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An exploration of care-burden experienced by older caregivers of adults with intellectual disabilities, in Ireland.

Accessible summary

- Older family carers of an adult with an Intellectual disability were asked about how they sometimes feel when supporting another person.
- Most carers felt a little stressed or strained.
- Older carers felt less stressed than younger carers.
- The value of supports which help carers were identified.

Abstract

Background: People with intellectual disabilities are experiencing increased longevity, and in parallel their family caregivers are also ageing. The literature identifies that these caregivers are at risk of burden. The aim of this study is to measure the level of caregiver burden among older carers of adults with intellectual disabilities in an Irish sample and to analyse the effect of socio-demographic factors upon experiences of caregiver burden.

Materials and Methods: 30 caregivers completed a survey questionnaire. Data was collected based upon participants self-reports of burden using the Zarit Burden Interview (ZBI) and a socio-demographic questionnaire. Data was analysed using SPSS Version 24.

Results: Over 57% of carers indicated a mild to moderate level of burden. Analysis indicated that younger caregivers experience significantly higher levels of burden, when compared to older caregivers.

Conclusions: This study contributes to our understanding of burden among an Irish population of older caregivers supporting an adult with an intellectual disability. It identified that carers do experience burden. The importance of proactive assessments and supports for these caregivers was revealed. This study highlights a lack of Irish research in this area and may pave the way for future research which could build upon its findings.

Keywords caregivers, intellectual disabilities, older adults, burden, Ireland.

Background

In Ireland, 69% of adults with an intellectual disability are cared for by a family caregiver within their own home (NIDD, 2017). Both government and social policy support this, however, community living continues against a background of limited community supports (Inclusion Ireland, 2013). In Ireland there are several factors which may impact upon caregiver experiences and may expedite burden experiences. These include an ageing population of adults with Intellectual disability and their family caregivers, a reconfiguring of disability services and changes in the traditional socio-demographic facilitators of family caregiving.

The life expectancy of people with intellectual disabilities is increasing (McCarron, 2011). Increased longevity has presented family caregivers with many challenges including increased care needs, failing health, ageing processes of their family member, financial concerns, and worries for the future (Dillenger & McKerr, 2010; Schoufour et al., 2014). In parallel, these caregivers are also ageing and may be experiencing both physical and psychological health problems (Grey et al., 2017). Therefore, a growing population of ageing caregivers supporting adults with intellectual disabilities may be at risk of caregiver burden.

In addition, Irish disability services have changed over recent decades. Their focus is upon equality for all and the participation of people with disabilities in society. The Disability Act (Government of Ireland, 2005) and the National Disability Strategy (Inclusion Ireland, 2013) underpins this. The current policy prioritization of de-congregation and greater social inclusion has resulted in an over-reliance upon families as principle care provider's (Brennan et al., 2017). This over-reliance needs to be understood within the context of a severe recession from 2008 which negatively impacted resources which support primary caregivers (Inclusion Ireland, 2013). Inclusion Ireland has further reported that austerity has led to cuts to respite services, residential places, home-help and personal assistant hours, all of which are services that are important to people with an intellectual disability and their families. McConkey et al., (2018) identified that funding for residential placements fell nationally by 9% during the period 2009-2014. This is despite a growing population of people with intellectual disability.

Therefore, more people will have to continue living with their families and for longer if funding remains curtailed. An Irish study undertaken by Lafferty et al., (2016) investigated caregiving experiences among a population of caregivers of adults with intellectual disabilities. They reported levels of psychological distress three times higher than among the general population. Furthermore, in Ireland there is also much anecdotal evidence of carers in crisis which is frequently reported in the media. (RTE, 2017, The Irish Times, 2016).

Burden has not yet been addressed among Irish caregivers of adults with intellectual disabilities. This study aims to address this gap in the literature. An Irish study may differ due to cultural differences and a reliance upon voluntary rather than statutory service providers. Additionally, Brennan et al., (2017) reported that the traditional socio-demographic facilitators of family caregiving (traditional family homes/one income families/primary female caregivers) in Ireland are in rapid decline. Caring for a family member with intellectual disabilities within the family home presents many challenges including experiences of burden. Literature which examined burden experienced by family caregivers of adults with intellectual disabilities identified several factors which may impact on burden. These include the health of the caregivers, ageing of adults with intellectual disabilities, stigma, gender and caregiver support strategies (Al-Krenawi et al., 2011; Bhatia et al., 2015; Chou et al., 2010; 2011; Grey et al., 2017, Janicki et al., 2010, Lewlleyn et al., 2010, Magana et al., 2015, McKensie & McConkey, 2016; Nam & Park, 2017).

