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ORIGINAL ARTICLE

Activities of daily living and transition to community living for adults with intellectual disabilities

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ABSTRACT

Background: As adults with intellectual disability (ID) in Ireland move to the community from residential settings, the changed environment is intended to increase opportunities for occupational engagement, autonomy and social relationships. It is important to consider how increased resources and opportunities available within the community can be optimized to promote engagement and quality of life.

Aims: This paper investigates if and how ADL and IADL performance of people ageing with ID is related to place of residence.

Methods: ADL and IADL performance of adults with ID in Ireland across different living situations was analyzed using descriptive and bivariate analysis of data collected from the Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing (IDS TILDA).

Results: Greater ability to perform ADL and IADL was noted in those living in independent or community group home settings when compared to traditional residential settings. Place of residence was strongly related to ADL and IADL performance.

Conclusion and significance: Given that people with ID will likely require physical and social supports to complete ADL and IADL when transitioning to community living from residential settings, an occupational justice perspective can inform occupational therapists working with people with ID, facilitating successful transitions to community living.

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ADL; IADL; community; transition; intellectual disability

Introduction

Transition to community dwelling marks a significant change in the provision of services to support people with disability and aims to include people with ID more equally in society. Historically, many people with intellectual disability (ID) in Ireland have lived most of their lives in congregated settings with little opportunity for ADL and IADL skill development [1]. This transition from traditional residential institutions was already achieved since the 1990s in many other countries, such as Sweden and Norway [2,3]. In Ireland, national policies such as *A Strategy for Equality* [4], *Time to Move on from Congregated Settings* [5] and international covenants [6] have also promoted the transition of adults with ID from residential or congregated settings to community dwelling. While this transition is in progress, it is not yet complete, with many people with ID in

Ireland yet to undergo transition to community-based living [5].

Transition to community dwelling has been promoted as a means of enhancing opportunities for participation and engagement in daily life, as well as promoting equality and inclusion of people with intellectual disabilities (ID) [7]. Occupational therapy is concerned with the facilitation of opportunities for people to engage in meaningful occupation, underpinned by the belief that engagement in meaningful occupation has a significant influence on well-being [8]. In recent years, occupational therapists have come to recognize that factors outside of the person have a significant influence on the ability of the person to engage in meaningful occupation, and that preclusion from engagement in meaningful occupation has a negative influence on well-being and quality of life [9]. This has evolved into a discourse on occupational

justice, occupational rights and how the promotion of fairness, equity and empowerment to promote engagement in meaningful occupation in turn promotes well-being and quality of life [10]. Occupational justice advocates for the removal of barriers to full and active participation in daily life, and recognizes the personal, subjective nature of occupation [10].

Occupational therapists acknowledge that engagement in meaningful occupation occurs as a result of interaction of personal, environmental and occupational factors to influence participation [11]. However, much theoretical literature in occupational therapy focuses on issues within the person (such as physical, spiritual, cognitive and affective factors) that affect participation, as opposed to environmental factors that influence participation in daily life [12]. Here, there is a more robust consideration of environmental aspects, particularly living situation.

In this study, a residential or congregated setting is defined as a residence shared by ten or more people [5]. Community dwelling refers to those living independently or those living with family, and those supported to live in standard homes within the community (dispersed housing) or with other people with disability (clustered housing) [5]. Those living within the community have been reported to generally enjoy greater overall quality of life, increased opportunities for choice, and greater participation in community life [7] due to increased potential for personalized supports [13].

Occupational therapists understand that such engagement in personally meaningful or socially valued occupations are required in order to maintain good quality of life and well-being, and the right to experience meaningful occupation is included in occupational rights [4,11].

Hasselkus, for example, maintains that ordinary, everyday occupations such as activities of daily living (ADLs) and instrumental activities of daily living (IADLs) give structure to the day, provide a sense of meaning, and form the basis for experiencing community life [14].

The changed environment following a transition to the community may facilitate greater engagement in ADLs and IADLs for people with ID and contribute to a person's sense of autonomy and independence [15]; though not inevitable without the right supports [16]. Transition to community living could be viewed as part of a process of removing barriers to participation in daily life, in line with an occupational justice perspective. This makes attention to opportunities for greater ADL/IADL independence particularly

pertinent when planning transitions from residential to community dwelling. It informs planning in terms of the supports currently required in one setting and thus the supports that need to move with the individual to facilitate successful transition to a new environment. This should ensure increased opportunities for engagement in meaningful occupation, and associated benefits for well-being, as well as promoting an occupationally just society.

