



# Confronting a Looming Crisis

People with learning disabilities and/or autism and their carers getting older

Rachel Forrester-Jones

Research commissioned by New Forest Mencap and funded by Awards for All.

Centre for  
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UNIVERSITY OF  
**BATH**



# **People with learning disabilities and/or autism and their carers getting older: confronting a looming crisis**

Rachel Forrester-Jones



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“Many years ago Valuing People identified the need to plan to support individuals with learning disabilities into old age, and also to support family carers to plan positively for the future. This report highlights that it is a priority to identify older carers and to plan with them, to ensure that not only are the needs of their relatives met, but their own needs are met too.”

**Vivien Cooper, OBE**

CEO, The Challenging Behaviour Foundation

## Executive summary

Increased longevity means that an increasing proportion of people living with a learning disability are aged 45 and over and are transitioning into older age/retirement. It also means that ageing family members are increasingly playing an extended caregiving role into later life. A small scale study was carried out in the New Forest, Hampshire during 2018-19. Twenty-one older carers (5 were male) were interviewed about their experiences of caring for their older adult family members with learning disabilities and/or autism. The average age of the carers was 75 though 20% of the sample were over 80 years old.

### Key findings:

Older carers are struggling to continue to care for their loved ones. Four main themes described their struggles:

1. Transition to retirement was felt to be a misnomer in the face of continuing responsibilities and duties to care and/or manage care. Little respite was available to take a break, take stock, or just do the things that most other 'retired people' do.
2. The Care Act 2014, despite its laudable goals, is yet to be applied sufficiently well to make a difference to the lives of people with learning disabilities and/or autism or their carers who took part in this study.
3. Challenges with social service provision including lack of continuity of social worker input, variable and declining levels of expertise, and pejorative attitudes towards carers appears to be worsening. That said, carers are understanding of the pressures on health and social care and are willing to work with them to improve the situation.
4. Carers' fears for the future as they contemplate who will care for their loved one once they are no longer able to care for them.

There is a need for age-appropriate housing, weekend activities for people with learning disabilities, and respite for carers. Transformational change which includes trust-building and co-production between health and social services and carers is needed to improve relationships between the parties. Meaningful partnerships between social workers and carers will reduce the problem of the frequent need of carers to urge social services to provide adequate care and support.

Information on options for people with learning disabilities transitioning into old age as well as practical support will help reduce the risk of crisis situations happening when older carers can no longer care.

# Recommendations for practice, policy and research

## Clinical and professional practice:

1. An integrated system whereby more precise figures of people with learning disabilities and their carers are logged and shared between the local authority and health service, and which are also shared with designated charities such as Mencap - to target those who have health and social care needs.
2. Clearer remits of the roles and responsibility of social care managers and support workers and their relationship to health provision, including direct tasks - to help ease the burden of the family carer's role.
3. Co-ordinated and appropriate respite, to enable carer's to have a 'night off' and/or longer stretches of time to rest, and enable life goals to be realised - putting carers on a more equal footing with non-carers who are enjoying retirement.
4. Combined carer and cared-for assessments which acknowledge mutuality and interdependence, and which are more family-oriented in approach; with assessors who understand and consider the ageing process.
5. Greater and more varied 'appropriate' specialist housing options with on-going updates of availability as part of a wider information sharing and communication strategy.
6. A way of organising designated social workers which allows for social care relationship continuity.
7. A family approach to assessing the need for and provision of adaptations including the use of appropriate technology to address changing needs of both people with learning disabilities and their carers to ease the growing older phases of their lives.

## Policy recommendations:

8. More emphasis and clear guidance for family members on the duty of the local authority to undertake comprehensive needs assessments (under s5 of the act) - with plans co-produced in terms of a whole family approach. This should include planning for future needs - to pre-empt crises

## Research recommendations :

9. A larger, more comprehensive UK-wide study which qualitatively interviews the experiences of both older people with learning disabilities, their older family carers, and practitioners specifically in relation to the Care Act 2014.

## Acknowledgments

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## 1. Introduction: People with Learning Disabilities are living longer - the national context

Improvements in medical and health care of people with learning disabilities (Emerson & Hatton, 2008; World Health Organisation, 2011; Tuffrey-Wijne, 2015) mean that life expectancy for this population (estimated to be around <sup>1</sup>2% of the total United Kingdom (UK) population) has increased. Whilst the life expectancy of people with learning disabilities including Down's syndrome was just 12 years in the late 1940s, people with learning disabilities in England are now expected to enjoy on average a lifespan of 65 (women) and 66 (men) (<sup>2</sup>NHS Digital, 2019) (although women with learning disabilities still die on average 27 years (median age at death being 59) and men 23 years (median age at death being 60) younger than the mainstream population (<sup>3</sup>LeDeR 2019)). Consequently, we now have an increasing proportion of people living with a learning disability who are aged 45 and over - the total number of this group living in England in 2019 estimated to be <sup>4</sup>549,403 (53% of the total (1,043,196) learning disabled population), 5% (26,723) of which are aged 85 or over. These figures are predicted to rise to 605,646 people aged 45 and over (55% of the total number: 1,108,257), 6% (37,953) of which will be aged 85 and over by 2030. The predicted number of people with <sup>5</sup>Down's syndrome who are 45 and over is 9,379 in

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<sup>1</sup> NHS Digital 2017-18 (collects and publishes data from across the health and social care system in England) estimates that around 2% of the population in England have a mild learning disability with 0.4% having severe or profound learning disabilities (NB: this figure is based on n=126,476 or 44.5% of the Quality of Outcomes Framework Learning Disability Register – which means that the data have not been extracted from all GP practices and so data coverage varies between CCGs). [Accessed 25/09/19]

<sup>2</sup> NHS Digital (published 24 January 2019) Health and Care of People with Learning Disabilities:2017-18 Summary Report <https://files.digital.nhs.uk/BA/4F4C1D/health-care-learning-disabilities-1718-sum.pdf> [Accessed 25/09/19]

<sup>3</sup> The Learning Disability Mortality Review (LeDeR) Programme Annual Report 2019. Figures taken from 1<sup>st</sup> April 2017-31<sup>st</sup> December 2018. [https://www.bristol.ac.uk/media-library/sites/sps/leder/LeDeR\\_Annual\\_Report\\_2018%20published%20May%202019.pdf](https://www.bristol.ac.uk/media-library/sites/sps/leder/LeDeR_Annual_Report_2018%20published%20May%202019.pdf) [Accessed 25/09/19]

<sup>4</sup> Projecting Adult Needs and Service Information (PANSI) (2018) based on Emerson and Hatton (2004) Estimating Future Need/Demand for Supports for Adults with Learning Disabilities in England. NB: these figures do not include Autistic Spectrum Conditions. [www.pansi.org.uk](http://www.pansi.org.uk) [Accessed 30/09/19]

<sup>5</sup> [www.poppi.org.uk](http://www.poppi.org.uk) POPPI v11 April 2019. and [www.pansi.org.uk](http://www.pansi.org.uk) v11 April 2019 [Accessed 30/09/19]

2019, rising to 9,524 in 2030. This overall improvement in longevity which reflects global increases in ageing populations (<sup>6</sup>United Nations Department of Economic Affairs Population Division, 2015) means that more people with learning disabilities can now transition into older age/retirement. It also means that by 2030, around 30% more adults with learning disabilities aged 50+ in England are predicted to require social care services with an estimated 164% increase in individuals over 80 needing social care (see Turner and Bernard, 2014:4).

## **Transitioning into older age**

Transitioning from one life stage to another is recognized as a time of upheaval that can be accompanied by environmental and social loss, and the making of important decisions (Forrester-Jones and Broadhurst, 2007). Whilst some people with learning disabilities will experience similar patterns of ageing to those of people without learning disabilities (see Stancliffe et al., 2013:5) and in the process suffer from age-associated diseases such as cancer (Tuffrey-Wijne, 2015), respiratory disease (Axmon, Höglund & Ahlström, 2017) and cardiovascular disease (de Winter, van den Berge, Schoufour, Oppewal and Evenhuis, 2016) others will age prematurely. For example, people with Down's syndrome have a 40% increased risk of Alzheimer's disease once they reach 50, rising to 50% once they are over 60 (Ballard, Mobley, Hardy, Williams, and Corbett, 2016). The period of age-decline for people with learning disabilities is therefore more prolonged than it might have been 20 years ago (Forrester-Jones et al., 2017: 1138) and is beset with increased health difficulties which tend to present at a much lower age in people with learning disabilities than the general population, including circulatory disease, chronic kidney disease, diabetes (as a result of muscular inactivity due to sedentary lifestyles, obesity, and antipsychotic drugs) (de Winter, Echteld and Evenhuis, 2014). Health conditions coupled with a decline in physical mobility, restricted access to appropriate social activities due to lack of transport, and the death of relatives and friends may also result in depleted social networks

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<sup>6</sup><https://www.un.org/en/development/desa/population/theme/ageing/index.asp> [Accessed 30/09/19]

(Forrester-Jones, 2014). That said, much more is known in the learning disability field about transitions from adolescence to adulthood than transitioning into old age.

## Older carers

An increased ageing population of people with long-term conditions including learning disabilities has been matched with an increase in the numbers of informal carers. In fact, unpaid care has increased at a faster rate than population growth, with 6.5 million carers now recorded in the UK (Carers UK, 2015), and 1.4 million people providing in excess of fifty hours of unpaid care per week recorded in 2012. It is estimated that 3 in 5 adults in the UK will become a carer at some stage of their lives (<sup>7</sup>Carers Trust, 2018) and a growing number of carers are also caring for more than one person in the household (e.g. an adult child and an older parent) either at the same time or at different periods within their life-cycle (e.g. an older parent and subsequently a spouse) (Hirst, 2014). <sup>8</sup>Wittenburg and Hu (2015:7) further estimate that in England, the number of disabled adults who are 65 and older being cared for by informal carers will rise from about 2.2 million in 2015 to about 3.5 million by 2035. Therefore ageing family members are increasingly playing an extended caregiving role into later life, and whilst 18% of the caring population are aged 55-64 years, 1.3 million carers are aged 65 years or over (NHS Digital in Hirst, 2014). The economic value of informal care, is estimated to be worth on average £9,000 per carer, or put another way, £132 billion in total per annum (Carers UK, 2015).

