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The experiences of older carers of people with learning disabilities: 'I just carry on with it'

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Abstract

Purpose

Since people with learning disabilities (LD) are living longer, their family carers are likely to continue their caring role for longer. The research reported here explores the experiences of older carers of people with LD.

Design/methodology/approach

Sixteen interviews with older carers were carried out and analysed qualitatively.

Findings

Three main themes emerged from the data: 'transition to retirement is a misnomer'; 'impact of caring role'; and 'fears for the future'.

Originality

Previous studies have not focused on the specific experiences of 'older' carers and their situation risks going unnoticed. Their experiences should be acknowledged by services and society and meaningful support provided.

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Introduction

While no data are specifically gathered on the number of older carers (65+) of people with learning disabilities (LD) (see Forrester-Jones, 2019a, p.37), we do know that 549,403 people with LD are aged 45+ [5% are 85+] (www.pansi.org.uk) so can reasonably infer that many of this number will be supported by older family carers.

UK research concerning older carers of people with LD (see Bibby, 2012) has largely focused on future planning once family carers could no longer provide support (e.g. Grant and Nolan 1993; Jokinen and Brown, 2005; Bowey and McGlaughlin, 2007; Davys and Haigh, 2008; Weeks *et al.*, 2009; Cairns *et al.*, 2014; Pryce *et al.*, 2017), finding that older carers felt anxious about the future (e.g. Hubert, 2006; Dillenburg and McKerr, 2011; Taggart *et al.*, 2012) but did not feel ready (Magrill, 2005) or had reservations about making future plans due to a perceived lack of alternative service options (Ryan *et al.*, 2014). Recommendations have mainly been directed at local authorities (LAs) to be more proactive in providing information and support to enable families to plan ahead (Walker and Hutchinson, 2018; Foundation for People with Learning Disabilities, 2002). There is little published evidence, however, to suggest that these recommendations have been heard and acted on. Whilst other studies have investigated long-term carers' quality of life (e.g. Grey *et al.*, 2018), Mahon *et al.*'s (2019) systematic review found only six UK based studies, positing "a gap in existing knowledge" (p.14473). The UK has had 25 years of "carer policy", including the Carers (Recognition and Services) Act 1995, the Carers and Disabled Children Act 2000, the Carers (Equal Opportunities) Act 2004, and the consolidating Care Act 2014 - emphasising equal treatment for both carers and the cared-for in relation to needs assessments and support. These have been accompanied by numerous

White Papers and policy directives such as *Valuing People* (Department of Health, 2001) which required services to produce a reliable plan for all service users living with older carers - reinforced in the consultation paper *Independence, Well-being and Choice* (Department of Health, 2005), the *Carer's Strategy* (Department of Health, 2008) and *Caring for our Future* (Department of Health, 2012). Given this policy interest, I aimed to explore the experiences of older carers of people with LD from their own perspectives to see how they were faring in 2019.

Method

The research was commissioned by New Forest Mencap (NFM), a charitable organisation developed by young parents of people with LD in the 1980s which provides day-time and evening leisure activities including a supper club and Gateway Award scheme for people with LD in two locations of the New Forest (South East of England). The study aimed to explore the experiences of older family carers as they continued to care for their older adult relatives with LD, the main objective being to help inform NFM on where their future resources were best placed in order to support both people with LD and their carers. This paper is an abridged version of the original report (see Forrester-Jones, 2019a); with further themes reported elsewhere (TLDR, 2021).

Open-ended questions with prompts were initially co-produced by NFM, a carer, and myself with the aim of enabling participants to share their stories. Apart from demographic questions about the carer and person with LD, these included the following:

1. How do you feel about [person with LD] getting older?

2. What changes (if any) have you noticed/experienced as [they] have got older?
3. What support do you think would be most helpful to you as they get older?
4. Please tell me about your experiences of caring?
5. What kinds of help do you get from services?
6. What do you like about the support you get?
7. Is there anything you don't like about the support?
8. (For those who do not get support) What are the barriers to getting support?
9. How could the needs of [your family member] be supported better?
10. How might your needs be better supported?

