

INTELLECTUAL DISABILITY, CARING AND ROLE REVERSAL

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Zoe has previously worked as a social care worker, and has experience of being a family carer in her personal life. She has also worked with groups such as Empowering People in Care and The National Parents and Siblings Association on various policy projects, and with the National Institute for Intellectual Disability (Trinity College Dublin) on various research projects related to disability, including an online archive of life stories of people with intellectual disabilities. Zoe has a particular interest in ensuring that research is inclusive, and made accessible to those groups who are the focus of the research.

Abstract

The current assumption is that people with disabilities are those in receipt of care, and that care is being provided by non-disabled family or friends. However, many services for people with intellectual disabilities are finding that those in receipt of their services are now in the position of providing care and support to their aging parents. This is a cause for concern for those services who may feel ill-prepared to support people with intellectual disabilities in this new role.

This purpose of this article is to introduce the concept of reciprocal care as it relates to intellectual disability and aged care. A short review of existing literature is presented, followed by the posing of a selection of questions for both disability service providers and those currently providing supports to Family Carers in Ireland. These questions do not have any obvious answers, and it is hoped that this paper will stimulate discussion of a topic which has only recently begun to emerge as a significant concern.

Keywords: Intellectual Disability, Family Care, Family Caregiving, Reciprocal Care, Family Support.

Introduction

According to Census 2011, there are 187,000 Family Carers in Ireland (Central Statistics Office, 2012). These are individuals who have answered “yes” to the question “Do you provide regular unpaid personal help for a friend or family member, with a long term illness, health problem or disability?” (Central Statistics Office, 2011; Q22). This in itself paints an unrealistically simplistic picture of the relationship between those requiring extra support, care and assistance, and those who provide it. This is particularly so where there is intellectual disability in the family.

The purpose of this discussion paper is to begin to unpick some of the issues which come to the fore when thinking about the mutuality of care (Williams &

Robinson, 2001) that an increasing number of families are experiencing as our population ages. It is not sufficient to state that people with intellectual disabilities only receive care. There are an increasing number of instances where aging parents are coming to rely on the children for whom they previously acted as Family Carer for the personal care, company and practical assistance that is the hallmark of being a Family Carer.

This paper discusses the demographic changes – which have occurred for many different reasons – contributing to this changing care landscape across the intellectual disability sector in Ireland in the 21st century. A search of the literature, and discussion with those providing support to families where there is an intellectual disability, highlights an increase in the number of older people with intellectual disability who are supporting and providing care to a parent. What then are some of the challenges facing health and social care services and families themselves as people with intellectual disabilities move from being “cared for” to providing the support which all Family Carers provide?

Changing Demographics

Aging society

The age profile of Ireland is changing significantly. Between 1926 and 2011, male life expectancy increased by 20.9 years (36.4%), while female life expectancy increased by 24.8 years (42.8%) (Central Statistics Office, 2015). In addition, the life expectancy of people with intellectual disability has increased significantly. Of those with intellectual disability, 12.4% are now over the age of 55, which represents a 60.3% increase in this age-group between 1996 (when these statistics were first collected) and 2010 (McCarron et al., 2011:2). Better access to health care, a reduction in the number of people living in institutions, and general increases in life expectancy in Ireland are generally accepted to be contributing factors in this increase (McCarron et al., 2011:2;). In the next ten to fifteen years, it is estimated that the largest age cohort in the intellectual disability community will be the over-50 age-group (McCarron et al., 2011:2). While an aging population with intellectual disability is not indicative in itself of an increase in their caring responsibilities, it becomes more likely that some individuals with intellectual disabilities, living at home, will experience their parents aging and needing care and assistance with daily tasks.

Increase in Carer Numbers

The number of people identifying in some way as a Family Carer has increased steadily in the last number of years. In Census 2002, 148,754 people indicated they were providing unpaid care. By 2006, the total number of carers aged 15 and over was 160,917, growing to 182,884 in 2011. This represents a 13.7% increase over that last five-year period alone (Care Alliance Ireland, 2015:3).

