILDA participants on five or more medicines and supplements rose from 59% in Wave 1 to almost 69% by Wave 2 and for excessive polypharmacy (10 or more medicines and supplements) from 24.8% at Wave 1 to 34% at Wave 2. This compares to 26% for polypharmacy (5 or more medicines) in the TILDA population.

Figure 5.5: Prevalence of the use of medications: Wave 1, Wave 2 and TILDA Wave 2.



5.4 Movement within and between settings and its relationship to service use

5.4.1 Understanding movement between Wave 1 and Wave 2

A total of 120 people (17.1% of the Wave 2 sample) moved their living situation during the period between Wave 1 and Wave 2 data collection. As may be seen in Table 5.1, there were more women than men who moved (66 females versus 54 males), the largest (54) were in the 50=64 years age range and most (64) had a moderate ID. However, all genders, all ages and all levels of ID were represented.

Table 5.1: Profile of confirmed movers.

	n	%
Gender:		
Male	54	45.0
Female	66	55.0
Age:		
43-49	30	25.0
50-64	54	45.0
65+	36	30.0
Level of ID:		
Mild	17	14.8
Moderate	64	55.7
Severe	28	24.3
Profound	6	5.2
Marital status:		
Single	119	99.2
Has a partner but not living with him/her	1	0.8

As may be seen in table 5.2 movement was from the full range of settings and into an equally full range of settings with three persons in the residential grouping moving to nursing homes but none moving out of such a setting.

Table 5.2: Living arrangements.

Wave 1 Residence	Moved to Residence at Wave 2							
	Family/ Independent		Community Group Home		Residential		Other	
	n	%	n	%	n	%	n	%
Family/ independent	6	66.7	4	6.5	0	0.0	0	0.0
Community group home	2	22.2	28	45.2	11	23.9	2	66.7
Residential	0	0.0	29	46.8	33	71.7	0	0.0
Other	1	11.1	1	1.6	2	4.3	1	33.3
Total	9	100.0	62	100.0	46	100.0	3	100.0

Each move was then examined and categorized into:

- lateral moves (movement to another living unit within a campus setting or institution, movement to another community group home or movement to a different family or independent home).

- More restrictive setting (movement from a community group home or from family/ independent to a campus setting or institution or to a nursing home or a closed mental health unit; or movement from family/independent to a community group home).
- Less restrictive setting (movement from a campus setting or institution to a group home or to family/independent; movement from a community group home to family or independent home).

As may be seen in table 5.3, there were 66 lateral moves, 15 moves to more restrictive settings and 31 moves to less restrictive settings. Again, moves in all three groupings included both males and females, all ages and all levels of ID but men were a little more likely to be involved in moves to less restrictive settings, and women in lateral moves; most movers were aged 50-64 but there were a high number of movers (42) over 65; and those with moderate ID featured most in all types of moves.

Table 5.3: Mover demographics by type of move

Demographic and health profile	Lateral *n*=66	%	More Restrictive *n*=15	%	More Community Based *n*=31	%
Gender:						
Male	24	36.4	7	46.7	19	61.3
Female	42	63.6	8	53.3	12	38.7
Age:						
43-49	16	24.2	3	20.0	9	29.0
50-64	30	45.5	9	60.0	13	41.9
65+	20	30.3	3	20.0	9	29.0
Level of ID:						
Mild	10	16.1	3	20.0	3	10.0
Moderate	36	58.1	10	66.7	14	46.7
Severe/ Profound	16	25.8	2	13.3	13	43.3

5.4.2 Understanding how decisions were made about moving

As may be seen in table 5.4, there were a variety of reasons offered for the move, regardless of type of move. Lateral moves were most often reported to be about accommodations to the service (45.5%), movement to more restrictive setting were usually (60%) in response to changes in health and mental health status and movement to less restrictive settings appeared driven by policy and transitioning planning considerations (61.3% and 41.9% respectively).