Until the scoping review of carer-related research and knowledge by Larkin, Henwood and Milne (2018), carer research had tended to be fragmented, documented in many different forms including articles, projects, reports and data sets, and were not synthesised. Consequently, they were difficult to locate and use. Larkin, Henwood and Milne's (2018) review found that this body of knowledge could be classified into four categories namely: impact of care – the consequences and sequela of caring; carer variables – the

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<sup>7</sup> <https://carers.org/key-facts-about-carers-and-people-they-care> [Accessed 29/09/19]

<sup>8</sup>Wittenberg, R., and Hu, B. (2015) Projections of Demand for and Costs of Social Care for Older People and Younger Adults in England 2015 to 2035 PSSRU Discussion Paper 2900 <https://www.pssru.ac.uk/pub/DP2900.pdf> [Accessed 30/09/19]

characteristics and features of different types of carer and caring situations; type of care – the nature of needs of the cared-for person and the features of the care situation; and support and carers – the provision and impact of general and specific help and support (Larking, Henwood and Milne, 2018: 57-58).

Older carers of people with learning disabilities, however, do not feature appreciably in the caring literature, which has tended to investigate the experiences of carers who are young, working, or supporting people with dementia and mental health problems, Larkin, Henwood and Milne (2018:55) stating “far less is about older carers or caring for someone with multiple needs”. The work that does exist on carers of people with learning disabilities has tended to involve very small samples - just 4 in the case of Davys and Haigh (2008), 5 in the case of Gant and Bates (2019) 9 in the case of Pryce, Tweed, Hilton and Priest (2017) and 12 (parents) in the case of Yoong and Koritsas’s (2012) study. All of this work has focused on future planning as a response to Mencap’s (2002) concern that local authorities are failing to plan for future housing needs, only responding to crisis situations (e.g. when a parent dies) (see Walker and Hutchinson’s 2018 systematic review of future planning of older parents). Bowey and McGlaughlin (2007) found that older carers either did not feel ready or were unwilling to make future plans, and recommended a more proactive approach by local authorities to provide information and support to enable families to make plans for the future. A more recent study (Bibby, 2013) however, found that take up of future planning opportunities remains poor with most parents not making future plans. Other studies have concentrated on one or two dimensions of caring such as the personal and psychological impact on carers (Dillenburger and McKerr, 2011). Chadwick et al., (2013) mapped the life experiences of family members in Ireland finding that the well-being of the family and challenges they face throughout their lives was affected by the availability of appropriate supports and information. Yet, their study, about family care-givers, did not specifically concern the experiences of older carers. Similarly, Public Health England (2016) report

*‘a reduction in the number of family carers of adults with learning disabilities getting a service for themselves as carers, with the number of family carers getting information/advice/signposting plateauing from 2010/11’*

and that

*‘over half (51.4%) of 6,160 surveyed family carers of an adult with learning disabilities (almost all of whom lived with the family carer) spend 100+ hours a week caring for that person, almost three quarters (74.3%) had been in a caring role for over 20 years and almost a third (30.2%) are not in paid employment due to their caring responsibilities’* (<sup>9</sup>Public Health England, 2016:85, 87).

However, these figures are not disaggregated for *older* carers (i.e. those who are 65 and over). This means that older carers of people with learning disabilities may be a growing ‘hidden’ population that is at risk of being forgotten about both in the literature, in policy, and in terms of receiving support.

## **Government Policy**

It is almost 50 years since the government’s White Paper *Better Services for the Mentally Handicapped* 1971 advocated care in the community, and 30 years since the White Paper *Caring for People* 1989 set out the principles for the subsequent National Health Service and Community Care Act 1990. This act followed the influential King’s Fund report ‘*An Ordinary Life*’, which promoted the principle of people living ordinary lives, in ordinary houses, in ordinary streets. Care in the community was therefore the service context in which most of the learning disabled people cared for by participants in this study were born. Two decades have also now passed since the government launched the 2001 White Paper *Valuing People* with its principles of rights, independence, choice and inclusion and the goal of enabling learning disabled people to “*lead full and purposeful lives in their communities and develop a range of activities including leisure interests, friendships and relationships*”. The UK subsequently signed the <sup>10</sup>UN *Convention on Rights of Persons with Disabilities* 2007 making a commitment to uphold human rights for disabled people in the same year as the Department of Health published *Putting People First* which stipulated that

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<sup>9</sup> Public Health England (2016) Learning Disabilities Observatory. People with learning disabilities in England 2015: Main Report Version1.0/Nov 2016 <https://healthwatchgateshead.co.uk/wp-content/uploads/2016/08/PWLDIE-2015-final.pdf> [Accessed 25/09/19]

<sup>10</sup> The Convention on The Rights of Persons with Disabilities adopted by the United Nations General Assembly on 13 December 2006. Resolution A/RES/61/06

anyone receiving social care could choose to have an individual budget. *Valuing People Now* (2009) then stipulated that newly formed partnership boards should progress health, housing and employment for learning disabled people. In the same year, the Autism Act 2009 put a duty on the Government to produce and regularly review an autism strategy and provide statutory guidance to local authorities to meet the needs of autistic adults in England. The Equality Act 2010 consolidated previous anti-discrimination law, extending the rights of individuals in areas of life beyond the workplace including in disability.

Gaps in provision of previous legislation, most notably post-code lottery outcomes of ‘street-level bureaucracy’ (Lipsky, 1980; Evans, 2010) in relation to eligibility, and inadequate carer’s assessments led to the <sup>11</sup>Care Act 2014 which introduced a single national minimum eligibility threshold across England, and stipulated that all local authorities are legally required to carry out a needs assessment of an adult if they appear to be in need of care and support. To be lawful, the assessment must think carefully about how best to maintain or improve the person’s ‘well-being’ including their: dignity; mental and emotional health; protection from abuse and neglect; autonomy and choice over their day-to-day life; ability to participate in education, work, training or recreation; social and economic well-being; social and family relationships; the suitability of their living accommodation; and their contribution to society. The assessment must be completed within a ‘reasonable time frame’ (around four to six weeks from when the request was made), and carried out by a competent and trained assessor (e.g. a social worker). The assessment should involve the person in every aspect of it, with the underlying assumption that they know best about their own needs. This goes beyond simply having the person present at the assessment and support from an independent advocate may be necessary to help their involvement in it. If an individual has ‘substantial difficulty’ in participating in their own assessment and care-plan, an ‘appropriate individual’ (e.g. a relative) or independent advocate should be asked about the person’s needs (including communication requirements).

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<sup>11</sup> The following section is paraphrased from Forrester-Jones (2019) Legal Considerations, Chapter 4 p.41-52 In *Understanding and Responding to Behaviour that Challenges in Intellectual Disabilities* (2<sup>nd</sup> Edition) Baker, P. and Osgood, T. (Eds) West Sussex, Pavilion

All relevant carers including family members should be involved in the assessment. An expert opinion from a psychologist, psychiatrist, or specialist behaviour nurse may also be needed in order to fully understand the person's needs (Department of Health and Social Care (2018)). A 'functional assessment' of the person's behaviour may also be necessary. The expert will describe and analyse the type of behaviour that challenges (e.g. frequently hitting others or hitting themselves; destroying objects) and assess what might be triggering it, including the impact of the environment (e.g. building, light, noise, other people), any past trauma, or anything else that might help explain the behaviour. They will also describe and analyse the purpose the behaviour that challenges serves the person (e.g. to communicate a message, or gain the attention of someone else).

The local authority (LA) has a duty to meet all of the person's 'eligible needs' identified in the assessment. 'Eligible needs' refer to those tasks a person is 'unable' to do on their own if unsupported (see <sup>12</sup>The Care and Support (Eligibility Criteria) Regulations 2015 no. 313 para 2 s(2)) due to or being related to a physical or mental impairment or illness. To be eligible for support, the person has to have two or more of the following 'eligible needs':

- Managing and maintaining nutrition;
- Maintaining personal hygiene;.
- Managing toilet needs;
- Being appropriately clothed;
- Being able to make use of the adult's home safely;
- Maintaining a habitable home environment;
- Developing and maintaining family or other personal relationships;
- Accessing and engaging in work, training, education or volunteering;
- Making use of necessary facilities or services in the local community including public transport, and recreational facilities or services;
- Carrying out any caring responsibilities the adult has for a child.

The LA must meet the person's identified needs by using a person-centred and person-led 'care and support plan' or a 'positive behavioural support plan'. The individual and their

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<sup>12</sup> [http://www.legislation.gov.uk/uksi/2015/313/pdfs/ukxi\\_20150313\\_en.pdf](http://www.legislation.gov.uk/uksi/2015/313/pdfs/ukxi_20150313_en.pdf) [Accessed 30/09/19]



family/carers should agree the plan and it should be reviewed at least annually. If the individual or their family do not think the support plan will improve their well-being, they can complain to the LA, or if necessary, the local government ombudsman. Alternatively, legal advice can be sought.

The LA will carry out a financial ‘eligibility’ assessment to determine whether or not the person needs financial assistance to pay for their care. Even if the individual is not financially eligible, the LA should still arrange the care.

