

שאלתה: **Adult people with learning disabilities**

1

TI: **Social Connections for Older People with Intellectual Disability in Ireland: Results from Wave One of IDS-TILDA**

AU: McCausland, Darren; McCallion, Philip; Cleary, Eimear; McCarron, Mary

SO: Journal of Applied Research in Intellectual Disabilities, v29 n1  
p71-82 Jan 2016

Background: The literature on influences of community versus congregated settings raises questions about how social inclusion can be optimized for people with intellectual disability. This study examines social contacts for older people with intellectual disability in Ireland, examining differences in social connection for adults with intellectual disability and other adults. Materials & Methods: Data were drawn from the IDS-TILDA study in Ireland. A nationally representative sample (n = 753) included adults aged 40 years and older, with additional comparison with general population participants. Predictors of social contacts were explored. Results: Residence, level of intellectual disability and age were significant factors determining social contact. People in institutional residences, older respondents and those with severe/profound intellectual disability had the lowest levels of contact; older adults with intellectual disability had much lower rates than general population counterparts. Conclusions: Community-dwelling people with intellectual disability have greater social contact than those living in institutions, but levels are below those for other adults in Ireland.

2.

**TI: Current Policy and Legislation in England Regarding Older People--What This Means for Older People with Learning Disabilities: A Discussion Paper**

AU: Turner, Sue; Cooper Ueki, Madeline

SO: British Journal of Learning Disabilities, v43 n4 p254-260 Dec 2015

Background: This paper seeks to explore the opportunities and challenges generated by current policy, guidance and legislation in England relating to older people, in terms of the practical implications for older people with learning disabilities. Methods: Using the broad themes housing, employment, social inclusion and isolation, care and support, and promoting better health and well-being, this paper discusses potential practical opportunities and concerns for older people with learning disabilities arising from policy and legislation such as current initiatives regarding integration, personalisation and the dementia policy. Consideration is given to the implications of changing policy and practice for both current and future generations of people with a learning disability as they reach older age. Conclusions: This discussion paper concludes that whilst there is potential for older people with a learning disability to benefit from policy and practice aimed at improving the lives of older people generally, the tendency for policy to be targeted at specific groups without adequately considering the diversity of those groups often leaves those with a learning disability at the margins of being able to make the most of changes.

3.

TI: **Overweight and Obesity in Older People with Intellectual Disability**

AU: de Winter, C. F.; Bastiaanse, L. P.; Hilgenkamp, T. I. M.; Evenhuis, H. M.; Echteld, M. A.

SO: Research in Developmental Disabilities: A Multidisciplinary Journal, v33 n2 p398-405 Mar-Apr 2012

Overweight and obesity are major health problems associated with increased cardiovascular disease risk, which is not sufficiently studied in people with intellectual disability yet. The present study was part of the Healthy Ageing in Intellectual Disability (HA-ID) study. The aim of this study was to establish (1) the prevalence of overweight, obesity and body fat percentage in older people with intellectual disability (ID) through measurement of Body Mass Index (BMI), waist circumference, waist-to-hip ratio (WHR) and skin fold thickness, and compare this with prevalence of overweight and obesity in the general population, and (2) the association of overweight and obesity with participant and treatment characteristics (gender, age, level of ID, Down syndrome, autism, independent living, smoking, (instrumental) activities of daily living ((I)ADL), physical activity and use of atypical antipsychotic medication) using regression analyses. In this cross-sectional study 945 persons, aged 50 and over with borderline to profound ID, living in central settings, in community settings and independently were included. Overweight and obesity were highly prevalent, with more obesity (26%) than in the general Dutch older population (10%) as measured by BMI, and 46-48% obesity as measured by waist circumference and WHR respectively. Women, people with Down syndrome, higher age, less severe ID, autism, people who are able to

eat independently, preparing meals and doing groceries independently, people with physical inactivity and use of atypical antipsychotics were significantly more at risk of being overweight or obese. This merits specific actions by policy makers and clinical practice to improve health outcomes

4.