This article aims to examine the performance of ADLs and IADLs of adults ageing with intellectual disability (ID) in Ireland across different living situations – independent or with family, residential setting, and community group home. This will serve to inform the supports that will be required in enabling successful participation after transitioning to a community setting.

Factors that influence ADL and IADL performance

Age, gender and cognitive abilities: In Ireland, the population of older adults with ID has doubled over the last two decades [17,18]. People with ID are now living longer and thus more than before experiencing a longer ageing process [19]. ADL and IADL performance has been found to decline with increasing age [20], however, Henderson et al. reported that health status is a more significant predictor of decline in functional abilities reflected in ADL performance, and is not an inevitable outcome of increasing age [21]. Hilgenkamp and Evenhuis also report that level of ID was the main predictor of ADL and IADL performance in their study of 1069 people with ID in the Netherlands [22]. People with all levels of ID participated in this study.

Gender has also been reported to influence scores on ADL and IADL measures [23], particularly for food preparation, shopping for groceries and household chores across populations of people with and without ID. Historically, men were not assessed on some IADL scale items, including meal preparation and laundry, presumably due to cultural and social role norms [24].

Finally cognitive ability has also been identified as a unique contributing factor [25]. Lifshitz et al. found that people with mild ID have more independent ADL function than those with moderate or severe ID, but found no significant relationship with age or gender [26]. Umb-Carlsson and Sonnander also found that level of ID was more likely than gender to influence ADL scores [23]. The relationships among these variables are apparently complex, and deserves more investigation.

Living arrangement: As daily activities and routines are significantly influenced by the environment in which a person lives, the person's place of residence is likely to have implications for the performance of ADLs and IADLs [27]. Older people with ID, and people with severe or profound ID, in Ireland are reported to be more likely to live in congregated settings or long-term residential care [5,28] heightening the potential for this variable to be influential.

Examples include that living situation may influence the supports available for completion of ADL and IADL activities; physical and social environments may be a barrier to participate in ADLs and IADLs; and constraints on staff numbers and availability of necessary adaptive equipment may further influence ability and opportunity to participate in ADLs and IADLs. Other studies suggest that community settings better facilitate opportunities for self-determination and autonomy [15], and both present a more ideal environment to develop and perform ADL and IADL skills and increase meaning for these tasks [15].

Opportunities and challenges of transition to community living: There are differing perspectives in the literature. Cooper and Picton found that although the process of de-institutionalization resulted in increased overall quality of life and decreased incidences of behaviours that challenge, there were no significant changes in ADL and IADL performance [29]. Qian et al reported similar low levels of engagement in ADLs and IADLs [22,30]. Bigby and Fyffe maintain that de-institutionalization entails much more than relocation to community, and requires significant levels of individualized support for staff and service users, as well as societal change focused on citizenship, inclusion and community engagement [31]. Differing strategies such as active support show promising findings for supporting adults with ID to more actively engage in daily life [30,32,33]. As the overall purpose of disability support services is to promote quality of life for people with ID, and to engage in meaningful occupations such as ADLs and IADLs are an important predictor of quality of life for people with ID, investigation into current engagement in ADLs and IADLs needs to be explored, in order to identify where strategies should be targeted to enable greater ADL and IADL engagement when placed in the community [30].

Methods

Data were drawn from the first wave of IDS-TILDA, a longitudinal study of adults with ID aged 40 years and over. The study explores the ageing profile,

health, social and community participation of people with ID in Ireland. Assessing ADL and IADL was a subtheme of physical and behavioural health sections of this study. Ethical approval for the study was obtained from the Faculty of Health Science Ethics Committee at Trinity College, the University of Dublin and 138 intellectual disability service providers, which participants were receiving services from.