If the individual has additional health and housing needs, the LA must notify the NHS or housing authority who will carry out their own assessments. The LA, NHS and other relevant agencies have a legal duty under the NHS Act (2006) and the Care Act (2014) to co-operate with one another to ensure that the person’s needs are met. For people with ‘a primary health need’, e.g. complex psychological or behavioural difficulties that require specialist care, or complex medication or feeding needs etc., they may be eligible for NHS ‘continuing healthcare’. Unlike social care, this type of medical care will be free regardless of the person’s financial circumstances and it can also be paid as a personal health budget (the individual agrees with the NHS how the money will be spent) or as a direct payment. A nurse assessor using a ‘decision support tool’ will assess on a continuum from ‘no needs’ to ‘priority needs’ a number of medical need ‘domains’ (see Department of Health and Social Care (2018) p. 6 para 20, Fig.1). If the person does not get NHS continuing healthcare, the NHS and the LA may agree to ‘joint funding’ the care. If the LA or NHS do not meet the individual’s needs according to the support plan (including providing a cheaper service which is less beneficial to the person’s well-being) they are acting unlawfully and families can make a formal or legal complaint.

Nevertheless, despite considerable policy and research in the interim decades the estimated 1 million learning disabled adults in England (<sup>13</sup>Hatton et al., 2016) remain disadvantaged in terms of relationships (Forrester-Jones et al., 2006), health and employment (McVilly et al., 2006; Forrester-Jones, Gore and Melling, 2010). Research findings consistently

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<sup>13</sup> Learning Disabilities Observatory. People with learning disabilities in England 2015: main report v1.0/November 2016 [https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/613182/PWLDIE\\_2015\\_main\\_report\\_NB090517.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/613182/PWLDIE_2015_main_report_NB090517.pdf) [Accessed 26/09/19]

demonstrate that what is most important to learning disabled people, including relationships, effective support and meaningful community engagement (Bhardwaj, Forrester-Jones and Murphy, 2017) is not realized in practice (Sango and Forrester-Jones, 2017). In a study utilizing focus groups with 68 learning disabled adults, Abbott and McConkey (2006) found that social inclusion (which was articulated as social interaction, acceptance, being in the community and opportunities) was not happening for individuals due to a lack of staff, accessible transport, the location of people's homes and concern about negative experiences in public. The importance of having the knowledge and acquiring competence to become an active member of the community was expressed, though it was felt that this was not recognized by support staff who, it was reported, lacked appropriate training.

Whilst 'supported living' is often regarded as the optimum living arrangement for people with learning disabilities and/or autism, affording choice and independence, (Bigby and Beadle Brown, 2016), it does not in and of itself equate to social inclusion (Johnson and Walmsley, 2010). Reinders (2002:5) argues quite reasonably that community is about people sharing their lives together. In any case, as an outcome of government policy emphasis for community and family-based support of adults with learning disabilities (Gant and Bates, 2019), the majority - around two-thirds - of adults with learning disabilities have been reported to live with their families, mainly parents (Emerson and Hatton, 2008; Cairns et al., 2013; <sup>14</sup>NICE, 2017, <sup>15</sup>BILD, 2019) many of whom are entering old age themselves, and are experiencing ill-health and frailty as well as longevity.

## **Carers**

It is now almost 25 years since the 1995 Carers (Recognition and Services) Act entitled informal carers to a 'needs' and 'ability to care' assessment. This was followed by the 2000 Carers and Disabled Children Act which gave local councils the power to provide certain

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<sup>14</sup> <https://www.nice.org.uk/guidance/ng96> [Accessed 26/09/19]

<sup>15</sup> <http://www.bild.org.uk/resources/ageingwell/olderfamilies/> [Accessed 30/09/19]

services direct to carers following an assessment. In the light of research identifying deficits in practice - including assessments not being routinely or widely promoted - and carers unsure of their right to an assessment (Seddon and Robinson, 2001; Carers UK, 2003; Audit Commission, 2004), the 2004 Carers (Equal Opportunities) Act placed a '*duty* on local authorities to inform carers about their rights in a proactive way' as well as 'offering services that support *carers beyond their caring role*, and to enlist the help of other statutory agencies' (Seddon, Robinson, Reeves, Tommis, Woods and Russell, 2007:1336-1337). As already mentioned above, the Care Act 2014 aimed to reform previous social care inequities, emphasising that carers were to be treated equally as those they cared for. Under section 10 of the Care Act each carer including a parent carer, is entitled to have their needs assessed by the LA regardless of the LA's view of the level of the carer's needs for support, or their financial means, or the financial means of the adult they are caring for. The carer does not have to live with the person they are looking after, or be caring full-time to have their own Carer's Assessment. The carer is also entitled to a Carer Assessment regardless of whether or not the person they are caring for has had a needs assessment, or if the local council have decided that the person being cared for is not eligible for support.

The Carer's Assessment should assess whether the carer has needs for support (or is likely to do so in the future) and if so, then what those needs are (or might be in the future). It should also assess whether the carer is able and willing, and is likely to continue to be able and willing, to provide care for the adult needing care (s5 (a) (b)), and what impact this has on the carer's life and well-being. Wellbeing is not defined precisely and whilst the examples provided by the Act are regarded as the most relevant to carers, they are not exhaustive or set in any order of importance - they should all be considered as aspects of wellbeing within the context of the individual's circumstances. As already mentioned, they include: personal dignity; physical and mental health and emotional well-being; protection from abuse and neglect; control over one's day-to-day life including feelings and choices about caring and support provided and the way it is provided; participation in work, education, training or recreation; social and economic well-being; domestic, family and personal relationships; suitability of living accommodation; the individual's contribution to

society. The assessment should also cover planning for emergencies (such as a Carer Emergency Scheme) – the local council should be able provide information concerning how to plan for an emergency. A combined assessment of both the needs of the carer and the person they are caring for can be undertaken at the same time if both agree.

Under section 20 of the Care Act, LAs are under a duty to meet the carer's 'eligible needs' subject to financial assessment. A carer's needs meet the eligibility criteria if: the needs arise as a consequence of providing 'necessary' care to an adult (that is, activities that the individual requiring support should be able to carry out as part of normal daily life but is unable to do so); as a result of carrying out the 'necessary' care, the carer's physical or mental health is deteriorating or is at risk of deteriorating; or the carer is unable to achieve at least one of the following outcomes:

- look after any other children they have responsibilities for;
- provide care to any other person;
- maintain their home in a fit and proper state (whether or not this is also the home of the adult needing care);
- eat properly and maintain proper nutrition;
- maintain and develop relationships with family and friends;
- take part in any education, training, work or volunteering the carer may wish to;
- making use of services in the community and social activities, hobbies etc. (see s3 (1) and (2) The Care and Support (Eligibility Criteria) Regulations 2015) and;

as a consequence, there is, or is likely to be, a 'significant' impact on the carer's wellbeing. Generally speaking, a carer will meet the eligibility criteria if there is (or is likely to be) a 'significant' impact on at least one of the areas of their wellbeing or a cumulative effect on their overall wellbeing as a result of caring for another person. 'Significant' is not defined in law and should be given its everyday normal meaning; in judging 'significant impact', local authorities will need to take into consideration how the individual judges the level of impact that caring has or is likely to have on their lives; this being underpinned by the principle that the individual is best placed to judge their own well-being.

In considering whether or not the carer can achieve the above outcomes, the local council must take into account any difficulties the carer has. The carer will be regarded as being unable to achieve an outcome if they:

- need assistance to achieve the outcome
- can achieve the outcome unaided but experience pain, distress or anxiety
- can achieve the outcome unaided but doing so endangers, or may endanger their's or another person's health and safety

Where the level of the carer's needs fluctuates, in determining whether the carer's needs meet the eligibility criteria, the local authority must take into account the carer's circumstances over such period as it considers necessary to establish accurately the carer's level of need.

Once eligible needs of the carer have been identified, the local authority assessor (normally a social work practitioner) should discuss the various service options which the local authority might provide or purchase for the carer. Where the carer's needs do not meet the eligibility criteria, the LA is required to provide them with advice on what services are available in the community to meet the needs they do have and to prevent or delay their need for care and support. This will ensure people are helped to access local services, which may be provided by the local authority or another organisation (see s13 para 114 Explanatory Notes Chapter 23).

Whilst laudable as this recent legislation is however, it is likely that in the wake of government austerity measures, ageing carers are trying to care for their loved ones in a seemingly ever decreasing social care environment.

### **Austerity measures**

Since the 2008 economic crisis, the government has introduced various austerity measures which have impacted health and social care. Since 2010, in England, LAs have been required to make further adult social care budget savings year on year. Other government actions have included allowing the private care market to expand, thereby reducing care prices, commissioning cheaper care provision (e.g. supported living models - which may provide

more independent living experiences for individuals - yet are also less expensive than residential care homes), and entrusting direct and personal care to low-paid, often poorly qualified and/or trained staff (Newton and Browne, 2008). By 2016, local councils had experienced five years of funding reduction amounting to £4.5bn tracked by previous Budget Surveys. Whilst the Spring Budget of 2017 included an additional £2bn for the period 2017/18–2019/20 as part of the Improved Better Care Fund (IBCF), this was reduced in 2018/19 to £674m and in 2019/20 to £337m (see 2018 ADASS Budget Report p.8). Such reductions have hit various counties hard, including Hampshire County Council (HCC) who announced in <sup>16</sup>September 2017 that Hampshire would be cutting its spending on social care by <sup>17</sup>£56m as part of a reduction in its overall spending by £140m by 2019; in addition to the £340m which had gone from the council's total budget since 2008. With such measures, as well as the introduction of the National Living Wage that drives up staff costs, and the influence of Brexit on an already stretched workforce capacity, adult social care markets are rapidly becoming more fragile. In this socio-economic landscape, those who need social care and those who care for them are increasingly becoming more reliant on the third sector. This may also be true of people living in Hampshire, and the New Forest area.

## **The New Forest**

As outlined by New Forest Mencap quoting the 2011 census, the old age ratio in the New Forest is 42.7 (compared to the overall UK ratio of 27.5) and the total dependency ratio is 70.7 (compared to the overall UK ratio of 55.1). <sup>18</sup>Predictions of population by age in the New Forest estimate a total figure of 52,800 people aged 65 or over in 2019 of which 9,900 (19%) are over 75 and 3,500 (7%) are over 90. These figures are expected to rise to a total of 64,300 people over 65 in 2030, 11,800 of whom will be 75 and over and 4,800 being 90 and over.