TI: **Quality of Life in Group Homes and Older Persons' Homes**

AU: Higgins, Laura; Mansell, Jim

SO: British Journal of Learning Disabilities, v37 n3 p207-212 Sep 2009

Older people with intellectual disabilities sometimes live in older people's homes rather than homes for people with intellectual disabilities. Little is known about their quality of life in these homes. A non-equivalent comparison group design was used to compare the quality of life of 59 people in three groups; older people without an intellectual disability living in older people's homes ( $n = 20$ ), older people with an intellectual disability living in older people's homes ( $n = 19$ ) and older people with an intellectual disability living in intellectual disability homes ( $n = 20$ ). Data were collected on participant characteristics, adaptive behaviour and three aspects of quality of life; community involvement, participation in domestic living and choice making. The three groups were comparable in terms of gender, ethnicity and additional impairments but the older people without an intellectual disability were older and had more adaptive skills than the other groups. Older people with an intellectual disability experienced better quality of life outcomes in terms of participation in meaningful activity and community access when they lived in intellectual disability homes compared with older people's homes. It was not possible to achieve reliability on the measure of choice-making. This study

provides some evidence to suggest that older people with an intellectual disability may be best served in intellectual disability homes rather than older people homes and that it is an area of research which needs further exploration.

5.

TI: **Prevalence and Associated Factors of Sarcopenia in Older Adults with Intellectual Disabilities**

AU: Bastiaanse, Luc P.; Hilgenkamp, Thessa I. M.; Echteld, Michael A.; Evenhuis, Heleen M.

SO: Research in Developmental Disabilities: A Multidisciplinary Journal, v33 n6 p2004-2012 Nov-Dec 2012

Sarcopenia is defined as a syndrome characterised by progressive and generalised loss of skeletal muscle mass and strength. It has hardly been studied in older people with intellectual disabilities (ID). In this study 884 persons with borderline to profound ID aged 50 years and over, were investigated to determine the prevalence of sarcopenia in this group. To identify the associations of sarcopenia, logistic regression analyses were performed with patient characteristics, mobility, physical activity, intake of energy and proteins, body mass index (BMI) and levels of CRP, albumin and vitamin D in serum. The prevalence of sarcopenia was 14.3% in the total group. In the age group 50-64 years prevalence was 12.7%. Sarcopenia was positively associated with mobility impairment and inflammation and negatively with BMI. The next thing to do is collecting longitudinal data to study the relation between sarcopenia and negative outcomes in older people with ID

.6

TI **"You Have to Care." Perceptions of Promoting Autonomy in Support Settings for Adults with Intellectual Disability**

AU: Petner-Arrey, Jami; Copeland, Susan R.

SO: British Journal of Learning Disabilities, v43 n1 p38-48 Mar 2015

This study from the south-western United States investigated the perceptions of persons with intellectual disability receiving support and of persons providing support regarding the autonomy of people with intellectual disability. The participants included 10 people with intellectual disability and 10 support workers. Through interviews, this qualitative investigation examined issues related to autonomy in support services. Analysis of participant interviews revealed that support workers and people with intellectual disability faced challenges that restricted the promotion of the autonomy of people with intellectual disability. Both groups of participants noted that support workers had to care about their work with individuals with intellectual disability to effectively promote their autonomy.

7.

TI: **People with Learning Disabilities and "Active Ageing"**

AU: Foster, Liam; Boxall, Kathy

SO: British Journal of Learning Disabilities, v43 n4 p270-276 Dec 2015

Background: People (with and without learning disabilities) are living longer. Demographic ageing creates challenges and the leading policy response to these challenges is "active ageing". "Active" does not just refer to the ability to be physically and economically active, but also includes ongoing social and civic engagement in the communities of which older people are a part. Active ageing should apply to all

citizens, including the experiences of older people with learning disabilities. Materials and Methods: This literature based paper explores the focus of active ageing discussions in relation to the general population drawing comparisons with the experiences of older people with learning disabilities. Results: It points out that older people with learning disabilities and their experiences are largely missing from broader policy discussions of active ageing. Conclusion: The paper concludes by arguing for inclusive research in active ageing which takes account of the concerns and interests of older people with learning disabilities.