Sample

The sample was randomly selected from Ireland's National Intellectual Disability Database (NIDD), which collects information from all people with ID who are using or requiring specialized services in Ireland across all levels of ID and in a full range of residential situations [34]. The sample consisted of 753 people aged 40 years and above, representing 8.9% of the ID population registered with the NIDD above 40 years of age. Written consent to participate was required from the individual and/or proxy consent by family/guardians.

The IDS-TILDA question protocol was developed in consultation with an international scientific advisory committee of experts in the field and further reviewed by advocate groups of people with ID. These groups also provided the direction on the supporting easy-read materials to enhance the inclusion of as many people as possible.

Measures

IDS-TILDA used an adapted version of the Lawton and Brody ADL/IADL scale demonstrated to be suitable for use in people ageing with ID [24]. The level of difficulty in ADL/IADL was indicated by: 'no difficulty', 'some difficulty', 'a lot of difficulty' and 'cannot do at all' and the areas of ADL and IADL performance included dressing, walking, moving around the home, bathing and showering, oral hygiene, eating, drinking, bed mobility, toileting, medication management, meal preparation, grocery shopping, telephone use, money management and domestic tasks including laundry and cleaning.

Living situation/place of residence was recorded as at home with family, living independently or semi-independently, community group homes, residential settings, nursing homes or specialist centres. For the purposes of statistical analysis, place of residence was recoded as: (1) Independent/Family, (2) Community group home, (3) Residential setting. Residential setting refers to a traditional congregated setting of 10 or

more people, in an area segregated from the wider community [5]. Community group homes refer to people with ID living together within the community with supports provided from paid staff [5]. Typically, housing less than 10 people although policy recommends no greater than four people in a dwelling [5]. Independent living refers to people with ID living independently within the community, or living with family within the community. Other demographic information recorded included age, gender and level of ID.

Statistical analysis

Data analysis was conducted using SPSS version 20.0 (IBM Corp., Armonck, NY). Descriptive statistics were used to report the demographic data and the degree of difficulty in ADL and IADL between the three types of living situation. A lower ADL or IADL score indicates less difficulty and a higher score indicates greater difficulty with the task reported. A chi-squared test of independence was conducted to test for a significant association between level of difficulty with ADLs and IADLs and type of residence.

Results

The sample profile by place of residence is illustrated in Table 1 below. Of the 753 participants, 55.1% were female, with the age range from 41 to 90 years and mean age for the total sample of 53.4 years (SD 9.6).

ADL by setting

Across each ADL examined, greater levels of ability were evident for people living in independent and community group homes (see Table 2). Over 70% of people living independently reported no difficulty for

each of the ADLs, with over 90% reporting no difficulty in walking, getting in/out of bed or toileting. Levels of ADL independence were markedly lower in residential settings. Higher levels of difficulty were noted by those in residential settings for all ADLs, especially cleaning teeth/dentures, getting out of bed, dressing and toileting. Over half of the people living in residential settings reported difficulty with bathing/showering (57.6%) and cleaning teeth (50.6%). This compares with 11.7% and 6.2% of people in independent settings and 21.3% and 15.5% of people in community group homes. These differences were significant.

It is noted that independence in performance of dressing was significantly higher in independent and community group home situations when compared to residential setting. Similar trends followed for eating and cleaning teeth.

IADL by setting

The proportion reporting difficulty with performance of IADL was higher than ADLs regardless of setting, with the highest percentage of reported difficulty by people living in residential settings compared with independent and community group homes.

Highest level of ability was in household chores with no difficulty in this task reported by 13.7% of people in residential setting, 41.6% of people in community group homes and 63.7% living in independent/family settings. The difference between settings was statistically significant (See Table 3).

Money management was the IADL with the highest reported difficulty in each setting, with 49.2% of those living independently, 78.0% of those living in community group homes and 95.2% of those living in residential care reporting significant difficulty with this task. Similar trends were noted for use of telephone,

Table 1. Demographic information of IDS-TILDA population.