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<sup>16</sup> <https://www.bbc.co.uk/news/uk-england-hampshire-41280642> [Accessed 03/09/19]

<sup>17</sup> <https://documents.hants.gov.uk/finance/EfficiencyPlan.pdf>

<sup>18</sup> 2018 Projecting Older People Population Information System POPPI v11 April 2019 Institute of public care/Oxford Brookes University - Figures based on Census 2011. [www.poppi.org.uk](http://www.poppi.org.uk) [Accessed 30/09/19]

The New Forest has other challenges too, such as providing services in a rural area with a sparse population, a declining support-worker pool, and where affordable and accessible transport is a scarce resource. Mindful of social inclusion philosophy, it may be argued that understanding and meeting the health and social care needs of older people with learning disabilities requires additional specialist support (Bigby, Bowers, & Webber, 2011; Bischoff, Sudore, Miao, Boscardin, & Smith, 2013) yet equally, according to Sense [www.sense.org.uk/helpfamiliesplan](http://www.sense.org.uk/helpfamiliesplan), support for family carers who continue to provide high levels of support to their loved ones as they themselves get older is a necessity. In addition there is a palpable need for provision to be made after family carers have died, in relation to appropriate placements and care provision for individuals with learning disabilities.

### **New Forest Mencap**

New Forest Mencap was developed by young parents of people with learning disabilities in the 1980s. It currently provides four leisure sessions per week in two locations, New Milton and Brockenhurst. They consist of evenings of activities, opportunities for socialising and a number of day-time outings during the year. They have also launched the Gateway Award scheme which is modelled on the Duke of Edinburgh Award, and expanded to include some day-time creative activities and a supper club. Staff and Trustees develop links with other like-minded organisations. New Forest Mencap regularly participates in the Hampshire Learning Disability Partnership Board which is co-ordinated by HCC. They are also part of the Hampshire Learning Disability Network which brings together all the other local Mencap organisations in the county. In seeking to inform their future provision, New Forest Mencap is trying to expand its connections with parents of people with a learning disability and seeks to understand the support they need. With a grant from Awards for All Lottery funding, New Forest Mencap commissioned this project. The overall purpose of the project was to find out how best to support older carers who continue to care for their older adult family members with a learning disability. Exploring individuals' experiences of caring in a qualitative way was regarded as the most appropriate method of achieving this goal (see Lyotard, 1991). I felt privileged to interview individuals who were kind enough to share their time with me. Again and again, I was struck by the love towards their family members, their

resilience in trying to provide good care for them, and their good grace when things went wrong. All of the participants had, at some stage in their caring lives, experienced immense difficulties in caring for their loved ones, and some now in their 80s continued to care with what they perceived as little hope of any break. Whilst their stories of navigating health and social care were all different (people with learning disabilities and/or autism are not a homogeneous group even though services sometimes treat them as such), some experiences were common to the group and these became the main themes of the research findings. Often in research, what participants say at interview is afforded comparatively little space in the final report. I wanted to make sure that this was not the case here and have included extensive quotes. I hope that in doing so I have, in some small way, provided a conduit for these carers' voices to be heard.

I have attempted to write this report in a way which is most accessible to participants, as well as useful to New Forest Mencap.

## 2. Aims and objectives

The **aim** of the study was to explore the experiences of older family carers as they continue to care for their older adult relatives with learning disabilities.

The **objective outcomes** were:

- to delineate issues common to older carers as they care for their loved ones;
- to provide practice and policy recommendations on how best to support older carers;
- for the findings to help inform New Forest Mencap on where their future resources are best placed in order to support both people with learning disabilities and their carers.



### **3. Study design, methods and ethical considerations.**

Since the study aimed to unveil crucial information pertaining to the experiences and perceptions of older carers in a particular area of the country, an exploratory case study research design was chosen whereby no prior assumptions or hypothesis were used. The way the research was organised, the methods used and the sample are described here.

#### **Recruitment strategy**

In the absence of reliable registers (see findings section below), and so that participation was truly voluntary with no coercion, an indirect approach to recruitment with simultaneous overlapping strategies was taken (see Bjornson-Benson et al.,1993). Adverts in the form of a poster about the research with an invitation to participate (the criteria being that the individuals would be over the age of 50 years) were placed in the local paper, on local noticeboards, and through a CCG (Clinical Commissioning Group) weekly e-newsletter. The research was also advertised through the New Forest Mencap network during September 2018.

Twenty-one carers (inclusive of 5 couples) responded to these invitations. Five responded to the newspaper advert and the others responded to the invitation via the New Forest Mencap network followed up with general invitations from the New Forest Mencap Chair, supporting the research that follow up strategies increase recruitment (Dillman, 1991).

Times of interviews were arranged by telephone or by e-mail. The original plan had been to organise three focus groups with 7 participants in each (with a total target number of 21 participants). However, mindful of carer's individual circumstances, which often entailed having to timetable their own lives according to the activities of those they cared for, it was thought that organising groups of people on the same day at the same time would prove impractical. It was therefore decided that participants would be invited for individual interviews, with a target sample of 20. Two individuals who initially showed interest in the study declined to be interviewed (one simply did not come for interview on the day) but the partners of five interviewees joined the study and so the final participant response rate (21 participants in total) exceeded the target, where 75% is the usual expected response rate for

interviews (see Sitzia, 1998; Kelley, Clark, Brown and Sitzia, 2003). Despite the small-scale nature of the study, the response rate is highly encouraging for a potential study replication in other areas and regions of England.

## **Limitations of the sample**

The study sample was small and purposefully chosen, which is the usual sampling technique used in explorative, qualitative research (see Palinkas, Horwitz, Green, Wisdom, Duan, Hoagwood, 2015). There are limitations to using such a non-random sample. For example, the purposeful illustrative approach risked gaining a homogenous sample which would not randomly pick up people from Black and minority ethnic communities (<sup>19</sup>Emerson, 2015) and the findings are not easily generalisable. In particular, the area of Hampshire where this research was commissioned to take place is not traditionally known for its diversity, the majority of Hampshire's population being White British as depicted in the 2011 Census, recording 44,142 people aged 65 and over of which only 274 (0.6%) belonged to an ethnic group other than White. Similarly the New Forest population associated with higher prevalence of learning disability were recorded in the 2011 Census as 0.3% Asian/Asian British: Indian; 0.0% Asian/Asian British: Pakistani; 0.1% Asian/Asian British: Bangladeshi; 0.4% Asian/Asian British: Other Asian; and 0.2% White: Gypsy or Irish Traveller (HCC, 2018:14). This lack of diversity was reflected in the study sample of carers and those they cared for although of course these figures do not take into account any hidden or changing populations. Furthermore, the catchment area for the project – the New Forest – cannot be regarded as representative of Hampshire as a whole. A much broader study would be needed. The benefits of small sample numbers however, are that data concerning a specific naturalistic phenomenon – in this case the experiences of older carers of older people with learning disabilities and/or autism – can be subjected to a deep-dive descriptive analysis in order to extract rich and detailed understanding of themes that are important to the participants and that might otherwise be missed with large random sample sizes (Coolican, 2017, 224).

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<sup>19</sup> Learning Disabilities Observatory. People with learning disabilities in England 2015: main report v1.0/November 2016

## Ethical considerations

Each participant was provided with an information sheet outlining the study and stating that it would be preferable if I recorded the interviews. Before each interview, I also explained the research orally to participants so that they understood the nature of the research and that their participation was voluntary. Each participant was subsequently asked to sign an informed consent form, in line with <sup>20</sup>University of Kent and Bath ethics and a favourable ethical opinion was received on 28.08.18. Consent forms were stored separately from the data. All participants had capacity to consent. The face-to-face interviews took place in a quiet and private location at the New Forest Mencap Nedderman Centre in New Milton, or in participants' homes depending on their preference, and at a time convenient for them. No payment was available to pay participants for their time. Each interview took on average 45 minutes.

Each participant was assigned a numerical code so that their interview was anonymized. With the consent of participants, interviews were recorded and uploaded onto the University of Bath secure X drive and password-protected. One participant requested not to have their interview recorded but did consent to me using a laptop to type their responses non-verbatim. Recorded interviews were transcribed, and stored within a secure password protected file. Once transcribed, the recording of the interview was deleted both from the Dictaphone and the computer. Since I transcribed the recorded interviews myself, it was possible to redact any information which might identify participants at the transcription stage. Given the small sample size and limited geographical location I also obscured the gender of the participants, replacing 'he' and 'she' with 's/he' and 'him' and 'her' with 'her/him'. The names of particular day centres and care providers were also redacted since the aim of the study was to explore the experiences of carers, rather than to evaluate particular services, which would not have been possible with a single data source. Transcribed anonymous interviews will be sent to a secure repository at the University of Bath for future research analysis.

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<sup>20</sup> NB the author moved from Kent to Bath during the start of the project, hence the project being reviewed by two ethics committees.

Whilst every effort was made to ask questions in a sensitive way, recounting events and struggles carers had experienced or were still encountering could be difficult for some participants. Where this occurred I asked individuals if they wanted to take a break from the interview for a cup of tea, or stop the interview altogether. This happened in two cases and both respondents requested to continue with the interview. Potential researcher-participant power differentials were minimised by sitting next to rather than opposite participants and, where appropriate, sharing my own personal experiences as a family carer. Participants generally reported that they wanted to participate in the research. For most, it was hoped that participation might lead to finding out more about what New Forest Mencap had to offer in terms of services and advice. At the same time, participants hoped that sharing their experiences might help other parents “in the same boat” as described by one individual:

*“We saw the research in the local Gazette. We saw a little ad wanting people in our situation to take part in the research and we thought a) it might help you and b) it might help us also.”*

*“If it is going to be for [] benefit then we are happy to answer any questions”*

Others felt strongly that participation presented an opportunity for their ‘voice’ to be heard, beyond their usual social networks. The Chair of Trustees provided transport from interview to interview, dropping me off then collecting me once the interview had finished. Alternatively, they worked in another part of the Nedderman Centre during interviews that took place there. The Chair’s availability proved very useful immediately post-interview for participants who had questions - usually concerning information about a specific issue, for which they were able to get an immediate response. At least two of the participants had not heard about New Forest Mencap prior to the research taking place and in this way the study helped to profile the organisation. I hope that the research will further advance our understanding of the needs of carers of people with learning disabilities and/or autism so that services can plan more appropriately for this demographic.