The literature identified that caring for an adult with intellectual disabilities can impact upon the caregiver's physical and psychological health (Grey et al., 2017). These caregivers reported more health problems and higher levels of burden than the general population. Several studies reported that caregivers who perceived their health as poorer also indicated higher levels of burden (Chou et al., 2010; McKenzie & McConkey., 2016). The literature also identified that younger caregivers experienced higher levels of ill-health and caregiver burden than older caregivers. (Chou et al., 2011; Grey et al., 2017; Lewellyn et al., 2010)

The evidence suggests a link between burden and mental illness (Bhatia et al., 2015; Chou et al., 2010; Lin et al., 2014). These studies reported that moderate to high levels of burden strongly predicts depression and mental illness. Chou et al., (2010) noted that 64-74% of their female sample had depressive symptoms and identified caregiver burden as an associated factor.

The experiences of older caregivers who are not only faced with their own ageing processes but that of their adult child with intellectual disabilities were found to impact upon burden. Factors specific to the individual with an intellectual disability including the level of support they require, the level of intellectual disability, along with the effects of frailty and ageing processes were strongly correlated to feelings of burden (Chou et al., 2011; Nam & Park, 2017). Nam and Park., (2017) identified that the severity of disability was associated with increased caregiver burden and poorer psychological health.

A burden of stigma was expressed by some populations researched. Caregivers expressed a highly stigmatising cultural phenomenon associated with having a child with disabilities especially among mothers (Al-Krenawi et al., 2011; McKensie & McConkey., 2016). These studies were based in low income countries (McKensie & McConkey., 2016) suggesting that experiences of burden are influenced by sociodemographic factors.

Experiences of burden was also identified as a gender issue in the literature (Chou et al., 2010; 2011; Kim & Chung, 2016). Caregiving as a largely female role appears to transcend all populations with many studies identifying a high proportion of female carers. One study by Piazza et al., (2014) found no differences between the sexes with respect to how carers experienced burden and their coping skills. In contrast Bhatia et al., (2015) reported that female participants reporting significantly more burden than males.

Studies which explored coping strategies, resources and supports which caregivers adopted to moderate feelings of stress, strain and burden were identified. Chou et al., (2008) investigated caregiver supports including respite provision. They invited all users of respite

services from one country to explore the effect of respite care upon the family. Results include improvements in the caregiver's social life and life satisfaction with relief from psychological stress and the overall burden of care noted. This study noted that socio-demographic disadvantages may hinder access to supports. The results indicated that well educated urban caregivers received more respite care than less educated rural caregivers. Kim & Chung, (2016) explored the impact of caregiver's attitude to stress and the psychological strategies used by carers to reduce caregiver burden. They reported that a problem-solving coping strategy helped to reduce stress and burden.

The available literature suggests that due to ageing processes and increased care needs, both caregivers and the person with an intellectual disability require support (Dillenger & McKerr, 2010; Schoufour et al., 2014). Vulnerable socio-economic groups have less supports and different coping strategies which may result in higher experiences of burden in this population (Al-Krenawi et al., 2011). The literature did not identify any Irish research examining burden among this population. This is despite an ageing population and policy prioritization of social inclusion and supporting people with intellectual disability within their family home against a backdrop of severely limited resources. This study seeks to address this lacuna.

Research Aims / Questions

The aim of this study is to measure the level of caregiver burden among older carers of adults with intellectual disabilities and to analyse the effect of socio-demographic factors upon experiences of caregiver burden. The study seeks to identify;

1. Do older primary caregivers of adults with intellectual disabilities experience caregiver burden?
2. What is the level of caregiver burden experienced by older caregivers of adults with intellectual disabilities?

3. Are experiences of caregiver burden influenced by caregiver's sex, age, educational level, employment history, marital status and finally the types of social support available to the caregiver?

