

Carers of Adults with Learning Disabilities:

'Where's the care in the Care Act?'

Abstract

The Care Act (2014) gave new rights to carers for assessment and aimed to provide a structure for a more personalised approach to care and support (DoH, 2014). The UK population is an aging one and research indicates that people with learning disabilities are part of this longevity (Emerson and Hatton, 2008; Foster and Boxall, 2015; Walker and Ward, 2013) with the majority of people with learning disabilities remaining in family care for many years (Cairns, et al. 2013; Gant, 2010). Thus carers are frequently providers of care for their relative with a learning disability and take on many levels of responsibility, often lasting for decades. This paper describes a research study involving 9 carers of adults with learning disabilities to establish their views on this piece of legislation, its likely significance to them and their relatives, and provides a forum for discussion and debate in terms of possible implications for practice.

Introduction

With an ageing UK population, and the reliance on family carers, research indicates that those carers aged over 65 are now more likely to spend at least 50 hours or more caring per week. The burden of such care is now disproportionately shouldered by the older generation (Loi, et al. 2016; Wanless, et al. 2006).

The first phase of the Care Act 2014 (the Act) came into force on 1 April 2015, with the second phase now being introduced from April 2020, with the aim of '*Creating a single modern law that makes it clear what kind of care people should expect.*' (Lamb, 2014). Legislation and policy aimed at supporting the work carried out by 'informal' i.e. unpaid family carers has developed apace in

the last 3 decades, such that carers are now seen as a service user group in their own right (Clements, 2012) making the relevance of legislation and to this group highly significant. How carers receive information such that they might benefit from it varies, professionals have a responsibility to facilitate this wherever possible.

The first phase of the Act aims to ensure that people's well-being, and the outcomes which matter to them, are at the heart of every decision that is made. This has implications for all professionals working with people with learning disabilities and their family carers. Significantly, the Act puts carers on the same footing as those they care for, with support for families and the notion of the 'Whole Family approach' being one of its key elements.

This study, although involving only a small number of participants, highlights the need to expand research and understanding into the way information is transmitted by professionals and those in-the-know, as well as the ways in which such information is received and understood by those for whom it is intended. In order to support the wellbeing of adults with learning disabilities it is vital that the needs and perspectives of their carers are understood. Understanding the role, perspectives and experiences of carers is beneficial in order to monitor, inform and enhance practice. Understanding how carers feel that legislation is explained is important in order to develop systems for future information provision, as well as providing a functional platform to enhance working together to support the health and wellbeing of the person in receipt of care services. Recognising carers perspectives, and developing ways of supporting them offers a range of potential benefits: emotional, practical and, not least given the current economic situation, financial (Power, 2014; Jordan and Drakeford, 2012).

Research indicates (Carers UK, 2015; Walker and Ward, 2013) that older adults are increasingly involved in providing care for friends and relatives, for many parents and carers of adults with learning disabilities, this is a scenario that has been present for decades, with practical, physical, emotional and financial implications.

Literature indicates that for the majority of carers of people who have a learning disability, anxieties about the future prevail (Cairns, et al. 2013; Gant, 2010). There is a felt need for more support, advice and information to be given by professionals, and for those professionals to evidence a greater awareness of any concerns (Cairns, et al. 2013; Carers UK 2015).

Aims of the research

The aim of this study was to explore the perspectives of carers of adults with learning disabilities regarding the Care Act 2014, examining the potential opportunities, concerns and misunderstandings arising from its implementation.

The Act places carers on an equal footing with those for whom care is provided (see for example s2, s12, s13, s25, s27, s67-8) and emphasises '*the importance of beginning with the assumption that the individual is best placed to judge the individual's well-being*' (DoH, 2014 p9). There does appear to be more scope within the Act for workers to appropriately (and necessarily) shift the focus away from (simplistic) calculations of hours of care provided onto a considered appreciation of an individual carers experience of caring in terms of the *impact on their life*. This however requires that both assessors and carers are aware of this and that effective relationships exist, as carers often cite poor relationships with professionals as being a significant barrier when planning future care arrangements (Gant, 2010) Thus, by recognizing and using the perceived potentials within the 2014 Act more creatively, professionals could support carers both in the (day-to-day) caring role *and* assist them in planning for the future – both their own and that of their relative, as the paths of each may not be the same.