Decrease in Numbers in Residential Accommodation

The last 20 years has seen a marked decrease in institutional living for adults with intellectual disabilities. There were 27,691 people registered as having an intellectual disability in Ireland in 2013, whether mild, moderate, severe or profound (Kelly & O'Donoghue, 2014:14). Sixty-seven per cent of those registered on the National Intellectual Disability Database (NIDD) (18,498 individuals) lived at home with parents, siblings, relatives or foster parents in 2013. This has implications for service delivery. Due to the Value for Money Review (Dept. of Health, 2012) and the National Disability Strategy and its attendant Implementation Plan (National Disability Strategy Implementation Group, 2013), there is an increased focus on people with intellectual disabilities living at home and in the community – in contrast to the large-scale residential centres which have characterised Irish service delivery for people with intellectual disability for hundreds of years. There was an increase of 78% between 1996 and 2013 in the number of people with intellectual disability living full-time in community group homes, while the numbers accommodated in residential centres decreased by 36% in the same period (Kelly & O'Donoghue, 2014:19).

Implications of these changes

While, examined in isolation, an increase in life expectancy and a reduction in the number of individuals in long-term institutional residential settings do not directly have an impact on the likelihood of people with intellectual disabilities providing care for their families, it is vital to view all these elements together. While the incidence of people with intellectual disabilities becoming full-time Family Carers for their parents is low, it is becoming more of a concern for service providers. The majority of people with intellectual disability are in receipt of some level of service support from a designated provider – 27,318 people, representing 98.7% of the total population registered on the NIDD (Kelly & O'Donoghue, 2014:20). Many of these services are now finding that the individuals they support are themselves providing care to aging parents, as they continue to live at home. For example, in the past 12 months, Care Alliance Ireland has become aware of two large service providers for people with intellectual disability seeing a marked increase in this phenomenon.

Literature Review

In reviewing the literature, it is clear that there has not been sufficient work undertaken in this area to make any conclusive statements regarding the prevalence or impact of people with intellectual disabilities being Family Carers themselves, particularly in Ireland. A number of separate member organisations of Care Alliance Ireland have spoken about a noticeable increase in the number of individuals that they support themselves providing care, companionship and support to aging parents. However, little information is readily available

to disability services in attempting to understand how best to support a person with an intellectual disability in their newly developed caring role. As discussed above, however, it is not as simple as the care responsibilities being transferred from one individual to another – taking an holistic view of such situations necessitates an understanding of the mutuality of care.

Mutual care

Families are the rudimentary building blocks of society, and are the primary units to which we feel most connected throughout our lives. Historically, the notion of family and intellectual disability is contentious, as the paternalistic and moralistic outlook of the decades leading up to the late 20th and early 21st centuries led to many families being separated, and people with intellectual disabilities being housed in large-scale institutions, with very little contact with their families post-admission (Atkinson, Jackson, & Walmsley, 1997; Hamilton & Atkinson, 2009; Hughes, Brennan, & Kelly, 2010). In addition, people with intellectual disabilities are often cast in the role of “dependent”, regardless of ability and situation (Goodley, 2001). Some parents of people with intellectual disabilities, particularly older parents, can be reluctant to acknowledge that their children are indeed adults with abilities, rights and responsibilities, and continue exerting parental control long past the point where it has become inappropriate (Williams & Robinson, 2001:61).

However, as parents age, very often the line between “caring” and “being cared for” becomes blurred, for all those involved. It can be difficult to see when the balance tips, as aging is a gradual process, with everyone involved adapting as the process continues (Foundation for People with Learning Disabilities, 2010). This is in contrast to many policies (Department of Health, 2012; National Disability Strategy Implementation Group, 2013) which see a clear line between the “carer” and the “disabled person”. Indeed, interdependence is a key feature of all relationships, with Keith (1992:172) pointing out that there is no “uncomplicated line” between dependence and independence.

Some research has highlighted this interdependence, with examples of people with intellectual disabilities being both cared for and a carer – Walmsley (1996) discovered that people with intellectual disabilities often spoke about situations of mutual care, discussing parents who were becoming increasingly dependent on them, although the parents often retained control over certain aspects of their lives (such as financial matters or romantic and sexual relationships).

