

Mutual caring and learning disabilities

The lived experiences of mutual carers
and the role of service providers

Dr Angharad John

Angharad.john@hotmail.com



Swansea University
Prifysgol Abertawe

Workshop content

- ▶ Introductions
- ▶ We will think about the roles and identities of people with learning disabilities (LD)
- ▶ Messages from research (previous research and my PhD findings)
- ▶ Putting these messages into practice

Some workshop aims/rules...

- ▶ Aim for the workshop to be interactive
- ▶ We are advocates for people with LD
- ▶ Confidentiality

**Ben is 31 and has learning disabilities.
He lives at home with his mum.**



What do you think could be Ben and his mother's roles within the family home?

How might Ben be treated or perceived by family members?

How might policy and practice perceive Ben?

How might society view Ben?

Ben is a carer for his 70 year old mother who has dementia. His mother also has had a stroke and is in a wheelchair.



“I am happy doing it at the moment but I would rather someone else to come in and do things like washing her down, changing her and things because it’s not a man’s job to do that see.... I’d like to go on a computer course and do another course to write and learn things like art and meet up with friends and mates and go out with them but you can’t.... Loads of people make fun of me as well. They say I’m “Mammy’s boy”. I starts to cry then, another issue then, I’m self-harming myself”

What are your experiences?

- ▶ Have you ever worked with a carer with learning disabilities?
- ▶ To what extent do you think policy and practice meets the needs of carers with learning disabilities?
- ▶ What might be the barriers (if any) to carers gaining support and recognition?
- ▶ Imagine you are Ben... What support would you want?

My research aim and question:

The research explored the act of caregiving between two individuals who provide reciprocal and mutual care to one another

Research aim: To gain a better understanding of the lived experiences of individuals within mutual caring relationships that include people with LD

Research question: From the perspectives of mutual carers and their service providers, what is it like to experience being in a mutual caring relationship where at least one person has LD?

Mutual care: Definition

“Over the years, as family carers start needing more support themselves, the families have often developed routines and ways of coping that mean that both the older person and the person with a learning disability are looking after each other. This is known as mutual caring”

(Magrill, 2010b, p.2)

- ▶ Definition illustrates interdependencies
- ▶ Practical care more easily recognised than emotional care
- ▶ Roles change slowly over time (Magrill, 2010) or happen at more urgent pace due to rapid change (Baker et al. 2012)

Terminologies: mutual care, reciprocity and interdependence

- ▶ The terms are closely aligned - define providing and receiving care
- ▶ Reciprocity is the response where each person contributes to the relationship, exchanging emotions or services
- ▶ Interdependency - both individuals are dependent upon the exchanging of emotions or services
- ▶ Mutuality involves the empathy, commitment, connection and togetherness of individuals

(Alexander, 2013; Baker-Ohler and Holba, 2009; Walmsley, 1993)

Based on the meanings of these terms, this research explored reciprocity between two individuals (what is contributed or exchanged) within relationships where there is mutuality (such as commitment and responsibility)

Why the need for this research?

- ▶ Research gap (Williams, Marriott & Townsley, 2008)
- ▶ Recognition and acknowledgment of mutual caring in research, policy and practice is scarce (Gant, 2000; Gates & Atherton, 2007; Henderson & Forbat, 2002; Magrill, 2010; Parker & Clarke, 2002; Williams et al., 2008; Williams, 2013)
- ▶ Individuals with LD seen as dependent upon care
- ▶ The literature highlights the need for further exploration into the lives of carers who are in a range of mutual caring relationships.
- ▶ The challenges that carers with LD face
- ▶ Ageing population - more people with LD living longer with older frail parents who need support themselves.

Methods

- ▶ Semi structured interviews with 51 mutual carers (43 with LD; 8 without LD) and 32 service providers.
- ▶ Service providers and mutual carers known to one another. Interviews conducted on individual basis. Rationale for semi-structured interviews
- ▶ Role of gatekeepers and building a rapport
- ▶ Criteria for participation, snowball sampling
- ▶ Thematic analysis - coding, establishing themes, making connections and establishing meaning of themes
- ▶ Ethical considerations - informed consent, accessible materials, emotional wellbeing.

Critical reflections of the research methods

- ▶ The role of reflexivity - objective-free research not possible. Previous relationship with some of the participants
- ▶ Large amount of data, at times difficult to manage. The role of snowball sampling
- ▶ Gatekeeping - pleasant surprises but some issues
- ▶ Very emotive subject for some. Long interviews - sharing details for the first time
- ▶ Reflections of interviews undertaken in family home
- ▶ Reflections of interviews undertaken in day centre

Key findings

- ▶ The carer identity has various meanings for mutual carers in the context of their other identities, e.g. *“I am her daughter, it’s my job to care”, “It’s not a mans job”*
- ▶ Mutual caring can be both a positive and negative experience for mutual carers
- ▶ It is important that mutual carers plan for the future as this enables greater choice and control in decision making
- ▶ Individuals with LD are sometimes treated negatively by others and can be vulnerable to harm and exploitation and this impacts upon their caring role
- ▶ Mutual carers are not always recognised and supported within their role as carers by family members and service providers
- ▶ Being in receipt of care can impact upon independence, choice and control

Quotations from carers with LD

“My sister and brother they didn’t want to know about mum or anything so it was all on my shoulders to look after her and do everything for her... But um you know when you are a carer and you’ve got a disability it is very very hard... I got so tired in the end and I dunno I got really ... I couldn’t cope anymore. So I just went out and went to see some friends and that and I started doing stupid things like taking drugs” *(Daughter aged 59 who cared for mother who died aged 54)*

“Its about time people started sticking up for people with learning disabilities and started speaking up... It makes me so angry it makes me so sad... to think someone with a learning disability is ignored. That they’ve got to look after somebody on their own and nobody carers, nobody wants to care, nobody wants to listen, nobody wants to see” *(Daughter aged 59 who cared for mother who died aged 54)*

“I have told him (mum’s social worker) about it (being a carer) but I don’t know if he’s been writing it down and not taking any notice putting it in the dustbin cause some social workers do.. They are not helping me get the extra support. And they haven’t told me about the dementia either...”