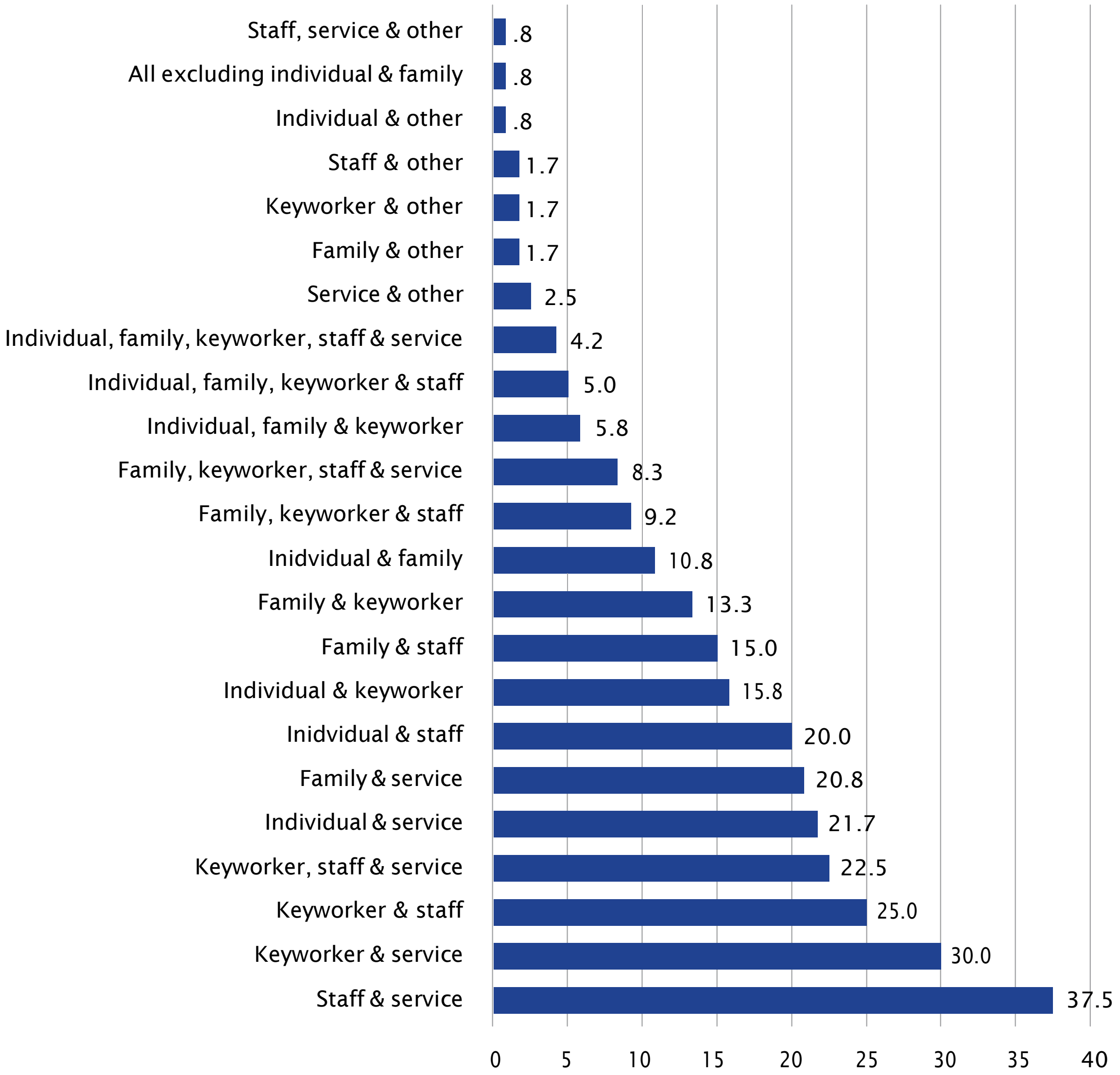
Table 5.4: Reasons for Moves*

Reason for move	Lateral *n*=66	%	More Restrictive *n*=15	%	Less Restrictive *n*=31	%
Change in health or mental health status	13	19.7	9	60.0	2	6.5
Loss or infirmity of primary carer	1	1.5	3	20.0	0	0.0
Service policy	3	4.5	1	6.7	19	61.3
Accommodate service	30	45.5	1	6.7	7	22.6
Not happy in previous residence	6	9.1	2	13.3	2	6.5
Funding/staff shortages	3	4.5	0	0	0	0.0
Lack of accessibility or other suitability of previous residence	7	10.6	2	13.3	1	3.2
Lack of nursing support	5	7.6	2	13.3	1	3.2
Lack of 24 hour care	5	7.6	2	13.3	1	3.2
Part of transition process	9	13.6	2	13.3	13	41.9
Personal Choice	8	12.1	2	13.3	3	9.7
Don't know reason	3	4.5	1	6.7	0	0.0
Other	3	4.5	0	0.0	1	3.2

*Note: Because there could be more than one reason, total “n’s” and “%” may add up to more than the total number.