Materials and Methods

A quantitative descriptive design involving a survey questionnaire was adopted. Data were collected in a single time-period in June 2018. A sample of primary older caregivers were invited to complete a self-administered postal questionnaire which comprised of the Zarit Burden interview ZBI (Zarit & Zarit,1983; 1990), and a sociodemographic questionnaire. These questionnaires were given to a gatekeeper of the organisation who arranged for the survey packs to be posted to potential participants. Ethical approval was sought and gained from both the university and the disability services' ethics committees.

Sample

This study involved contacting a purposive sample of 185 caregivers aged 55 years or over. Access to the sample was granted through contacting a gatekeeper within a large voluntary disability organisation in southern Ireland. The sample were family caregivers of adults with a diagnosed intellectual disability over 18 years of age who at the time of the study, were living in the family home. All those with an intellectual disability were included irrespective of their level of ability. 30 caregivers responded which represented a response rate of 16%. Whilst this sample is small it creates knowledge on a topic that there is currently none thus adding to the body of literature.

Measures

Zarit et al., (1980) describes the concept of caregiver burden as how caregivers perceive their emotional, physical, social health and financial status as a consequence of caring for their relative. Therefore, caregiver burden is an individual and subjective experience. Some caregivers may experience extreme burden while others in similar circumstances may not. Burden was explored using a measurement tool, entitled the "Burden Interview" ZBI (Zarit and

Zarit., 1983; 1990) which has been widely used amongst different types of carers (Mapi research trust, 2017). The ZBI is a structured self-report questionnaire which has 22 questions which address the multi-factorial aspects of caregiver burden including the physical, psychological, social, financial and relationship difficulties which caregivers may experience. The ZBI is a one-page document with clear and uncomplicated language which is easy to complete. The scale has a 5-point rating from experiences of “never” to “nearly always”. The ZBI interprets the scores with a score of 0-21 indicating little or no burden, 22-40 indicating mild to moderate burden, 41-60 indicating moderate to severe burden and finally 61-88 indicating severe burden. Reflective of a Likert scale higher scores indicate higher burden experienced by participants while lower burden scores indicate less burden.

The validity and reliability of the research tool was investigated by Braun et al., (2010) who recommended the ZBI as a valid and reliable tool to assess caregiver burden. Furthermore, Ko et al., (2008) reported good internal consistency and test-retest reliability. The literature identified several studies which adopted the ZBI when investigating caregivers of adults with intellectual disabilities (Bhatia et al., 2015; Grey et al., 2017; Piazza et al., 2014).

The socio-demographic questionnaire identified caregivers age, sex, marital status, education level, employment status and information relating to supports

Data analysis

The completed survey questionnaires were coded and entered in the IBM SPSS Statistics version 24. Descriptive statistics were used to describe the demographic characteristics of the caregivers. Caregiver burden were described using the mean (SD), median (interquartile range, IQR) and minimum and maximum.

Univariate analyses were performed to investigate the relationships between variables including the socio-demographic characteristics of the respondents, supports availed of and caregiver burden separately.

Results

Thirty caregivers (16%) completed the questionnaires, of whom the majority were female (77%), aged 65 years or older (70%) and had been educated to at least secondary level (77%). Forty percent had a third level education. Less than half of the respondents were married (47%). Half of the respondents received government support or were retired while the other half were in paid employment (27%) or self-employed (23%)(see Table 1).

The supports availed of by the respondents are presented in Table 2. Several of the respondents detailed more than one supports which they availed of. Most respondents (73%) had family support. Over one quarter (27%) received respite care.

Caregiver burden scores were calculated for the 30 respondents. The scores on the ZBI are summarised in Table 3. The mean (Standard deviation) was 32.07 (19.72) on the ZBI. The median (IQR) was 28.5 (21.0 to 42.5), indicating that, in general, respondents had mild to moderate level of burden. When categorised (see Table 4), most respondents (56%) were in the mild to moderate burden group. Equal numbers (17%) were in the little or no burden group and the moderate to severe burden group. Three (10%) respondents were in the severe burden group. The distribution of scores was positively skewed, with most respondents having relatively low scores and some having higher scores than the main group of respondents. The possible range of scores in the ZBI were from 0-88. The minimum score observed among the respondents was 2 while the maximum score was 78.

The results of the statistical tests performed to investigate the relationships between the demographic variables, supports availed of and caregiver burden of older primary caregivers are summarised in Table 5.