Quotations from carers without LD

“I think she’ll probably go downhill a bit once I’ve gone yeah... The last couple of years she’s helped me. Wouldn’t say she’s my carer but as I said when I had my hand done... She was helping me a little bit around the kitchen, opening pots or um tops on things”
(Sister aged 82 caring for sister with LD aged 74)

“And Jane supports me by like um saying I’m needed. An then you hear the big C word and it frightens you.. And then the first thing that’s in your mind is “how’s Jane going to act”... things like that frighten you. You assume you’re living forever for Jane and if I die before Jane I don’t know what would happen to Jane’ (Husband aged 49 caring for wife with LD aged 48).

Quotations from service providers

“I think we’re all living longer and older. And that goes for people with learning disabilities, they’re living longer. So mutual caring is definitely going to be on the increase um and also I suppose as well... usually the person with learning disabilities is left at home and they do the caring... we’ve just gotta make sure they don’t get forgotten”

“A lot of parents become reliant on those benefits from their son or daughter. There’s a dual dependence then there really. They’re dependent on their child emotionally and financially and maybe physically as well when that child then, the issue you probably want to discuss today, becomes a carer for their parents’ as well”

“You’re making me think now, is that gunna be another kind of, you know, result of cuts. Is that you know, more people with a learning disability are going to be in the house, looking after their parents?”

“But would a person with a learning disability go into a carer centre? I don’t think so”

Impact of the research

“One of your questions was ‘do you see yourself as a carer’ and he very assertively said ‘yes I am’. And I had a little smile in my head because I kinda know the path that lead up to that was around your research. Rather than saying ‘well I find things a bit difficult and that’s why I cut myself to his GP, I could see Davis saying ‘well I care for my mum and its hard work caring for mum and that’s why I cut myself’. And those statements are subtly but quite importantly different”

“He was very proud to take part in your research because he felt, he kinda felt important”

“It’s (the research) making me use my brain and actually making me think about what these things mean... I suppose its something I’ve not particularly given thought to...”

Implications for Policy and Practice

- ▶ To recognise service users as interdependent. Access to carers allowance and carers assessments
- ▶ Increased awareness of mutual caring through incorporating this in staff training
- ▶ Professionals to provide practical and emotional support
- ▶ Redesigning unified assessments
- ▶ Including people with LD in carers centres
- ▶ Implications for policy and practice add an empirical evidence base to the key principles of the Social Services and Well-being (Wales) Act 2014 (Welsh Government, 2016)

What might you take home from the workshop today?



Conclusions

- ▶ Mutual carers need to be recognised and supported as individuals who have multiple and fluid identities
- ▶ Assessments need to consider the needs and feelings of mutual carers and their home environment and support networks
- ▶ Mutual carers need to be empowered in their choices and decision-making and to be aware of their rights and entitlements
- ▶ For policy and practice to recognise that caring roles and responsibilities within caring relationships are constantly evolving
- ▶ Policy and practice to recognise the vulnerabilities of people with LD, including how they can be exploited and discriminated against
- ▶ Being a carer can be more complex for people who have LD - why?

References

- Alexander, C. E. (2013). Mutuality and reciprocity in relationships: Generalist social workers' considerations and strategies for managing their relationships with clients (Doctoral dissertation, University of Calgary).
- Baker-Ohler, M., & Holba, A. (2009). The communicative relationship between dialogue and care. New York-Cambria Press.
- Barnes, M. (2012). Care in everyday life. An ethic of care in practice. Bristol: The policy press.
- Fine, M & Glendinning, C. (2005). Dependence, independence and interdependence? Revisiting the concepts of care and dependency. *Ageing & Society*, 25(4), 601-621
- Heron, C. (1998). Working with carers. London and Philadelphia: Jessica Kingsley Publishers.
- Kittay, E.F. (1999). Love's labour: Essays on women, equality, and dependency. New York and London: Routledge.
- Lloyd, L. (2003). Caring relationships: Beyond 'carers' and 'service users'. In Stalker, K. (Eds). *Reconceptualising work with carers: New directions for policy and practice. Research highlights in Social Work*, 23 (pp. 37-55). London: Jessica Kingsley Publishers.

References

Gilligan, C. (1982). *In a different voice. Psychological theory and women's development.* Cambridge, MA: Harvard University

Gant, V. (2010). Older carers and adults with learning disabilities: stress and reciprocal care. *Mental health and learning disabilities Research Practice*, 7(2), 159-172

Gates, B., & Atherton, H. (2007). *Learning disabilities toward inclusion* (5th Ed.) Edinburgh: Churchill Livingstone

Held, V. (2006). *The ethics of care: Personal, political, and global.* New York: Oxford University Press

Phillips, J. (2007). *Care.* Cambridge: Polity Press

Tronto, J. C. (1993). *Moral boundaries: A political argument for an ethic of care.* New York: Routledge.

Williams, V. & Robinson, C. (2001). "He will finish up caring for me": People with learning disabilities and mutual care. *British Journal of Learning Disabilities*, 29(2), 6, 56-62