As the interviews progressed, participants highlighted aspects of caring that were significant to them. The iterative approach taken allowed for subsequent interviews to include these aspects by re-ordering or reassigning questions to prompts, and inserting additional prompts.

Recruitment

In the absence of reliable registers and to ensure voluntary and non-exclusionary participation, an indirect approach to recruitment with simultaneous overlapping strategies was taken (Dillman, 1991). Poster-adverts detailing the research with an invitation to participate were placed in local newspapers, the Clinical Commissioning Group (CCG) e-newsletter and via a LD charity network.

Ethical considerations

Information about the aims, and voluntariness of the study, and uses to which the data would be put was provided to participants (who all had capacity) verbally and via an information sheet. Following signed consent, recorded interviews took place in a quiet, private location at the charity or in participants' homes, each lasting around 45 minutes. Recordings were uploaded onto the University secure X-drive. One participant requested not to have their interview recorded but consented to their

responses being typed in-situ. Interviews were redacted for identifying details at the transcription stage.

Recounting experiences proved distressing for two participants. Whilst offered to end the interview, both wished to continue and were able to access support from the charity post-interview (all participants were given this option). A favourable ethical opinion for the study was received from the university research ethics committee (Ref:280818).

Analysis

Interpretative Phenomenological Analysis (IPA) enabled an iterative process whereby findings from initial interviews influenced subsequent interview prompts, confirming and adding themes. By analysing the text line-by-line and attributing codes to what participants had said (using NVivo 12 software) I was able to describe their experiential worlds rather than extracting data based on preconceived theories (Smith, 2010). Once coding was complete, recurring patterns of meaning (thoughts and feelings) became subthemes or aspects of caring that were important to participants. Subthemes were then grouped into broader 'superordinate' themes, with direct quotes used to evidence these. An opportunity for thematic member checking was provided to three participants at the draft stage of writing and to all participants at an open-discussion feedback event - leading to refinement of the themes.

Findings

Sample characteristics

The sample included 21 older carers (including 11 interviews with individual carers and 5 with carer couples). The average age was 75 years (of 18 participants who volunteered their ages). Four were aged 80 years or above. Six were single carers and, of the others, five reported the ages of their co-caring partners/relatives (age

range 76 to 93 years) who were not interviewed. The average age of carers' relatives with LD was 45 years (range: 27 to 56 years). Half were living at home with their families and half lived in supported living with paid support. All but three carers were officially retired. All of the cared-for individuals had been assessed by their LA as having eligible care needs with twelve receiving Direct Payments (DPs). All but one were currently receiving social care ranging from e.g. a local day centre 5 days a week to 33 hours weekly help with domestic tasks.

Interviews

The following themes describe how carers experienced and made sense of their role.

Theme One: Transition to retirement - a misnomer for carers

Participants felt that their caring obligations had continued/increased regardless of whether or not their loved one¹ lived at home or in supported living, or received DPs or LA-organised care. The following subthemes describe how participants articulated their situation.

Subtheme one: Complexity of caring as loved ones age

Generic annual health checks were 'on offer', but all but one participant reported an absence of access to specialist LD health care (also found by Heslop *et al.*, (2013). Consequently they had to arrange and/or provide direct health and social care:

"I have to be there to take Josh² to the hospital...When we moved here I was concerned about check-ups. I do all the cooking, washing, and ironing...(015)

¹ The term 'loved one' is used since this appeared to reflect how participants felt and talked about their adult family members. This term was agreed by NFM and participants attending a feedback event.

² Pseudonyms are used to maintain confidentiality.