The researcher, due to the small number of respondents in the 85+ category combined these with the 75-84 age group for the statistical analysis. Analysis could not be undertaken on the relationship between caregiver burden and paid support and support from friends due to the small numbers who received these supports. The demographic variables investigated were:

age group, sex, marital status, education level and employment status**.** There was a statistically significant difference in the distribution of caregiver burden scores between the age groups (p=0.010). Pairwise comparisons identified a difference between the 65-74 years age group and the 75+ age group only (adjusted p=0.008), with those in the 65-74 years group having significantly higher burden.

Data analysis identified that caregiver's sex (p=0.886), marital status (p=0.622), education level (p=0.890) and employment status (p=0.800) were not significantly associated with caregiver burden. Receiving respite care (p=0.298) and having family support (p=0.368) were also identified as not significantly associated with caregiver burden in this study.

Discussion

The majority of caregivers were female (73%) and their age range was evenly distributed between the ages of 55-85 years. This is consistent with previous research which identified a high percentage of samples were female (Bhatia et al., 2015; Chou et al., 2008; 2011; Grey et al., 2017; Llewellyn et al., 2010).

40% of the sample reported having a third level education which contrasts with previous studies which reported a low percentage of people with third level qualifications(Al Krenawi et al., 2011; Chou et al., 2010; 2011; Lin et al., 2014). However, Piazza et al., (2014) also reported that 43% of carers had attained a third level education.

50% of the carers in this study were in receipt of governmental support or were retired, which is similar to the findings of Chou et al, (2011). This is indicative of the sample population being studied namely older caregivers. In Ireland, 66 years is retirement age and as approximately 70% were above or at this threshold, it was expected that a large proportion of this population would not be employed. Comparisons with the existing literature is limited as often the samples were female only (Chou et al., 2010; Kim and Chung, 2016) or the samples included carers of all ages who support a family member with an intellectual disability. A female only sample may

differ as traditionally caregiving is a female role and it would be expected that a large percentage would not be employed.

Respite care as a support service was accessed by over a quarter (26.7%) of carers, the majority (73%) of whom reported that family members were their main support in caring for an adult with an intellectual disability. This finding is consistent with Chou et al., (2011) whose participants were more likely to use family support. The fact that so many carers are reliant on family support may suggests that caregiver burden may increase in the future, due to changes in family dynamics in Ireland as identified by Brennan et al., (2017). Due to smaller family sizes and an increase in one parent families, caregivers have fewer family members with whom to share the burden.

This study identified that caregivers of adults with intellectual disabilities do experience burden. Caregiver burden scores indicated that in general respondents had mild to moderate burden on the ZBI scale, consistent with the findings of Bhatia et al., (2015). However, this study differs, as it identifies a positive skew in distribution with most respondents having low scores on the ZBI. Bhatia et al., (2015) identifying that the distribution was negatively skewed with relatively high scores on the burden scale.

A statistically significant difference in the distribution of caregiver burden scores between the age groups was identified in this study. Namely that caregivers in the 65-74 age bracket have significantly higher burden levels than caregivers aged 75+ only. The association between positive caregiver experiences and increased caregiver age is evidenced in previous literature. Chou et al., (2010) reported that younger caregivers reported a higher level of burden. Similarly, Grey et al., (2017) reported that caregiver age was the only variable significantly independently associated with caregiver burden, suggesting older age was associated with lower levels of burden, a finding also identified in this study. Grey et al., (2017) found that older caregivers' experienced greater satisfaction with available supports and adopted active coping mechanisms which were associated with lower levels of burden and better health outcomes. The literature suggests several reasons why younger caregivers are at higher risk of caregiver

burden with Lewellyn et al., (2010) suggesting that older caregivers are more accepting of situations than their younger counterparts which may influence stress and burden.

This present study identifies that perhaps changes in the family dynamics and supports available to ageing primary carers may influence burden levels. The retiring of a spouse may lead to the sharing of caring duties or increased age may lead to freedom from financial pressures such as mortgages or the stress of juggling caring with fulltime employment. Perhaps older caregivers have over time adapted and honed their caregiving skills with age. Grant et al., (2003) suggests that caregivers over time develop an expertise or "art and craft" of caregiving. These factors may have a positive effect on reducing caregiver burden. One family caregiver's who contacted the researcher offered some qualitative commentary which may partially explain this finding. She explained that her caring skills have been refined over the years. She enjoys the company of her son and takes great pride in her caregiving skills.