8.

TI: **Working Alongside Older People with a Learning Disability: Informing and Shaping Research Design**

AU: Herron, Daniel; Priest, Helena M.; Read, Sue

SO: British Journal of Learning Disabilities, v43 n4 p261-269 Dec 2015

Background: There has been an increase in inclusive research in the learning disability field; however, this has not been reflected within learning disability and dementia research, where little is known from the perspective of people with learning disabilities. This paper will define inclusive research, explore reasons for the dearth of inclusive dementia research, and identify the challenges of conducting dementia research involving people with learning disabilities. Materials and Methods: Examples of working with people with learning disabilities to develop elements of a PhD research study will be detailed and critically discussed. Results: These experiences aided the creation of accessible material about dementia for a PhD research study. Subsequently, this helped to overcome challenges of communication within the research study and helped to promote the participation of people with learning

disabilities and dementia. Conclusion: Sharing these ideas about how we worked together will help others who are seeking to engage and achieve more inclusive research practices with marginalised populations.

9.

**TI: Attitudes towards People with Disabilities--What Do People with Intellectual Disabilities Have to Say?**

AU: Corr McEvoy, Sandra; Keenan, Emer

SO: British Journal of Learning Disabilities, v42 n3 p221-227 Sep 2014

Attitudes towards people with intellectual disabilities have traditionally been very negative, resulting in people with intellectual disabilities being treated badly by other. This claim was explored by conducting focus groups with adults who have an intellectual disability to find out about their everyday experiences in different places and using different services. Participants reported being treated well by some people and in some places, but being treated less favourably by other people and in other places. Being treated well happened in their home, in college, in work and in their services. People were treated less well when they were out and about, using public transport, in school or work.

10.

**TI: How Do People with Learning Disabilities Experience and Make Sense of the Ageing Process?**

AU: Newberry, Gayle; Martin, Carol; Robbins, Lorna

SO: British Journal of Learning Disabilities, v43 n4 p285-292 Dec 2015

Background: Not enough is currently known about how people with learning disabilities experience and understand the ageing process.



This is particularly important as the population of older people with learning disabilities is growing due to increased life expectancy. This article draws on the first author's doctoral research study, which aimed to fill this gap in the literature by exploring how people with learning disabilities experience and make sense of the ageing process and old age. Materials and Methods: Seven people with learning disabilities aged 60 or more were interviewed, and their accounts were analysed using interpretative phenomenological analysis. This approach allows the participant's lived experience to be explored in detail. Participants' accounts were analysed individually, followed by a group analysis. This article presents the results of the group analysis, illustrated by quotes from individuals. Results: The master themes arising from the group analysis were as follows: quality of relationships is central to enjoyment of life, including subthemes on the importance of affection and companionship, distress at lack of closeness and anxiety about ability to satisfy others; powerlessness; needing a sense of purpose; and making sense of getting older, including subthemes on reactions to changes with age, life review and looking to the future. Conclusions: Clinical implications of the findings include the need for services to support older people with learning disabilities in maintaining friendships and meaningful activities. This study demonstrates that some older people with learning disabilities can engage in a process of life review and raises the possibility that learning disability services could play a useful role in facilitating this process. Understanding of the ageing process varied between participants and tended towards a negative, stereotypical view of ageing. The findings suggest that people with learning disabilities could benefit from psychoeducation on the ageing process to aid them in making sense of the changes they experience as they get older.

11

**"TI I Never Thought about It": Teaching People with Intellectual Disability to Vote**

AU: Agran, Martin; MacLean, William; Andren, Katherine Anne Kitchen  
SO: Education and Training in Autism and Developmental Disabilities, v50 n4 p388-396 Dec 2015

Despite an increasing commitment in promoting the full inclusion of people with intellectual disability in their communities, it appears that few adults with intellectual disability participate in elections as registered voters. We surveyed a variety of stakeholders about voting by people with intellectual disability using quantitative and qualitative methods. The majority of respondents indicated that people with intellectual disability knew what voting is, expressed an interest in voting, and were registered to vote. However, few respondents indicated that individuals with intellectual disability were provided with voting instruction or had voting included in their service plans. Barriers to greater participation are discussed and future areas of research are suggested.