This made caring more complex, especially as individuals' loved ones became more mentally and/or physically frail with age. Over half the participants were considering adaptations to alleviate individuals' deteriorating mobility:

"... Claudette's walking is deteriorating...so she [uses] one of these rollator things now..." (001)

Other behavioural changes could be challenging for some carers to manage:

"More difficult definitely...more stubborn; never pliable but [I] could insist. But not now - can talk to Tom until you are blue in the face and battle – no such thing as 'no'." (018)

The above problems were balanced by some participants experiencing their loved ones making positive progress:

"Jacob is getting slightly better as he gets older – more confident..." (014)

A few participants reported the beginnings of care reciprocity within the family unit (Fyffe *et al.*, 2015), illustrating a more strengths-based perspective of the person with LD (Howe, 2017):

"...things have changed round now. I broke my leg last year...and Juliette now says 'this old dear' and she takes hold of my hand [laughs]. We laugh about it, but ... it is good from her point of view that someone else needs looking after." (007)

Subtheme two: Carers as 'care managers'

Carers described 'managing' their loved one's affairs, including finances and organising paid carer availability to support timetabled activities. Almost all organised at least two weekly activities. Whilst some participants had upskilled themselves in the process, becoming 'experts' in e.g. financial and legal matters, this work was time-consuming and frustrating:

"I settle the bills...I feel like I am a qualified accountant and trying to set it up...really was a nightmare." (010)

“Well Harrison he has just been converted onto Personal Independence Payment and... one of the things I need to do is sit down and work out how much money he gets, and use that money for his activities. But ... I’ve got a list as long as your arm of the things I need to do... (020)

These descriptions stretch the traditional concept of ‘caregiving’. For many, the tasks of recruiting and paying carers, keeping records/timesheets or receipts for services from agencies, were confusing and overwhelming:

“I like the fact that we can decide and control who comes in and does the support....but I don’t like the fact that effectively I have to run a business. I have to employ these people... I don’t even know what those rules and regulations are so I’m probably breaking god-knows how many laws because I haven’t got the time to sort that out.” (020)

Not quite, from this carer’s perspective, the ‘freedom and choice’ that DPs promise to provide. Similarly, timetabled activities only worked when family carers were managing the practicalities:

“The reason it works well [supported living] is because I am here and live around the corner. But if I didn’t live around the corner, it would not work well and this is what needs to be addressed. Because whether or not the care agencies are good...they aren’t really the managers of the situation. So if I dropped dead tomorrow, you know, there would be nobody...” (012)

Thus, even when not directly responsible for activities, carers were overseeing them (Eley *et al.*, 2009).

Subtheme three: Pressure to find ‘adequate support’

Day services have reduced and closed both as a result of changing ideas about their value, and to save local authorities money in the context of austerity (Unison Report, 2019). People with LD are therefore more reliant on the third-sector and their families to find alternatives (Forrester-Jones *et al.*, 2020):

“[The agency] closed, and the day centre closed. We get over-looked. Not a lot to do – café and drink and come home.” (018)

For others, reductions to day service provision meant that what was offered was not always appropriate:

“Claude doesn’t like going to the day-centre and sticking bits of paper together... the other day he brought home a bloody sheep that he had made with the inside of a toilet roll with cotton wool stuck on it. He is 54 years old!” (020)

A reduced ‘pool’ of staff curtailed opportunities for one-to-one care that accommodated compatible personalities:

“The carers are not Trevor’s type of people” (004).

Whilst personality clashes exist in most workplaces, the nature of protracted one-to-one and/or intimate care may intensify these. A lack of staff support also often left older parents/family members supporting their loved ones in activities that highlighted the generation gap between them and left them feeling uncomfortable:

“Well...we can’t take Vera to things like discos...and when we go on holiday we feel a bit stupid ... going onto the dance floor at our age [both over 85 yrs]...we do try...I always feel that Vera could do with having a companion.” (006)

Theme one demonstrates how age-related health deterioration of people with LD and their carers can impact on the day-to-day functioning of family life with the older carer’s role becoming more intense with reduced formal support (Carers UK, 2015). Whilst DPs have enabled many people with LD to achieve more independence (Riddell *et al.*, 2005), employing carers can be complex (Shearn and Todd, 1997) with a care market that doesn’t always offer real choice. In the absence of an ‘informal carer job description’, family carers took on care manager/support worker roles, including arranging care that met needs, and accompanying individuals to social events.