Limitations

The sample size in this study was small. This was likely related to the sampling process. Caregiver burden is an emotive issue and this research study may have been the first time some of these caregivers were asked about their experiences which may have affected the response rate. The research findings identified mild to moderate burden which was positively skewed as caregivers who responded documented a high level of familial support. It could be surmised that, perhaps those caregivers who did not respond were those experiencing higher levels of burden and may not have had the time or motivation to complete the survey.

In addition, the sample was restricted to one geographical area in Ireland and one service provider. Consequently, the ability to generalise the research findings to other populations is limited and variables such as the individual characteristics of the adult with intellectual disabilities the level of intellectual disabilities or presence of behavioural issues and their impact upon caregiver burden were not considered. A majority of caregivers who participated in this study, had a third level education. . This study presents us with two possibilities, the first is that the sample is more representative of primary caregiver with a third level education

or secondly that caregivers in this age bracket who have a third level education were more inclined to respond to this survey.

The present study creates knowledge on a topic where there was previously none which could potentially be expanded upon to plan and guide future research and practice. This may contribute to the development of future research and services which are based upon the individuals' needs and experiences.

Conclusion

This study contributes to our understanding of caregiving experiences within an Irish context. Those who responded to the survey generally experienced a mild to moderate level of burden. Further analysis indicated there was a statistically significant difference in caregiver burden scores between the age groups with younger caregivers experiencing higher levels of burden. In a climate of finite resources, the identification of those caregivers who are most burdened may facilitate the provision of timely supports not only for the person with intellectual disabilities but also their primary caregiver. The author hopes that this study will draw attention to the lack of Irish research in this area, but also pave the way for future research which could build upon its findings. Future research can be informed by this research study which identified that several caregivers who responded to the survey either contacted the researcher or her research supervisor to talk, for support or indeed wrote additional information on the survey questionnaire. This may signify that a qualitative study with a smaller sample would better suit exploring burden among this sample or the questionnaire could be administered over the phone. Ageing caregivers will challenge not only society and intellectual disability services but also family dynamics. Policy and services need to identify those who are most burdened and facilitate the provision of timely supports for not only the person with an intellectual disability but also their ageing caregivers.

Tables

Table 1. Socio-demographic characteristics of respondents, n=30

	n (%)
Age group (years)	
55-64	9 (30.0)
65-74	10 (33.3)
75-84	8 (26.7)
85+	3 (10.0)
Sex	
Male	7 (23.3)
Female	23 (76.7)
Marital status	
Single	6 (20.0)
Married	14 (46.7)
Widowed	10 (33.3)
Education level	
Did not finish secondary school	7 (23.3)
Leaving certificate	11 (36.7)
Third level education	12 (40.0)
Employment status	
Paid employment	8 (26.7)
Self-employed	7 (23.3)
Government support / retired	15 (50.0)

Table 2. Supports availed of

	n (%)
Family support	22 (73.3)
Respite care	8 (26.7)
Paid support	4 (13.3)
Support from friends	4 (13.3)
Other	9 (30.0)

Table 3. Summary statistics for scores on the caregiver burden scale

Summary statistics				
n	possible range	observed range	mean(SD)	median(IQR)
30	0 to 88	2 to 78	32.07 (19.72)	28.5 (21.0 to 42.5)

*A higher score reflects greater caregiver burden

Table 4. Caregiver burden group, n=30

	n (%)
Little or no burden	5 (16.7)
Mild to moderate burden	17 (56.7)
Moderate to severe burden	5 (16.7)
Severe burden	3 (10.0)

Table 5. Results of Univariate analyses investigating factors associated with caregiver burden.

	median (IQR)	p-value
Age group (years)		0.010[1,3]
55-64	33 (14 to 41)	
65-74	40.5 (28 to 62.5)	
75+	21 (17 to 26)	
Sex		0.886[2]
Male	26 (21 to 40)	
Female	29 (21 to 44)	
Marital status		0.622[1]
Single	37.5 (17.8 to 62)	
Married	29.5 (21 to 37.8)	
Widowed	24.5 (13.8 to 47.3)	
Education level		0.890[1]
Did not finish secondary school	28 (21 to 44)	
Leaving certificate	23 (21 to 47)	
Third level education	31.5 (8 to 41.5)	
Employment status		0.800[1]
Paid employment	33.5 (11.3 to 40.5)	
Self-employed	26 (17 to 40)	
Government support / retired	25 (21 to 48)	
In receipt of respite care		0.298[2]
No	27 (20 to 40.5)	
Yes	34.5 (22.3 to 55.3)	
Family support		0.368[2]
No	38.5 (18 to 68)	
Yes	27 (21 to 37.8)	