According to the limited research available, the types of care provided by people with intellectual disabilities, as with all Family Carers, ranges from companionship to significant daily care tasks such as bathing, cooking, and so on (Foundation for People with Learning Disabilities, 2010; Williams & Robinson, 2001). Many people with intellectual disabilities have experience of raising children (their own children or their siblings) and working in the

care field, either voluntarily or in a paid capacity (Hughes et al., 2010). It is inaccurate to continue with the belief that people with intellectual disabilities are exclusively consumers of care rather than providers of care.

Carers Needs Assessments

Carers Needs Assessments have been in place in the United Kingdom since 1995, with all Family Carers having a right to an assessment of their needs (Carers (Recognition and Services) Act 1995). Work is currently underway in Ireland for a similar intervention to be made available (initially assessing the needs of carers of older people, and perhaps in time extending to other care assessments) to enable all Family Carers to have their needs (in relation to providing care for their loved one) assessed. This is a response to the successful articulation of the value carer assessments can have, and the significant research which details the challenges Family Carers find themselves facing (Care Alliance Ireland, 2015; O'Sullivan, 2008; Stokes, 2010; The Carers Association of Ireland & Royal College of Psychiatrists, 2009). A number of studies looking at the impact of Carers Assessments in the UK have highlighted the existence of mutual care, and the need to see people with intellectual disabilities as carers, with the right to an assessment of their own needs as Family Carers, rather than simply the person "cared for".

Williams & Robinson (2001) undertook qualitative interviews with 51 families where intellectual disabilities were identified and who had undertaken a Carers Needs Assessment – the focus of the interview was primarily the parent of an adult child with an intellectual disability. Within the interviews, it became clear that the parents, the traditional "Family Carers", were in some cases relying on their adult children with intellectual disabilities to provide care and support, in most cases without acknowledging them as being part of a situation of mutual care.

These scenarios involving mutual care can often be missed by health and social care professionals, only coming to light during a crisis, at which point appropriate supports may not be available and an inappropriate reaction (due to the lack of available supports) is prompted from disability and generic aged care services (Foundation for People with Learning Disabilities, 2010).

Challenges for Services and Supports

Having outlined some of the background and existing literature on the subject, it can be asked: what are the practical implications for service providers in Ireland as instances of mutual care and people with intellectual disability acting as carers increase? What are the challenges faced by people with intellectual disabilities who are Family Carers? How can both of these issues be overcome?

Challenging the Dominant Discourse

As discussed above, it is relatively recently that people with intellectual disabilities have been seen as individuals with rights and responsibilities, the same as all other individuals. The dominant discourse in Ireland has primarily hinged upon people with intellectual disability needing care, rather than being able to be providers of care (Hamilton & Atkinson, 2009; Hughes, 2014; Hughes et al., 2010; Sweeney, 2010). Debates, for example, as to the ability of people with intellectual disability to be parents and to raise families are frequent, tying in to the outdated capacity legislation which frames the issue.

Many parents remain highly influential in their adult children's lives, in particular where their child has an intellectual disability. Williams & Robinson (2001) found in their study that although it was clear that adult children with intellectual disabilities were providing varying degrees of care and support to their aging parents, neither party recognised this as an example of mutual care, with parents identifying themselves as the carers, and their child as the recipient of that care.

However, in order for parents to feel safe so identifying their children with intellectual disabilities as a carer, it is vital that there is a support net for adults with intellectual disabilities who are providing care to their parents in this way.

It must be pointed out that although the phenomenon of older adults with intellectual disabilities living long enough to provide this type of care to aging parents is relatively recent, it is clear from multiple examples that people with intellectual disabilities are very capable of supporting family members throughout their lifespan. Numerous oral history projects involving people with intellectual disabilities have highlighted the skills that people with intellectual disability have displayed in this area (Atkinson et al., 1997; Hamilton & Atkinson, 2009; Hughes et al., 2010; Walmsley, 1993, 1996). Yet, the dominant discourse is still that people with intellectual disabilities are the ones who will need care and support throughout their lives. They are seen as consumers of care, not as providers. In order for those assisting both Family Carers and people with intellectual disability to provide the support needed in these situations, society must understand that people with intellectual disabilities have huge capacity to provide care at different levels, especially if given the correct support. This change in discourse will necessitate people with intellectual disabilities being included as Family Carers in assessments, medical visits, etc., as appropriate.