## **Analysis**

Each of the 16 transcripts (5 of the interviews were with couples) was subjected to Interpretative Phenomenological Analysis (IPA). IPA, which combines psychological, interpretative and idiographic components is an inductive method of coding allowing for the voice of participants to speak rather than extracting data based on preconceived theories or a hypothesis (Smith, 2010). In analysing the text line by line and attributing codes to what participants had said (with the help of NVivo 12 software program for qualitative and mixed methods research) I attempted to suspend any preconceptions about the data that I might have so as to describe the experiential world of the participant. In this way, I hoped to understand what the experience of caring was like for participants (phenomenology) and how they made sense of these experiences (interpretation). Once coding had been completed, recurring patterns of meaning (thoughts and feelings) became subthemes – aspects of caring which were important and mattered to the participants. Subthemes were then grouped together into broader ‘superordinate’ themes, and direct quotes from 15 of the 16 interviews (one interview was not recorded) are used to evidence these.

## **A note on terminology**

Terminology and labelling around disability changes over time and across countries and cultures. It is a very important aspect of people’s personhood and identity. It is also, understandably, a contentious issue, discussion of which - if left unbounded - can sometimes take time and space away from other important life experiences. In the UK, the term ‘Subnormal’ was used in the 1959 Mental Health Act up until the 1980s when ‘People with Mental Handicap’ became the preferred term. In the 1990s, with the incoming National Health Service and Community Care Act 1990, the Department of Health’s official term became ‘People with Learning Disabilities’ and this is the usual term used in UK services today. More international classifications (i.e. DSM-5 and ICD-11) use the term Intellectual Disability or Intellectual and Developmental Disability (the term also currently used by the International Association for the Scientific Study of Intellectual and Developmental Disabilities (IASSIDD)). In this project, I use the terms ‘people with a

learning disability' and 'learning disabled' interchangeably as well as 'people with a learning disability and/or autism' and 'autistic person', to reflect the current move towards more identity first language rather than person first language (Kenny et al., 2016). I also use the term 'loved one' to denote a person being cared for since this seemed to reflect how participants felt and talked about their adult family members. 'Family' and 'informal carers' as well as 'older carer' are the terms used to denote the study participants.

## 4. Findings

### Prevalence of learning disability and older carers in the New Forest.

The ability to forecast future demand for health and social care is now an important component of commissioning; setting the scene for service planning, market development and demand management. NFM wished to know the total number of people with learning disabilities including the numbers of those aged 45 and older, and the numbers of older carers in the New Forest area in order to plan their own future service provision.

Population based analysis can provide amongst other things, indications of the prevalence of conditions such as learning disabilities that may require a social care response, help with exploring the relationships between population locations and service and community facilities, and help with identifying the numbers of people to contact within particular target populations in moving from a reactive to a proactive service. The Institute of Public Care provides such projections, derived from Office for National Statistics (ONS) data (see [www.poppi.org.uk](http://www.poppi.org.uk) and [www.pansi.org.uk](http://www.pansi.org.uk) version 11 April 2019).

<sup>21</sup>Projecting Adult Needs and Service Information (PANSI) (Institute of Public Care (IPC) Crown copyright 2018) data shows that the total number of people with a learning disability aged 18 to 64 living in the New Forest is predicted to be 2,318 in 2019 with the following estimates: 525 moderate to severe learning disabilities; 136 severe, 60 with Down's syndrome, 43 with challenging behaviour, 938 with autistic spectrum disorders. In addition, this data set estimates that 174 people with moderate or severe learning disabilities live with their parents. By 2035 the total number of those with a learning disability is predicted to be 2,203, with 503 having a moderate to severe learning disability, 132 with a severe learning disability, 57 with Down's syndrome, 41 with challenging behaviour and 888 with autistic

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<sup>21</sup> Projecting Adult Needs and Service Information (PANSI) NB figures may not sum due to rounding [www.pansi.org.uk](http://www.pansi.org.uk) v11 April 2019 [Accessed 27/09/2019]

spectrum conditions. It is also estimated that 171 with a moderate or severe learning disability will be living with a parent (see table 1 below):

**Table 1: People aged 18-64 predicted to have a moderate or severe learning disability and be living with a parent, by age, projected to 2035 from 2019 [www.pansi.org.uk](http://www.pansi.org.uk)**

**Data for: New Forest**

*Table produced on 06/11/19 15:39 from [www.pansi.org.uk](http://www.pansi.org.uk) version 11 April 2019*

	2019	2020	2025	2030	2035
People aged 18-24 predicted to be living with a parent	45	44	43	48	47
People aged 25-34 predicted to be living with a parent	45	45	44	42	43
People aged 35-44 predicted to be living with a parent	43	42	44	45	44
People aged 45-54 predicted to be living with a parent	29	29	26	25	26
People aged 55-64 predicted to be living with a parent	12	12	12	11	10
Total population aged 18-64 predicted to be living with a parent	174	172	169	171	171

Figures may not sum due to rounding. Crown copyright 2018

*This table is based on a set of prevalence rates for adults with a learning disability living with a parent, established as a proportion of those known via learning disability registers (the administrative rate as established by Eric Emerson and Chris Hatton of the Institute for Health Research, Lancaster University, entitled Estimating Future Need/Demand for Supports for Adults with Learning Disabilities in England, June 2004).*



<b>Rates applied to the administrative rate are as follows:</b>	
<b>Age range</b>	<b>%</b>
20-24	62
25-29	54
30-34	49
35-39	42
40-44	36
45-49	27
50-54	18
55-59	12
60-64	5

*These predictions are based on Estimating the prevalence of severe learning disability in adults - working paper 1, July 2009, Institute of Public Care, using LD registers from Sheffield and Leicestershire. Both sets of registers held information about the number of people with complex or severe learning disabilities and the number of people living at home with their parents. From the information on the individual databases, prevalence rates for people living at home were calculated by age bands.*

*The above prevalence rates have been applied to the administrative rate to give estimated numbers of people with a moderate or severe learning disability predicted to be living with a parent, to 2035.*

Caution is needed when interpreting these figures. They are predictions only and whilst<sup>22</sup> most tables are connected to the population projections in terms of the calculations, the data sets are not linked (apart from the learning disability baseline figure and the severe learning disability figure). Particular care needs to be taken when considering the autism spectrum conditions figures since these do not show the breakdown of people with autistic spectrum conditions and learning disabilities, and those without learning disabilities. Hence, it is likely that the numbers of people with both learning disabilities and autism

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<sup>22</sup> Personal communication: Andy Backinsell, Institute of Public Care 07/11/19

spectrum conditions will be lower. The predictions provided in Table 1 are also based on 2004 figures –the Institute of Public Care have been unable to update these<sup>23</sup>.

Nevertheless, the figures presented above indicate a fairly steady trend of people with learning disabilities in the New Forest needing care and support over the next 15 years, including those living with their parents.

Perhaps more significantly, <sup>24</sup>Projecting Older People Population Information System (POPPI) figures (also held by the Institute of Public Care (IPC) and using Office for National Statistics data) show that the total number of people with a learning disability aged 65 and over living in the New Forest in 2019 is predicted to be 1,099 (of which 167 are over the age of 85) with 145 estimated to have moderate to severe learning disabilities, 2 with Down's syndrome and 490 with autistic spectrum disorders. These figures are expected to rise to a total number of 1447 by 2035 (of which 300 will be over the age of 85), 183 will have moderate or severe learning disability, 2 with Down's syndrome, and 649 with autistic spectrum disorders. Again, whilst taking into consideration the limitations of the data set, these figures indicate a steady aging population of people with learning disabilities living in the New Forest over the next 15 years.

The publication <sup>25</sup>*Health Needs Assessment of Adults with Learning Disabilities in Hampshire* (HCC, 2018) quoting <sup>26</sup>NHS Digital, recorded around 0.4% (or 3,922) of the 2015/16 registered population of Hampshire having a learning disability, based on 'adults with learning disabilities (aged 18 or over), resident or registered with a GP within Hampshire, living in the community or in residential care (run by the local authority and other providers)' (HCC, 2018:8,12). NFM had asked Southern Health NHS Foundation Trust (SH) for up to date statistics on the numbers of people with a learning disability in November

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<sup>23</sup> Personal communication Jackie Daru, Principal Consultant, [www.poppi.org.uk](http://www.poppi.org.uk) v11April2019

<sup>24</sup> Older People Population Information System (POPPI) 2018 (rounded up figures) with Predictions based on prevalence rates reported by Emerson and Hatton (2004) Estimating Future Need/Demand for Supports for Adults with Learning Disabilities in England, Lancaster University. [www.poppi.org.uk](http://www.poppi.org.uk) v11April2019 [Accessed 12/09/19]

<sup>25</sup><http://documents.hants.gov.uk/public-health/2017-10-13FinalLearningDisabilitiesNeedsAssessment2017.pdf>

<sup>26</sup> <http://digital.nhs.uk/catalogue/PUB23781> [Accessed 12/09/19]

2016. At this time, SH provided a figure of <sup>27</sup>4273 (from 2014) people with a learning disability ‘known on the Hampshire GP Quality and Outcome Framework (QOF)’ but cautioned that this figure was probably wrong and under-estimated – and that health facilitators were working with GP practices to validate their lists to calculate the number of people with a learning disability who were registered, and to offer them annual health checks. Following a later request in November 2018, SH provided a figure of around <sup>28</sup>1,018 people with learning disabilities and/or autism known to the learning disability team based on GP registers – again this being an approximate figure since the learning disability registers were “*an on-going piece of work*”. A further request for up-to-date figures made in September 2019 was not responded to.