[1]from Kruskal-Wallis test

[2]from Mann-Whitney U test

[3]pairwise comparisons revealed a statistically significant difference between the 65-74 years age group and the 75+ years age group (adjusted p=0.008)

References

Al-Krenawi, A., Graham, J.R., & Al Gharaibeh, F. (2011). The impact of intellectual disability, caregiver burden, family functioning, marital quality and sense of coherence. *Disability and Society*, 26(2), 139-150. https://doi.org/10.1080/09687599.2011.543861

Bhatia, M.S., Srivastava, S., Gautam, P., Saha, R., & Kaur, J. (2015). Burden Assessment, Psychiatric Morbidity, and their Correlates in Caregivers of Patients with Intellectual Disabilities. *East Asian Arch Psychiatry,* 25, 159-163. https://search.proquest.com/docview/1766617145?accountid=14504

Brennan, D., Murphy, R., McCallion, P., & McCarron, M. (2017). "What's going to happen when we're gone?" Family caregiving capacity for older people with an intellectual disability in Ireland. *Journal of Applied Research in Intellectual Disabilities*, 32(2), 226-235. https://doi.org/10.1111/jar.12379

Braun, M., Scholz, U., Hornung, R., & Martin, M. (2010). The Burden of Spousal Caregiving: A Preliminary evaluation of the German version of the Zarit Burden Interview. *Aging and mental Health,* 14(2), 159-167. https://doi.org/10.1080/13607860802459781

Chou, Y.C., Tzou, P.I., Pu, C.Y., Kroger, T., & Lee, W.L. (2008). Respite care as a community care service: Factors associated with the effects on family carers of adults with intellectual disability in Taiwan. *Journal of Intellectual & Developmental disability,* 33(1), 12-21. https://doi:10.1080/13668250701832500

Chou, Y.C., Pu, C.Y., Fu., L.Y., & Kroger, T. (2010). Depressive symptoms in older female carers of adults with intellectual disabilities. *Journal of Intellectual Disability Research, 54*(12), 1031-1044. https://doi:10.1111/j.1365-2788.2010.01332.x

Chou, Y.C., Fu, L.Y., Lin, L.C., & Lee, Y.C. (2011). Predictors of subjective and objective caregiving burden in older female caregivers of adults with intellectual disabilities. *International Psychogeriatrics*, 23(4), 562-572. https://doi.org/10.1017/S1041610210001225

Dillenger, K., & McKerr, L. (2010). “How long are we able to go on?” Issues faced by older family caregivers of adults with disabilities. *British Journal of Learning Disabilities,* 39, 29-38. https://doi.org/10.1111/j.1468-3156.2010.00613.x

Government of Ireland, (2005). The Disability Act. http://www.irishstatutebook.ie/eli/2005/act/14/enacted/en/print.html (accessed 22/08/2018)

Grant, G., Nolan, M. & Keady, J. (2003). Supporting families over the life course: Mapping temporality. *Journal of Intellectual Disability Support,* 47(4-5), 342-351. https://doi-org.ucc.idm.oclc.org/10.1046/j.1365-2788.2003.00495.x

Inclusion Ireland, (2013) Implementing the National Disability Strategy. Inclusion Ireland Position Paper. www.inclusionireland.ie/sites/default/files/documents/Submissions/position_paper_on_implementing_the_nds_final_version_15_jan_2013_sk.pdf (accessed 23/07/2018)

Janicki, M.P., Zendell, A., & DeHaven, K. (2010). Coping with Dementia and older families of adults with Down Syndrome. *Dementia,* 9(3), 391-407. https://doi.org/10.1177/1471301210375338

Kim, G., & Chung, S. (2016) .Elderly Mothers of Adult Children with Intellectual Disabilities: An Exploration of a Stress Process Model for Caregiving Satisfaction. *Journal of Applied Research in Intellectual Disabilities*, 29, 160-171. https://doi.org/10.1111/jar.12166