12.

**TI: Money, Finance and the Personalisation Agenda for People with Learning Disabilities in the UK: Some Emerging Issues**

AU: Abbott, David; Marriott, Anna  
SO: British Journal of Learning Disabilities, v41 n2 p106-113 Jun 2013

In the UK, policy on adult social care places an emphasis on maximising choice and control for service users, including people with learning disabilities. The shift from the provision of organised services for groups of people to offering individual and personal budgets and

pots of money for people to buy their own services has major implications for the way in which people with learning disabilities are offered the opportunity to be much more "hands-on" with managing their own financial affairs. Some of the financial implications of personalisation are arguably quite complex, and it is not clear how well people with learning disabilities are being supported with this. This paper highlights some key and emerging issues on the topic of money and personalisation and draws on interviews with a range of staff in learning disability services and highlights their views, hopes and concerns about the best ways to support people with money matters. The response of mainstream financial institutions to the needs of people with learning disabilities and the political and economic context in which the personalisation agenda is developing are also discussed.

13

TI: **An Investigation into the Public Health Roles of Community Learning Disability Nurses**

AU: Mafuba, Kay; Gates, Bob

SO: British Journal of Learning Disabilities, v43 n1 p1-7 Mar 2015

International studies have shown poor uptake of public health initiatives by people with learning disabilities. In addition, studies have shown that people with learning disabilities experience poor access to public health services. The contribution of community learning disability nurses in meeting the public health needs of people with learning disabilities has evolved differently across the UK resulting in conflicting understanding of this role. This paper reports on a study that explored and explained the contribution of community learning disability nurses in the implementation of public health policies for people with learning disabilities. The study demonstrates that community learning disability

nurses are involved in health surveillance, health promotion, health facilitation, health prevention and protection, health education, and healthcare delivery.

14

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16.

**TI: Support Needs of Siblings of People with Developmental Disabilities**

AU: Arnold, Catherine K.; Heller, Tamar; Kramer, John

SO: Intellectual and Developmental Disabilities, v50 n5 p373-382 Oct 2012

This qualitative study examines the support needs of adult siblings of people with developmental disabilities. A survey completed by 139 siblings of people with developmental disabilities captured the needs of adult siblings through 2 open-ended questions. A grounded theory approach was used, and the sibling responses anchored the analysis, interpretation of findings, and discussion using the constant comparison method. Eleven core variables and 3 overarching themes emerged. Three overarching themes for sibling support needs include: (a) getting disability-related information, (b) getting support for their caregiving role, and (c) enhancing the formal support system to address sibling needs.

17.

**TI: Relationships between Leisure Participation and Quality of Life of People with Developmental Disabilities**

AU: Badia, Marta; Orgaz, María Begoña; Verdugo, Miguel Á.; Ullán, Ana M.; Martínez, Magdalena

SO: Journal of Applied Research in Intellectual Disabilities, v26 n6 p533-545 Nov 2013

Background: Studies of people with developmental disabilities suggest that participation in leisure activities might be a key factor for good quality of life. This study explores the relationships between objective and subjective quality of life and leisure participation of adults with developmental disabilities. Materials and Methods: A cross-sectional design was used with a convenience sample of 125 people, aged 17-

65, living in the community. Participants completed the subjective scale of Integral Quality Scale and the Leisure Assessment Inventory in the form of an individual interview. Staff completed the GENCAT Scale. Results: No relationship was found between objective quality of life and leisure participation. However, correlations between some leisure participation dimensions and specific subjective quality of life domains were observed. The results establish a predictive relationship between leisure participation and material, emotional, and physical well-being. Personal and environmental variables analyzed were not found to have a moderating effect on the relationship between leisure participation and quality of life. Conclusions: These findings indicate that some aspects of leisure participation may significantly contribute to enhancing the quality of life of young people and adults with developmental disabilities living in the community.