Theme Two: impact of caring role

Subtheme one – never ‘off duty’

Carers understood that ‘things could go wrong’ with service provision, but the risk of this meant that they felt the need to always be ‘on call’ to mitigate problems:

“...this week Cindy hasn’t had any carers...one carer is off sick, another one has gone [to another] crisis...and another one is on holiday...so if one of the carers doesn’t turn up we have to phone the agency. So how does that work if we aren’t there? (005)

Independent living did not stop carers’ loved ones from requesting support daily and/or ‘coming home’ for weekends. Thus family carers were never really ‘off duty’:

“Jacob lives in a flat on his own but...he will phone me three or four times a day and he is at home with us at the weekend” (014)

Subtheme two: the need for ‘respite’

Participants talked about ‘respite’ in the context of a ‘break’ from the stress of caring duties. But none of the participants with loved ones at home had received routine respite for some years (corroborating Dillenburg and McKerr, 2011); saying that this service had been the first to ‘go’ in the run of service cuts:

“No respite...we haven’t had that for years and years. It would be a holiday for Audrey as well....” (019)

Even when a carer had occasionally been offered respite (one week in a residential care home in the case below), the task of organising it was daunting:

“...that’s the thing about Harrison going into respite. I’d have to label all his clothes. I’d have to fill out a form telling them how to look after him. I’d have to get him there and then ... pick him up when he wasn’t enjoying it and [social worker] was absolutely adamant that ‘oh he’ll love it there’ – Oh you’ve spoken to him for 5 mins? You’ve never met him before - you don’t know him” (020)

Some carers with loved ones living elsewhere had been able to organise a 'break away' but reported never really escaping their caring responsibility:

"We can get a break... for a few days but it never leaves you. Louise phones when we are away" (008)

Participants also reported little flexibility for holidays:

"The trouble is Cindy gets anxious quite a lot so things like holidays and days out and time with grandchildren are all the things that are compromised. You know we haven't been out for an anniversary dinner for 27 years" (005)

For most, what might be regarded as a natural and normal expectation (e.g. having a holiday), was often not realised. Most also reported that as they themselves got older, there were fewer friends/relatives to help, supporting Iacono *et al.*'s (2016) argument that shrinking support networks make family coping more difficult. For some, this led to feelings of loneliness and isolation:

"I have no one – my social life has shrunk - a lot of my friends have died and my other children have moved away. I have a dinner service for 18 people and it just sits in a dresser all forlorn...I have no time for a social life. I am hacked off with the care Bryn has and my fun loving Bryn has disappeared - the standard of care is difficult." (016)

The experiences described above demonstrate protracted (up to 56 years for some) caring roles, with little respite, resulting in many individuals feeling their own lives were restricted and lacked social support.

Such feelings may also reflect a sense of being invisible, forgotten (Chadwick *et al.*, 2013):

"I do feel isolated. I know people - the other mums - but you know they are all tied up ...they work" (009)

And not properly regarded by services:

“I got a letter saying ‘oh Harrison has been assessed for dementia’ and I didn’t know anything about it. So I rang them up to say ‘when is he going to have his annual review? And why am I not finding out about these things?’ and they said ‘Oh yeh we are trying to find out what sort of annual review to do.’ Well the clue is in the title – it should be annual”.

There is therefore a need for services to adopt a culture that acknowledges, values and celebrates the work of informal caregivers.

Theme Three: Fears about the future

Subtheme one: diminishing capacity to care

Similar to previous studies (e.g. Bowey and McGlaughlin, 2007) fears of diminishing capacity to care was a pressing issue for all participants, yet they “*struggled on*”:

“I’ve had three months of health problems and my husband also has health problems. I’m not getting any younger – trying to make sure Audrey stays safe. It is really hard.” (019)

Subtheme two: who will take over?

‘Struggling on’ appeared to also reflect uncertainties around who might ‘adequately’ take over their role once they couldn’t continue:

“And that is our problem, you know if we die. Who will take over? Not who will pay for it, but who will do it? What sort of support will there be?”(006)

Yet few explicit plans had been made, corroborating previous research (Taggart et al., 2012; Pryce et al., 2015) :

“As I get older...there is nothing I can do, I do my best. All I want is to see him well treated. My aims are modest. I just want him to be safe, healthy and happy.” (002)

with almost all participants reporting that they hoped other family members would assume responsibility:

“I am 78. It is something that worries me about what is going to happen. Originally I had spoken to my daughter and arranged in a way that Josh could live with her but life gets in the way...” (015)