A review of the reasons for moving does raise a question about who was involved in the related decision-making. In *figure 5.6* it is clearly illustrated that there were a variety of decision-makers. It was equally clear that almost all decisions involved staff, and many only involved staff and the services administration. This means that in a large number of cases the individual with ID did not feel that they were involved in the decisions around their move.

Figure 5.6: Who was involved in making decisions about Moves*



*Note: Other here tended to be individuals external to the service not known to the individual with ID, e.g., the administration of a receiving service.

As may also be seen in table 5.5, people with ID reported they were only involved in 25-33% of decisions, with surprisingly, the lowest percentage (25.8%) involved in decisions about movement to less restrictive settings

Table 5.5: Decision-makers by type of setting

Who was involved in decision to move?	**Lateral** *n*=**66**	**%**	**More restrictive** *n*=**15**	**%**	**Less Restrictive** *n*=**31**	**%**
Myself	22	33.3	5	33.3	8	25.8
Family	14	21.2	6	40	10	32.3
Keyworker	20	30.3	6	40	12	38.7
Staff	30	45.5	7	46.7	17	54.8
Service	54	81.8	11	73.3	29	93.5
Other	1	1.5	2	13.3	2	6.5

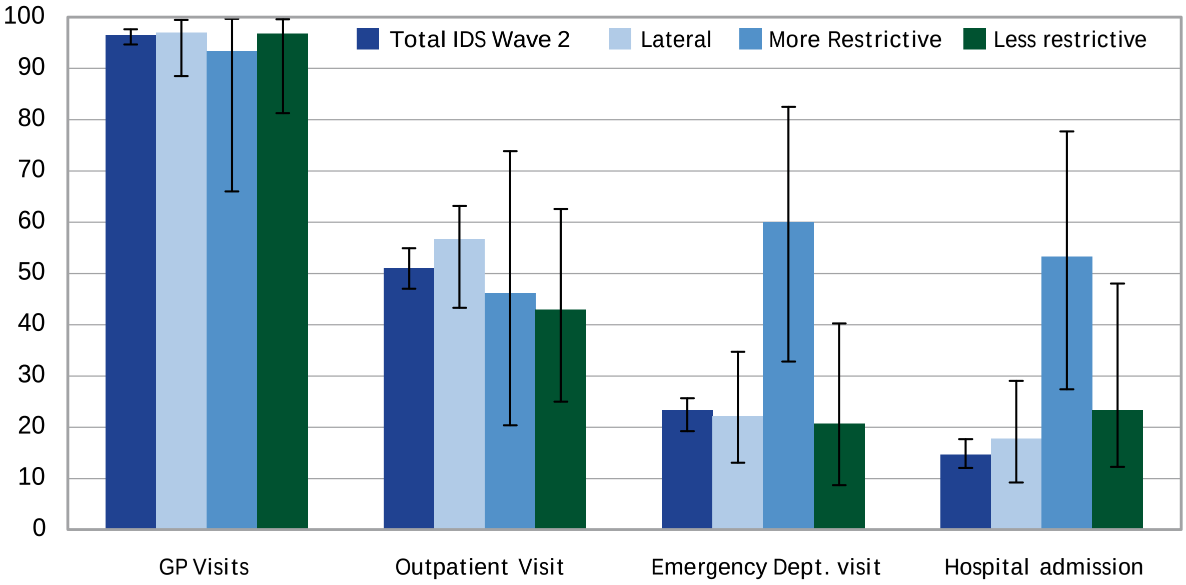
A particular concern was that only 20% of those who moved indicated that they that they had the opportunity to view the proposed alternative accommodation prior to their move and no more than 60% said that they had wanted to move. However it should be noted that post-movement, 82.4% of the 120 movers indicated that they were happy with their move to another living situation.

5.5 Services utilisation after a change in living situation

5.5.1 Health service utilisation

There were little changes for all movers in GP and outpatient visits. However, as illustrated in figure 5.7, for those who moved to more restrictive settings there was an increase in their rate of use of emergency departments (60% as compared to 22% and 20.7%) and hospitalisations (53.3% as compared to 17.8% and 23.4%). The extended CIs argue for some caution in the interpretation of these findings; however they do seem consistent with the prior findings that changes in physical and mental health status were a primary reason for movement to more restrictive settings.