18.

**TI: The Uptake of Secondary Prevention by Adults with Intellectual and Developmental Disabilities**

AU: Ouellette-Kuntz, H.; Cobigo, V.; Balogh, R.; Wilton, A.; Lunsy, Y.

SO: Journal of Applied Research in Intellectual Disabilities, v28 n1 p43-54 Jan 2015

Background: Secondary prevention involves the early detection of disease while it is asymptomatic to prevent its progression. For adults with intellectual and developmental disabilities, secondary prevention is critical as they may not have the ability to recognize the early signs and symptoms of disease or lack accessible information about these. Methods: Linked administrative health and social service data were used to document uptake related to four secondary prevention guidelines among adults with intellectual and developmental

disabilities. Rates were compared to those from a general population sample representing the same age ranges. Results: Of 22% of adults with intellectual and developmental disabilities had a periodic health examination in a two-year period (compared to 26.4% of adults without intellectual and developmental disabilities). Adults with intellectual and developmental disabilities were less likely to undergo recommended age and gender-specific screening for the three types of cancer studied (colorectal, breast and cervical). Conclusions: Adults with intellectual and developmental disabilities in Ontario experience disparities in secondary prevention. As changes to primary care delivery and secondary prevention recommendations in the province and elsewhere continue to evolve, close monitoring of the impacts on adults with intellectual and developmental disabilities combined with dedicated efforts to increase access is warranted.

19

TI: **Prevalence and Correlates of Psychotropic Medication Use among Adults with Developmental Disabilities: 1970-2000.**

AU: Valdovinos, Maria G, Schroeder, Stephen R; Geunyoung Kim

SO: International Review of Research in Mental Retardation; 2003, Vol. 26 Issue 1, p175-220

The article focuses on the prevalence and correlates of psychotropic medication use among adults with developmental disabilities. People with mental retardation are considered to be the most medicated in the society. Psychotropic medications can be classified into seven groups namely neuroleptics, antidepressants, anxiolytics, sedatives, stimulants, anticonvulsant, mood stabilizers, and others. Major tranquilizers were classified as antipsychotics or neuroleptics. Minor tranquilizers, hypnotics, and sedatives were classified as anxiolytics.



Several correlates were identified with psychotropic medication use such as age, gender, level of mental retardation, presence of a psychiatric diagnosis, existence and severity of problem behaviors, living setting, and size.

20.

TI: **Autonomy in residential facilities and community functioning of adults with mental retardation.**

AU: Heller, Tamar; Miller, Alison B. Factor, Alan

SO: Mental Retardation; December 1999, Vol. 37 Issue 6, p449-457,

Over a 3-year period, we examined whether the autonomy of 58 adults living in residences for people with developmental disabilities was associated with their adaptive behavior and community integration. Degree of resident autonomy included measures of opportunities for choice-making and level of involvement in policymaking. All of the participants lived in nursing homes at baseline and in residential settings for people with developmental disabilities at follow-up. Results indicated that opportunities for autonomy in residential settings were related to residents' adaptive behavior and community integration. More opportunities for choice-making in residences was associated with greater adaptive behavior, whereas smaller residence size and more resident involvement in decision-making were associated with greater community integration. Reprinted by permission of the publisher.

21

TI: **Changes in services and supports for people with developmental disabilities: New challenges to established practice**

AU: Bradley, Valerie J

SO: Health & Social Work25.3 (Aug 2000): 191-200

The changes that are emerging in systems of support for people with developmental disabilities are part of a trajectory of reform that began decades ago. The notion of inclusion has been a motivating force for reform in the field of developmental disabilities through the past 25 years.