Hampshire County Council (HCC) Adult Services department was also approached by NFM in December 2016 to provide the number of adults with a learning disability and/or autism living in the New Forest area, as well as the number of family carers providing support to their relatives with a learning disability and/or autism. A figure of 739 was provided inclusive of 506 receiving a service (with around 500 receiving a service at any one time). This figure did not reflect the numbers ‘known’ to the local authority (‘known’ relating to those who had been placed into the area by another local authority, or referrals by a GP, police, or health who, following assessment, were deemed ineligible for social care). A later request from NFM in November 2017 resulted in a more detailed breakdown of figures (see table below) with a total figure of 490 people with a learning disability receiving a service and 700 ‘known’ to the learning disability team.

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<sup>27</sup> Personal communication SH 24 Nov 2016

<sup>28</sup> Personal communication SH 12 Nov 2018. It is not known whether or not this figure includes children

**Table 2: Breakdown of numbers and ages of people with learning disabilities with commissioned services or 'known' to the learning disability team in the New Forest Area.**

<b>Age</b>	<b>Number with commissioned service</b>	<b>Number with no current provision (see notes below)</b>	<b>Total number in this age group living in NFD and known to LD team</b>
18-20	10	9	19
21-30	122	46	168
31-40	104	18	122
41-50	95	20	115
51-60	103	33	136
60+	56	84	140

Notes: in house services do not count as commissioned - so there are some people known to the team who are listed with 'no provision' who go to in-house services. This accounts for only around one or two people in each column. 'Telecare' is not included in the number of people with a commissioned service, as that may be just a piece of equipment - those people would be in the second column if that is all they have.

Source: HCC 2017

The data sets used above are not comparable (e.g. the HCC figures include people in receipt of a funded package and represent only a proportion of the PANSI estimates) and therefore provide different figures (<sup>29</sup>although interestingly, the figures provided by HCC are similar to the estimated PANSI figures for people with moderate to severe learning disabilities). This highlights the difficulties for organisations like NFM - in the absence of any readily available and reliable central register - knowing who exactly is receiving social care support and who might need it, and how to strategically build support services. Data that is more consistently or routinely recorded or aggregated across the whole authority area/provision

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<sup>29</sup> Personal communication Jackie Daru, Principal Consultant IPC 07/11/2019

would help, including the exact numbers of people who have a learning disability and autism.

Incomplete data sets are not extraordinary to HCC or SH. Nationally, data sets for learning disability are generally incomplete. This is due to a number of factors including the tendency for learning disability not to be the focus of information gathering (e.g. where only primary social care need is recorded), or where classifications (e.g. mild, moderate, severe) are not recorded or where physical disabilities have been conflated with learning disabilities.

Similarly, no accurate data about carers is kept. Estimations for the New Forest in 2019 are that <sup>30</sup> 7,841 people aged 65 and over are providing unpaid care to a partner, family member or other person, this figure predicted to rise to 9,437 by 2030. However, similar to the estimates for people with learning disabilities, the proportion of these unpaid carers who are supporting people with learning disabilities and/or autism is unknown. But, given the predicted numbers of people with learning disabilities, it is likely that parents and other family members living in the New Forest who are approaching older age, many now in their 70s, will continue to care for their middle-aged/older children/relatives with learning disabilities, again, highlighting the need for strategic planning regarding social care provision.

## **The sample**

The sample was made up of 21 older carers, five were men. The average age of the carers was 75 years old (based on 18 participants' ages) though if one outlier age of 52 was removed, the average was 77 with an age range between 64 to 86 (4 or 20% of the sample aged 80 or above). Whilst this average and range depict the interviewees' ages, five participants also reported the ages of their partners/relatives who were not interviewed but who were equally caring for their loved ones. These individual's ages ranged from 76 to 93 and they were all male (according to the 2011 Census, carers over 85 are more likely to be

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<sup>30</sup>[www.poppi.org.uk](http://www.poppi.org.uk) [Accessed 25/09/19]

male (59%) than female (41%)). Apart from three, all the carers were officially retired. This group profile appears to mirror more national findings suggesting that an increasing proportion of people with learning disabilities are being cared for by a family member over the age of 70 (see Pryce et al., 2017).

The 16 individuals who were being cared for had either been diagnosed at some point in their lives as having a learning disability that is, meeting criteria of: a significant reduced ability to understand new or complex information and/or learn new skills (impaired intelligence/IQ of less than 70), significant impairment of social or adaptive functioning, or ability to cope independently, and onset of the impairment before the age of 18, with a lasting effect on development (NICE guideline [NG96] 2018; DSM-5; ICD-11; DH, 2001; DH, 2009), or in the case of two individuals, were regarded as learning disabled in relation to social service provision. Five had syndromes including Smith-Magenis Syndrome and Down Syndrome, two had cerebral palsy, and seven were autistic people in addition. Five also had physical disabilities and six currently had additional health problems including osteoarthritis and obesity. Two were reported as having challenging behaviour. Learning disability classifications therefore ranged from mild to severe. Their average age was 45 years with an age range of between 27 and 56 years (50% of this group were over the age of 50 years). Eight were living at home, the others were living in supported living or private flats.

All of the cared for individuals were in receipt of local authority personal budgets with twelve receiving Direct Payments. All apart from one were receiving some kind of social care support, ranging from, for example day service provision at a local day centre 5 days a week to 33 hours per week support from a carer helping with domestic tasks such as shopping and cooking.

*“[Loved one] tried [name of day service] computing and s/he also goes to Aqua Aerobics’ locally with someone who cares for [her/him] – that’s all paid. S/he pays for [their] own entertainment. [name] Arts Centre – [name of learning disabled person] pays for it all.” (018)*

Almost all family carers however organised, at minimum, two activities per week for those they cared for:

*“Carer takes her/him out 9-4 Mon to Friday. S/he enjoys it as it is a varied timetable. Not an awful lot happens here [rural location] so we have to find our own activities – [name] Farm voluntary work, swimming and gym.” (o18)*

## 5. Main Themes

The delineated themes from the data are presented and accompanied by substantive quotes from the participants, which in so far as was possible have been unaltered by the author to maintain the participants' authenticity – apart from where there was a risk that anonymity might be compromised. The quotes selected were assessed as the most representative, and the ones that best articulated the substance of the themes. Three dots indicate a pause in the participant's speech. Identifying information is replaced within square brackets.

Four distinct yet interrelated themes emerged from the data analysis, each comprising of subthemes. These describe how the participants experience their caring role, and how they perceive and make sense of these experiences.

### **Theme One: Transition to Retirement - a misnomer for carers “*I just get on with it. You either do or you don't*”**

Whilst the majority of the participants had formally retired from full-time paid employment, there was a sense that the transition from their working lives had not been accompanied by a withdrawal from responsibilities. In fact, it appeared that their emerging state was one of more not less obligation, and stress which was linked to the impact of their loved one getting older. The following subthemes describe each of these components:

#### **Subtheme: The impact of changes in health**

In general, people with learning disabilities and/or autism experience a poorer health profile than the general population, with a conflation of genetical medical conditions such as Smith-Magenis syndrome (symptoms of which include sleep disturbance), and additional health difficulties that develop such as sensory impairments. These latter conditions may go undiagnosed or misdiagnosed because general practitioners find it hard to distinguish the symptoms. Most of the individuals in this study had health problems including obesity, which in some cases was due to lack of lifestyle choices, advice and support regarding diet and exercise; paid support to help someone to buy ready meals was felt by some parents to



be unhelpful in this regard. Other carers, particularly those caring for a person with Down's syndrome, reported that they had observed their loved ones becoming 'more forgetful' and were concerned that they might be 'getting dementia'. According to NHS Digital, current figures for NHS West Hampshire CCG (from 56% of patients registered in GP practices) indicate that 1.3% of registered patients with a learning disability have dementia (compared with 1.0% of the general population), 12.4% have depression (compared with 13.1% of those without a learning disability) and 4.7% have severe mental illness (compared with 0.7% of the general population). Down's Syndrome accounted for 11% of the population of people registered with a learning disability (7% in the age-group 55 to 64 and 7% for the age-group 65-74). Those with Down's Syndrome and dementia in addition accounted for 0.6% (with equal proportions in the age categories of 45-54 and 55-64). It is likely then, that the concerns of some parents were realistic. However, despite most of the participants reporting that annual health checks were on offer to their family members, getting the 'right' or 'specialist' health care for their loved ones (in two cases this related to sensory impairments) was difficult, resulting in family carers having to arrange or 'sort out' appointments with GPs and hospital consultants. Barriers to accessing healthcare including sight, hearing and dental checks have been reported as problematic for people with learning disabilities in the wider literature particularly if they are living independently or with family (see Heslop et al., 2013). In the absence of specialist learning disability health care (e.g. only one of those interviewed mentioned that they had had access to a learning disability nurse), many reported that they themselves provided direct health as well as social care:

*"I have to be there to take [her/him] to the hospital – s/he had cancer. When we moved here I was concerned about check-ups. I do all the cooking, washing, and ironing. Nothing I find difficult. I'm not asking for help at the moment. We never know do we...?" (015)*

*"We are there. We are constant parents for her/him...actually part of [name] syndrome is a sleep disorder so you know that becomes our life as well..." (005)*

Growing frailty, both mentally and physically as a characteristic of their aging loved ones meant that over half of the carers reported having to think about adaptations, particularly where their family members were experiencing reduced mobility:

*“Well yes, as s/he... umm her/is walking is deteriorating because of her/is knee so s/he has to use one of these rollator things now which s/he didn’t used to.” (020)*

*“Umm s/he has curvature of the spine and as s/he gets older that will probably become more of a problem but at the moment s/he has to go up two flights of stairs to get to the flat. So at some stage we have thought that we would need to get her/him somewhere to live with a lift.” (004)*