“Our son is very good...We can trust that if we are not around, he will make sure that Trevor is cared for....we sort of work as a team..” (004)

Some wanted to plan ahead, but the idea and practicalities were daunting:

“It will take about a year for the process to work and [care agency] are aware because they have houses and [they know] that I would like Claudette in one. ...what I don't want to happen is that I drop down dead and Claudette loses me, and her home. Claudette would be much better off going into care and me visiting her and she gets into the routine before something happens to me. So that part of it is a worry really but she gets so distressed every time I talk about her leaving home...because she doesn't know what it would be like I think, she has no concept. I'm sure I would be lonely and would miss her as we are a bit like Darby and Joan you know and she is a reason to get up in the morning....I do need to [make plans]...but...I know I will miss her and I will definitely miss her financially.” (001)

Finally, lack of concrete plans had led a few participants to resort to making arrangements in the expectation that their loved one would predecease them:

“I hope Jacob goes [dies] before me. We have organised his funeral...I was ill earlier this year and so I am anxious.” (014)

This theme demonstrates the emotional and practical difficulties of future planning. Avoidance of the issues was the inevitable default position for many carers, which could in the long run unwittingly stymie their opportunity to think about new possibilities for their own lives (Allen, 2011, p.30 in Pryce *et al.*, 2017). Yet the theme also highlights what Ryan *et al.* (2014) called relationships of 'mutual interdependence'. Participant 001 helps us to comprehend the reluctance to relinquish a role which mediates feelings of life-satisfaction and self-worth (Bibby, 2013; Gant and Bates, 2019) as well as perceived and real losses tied up with finance and emotion that emerge when contemplating future plans. Walker and Hutchinson (2017) call for understanding by statutory agencies' of families *current* needs, with the proviso that these needs may change rapidly. Regular and responsive appropriate assessments of family situations - which do not always have to be formal – would help activate future plans.

Discussion

The sample of carers interviewed in this study lacked diversity so that specific difficulties faced by carers unrepresented in the sample (e.g. carers from BAME groups) may not have been identified. Nevertheless, the experiences recounted were not dissimilar to those found in Hubert's (2006) study of older parents from BAME communities in London, including feelings of isolation, anxiety, and worries about the future.

This study's particular strength was in empowering older carers by enabling their authentic voices to be heard. This highlighted the emotional as well as physical and practical implications for them and their families, demonstrating the complexity of

the issues they grapple with and the fragility of their own support networks at this stage in their lives. Despite over two decades of policies and policy directives and research outcomes, it is clear that future planning for older carers of people with LD remains absent or very limited. This risks LAs having to respond to crises (e.g. when carers die) leading to inappropriate placements of people with LD (Thompson *et al.*, 2004) and/or unresolved grief (Forrester-Jones and Broadhurst, 2007; Forrester-Jones, 2014) contributing to, in some cases, clinical depression and challenging behaviour (Forrester-Jones, *et al.*, 2017; 2019b). Whilst dissemination of this study's themes led to an immediate response from the LA via 'carer drop-in' sessions providing information about available services, COVID-19 has only further highlighted the plight of older carers (Forrester-Jones, 2020) across the UK, and the arrangements for their support need to be urgently re-visited.

A number of implications for practice arise from the study's findings. Space precludes a detailed list but some of the more significant include the following:

1. We need more clearly defined care manager/support worker roles that will help older carers to navigate complex systems and complete bureaucratic tasks regarding, for example, direct payments;
2. For the benefit of both individuals with LD and older carers, we need to find ways to enable individuals to engage in social activities accompanied, not by their 'mum and dad', but by more appropriate 'companions';
3. We need a co-ordinated short breaks system that is designed to benefit both adults with LD and their older carers. This would enable carers to have a 'night off' and/or longer stretches of time to rest, allowing them to enjoy and

realise the 'retirement phase' of the life-cycle while continuing, if they wish, to play a role in caring for their loved one;

4. Perhaps most crucially, to pre-empt crises, we need focused, direct and sensitive support to help older carers and their loved ones make realistic plans for the future.

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