The current study invited adult carers of adults (18 years +) with learning disabilities to discuss their experiences and understandings of the 2014 Act. The aim was to discover and explore perspectives, feelings, hopes, and fears, as well as capturing some of the contemporary realities of the impact of caring on the life of the carers, using the 2014 Act as an interpretative 'filter'.

Data Collection, Method and Interview Schedule

Prior to the commencement of the project ethical approval was granted by the university ethics committee.

In order to explore the potential impact of the 2014 Act from a carer's perspective, a qualitative methodology was used (Creswell, 2013), utilising semi-structured interviews as the primary method. Qualitative approaches to research can be seen as a way of rebalancing power in the researcher–participant relationship and encouraging a focus on marginalised groups, their understandings and experiences (O'Connor and O'Neill, 2004). One of its strengths lies in uncovering more about people's experiences through the power of narrative and opportunities for explanation and exploration – such a design therefore locates the logic of the research within the frame of reference of the participants (Green and Thorogood, 2013).

The chosen methods incorporated face to face semi-structured interviews. These were selected as the preferred method of data collection as they allowed carers the opportunity to express their opinions and perspectives in a private and relaxed manner, respecting the need for sensitivity in exploring personal issues. Semi-structured interviews also allowed the researcher the opportunity to ask spontaneous questions, recognising and responding to the sensitivities of the situation and the participants need for free expression. In addition, any questions regarding the author's own background (as a parent of a child with a severe learning disability) were answered in as honest and appropriate a way as possible. In this way, the overall approach emphasised the importance and value of reflexivity, moving some way towards what Kinsella and Pitman (2012) refer to as *phronetic* research with its emphasis on the responsive use of both personal and professional knowledge within the research process. As Flyvbjerg points out: "*The result of phronetic research is a pragmatically governed interpretation of the studied practices...phronetic research is an analytical project, but not a theoretical or a methodological one*" (2012: p140). With the use of reflection and discussion with colleagues

throughout the process, due regard was given to equality and fairness. By standardizing the interview schedules, data reliability was enhanced and the possibilities for replication enhanced.

Participants were recruited via contact with a local carers' group providing support to carers looking after family members with learning disabilities who they felt may be interested. From this three carers participated. Information was also posted in key areas in the local community, and two participants came forward from this. The remaining participants ($n=4$) were recruited through a combination of word of mouth and snowballing technique.

Further details can be found in Table 1.

A letter that describing the process of the study, the objectives and contact details was sent to prospective participants when they made informal contact. When they confirmed their willingness to participate, they were sent a participant information sheet and the interview schedule. Such a proactive approach aimed to respond to the perceived hierarchy in the researcher-participant relationship, and was seen as an opportunity to provide some balance between interviewer and interviewee.

Topic areas suggested in the interview schedule included:

- The Care Act (2014).
- Their experiences of being a carer for an adult with a learning disability.
- Feelings about the future.

Participants were interviewed separately for between 20 and 70 minutes and, with their signed consent, narratives digitally recorded and transcribed verbatim. Questions were devised by the researcher in conjunction with academic colleagues and were taken to each interview as a prompt/guide for the interviewer. Participants were offered a choice of venue for the interview to take place. Eight selected their own homes, whilst one suggested a neutral venue.

Participants.

Participants were reminded at the outset that they were free to leave the interview at any time; in addition, given the sensitive nature of the discussions, all were made aware of support services, including counseling services that they could access. There was no way of knowing if these services were subsequently accessed, although no concerns were expressed or were made apparent by participants either during or following the interviews.

The interviews were approached thematically (Braun and Clarke, 2006), seeking to identify themes and patterns, utilizing an inductive approach to analysis. A coding framework was devised to identify salient areas of discussion. This allowed for the identification of elementary thematic patterns and formations, which were subsequently developed into more manageable sets of themes. These were then refined and arranged in order to yield meaningful and potentially useful themes: reflexivity was key to the interrogation of the data set.

Key Findings and Discussion

The data from the coded transcripts produced several themes.