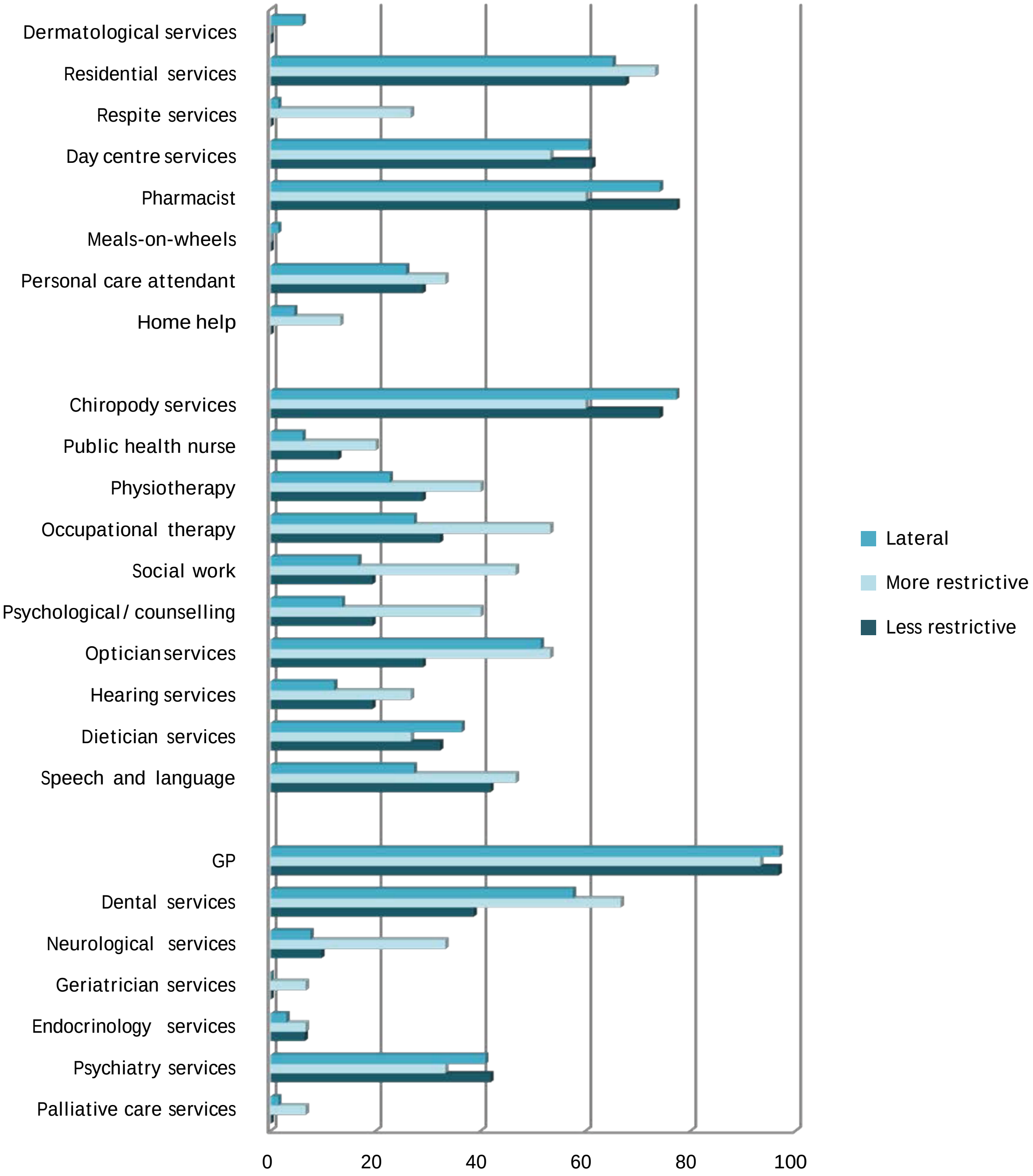
Figure 5.7: Health service utilisation by people who moved between Wave 1 and Wave 2.



5.5.2 Specialist health and social care services

A more complex picture emerges in terms of use of specialist health and social care services as is illustrated in *figure 5.8*. The most striking differences are for people who moved to more restrictive settings. For this group there are higher levels of use of occupational and physiotherapy, and of social work, psychological/counselling, dental, neurological and respite services with rates ranging from 26.7% to 53.3%. Geriatrician and palliative care service utilisation has increased substantially for people in more restrictive type settings reflecting the more complex health needs of this population. What is unclear is whether movement to more restrictive settings was influenced by the need for such services or that placement in more restrictive settings means that such services will be offered and availed of.