Demographic profile of respondents	Independent/Family (N = 129)		Community group home (N = 268)		Residential setting (N = 356)		Total (N = 753)	
	N	%	N	%	N	%	N	%
Gender								
Male	61	47.3	123	45.9	154	43.3	338	44.9
Female	68	52.7	145	54.1	202	56.7	415	55.1
Age (years)								
40–49	61	47.3	98	36.6	129	36.2	288	38.2
50–64	58	45.0	136	50.7	147	41.9	343	45.6
65+	10	7.8	34	12.7	78	21.9	122	16.2
	51.5	SD 7.76	53.7	SD 8.8	55.7	SD 10.4	Total 54.25	SD 9.570
Level of ID								
Mild	54	48.6	71	29.1	41	12.1	166	23.9
Moderate	51	45.9	130	53.3	142	41.8	323	46.5
Severe/Profound	6	5.4	43	7.3	157	46.2	206	29.6

with nearly half (49.6%) of those living in community group home and 29.4% of those living independently or with family reporting a lot or complete difficulty with this task compared with 82.4% of adults living in residential care (See Table 3).

Differences in performance of IADLs between settings (independent, community group home settings and residential settings) were significant. Over 70% of adults with ID living in residential setting reported a lot of difficulty or cannot do it in all the IADLs.

Discussion

This paper examined ADLs and IADLs of older Irish adults living in residential settings with a view to understand what challenges exist in supporting occupational engagement as people transition to community dwelling, in line with current Irish policy on de-institutionalization and subsequent service planning. People ageing with ID may be at increased risk of occupational marginalization, a form of occupational injustice where the person is precluded from meaningful engagement through lack of autonomy in occupation, often exacerbated by social norms, or beliefs that people with ID cannot engage in certain occupations [34]. Successful ADL and IADL performance is

an essential aspect of occupational engagement in daily life, it is important to understand appropriate supports that will need to be in place to allow people to complete these tasks successfully in the community, while optimizing opportunities for autonomy, growth and development in line with an occupational justice perspective [35]. The chi-square analysis carried out indicated a very significant difference in levels of ADLs in relation to place of residence. Older adults living independently or with family and those in the community group home performed better in all the ADLs than those in residential settings. Those living in residential settings reported higher levels of difficulty with ADL and IADL performance. This indicates that these individuals currently require significant levels of support in order to complete daily activities. There is also evidence that the higher functioning residents tend to make these transitions first to the community [36].

The results showed that levels of difficulty in IADLs were significantly associated with place of residence. Occupational therapists understand that the physical, social, cultural and institutional environment influences occupational engagement, as well as factors within the person, and the occupation itself [37,38]. For all IADL items, the scores for those in residential

Table 2. ADL Performance by place of residence.

	Types of residence 3 categories											
	Independent/family <i>n</i> = 129				Community group homes <i>n</i> = 268				Residential <i>n</i> = 356			
	No difficulty %	Some difficulty %	A lot/cannot do at all %	<i>x</i> ² <i>p</i>	No difficulty %	Some difficulty %	A lot/cannot do at all %	<i>x</i> ² <i>p</i>	No difficulty %	Some difficulty %	A lot/cannot do at all %	<i>x</i> ² <i>p</i>
ADLs												
Dressing including shoes and socks	83.5	9.4	7.0	*	75.8	15.8	8.5	*	32.6	31.2	36.3	*
Walking across room	93.0	3.1	3.9	*	93.6	3.4	3.0	*	69.4	9.3	21.3	*
Bathing and showering	72.2	41.46	11.7	*	41.7	37.1	21.3	*	10.7	31.8	57.5	*
Cleaning your teeth/dentures	86.7	7.0	6.2	*	70.6	14.0	15.5	*	32.6	16.9	50.6	*
Eating/cutting up your food	83.6	10.9	5.4	*	69.7	20.1	10.2	*	38.7	34.5	42.2	*
Getting in and out of bed	95.3	1.6	3.2	*	91.6	5.7	2.6	*	69.7	7.9	22.5	*
Using toilet including getting up and down	94.5	3.1	2.4	*	93.1	3.5	3.4	*	64.3	10.8	25.0	*

*Indicates significance at $p < .001$.

Table 3. IADL Performance by place of residence.