*“but s/he is getting more middle aged - ‘oh my back hurts’ and ‘my knee hurts’. And when s/he falls over, which isn’t very often, s/he lands on her/his knees and of course s/he has a puffy old knee for a few weeks after that so I have to keep an eye on her/him but s/he has to be taken everywhere. You see s/he can’t go on her own.” (005)*

Increased health problems caused carers anxiety since they worried about what support might be available as they themselves experienced varying degrees of age-related illnesses which began to limit their caring capacity including no longer being able to drive individuals to GP and hospital appointments. These concerns appeared to be exacerbated by a lack of trust that formal support would be available, as exemplified below:

*“As s/he gets older, if you can cope in the last years.... 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 [name] stays safe. It is really hard.” (018)*

*“Scary! Absolutely. We knew when we were told s/he would always need care and you go with it. But as it gets closer and we have hiccups with health; how on earth is s/he going to cope ‘cos care is just not there. It scares me that the support isn’t going to be there. Agencies always letting her/him down –you have to cancel your life.”*

*“We are getting older, we can’t do it anymore and there just isn’t the accommodation provided or expertise and I am fortunate that [name] is able as s/he is.” (011)*

Uncertainty concerning the ability of services to react positively and appropriately has been found elsewhere (see Walker and Hutchinson, 2018). The above quotes also demonstrate

how health problems of carers also act as triggers for anxious thoughts and feelings about the future; thoughts that may impede their own health recoveries. The quote below reveals how the impact of a family member's previous living environment breakdown has had secondary outcomes for their own wellbeing – something that formal paid carers do not ordinarily have to endure:

*“I think actually things have got more challenging and I say we had these two very horrendous difficult experiences of residential and I think the second one where s/he was really bullied by one of the ladies sharing the house. Something happened to her/him there and it's not really got right and it's never really got right. So it doesn't take a great deal to bring on anxiety and so that is something we have to be constantly aware of and not always being able to be as strong as we would like is to be in terms of her/him coming to stay with us. S/he likes the flat and loves to tell people 'I live on my own', but any excuse to stay the night with us. Quite a tight rope with her/him.” (O11)*

Other behavioural changes linked to the ageing process could be very challenging for some family carers to manage:

*“S/he has definitely become more autistic, more routines. I am having a real battle with her/him.” (O19)*

*“More difficult definitely - more stubborn; never pliable but [ I ] could insist but not now - can talk to her/him until you are blue in the face and battle [for example] about throwing an old pair of shoes out. I tried to put them into the bin. We keep getting them out of the bin and they go back into the cupboard – no such thing as 'no'.” (O18)*

The above problems were balanced by some participants' experiences of their loved ones becoming 'calmer' or more 'confident' as an outcome of being more independent. Alternatively, they had simply slowed down as they aged or had reached a plateau of skill acquisition, and were therefore easier to manage:

*“[S/He is] getting slightly better as s/he gets older – more confident in her/himself and his/her life.”*

*“No, s/he seems to have got calmer as s/he has got older. Never given me any trouble but sometimes there was frustration, that kind of thing.” (O15)*

*“As s/he has got older, s/he has improved as s/he has become quieter, will take dinner plates out and is happy to sit and watch TV.” (014)*

*“S/he is on the up, s/he has taken flight, s/he is really loving life at the moment” (004)*

Finally, a few participants reported that their loved ones were beginning to adopt what Perkins and Haley (2013) and Fyffe et al., (2015) referred to as reciprocal or mutual care within the family unit where by the person with a learning disability has both a care- giving and carer-receiving role illustrating a more strengths-based perspective of the person with a learning disability (Howe, 2017).

*“It is funny because things have changed round now. I broke my leg last year and it is not as strong as it was. And s/he now says ‘this old dear’ and s/he takes hold of my hand [laughs]. We laugh about it, but in actual fact it is good from her/his point of view that someone else needs looking after.”*

### **Subtheme: Hidden aspects of care – carers as ‘care managers’**

It did not appear to matter whether the person with a learning disability and/or autism lived at home (50% of those being cared for) or in supported living (again, 50%) or whether they received direct payments or care directly through social services – family carers continued to hold the primary care role, though this was not necessarily what they wanted. This role included not only direct support with health care, but supporting or doing domestic chores and other daily tasks such as shopping, transport, and social activities. It also included ‘managing’ their family member’s affairs, including their finances, and organising carer availability commensurate with timetabled activities. Whilst individual family carers reported that they had upskilled themselves in the process, often becoming ‘experts’ in financial and legal matters, this type of work could be time consuming, complex, and frustrating as exemplified by participants’ statements provided below:

*“I settle the bills and that is a nightmare –I feel like I am a qualified accountant and trying to set it up it really was a nightmare –anyway we got it sorted out eventually. I just pay the bills on line” (010)*

*“Well s/he gets umm s/he has just been converted onto PIP [Personal Independence Payment] umm and I... one of the things I need to do it sit down and work out how much money s/he gets in, and use that money more for her/him to do activities. But you know I’ve got a list as long as your arm of the things I need to do, you know, s/he’s been on PIP since Sept last year and s/he’s got the mobility allowance so s/he’s entitled to a new car. And I know s/he’s entitled to a new car and I know that the car we’ve got needs replacing, but, you know, when do I have 5 mins to buy a new car - if it only took 5 mins?” (020)*

*“You have to do an awful lot of thinking” (002)*

*“S/he manages very well really but it would not work if my husband and I were not there and it is me obviously. Umm as I say s/he does very well but s/he has probably reached her/his limit of her/his capability. (014)*

*“Well everything I find out, I find out from myself, and I struggle...” (016)*

The quotes above reflect the time needed for so-called ‘hidden’ aspects of care. These stretch the concept of ‘care-giving’ that traditionally includes notions of ‘caring about’ someone through expressed concern, emotion or financial/gift giving (Grant and Ramcharan 2001), and instrumental and motivational care (Parker, 1981; Nolan et al., 1996; Forrester-Jones and Broadhurst, 2007). Whilst personal budgets paid via direct payments have afforded individuals with learning disabilities and/or autism a sense of independence and choice of services to meet their social care needs, for many, including the carers whose loved ones lack capacity to budget themselves, the task of a) recruiting carers, b) paying them, c) keeping records, and d) providing information including timesheets signed by personal assistants, or receipts for services from agencies, can be confusing and overwhelming:

*“We employ an agency. We couldn’t have a PA because you can’t work with [name of person with learning disability] all the time - it’s quite hard...” (005)*

*“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 ought to be paying into a pension for them, if anything happened I would have had to get rid of them, I would have to pay redundancy pay. I ought to comply*

*with all the rules and regulations about employing 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. The other thing I didn't like at the beginning. They sent a letter to say yes [name] [has been] been awarded - it was 8 hours s/he got... [social services] asked me to open a bank account and then that was it. There was no more communication unless they send letters out which were addressed to [name] saying 'you know this is how much money you have received this week, this month' so there were two and a half months' worth of money in the bank account before I realised that money was going in there and then I looked at all the paperwork and I think 'well hold on a minute because it's an amount, a little bit different each month - I think - how much does that equate to? How much do I pay these people?' So because I said 'look, this is how much money has gone in. Its supposed to cover 14 hours a week so how much do I pay them?' So they told me '£12.50' so every time I'm in contact with social services they tell me 'oh you should only pay them £12.10.' Well I'm not going to give my people a pay cut. I'd rather take the hit and pay them £12.50."*

The carer above was faced with the practical outcomes of employing carers as well as the uncertainty of this role which appears to be counterintuitive to the 'freedom and choice' that direct payments promise to provide people with disabilities and their carers. Whilst a Direct Payments (DP) support service is available in the county (either funded by HCC or provided by additional Direct Payment funds) this potential support was not a feature of the delineated themes and it may have been that carers did not know about the service. The limited literature on this topic critiques the emergence of a 'support market' that is not always appropriate for recipients (see Priestly, Jolly, Pearson et al., 2006) but more research is needed to explore this aspect of the direct payments model.

Routine timetables of activities, usually as the result of a care assessment, provide a purpose to get up in the morning and a structure to the day for people with learning disabilities and/or autism. Yet, there was also a sense that the timetable only worked so long as family carers were managing the practicalities to make them work:

*"The biggest problem with carers is that - these particular carers are excellent. It is a very good little company and I had a fight with Hampshire County Council for paying for them. Anyway, I think I won that. But they [carers] are really really good but you know - if I am here. 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 or whatever they are, they aren't really the managers of the situation. So if I dropped dead tomorrow, you know there would be nobody to, well that is not quite true, my son would pick up the bits but it wouldn't be in the same way as though I was round the corner and all of that". (012)*

The next two participants' quotes exemplify how family carers have to reorganise their own lives to accommodate their loved one's routines in the absence of support to help them engage in their own activities:

*"I can go to the meetings (New Forest Mencap meetings) if the carer can get to change her night." (009)*

*"I'm quite happy to look after her/him and I want to be sure that when I'm at work and away from home that s/he is being properly looked after all of the time. And I will happily look after her/him at the weekends. Ok there are odd times when I think 'yeh', like this weekend I have been asked to work overtime so I contacted all of his/her carers and said 'if any of you can do any hours this weekend I would appreciate it.'" (020)*

Furthermore, participants reported that independent living did not stop their adult children from going 'home' for weekends, or indeed, getting support from their parents on a daily basis. Thus, family carers were never really 'off duty':

*"Umm s/he lives in a flat on her/is own but, for example, s/he will phone me three or four times a day and s/he is at home with us at the weekend. Saturday, s/he stays with us Saturday night till Sunday. Goes back Sunday evening, and s/he will take any and every opportunity to come and stay so just now because it is Christmas, s/he has been with us for a fortnight". (014)*

*"S/he is very very able but emotionally very dependent on someone like me particularly and in particular one of his/her Thursday support workers. The Flat is in [place name] – it wouldn't work if it wasn't... it is like 4 mins in the car. I mean you know the sorts of things that happen – s/he phoned at 2am the other morning 'oh oh oh I have this awful pain'....I was sort of saying 'oh well perhaps you can wait till morning' and in the end we had to go out and get her/him and take her/him to hospital. For example if the washing machine flooded who will s/he call? S/he is ok at night but if you have a big*

*storm s/he gets very frightened and anxious. In the middle of the night an alarm went off, and not the smoke alarm, so we had to go over and it was the carbon monoxide alarm battery had run out. S/he has got care but on top of the list is 'us' so anytime we go away we have to organise – both our other adult children are not on the doorstep so going away is quite a task – we have to make sure all eventualities are covered. It's been 10 years since we have been away for a fortnight" (007)*

So, while family members may not be directly responsible for day-to-day hands-on care, as Eley et al., (2009) stated, they “keep an eye on” their loved one’s life, including providing financial and socio-emotional support and in many cases, facilitating the maintenance of relationships between their loved one and other family members including siblings. The above quote also illustrates how the relentless need to provide support means that what would be regarded as a natural and normal expectation i.e. having a holiday, is often not realised.