For the purpose of this paper, 1 theme will be discussed: *'Knowledge and implementation (of the Care Act, 2014)*

Table 1: Participant Information

	Participant M/F	Age Range	Parent (P) or Sibling (S)	Nature of disability/diagnosis of participants relative ¹
1	F	50-60	P	Learning Disability/Physical Disability
2	M	60-70	P	Severe Learning Disability/Autism
3	F	60-70	P	Learning Disability/Cerebral Palsy
4	F	60-70	S	Learning Disability/Autism
5	F	70-80	P	Learning Disability/Autism
6	M	70-80	P	Learning Disability/Autism
7	M	70-80	P	Downs Syndrome
8	F	60-70	P	Learning Disability/Cerebral Palsy
9	F	70-80	P	Down's Syndrome

1. Knowledge and Implementation of The Care Act (2014)

All participants said they had heard of the Care Act, and three participants said they had discussed elements of it at meetings they attend at the carers centre. It was felt that there was a lack of readily available information about this relatively new piece of legislation, unless 'you know where to look'. This reflects findings from other research which indicates how carers feel they lack information on a variety of topics during their caregiving career(s) (Cairns, et al. 2013). Even when carers of people with learning disabilities had heard of

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The broad categorization used here reflects that adopted by the participants when discussing their relative and in no way attempts to minimize the inherent complexities involved in diagnostic categorization.

the Care Act (2014) and had an opportunity to read it there were still noted problems:

'Well there's too much volume in terms of the actual wording they use. Even the abbreviated notes are complicated'.

None of the participants reported obtaining information from practitioners, and two spoke of the Act in less than glowing terms:

*'The Care Act....well that's a load of b*****ks really isn't it?'*

and

'Call me cynical if you like but the Care Act won't make any difference to us. Haven't they just put part of it (implementation) back?'

The general response to any impact-related theme appeared to be 'wait and see.' Carers described how they felt as though they had 'heard it all before' when it came to political will to support them. All participants recognised that their own lives were subjected to a range of limitations not experienced by their peers who did not have responsibility to provide care for an adult with a learning disability. The age of the carers in this research ranged from 56 – 79 years and for some, the ways in which they received information that may support or inform their role was also a source of some concern:

'I'd rather read a piece of paper than go on a website, and at my age there's no way I'm going to learn. I can use a computer, but I only ever use it for certain things I want to do. I certainly wouldn't read a load of legal documents on it, whereas people who are 20 or 30 years younger than me would, that's what they use for their information. I use the library and a book'.

For others though the pressure on practitioners was acknowledged:

'You'd hope those in the field would let us know about it - we've had several (carers need assessments) over the years, although I do

believe there have been some new guidelines to follow up with carers - trouble is the lack of social workers. They are pressurized though with so much work - and don't get me started on the health service!

If carers were unaware of the potentials within the 2014 Act, then this was amplified when considering the people with learning disabilities for whom they provided care. None of the participants felt their relative was aware of the introduction of the 2014 Act. This is an area fertile for future research, as although information regarding new legislation is disseminated to staff, and to key areas, such as carers-centres, the people for whom it has the likelihood to impact upon most have never heard of it, thus there is no parity. One carer who was active in carer meetings and represented carers on a number of groups suggested that the onus was on carers to tell their relative about it, and the relevance and appropriateness of this was questionable:

'Communication is so important. Getting a piece of paper through the post saying this is the latest legislation, what do you think about it, and then having to plough through a 28 page booklet is not the way to do it. Not the way to communicate stuff that affects your child and your support. What is needed is for professionals to let us know about it.'

For practitioners working with people with learning disabilities *and* carers, a thorough understanding of the 2014 Act would better facilitate the provision of meaningful advice and support. As participants often expressed concerns regarding the future for the person for whom they provided care, especially regarding accommodation and health, the feeling that there was a lack of joined-up working, and a lack of information was a symptom of the central importance placed upon communication.

'Cross -fingers nothing goes wrong in his mouth. Health is part of social care and it's all linked together. It's still part of the Care Act as well. I even asked our dentist if he knew how to access it. And he didn't either. That's bad, lack of communication. I didn't know where to turn'.