	Types of residence 3 categories											
	Independent/family <i>n</i> = 129				Community group homes <i>n</i> = 268				Residential <i>n</i> = 356			
	No difficulty %	Some difficulty %	A lot/cannot do at all %	<i>x</i> ² <i>p</i>	No difficulty %	Some difficulty %	A lot/cannot do at all %	<i>x</i> ² <i>p</i>	No difficulty %	Some difficulty %	A lot/cannot do at all %	<i>x</i> ² <i>p</i>
IADLs												
Making a hot meal	31.2	26.4	42.2	*	8.9	19.1	72.0	*	1.7	4.3	94.0	*
Shopping for Groceries	45.2	21.0	33.9	*	17.9	26.8	55.3	*	4.3	8.7	87.0	*
Making a phone call	59.5	11.1	29.4	*	33.2	17.2	49.6	*	5.8	11.8	82.4	*
Managing money	23.8	27.0	49.2	*	5.5	16.1	78.3	*	0.9	4.0	95.2	*
Household chores	63.7	16.9	19.4	*	41.6	26.5	31.9	*	13.7	13.1	73.1	*

*Indicates significance at $p < .001$.

settings indicated a significantly greater level of difficulty in engaging in IADLs, compared with other settings. To some extent this trend may be explained by greater prevalence of severe or profound ID in residential care. Over 70% of adults who lived in residential settings were reported to have a lot of difficulty in all IADLs. There were also greater numbers of those in the older age categories living in residential settings. Age, level of ID, mobility, gender and a multitude of other factors could influence ADL ability and performance [22,25].

An occupational justice perspective highlights the importance of working with people with ID to facilitate engagement in meaningful occupation, regardless of living situation. As adults ageing with ID transition from residential settings to community dwelling, new challenges and opportunities emerge in terms of engagement in ADLs and IADLs [30]. The high percentage of those reporting significant difficulties with ADL and IADL in the present study is an indicator of the need for increased supports and training, regardless of place of residence. An understanding of the supports required could facilitate greater opportunities for participation in daily life through more informed and efficient service planning and provision, for people with ID of all abilities, particularly as people continue to transition from traditional congregated settings to community dwelling.

Influence of environment & relocation: ADL and IADL performance

Occupational justice posits occupational therapy as a profession concerned with removing barriers to meaningful occupation [9]. Occupational therapists understand that the environment in which a person lives has a significant influence on the person's opportunities to participate in daily life, and in facilitating or hindering performance of occupations [12,27]. This is supported by the findings of the present study that those who are living in the community have higher levels of ADL and IADL ability, and is consistent with the findings of other studies [20,37].

An unsuitable physical, social, cultural and institutional environment can result in limited opportunity for ADL and IADL performance, which may be a contributing factor in difficulty in ADL and IADL performance in residential settings as some people do not have the opportunity to perform or participate in IADL activities on a regular basis. If these functions are not practiced regularly the ability to develop these skills and/or perform them will be lost. This could be viewed as a form of occupational deprivation of

people with ID, where due to factors outside of the control of the person, they are precluded from the engagement in occupation [39].

Living within the community may support opportunities for autonomy and social participation if appropriate supports are available. However, Bigby found that the transition to community living did not automatically bring benefits such as increased independence and social engagement, if appropriate supports to facilitate community engagement were not provided [40]. In this study, abilities to complete IADLs such as hot meal preparation, grocery shopping and money management were very low. The environmental set-up of traditional residential settings does not facilitate optimal participation in some IADLs. For example, meals may be prepared centrally and distributed to residents, eliminating the possibility of grocery shopping, and reducing potential participation in money management. This could also be viewed as a potential form of occupational deprivation, as the person does not have the opportunity to grow and develop through engagement in identified meaningful occupations [39]. It also contradicts the occupational right to develop through experiencing occupation [11].

The social and cultural environment of the setting can also influence the person's ADL and IADL performance. Assumptions by staff or family members that a person is not able to complete occupations without due consideration to the needs, wishes and abilities of the person could also be viewed as occupational marginalization [35]. Reluctance of staff members or family to take any risk in giving adults with ID household tasks to complete may further contribute to learn helplessness, which may increase their dependency level on others such as staff members, relatives, and parents for their IADL needs [41]. Active support is a strategy that has been used successfully with people with ID to enable them to engage successfully in daily life within the community [31,33,34]. Consideration of the influence of the physical, social and cultural environment is particularly relevant for those who are preparing for transition to community living from traditional congregated settings, who may find different opportunities, resources and challenges within the community. As Ireland makes a concerted effort to further reduce the numbers of people in congregated settings it will be important to ensure that the appropriate environmental, physical and social supports for ADL and IADL mastery and performance are available before, during and after the transition process as this will facilitate a successful and

genuine transition and engagement in community life. Subsequent waves of data collection for IDS-TILDA will offer a unique opportunity to gauge how much ADL and IADL competencies increase after transition and their relationship to future quality of life.