22

TI: **Growing older together: ageing and people with learning disabilities and their family carers**

AU: Walker, Carol; Ward, Cally

SO: Tizard Learning Disability Review, v.18 n.3, pp.112-119, 2013

Purpose - This article aims to explore the new challenge posed by the first generations of people with learning disabilities who are now living into older age in significant numbers. Most are living with family carers, who are themselves ageing. This represents a major transition in people's lives and one to which services must respond if a normal life event is not to be turned into a crisis. Though this issue has been acknowledged by government, much more needs to be done to provide people with learning disabilities and their families with the necessary support to enjoy a healthy and active old age.

Design/methodology/approach - This article draws on the work of the authors for over a decade in this field.

Findings - Learning disabled people are likely to experience the age discrimination common in much older people provision and practice and the caring relationship is undermined in the short and long term. Evidence on the extension of personalisation indicates that it presents very considerable challenges

for this group of families. Practical implications - More information is needed on this growing population. More preventative support is needed to sustain the caring relationship while the family is living together, to support families to plan for the future, and to provide support when the caring relationship breaks down. Originality/value - The article draws together data from the fields of ageing, learning disability and family care to highlight the increasing challenge, which this growing, but neglected, population presents both for policy and practice. It examines the implications for both the older people themselves and for the ageing family carers with whom the majority live and of current government policy in social care and welfare benefits for this very vulnerable group.

23.

TI: **The Case for a New 'Case' Management in Services for People with Learning Disabilities**

AU: Cambridge, Paul

SO: British Journal of Social Work38.1 (Jan 2008): 91-116

Micro-organization is currently fragmented in services for people with learning disabilities. Care management, person-centred planning (PCP) and direct payments have developed through separate policy strands, with tasks and agency responsibilities blurred. A wide diversity of care management arrangements currently operate, with the relationship between care management, PCP and direct payments imprecisely defined. PCP and direct payments have also been variably implemented. This paper argues for a new 'person-centred case management', with these different devices better integrated and decision-making and action more person-centred. Drawing on practice experience from the original British case management experiments, the

new 'case' management would be centred on the needs and wants of individuals, be conducted independently from assessment, operate outside the public sector and be able to access personal budgets. It would consequently have the capacity to further de-institutionalize services and support and transfer more control to people with learning disabilities.

.24

TI: **Out of Area, Out of Sight: Review of Out-of-Area Placement Arrangements made by Social Services and Health for People with Learning Disabilities from the West Midlands**

AU: Goodman, Nicholas; Nix, Jane; Ritchie, Fiona

SO: Tizard Learning Disability Review 11.1 (Feb 2006): 35-43.

In 2004/2005 local partnership boards requested West Midlands South and Birmingham & The Black Country Strategic Health Authorities (SHAs) to review and report back on the circumstances of adults with a learning disability placed out of area. There are currently 623 known adults with learning disability living out of area at an annual cost to commissioning services of £35 million. In 1993 the Mansell Report predicted major problems and potential consequences relating to future planning of services for people with learning disabilities and complex needs. Twelve years on this has become a reality, as more people are living in higher-cost services away from their original district and families. There is no evidence from this review that out-of-area services are any worse or any better than local services. The review does not set out to make a direct comparison of out-of-area placements and services provided locally, nor does it reflect on the number of people being imported into the West Midlands. With lack of monitoring and reviewing of placements, many people have been left solely to the

care of provider organisations. Commissioners of services are becoming reliant on the Commission for Social Care Inspection (CSCI) to raise any concerns with them. This review calls for specific action to be taken now to reverse this trend of increasing out-of-area placements and to make more cost-effective local solutions.

25.

TI: **Recent trends in social services for adults with learning disabilities in England**

AU: Kozma, Agnes

SO: Tizard Learning Disability Review, v.13 n.4, pp.44-47, 2008

Councils in England spent £14.24 billion on social services for adults and older people in 2006-07. This is gross expenditure: all costs incurred by councils before any income from fees and charges or from others sources is netted off. Most of this sum (60%) went to financing services for older people. Services for people with learning disabilities had the second largest share: 22% of total spending that amounted to £3.12 billion