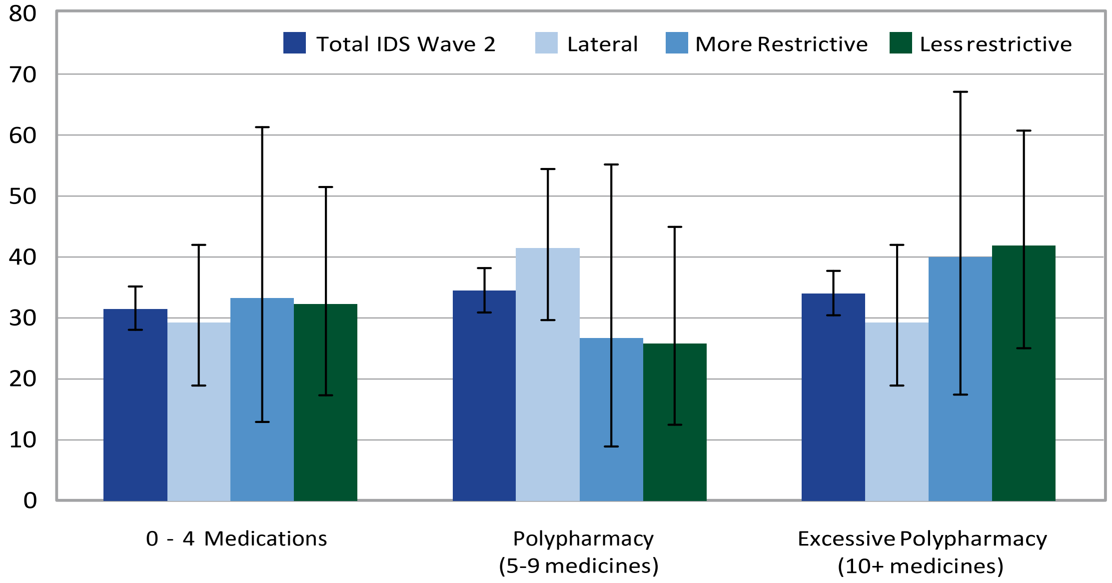
Figure 5.8: Specialist health and social care service utilisation by people who moved between Wave 1 and Wave 2.



5.5.3 Medication use

Figure 5.9 suggests that levels of polypharmacy (5-9 medicines) are somewhat higher for those who were involved in lateral moves (41.5% as compared to 26.7% and 25.8%) and that excessive polypharmacy was higher for those moving to more and to less restrictive setting but again the size of confidence intervals and opposite findings for polypharmacy versus excessive polypharmacy would suggest that there is no effect on medication use. However the relatively high levels of polypharmacy and excessive polypharmacy overall are still of concern.

Figure 5.9: Use of medications by people who moved between Wave 1 and Wave 2.



5.6 Conclusion

In the midst of general population austerity-related concerns about loss of Medical and GP visit cards and reported difficulties in accessing health services and specialist health and social care services, level of access and usage of all such services appear similar from Wave 1 to Wave 2 for people with ID.

The most interesting changes in service utilisation occurred for people (*n*=120; 17.1%) who moved living situation between Wave 1 and Wave 2. The influence of the HSE report (2011), Time to move on from congregated settings: a strategy for community inclusion would have suggested that most moves would be to less restrictive settings; the finding in IDS-TILDA that there were more lateral moves and moves to more restrictive settings helps illustrate the complexity in people's lives influencing moves including the impact of health and mental health concerns. Of greatest concern in this data are the relatively low levels of personal involvement in such moves reported by people with ID and the additional finding that most decisions around moves were reflecting services needs and concerns and discussions and decisions among services administration and staff. If there is actually more opportunity for people with ID to be part of these decisions than the data suggests, at the least this means that the need for moves and transfers is not being well discussed with people with ID so that they fully understand the role they do and may play in those decisions. This needs to be better addressed.

The apparent differences in service use experience for those who move, with for example persons moving to more restrictive settings reporting having higher levels of use of occupational and physiotherapy, and of social work, psychological/counselling, dental, neurological, geriatrician and palliative services deserves further investigation. If movement to more restrictive settings was to facilitate access to such services because they were not available in less restrictive settings, then it will be more difficult to realize public policy intent around the reduction of congregate settings if such health and social care services, when needed, are not easily accessed in the community.

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