Implications for occupational therapy practice

Occupational justice promotes approaches to implement occupational therapy's core beliefs of the relationship between occupation, well-being and human rights [35]. Occupational justice aligns well with a human rights perspective [42,43] and its adoption permits challenges faced by those transitioning to community dwelling to be named, and therefore more easily addressed.

An occupational justice perspective provides a clear mandate for occupational therapists working with people with ID who are transitioning to community living to promote engagement in meaningful occupation in community living. It demands occupational therapists to work at societal as well as an individual level to promote equality and opportunities for meaningful occupation [42].

Transition to community dwelling for adults with ID clearly holds a number of opportunities for occupational therapists. Occupational therapists have a unique perspective on the benefits of engagement in personally meaningful or socially valued occupations for maintenance of health and well-being [42]. ADL and IADL are important aspects of self-care, and are included in OT conceptual and practice models such as the Canadian Model of Occupational Performance and Engagement (CMOP-E)[44]. Furthermore, self-care activities form part of everyday routines and habits, and play a role in shaping occupational identity, self-concept and self-efficacy [45]. Currently, people with intellectual disabilities in Ireland living in residential settings have lower levels of engagement in ADLs and IADLs compared with people in community and independent settings.

With an understanding of physical, social, cultural and institutional environments and how this affects participation in daily life, occupational therapists are well placed to analyze and adapt these occupations and environments, in order to facilitate increased opportunities to engage in meaningful occupations [44]. This is particularly relevant for those who are in the process of transitioning to community living, as the facilitation of an environment that can promote greater occupational engagement could contribute to successful community transition, and play a valuable

role in ensuring that people with ID can achieve and sustain true community inclusion and citizenship.

Limitations and directions for future research

There are some limitations to the present study. For example, multiple the Chi square tests were conducted on a large sample, it is more likely to obtain a significant result.

It is not possible to definitively ascertain the reasons for lower levels of ability in ADL and IADL performance noted in residential settings when compared with independent and community group home settings. Future studies may explore in more depth the reasons for lower ability in ADL and IADL performance across different settings. This would facilitate a greater understanding of the impact of living situation on the person's ability to perform ADLs and IADLs, and could assist in informing service planning and provision to ensure that appropriate supports are provided to enable people with ID to fully engage in ADLs, IADLs and community life.

ADL and IADL performance should not be the sole factor considered in planning transition to community. Future research would benefit from a multifactorial analysis of ability and engagement in daily life before and after transition to the community. Additional factors to examine might include literacy, numeracy, current supports staffing and adaptive aids available, and measures of cognitive impairment as well as measures of ADL and IADL performance in order to gain a more holistic insight into the individual's ability to participate in daily life within the community following transition.

Through longitudinal research, it will be possible to track changes in ADL and IADL performance across differing settings, and before and after transition to differing setting and further consider the contributors to changes in ADL and IADL performance across different living situations.

Conclusion and recommendations

This study utilizes occupational justice to examine how living situation influences performance of ADLs and IADLs. Possible challenges to occupational engagement of adults ageing with ID situated within physical, social, cultural and institutional environment were highlighted. It was found that those living independently or in community group homes generally had higher levels of ability in ADL and IADL performance in comparison to traditional residential settings. The findings also showed that older adults in

residential settings are less active in performance of ADL and IADL. As adults with ID prepare for transition to community living from traditional residential settings, it is essential to consider how the changing physical, social and cultural environment will impact on those who are transitioning, and how this new environment will influence their opportunities to engage in the activities of daily life, and how the increased resources and opportunities available within the community can be optimized to afford optimal engagement, participation and quality of life for people ageing with ID within the community. Occupational therapy utilizing an occupational justice perspective guides occupational therapists to work with adults with ID before, during and after transition to maximize potential for successful transition to community living, and full and active engagement in daily life of the community.

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