Accessible Supports

In providing supports to people with intellectual disabilities and literacy difficulties, there are numerous guidelines available which include the use of picture symbols, plain language and audio and video presentations (Accessible Information Working Group, 2009; National Health Service (UK), 2015). Intellectual disability services in Ireland are increasingly making

use of these guidelines to ensure their information is equally accessible to all those who use and work in their services. However, while many leaflets and informational products for Family Carers use plain language, there is some way to go to ensure the same level of accessibility. This applies equally to information from independent Family Carer support services and State support services. An increasing reliance on web-based supports – while heightening accessibility in a general sense, in particular for socially isolated carers who have a web connection – is not appropriate for all types of carer, including people with literacy problems and older carers who may not be as comfortable using technology as their younger peers.

In many instances, people with intellectual disabilities can be isolated due to the perceived dangers which their families wish to protect them from. As a result, people with intellectual disabilities who find themselves increasingly providing care and support to their parents may not know where to turn for support (Williams & Robinson, 2001:61) – or indeed may be discouraged from doing so by family members afraid of the family being separated, and of the stigma which persists in certain sectors such as mental health.

Intellectual Disability Services and Family Carer Support Services Working Together

Although great strides have been made in attempting to ensure that different sectors and government departments communicate with each other and work together (Department of Health, 2012; National Disability Strategy Implementation Group, 2013), there is little evidence that those services providing supports to people with intellectual disabilities are collaborating sufficiently with Family Carer support organisations on this topic. This needs to change if people with intellectual disabilities who are Family Carers are to successfully continue in their role – in particular where care situations evolve into a higher level of intensity and complexity.

Implications for Social Workers

Social workers are often a key point of contact between people with intellectual disabilities and their families- and are therefore likely to see evidence of these changing roles and their attendant challenges first-hand. The social worker has a responsibility to challenge the dominant discourse within society (as outlined above) and to challenge the perceptions of the aging parents- in a sensitive and appropriate manner. This responsibility, however, should not begin at the point of crisis, nor at the point that it becomes clear that these traditional roles within the family are being reversed. Increasing the understanding of family and friends who may have erroneous and lower expectations of the abilities of their loved ones who have intellectual disabilities is a key role which social workers should be playing at every life stage and at every intervention and support level. Facilitating people with intellectual disabilities to access the workforce in a meaningful way, which builds their existing

skills and introduces new knowledge and skills is critical work which social workers must be involved in to enable young and aging adults with intellectual disabilities to be well placed to be acknowledged as having the capacity to become Family Carers should the need arise.

Work must also take place, sensitively, with the aging parents who are now in need of increased care and support from their children. As outlined earlier, the increase in life expectancy and the process of de-institutionalisation has combined to create a cohort of maturing people with intellectual disabilities who may be receiving “mixed messages”- the service and those involved in their daily support are increasingly encouraging independence, yet their parents may have been told that their children would never be independent, and would always need “looking after”. The navigation of these issues, in order to ensure all parties are heard and have the correct supports in place, is a key task for social workers, and will necessitate good interagency collaboration and some innovative thinking into the future. The instances of the type of “role reversal” discussed here will not diminish over time, but will become an even bigger issue for all those working in the fields of aged care, disabilities and family support.

Conclusion

While not yet recognised as a significant issue in Ireland, it has become clear that there are many people with intellectual disabilities who have found themselves in the role of Family Carer, undertaking the daily tasks, such as cooking, personal assistance and companionship, which traditionally were the responsibility of their own Family Carer. While the research on the topic is minimal, particularly from an Irish perspective, anecdotal evidence from a number of intellectual disability support services across the country indicates that it is a growing issue, and one which those services may feel ill-equipped to respond to adequately at the current time.

It is clear that in order to fully understand the challenges facing people with intellectual disabilities who are themselves Family Carers, both intellectual disability services and Family Carer support services must acknowledge this role reversal and respond with suitably tailored levels of support for both parties. Until the dominant discourse is changed, and the notion that people with intellectual disabilities are exclusively consumers of family care rather than also, in some situations, being providers of that care, these families will continue to fall between two stools and will not receive the supports that all the parties involved need in order to continue to live in the community, in the family home.

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