Discussion

These findings have a number of implications for both learning disability practice and further academic and practice-based research. Practitioners and service providers need to continue to develop their awareness and understanding of the unique challenges facing the carers of adults with a learning disability and those factors referred to above that are likely to mediate both current and future responses to their needs and those of their relative. This is particularly important where governmental, professional and broader societal expectations are increasingly focusing on the role of the family as the main source of support, with ideologically-driven practices (Jackson and Irvine, 2013) such as personalization, currently very much to the fore in terms of overarching service design and delivery structures. It is essential that the needs of both the adult with a learning disability and their carers are acknowledged, validated and planned for holistically, in order for this to be seen and experienced as a meaningful process. Assessments and interventions must systematically identify all elements of need within the whole family-based situation, with clear implications for practice at a number of levels.

The 2014 Act now puts the principle of well-being on a statutory footing, such that the promotion and maintenance of physical, emotional and mental well-being are now *duties*. In the context of practice with adults with learning disabilities and their carers, professionals need to know that whilst a definitive explanation of 'well-being' is absent, there is an opportunity here for significant creativity. What would constitute well-being needs to be considered on an individual basis, and a skilled professional should be able to develop a relationship with carers significant enough to enable a discussion of this to take place (Gant and Bates, 2017). Whilst carers did seem to recognise the significance of the legislation, their main concern was if, when and how its application would impact their lives in ways that were meaningful.

Likewise, although dealings with professionals were seen as complex, the

changes in eligibility criteria brought about by the Care Act (introducing a minimal eligibility threshold) should have an impact on future plans and reduce the uncertainty that carers experience. These potentials do however need to be made visible to carers – and that these are important to them can only be made apparent to professionals if carers are listened to – which is sometimes not the case (Heslop, et al. 2014).

Inequalities and differences will often characterise the lives of people with learning disabilities and their families, but carers need to be seen as co-experts, with their views respected and listened to. This also presents a challenge - to ensure that carers views do not obscure the views and wishes of the person with a learning disability. Balancing the interests of a variety of stakeholders, and dealing with the ever-present constraints of finite resources is an on-going test to the skills of practitioners and a constant source of tension for carers. Practitioners need to know what is important to people *in their lives* (Sanderson, 2013) such that partnership working should promote their broader health and well-being needs, with choice and control leading to enhanced feelings of competence and confidence. By practitioners drawing upon knowledge from a range of sources (including legislation), this enables them to respond effectively to real-life situations and help to bring about meaningful change in peoples lives (Hothersall, 2016).

Limitations of the study and recommendations

This was a small-scale research project limited by sample size, which although varied in age, lacked diversity of ethnicity. This reflects the demographics of the area in which the study took place. A more diverse participant group may have yielded previously unknown areas. This study concentrated on carers who have a relative with a learning disability, and clearly there may be many similar issues regardless of the nature of the disability that suggests myriad avenues for future research, particularly in ever-changing socio-political and economic contexts. Participants that volunteered their time were all aware of the implementation of the Care Act (2014), and of themselves as carers and what this implied. Anecdotally however, this is not representative of all carers and future research needs to

locate and obtain the perspectives of 'hidden' carers.

There are a number of important messages for both practice and further research that emerge from this study. For practice, opportunities exist to develop and evolve creative interpretations of 'well-being', maximising the potentials of such statutory requirements (Herring, 2016). Additionally, utilisation of the enhancement in carer's status allows for opportunities to approach practice more holistically, enhancing collaborative possibilities with the support of statutory powers. Furthermore, highlighting the role of parent-carers and the presence of reciprocal care-giving allows practitioners and policy makers to respond more pragmatically to real need, rather than assuming that such relationships are normative and therefore not requiring of support and maintenance.

For future research, work is required to make heard the voices of people with learning disabilities themselves in relation to how their care is being supported. Training for practitioners in how they engage with the Act, and how well this is happening needs to be properly evaluated in order that policy-makers can further enhance the nascent potentials such that real differences can be seen, and sustained. The population of adults with learning disabilities is growing, and opportunities for *better* practice and the utilisation of a more vibrant and creative evidence-base are now visible, although effective knowledge development, use, transfer and dissemination for all practitioners needs to be considered as routine if sustainable improvements are to be realised (Heinsch, Gray and Sharland, 2015).

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