Ko, K.T., Yip, P.K., Liu, S.I., & Huang, C.R. (2008). Chinese version of the Zarit Caregiver Burden Interview. A validation interview. *American Journal of Geriatric Psychiatry,* 16(6), 513-518. https://search.proquest.com/docview/195993440?accountid=14504

Lafferty, A., O' Sullivan, D., O' Mahoney, P., Taggart, L., & van Bavel, B. (2016). Family carers experiences of caring for a person with intellectual disability. Final report. National Disability Authority, Dublin http://nda.ie/nda-files/Family-Carers'-Experiences-of-Caring-for-a-Person-with-Intellectual-Disability.pdf (accessed on 23/07/2018)

Lin, L.P., Hsu, S.W., Kuo, M.T., Wu, J.L., Chu, C., & Lin, J.D. (2014). Onset aging conditions of adults with an intellectual disability associated with primary caregiver depression. *Research in Developmental Disabilities,* 35, 632-638. https://doi.org/10.1016/j.ridd.2013.12.013

Llewellyn, G., McConnell, D., Gething, L., Cant, R., & Kendig, R. (2010). Health status and coping strategies among older parent-carers of adults with intellectual disabilities in an Australian sample. *Research in Development Disabilities,* 31(6), 1176-1186. https://doi.org/10.1016/j.ridd.2010.08.003

Magana, S., Li. H., Miranda, E., & Paradiso de Sayu, R. (2015). Improving health behaviours of Latino mothers of youths and adults with intellectual and developmental disabilities. *Journal of intellectual disability research,* 59(5), 397-410. https://doi.org/10.1111/jir.12139

Mapi Research Trust. (2017). *The ZBI Scaling and Scoring Version 5.0*. France, Mapi Research Trust.

McCarron, M. (2011.) *Growing older in Ireland with an Intellectual disability 2011: First results from the Intellectual Disability Supplement to the Irish Longitudinal study on ageing (IDS/TILDA)* Dublin, School of Nursing and Midwifery, Trinity College Dublin.

McConkey, R., Kelly, F., Craig, S., & Keogh, F. (2018). Irish persons with intellectual disability moving from family care to residential accommodation in a period of austerity. *Journal of applied research in intellectual disabilities,* 31(5), 833-839. https://doi.org/10.1111/jar.12439

McKensie, J., & McConkey, R. (2016) Caring for adults with Intellectual Disability: The perspectives of family carers in South Africa. *Journal of Applied Research in Intellectual Disabilities,* 29, 531-541. https://doi.org/10.1111/jar.12209

Nam, S.U., & Park, E.Y. (2017). Relationship between caregiving burden and depression in caregivers of individuals with Intellectual disabilities in Korea. *Journal of Mental Health,* 26(1), 50-56. DOI: 10.1080/09638237.2016.1276538

NIDD. (2017). http://www.hrb.ie/fileadmin/2._Plugin_related_files/Publications/2018_pubs/Disability/NIDD/NIDD_Annual_Report_2017.pdf (accessed 23/07/2018)

Piazza, V.E., Floyd, F.J., Mailick, M.S., & Greenberg, J.S. (2014). Coping and Psychological Health of Aging Parents of Adult Children with Development Disabilities. *American Journal on Intellectual and Development Disabilities,* 119(2), 186-198. https://search.proquest.com/docview/1513199949?accountid=14504

RTE.(2017) https://wwwrte.ie/news/primetime/2017/1207/925748-prime-time-carers-in-crisis/ (accessed 07/05/2019)

Schoufour, D., Evenhuis, H.M., & Echteld, M.A. (2014). The impact of frailty on care intensity in older adults with intellectual disabilities. *Research in Development Disabilities*, 35, 3455-3461. https://doi.org/10.1016/j.ridd.2014.08.006

The Irish Times (2016) Carers in Crisis: 'What will happen to Sinéad when we go? https://www.irishtimes.com/life-and-style/health-family/parenting/carers-in-crisis-what-will-happen-to-sinéad-when-we-go-1.2882069 (accessed 07/05/2019)

Zarit, S.H., Reever, K.E., & Bach-Peterson, J. (1980). Relatives of the impaired elderly. Correlates of feelings of burden. *The Gerontologist,* 20(6), 649-656. https://doi.org/10.1093/geront/20.6.649

Zarit, S.H. & Zarit, J.M. (1983; 1990). *The Burden Interview.* eprovide.mapi-trust.org (accessed on 7/12/2017)