Whilst family carers understood that occasionally things could go wrong with services, the perceived increased risk of this meant that many felt that they always had to be ‘on call’. The quotes below all show how a lack of continuity of carers can negatively impact on the experience of getting support for both the person with a learning disability and their family carers:

*“The council pay for an agency to take her/him but s/he is only allowed two and a half hours and sometimes they don't turn up. Sometimes they ring up and let her/him down and s/he gets upset. I never tell her/him anything unless we are actually going. I won't tell her/him the day before. If someone said it was next week s/he would think we are going to do that now. They are talking about taking them swimming which s/he has been wanting to do but unless they all want to go they won't have the staff to take her/him so now s/he pays someone privately to take her/him swimming. They knew if s/he was let down s/he would get upset. They knew they would have to warn us well in advance but some of the [staff] didn't realise. S/he wasn't told one day when we had sorted out privately [to take her/him swimming]. They turned up in the middle of the day - we said 'too late'.” (003)*

*“...so for example this week s/he hasn't had any carers you know because one carer is off sick, another one has gone to [place name] because they have a crisis in [place name] and another one is on holiday and [name] can only have a small care team and*



*so you know if a new, 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? If you ask [name of loved one] you know 'do you want a carer'? S/he would say to you 'go away I don't need you' and then you know s/he would be left and the house would be on fire. S/he is living at home. What happens is, there needs to be someone with her/him and so s/he finds the transition from us to a carer quite difficult. If s/he knows them well that is less difficult. If s/he doesn't know them at all s/he wouldn't... they wouldn't even get through the door.. umm.. and so the agency sending other people and s/he not knowing them well doesn't work. So, so the transition is also a difficulty even if s/he really really likes the person and knows them well but it is a difficulty but we can get over that because we know her/him and they know her/him.” (005)*

*“S/he has the same carer who works for herself. [name] knew her/him through the service so she [the carer] already knows [name]. Her daughter is at school now so it doesn't work as well as she doesn't have a backup if she is ill or her daughter is ill - it happens enough to be a bit of a problem”. (018)*

*“I would like for [name of loved on] continuity of care. We tried having an agency and there was no continuity - we were linked to two carers who were supposed to get to know her/him but that didn't happen - they said they couldn't care for her/him. Sitting with his/her hat and coat on and last minute they [the carers] would say they weren't coming. I like the one-to-one support but when [care agency] has no back up, it all breaks down”. (015)*

*“Every now and again with no notice they will phone me up and say 'tonight's carer is off' and so [loved one] will come home and I think 'Oh bugger I have to cancel what I was doing' but sometimes I don't even bother coz I think 'oh well'... but sometimes it is quite nice that I can go home later and have my dinner at half past six rather than half past five. We run the house like an army camp if I'm honest – routine-oriented and people will know not to ring if we are having our tea. I don't, it is quite umm... and that's quite nice when s/he's not there... I'm not running the house quite like an army camp.” (001)*

The latter four quotes above concerned carers who were 'managing' direct payments for their loved ones. HCC (2018:6) states that the “*use of direct payments has increased overtime, which may demonstrate that people with learning disabilities who use social care are now more likely to manage (with support) their own care, and spend money on the support they feel they need*

*most, in a way which is suitable for their individual needs.”* Whilst there is no doubt that the implementation of the relatively simple idea of <sup>31</sup>direct payments (since April 1997) has provided an important means for many people with disabilities of achieving more independence and hence social justice (Riddell, Pearson, Jolly, Barnes, 2005), the practice of organising direct payments so that people with learning disabilities can really benefit from them has proved to be rather more complex (see Shearn and Todd, 1997; Holeman and Bewley, 1999; Spandler, 2004). Similarly, the quotes above reflect how the outcomes of more personalised budgets appear to be a far cry from the intended ideal. Making sure that the level of care meets their loved one’s needs and making the necessary arrangements appears to have become part of the informal carer’s role, at least for the participants in this study, corroborating earlier findings (see Williams, Simons, Gramlick et al. 2003).

### **Subtheme: Increasing costs of transport and ‘adequate support’**

Austerity cuts have meant not only an increase in the closure of care homes and contract hand-backs, but also day service erosion (1 in 3 local authorities have already closed their day services (<sup>32</sup>Unison Report, 2019)) with little or no alternatives to mitigate these impacts. Whilst personalised care plans promising more independence, choice and a conduit to community social inclusion have outmanoeuvred traditional collective provision, in practice, people with learning disabilities are becoming more reliant on third sector organisations for care and support including charities (Power, Bartlett and Hall, 2016) such as New Forest Mencap, as well as social enterprises (Walker and Hayton, 2017). This has led to many carers feeling that in order to get the ‘right’ support for their loved ones, they now have to find alternatives and organise introductions and transport to these themselves:

*“The day centre closed which is how we met the Saturday girl....but it is such a massive organisational pursuit” (001)*

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<sup>31</sup> Department of Health (1996) Community Care and Direct Payments Act: The Stationery Office, London

<sup>32</sup> [https://www.unison.org.uk/content/uploads/2016/11/24149\\_The\\_Damage\\_care\\_in\\_crisis\\_web.pdf](https://www.unison.org.uk/content/uploads/2016/11/24149_The_Damage_care_in_crisis_web.pdf) [Accessed 28/09/19]

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

*“Umm... so I guess the major thing is that now I have to ferry [name] to and fro which I didn’t have to do before because of this taxi service [now not provided]... so really I am confined to the home apart from the time [name] is at the day centre or with [her/his] carer...” (009)*

For others, reduced options of day service meant that what was on offer wasn’t necessarily appropriate to the individual:

*“Well I know s/he doesn’t like going to the day centre and sticking bits of paper together... you know and the other day s/he brought home a bloody sheep that s/he had made with the inside of a toilet roll with cotton wool stuck on it. S/he’s 54 years old. S/he doesn’t want to be doing that kind of thing. I mean I can’t quite imagine her/him doing it and I can’t imagine s/he say if I said ‘Oh let’s make one of those sheep at home’ coz I’d get the full ‘tell me where to go’. Were as at the day centre, they probably wouldn’t - they’d probably be a bit grumpy. It would be interesting actually to see, to know. That’s the other thing at that day centre. S/he been there now coming up to two years in April - it could be three, I don’t really remember when it happened, but umm I rang them up after s/he had been there a year, or soon after, because something happened. Oh that’s it, I got a letter from some medical people saying ‘oh [name] has been assessed for dementia’ and I didn’t know anything about it. So I rang them up to say, you know, ‘when is s/he going to have her/ is 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”. (020)*

*“The Day centre is more like a baby minding not quality activities. [name of service that had closed] horticultural green house was good”. (008)*

For some participants, even when they could get daily or weekly care for their loved one, it didn’t quite work out for various reasons including simple personality incompatibilities between the carer and cared for, one participant stating *“The carers are not his/her type of people” (004)*. Whilst we might expect to experience awkwardness or personality difficulties within any work environment, such issues can be more intense within a care environment especially when more personal and intimate care is being provided, or when carers are

spending protracted amounts of one-to-one time with their client. Yet, in the current climate of service cuts, there may not be the breadth of paid staff to enable choices, changes, or recycling of carers. Equally, the prospect of ‘losing a good [paid] carer’ caused concern for some carers:

*“The carer herself is in her 50s so she may not wish to do it for ever. We might still be ok, and be able to get someone else, but if something happens to us then what will happen then? If we could really feel sure that her/his current carer will be around for a few more years.... But they like to travel a lot. The other [carer] that we had gave up because she was getting married and she just passed all her social services exams and she is up to here in work and they work them to death - but she does go and see [loved one] - just on the odd occasion”. (006)*

The quote above also reveals a perennial problem with the current social care system – that, due to poor wages, ‘good’ staff will strive towards, and get promoted.

Other participants said that they had to supplement daily pursuits or in the event of the day centres closing or transport issues, replace them with their own routines and day-to-day activities, leading to further dependency:

*“The county council ran a day centre which s/he loved but they gradually took everything away, and the day centre closed... most of his/her activities are now with me”*

*“What worries me is that s/he is more dependent on us organising things for he/im”*

The quote below demonstrates how informal community networks can really help bridge the gap between family carers having to organise activities and their loved one having some semblance of independence, though sadly, these types of stories were few and far between:

*“But the church have done a lot in the last few months and that outside source ...and s/he was at another church before that and they were lovely there as well. They are mostly older people and they loved [loved one] but s/he didn’t get invited out. There wasn’t a lot going on socially for her/him to get involved in...The church [currently attended] have been wonderful – they have a lot going on socially.”(010)*

Doing things with an adult child/family member was not always what either party necessarily wanted, especially given the wide generation gap between adult child and

parent. In the following quotes, parents reflect on how their current living situation may be limiting their adult child's life opportunities:

*"I feel that s/he is missing out on a lot and especially being stuck with an elderly mother - there is no future in that and I am getting older. I am now 70 so ummm I'm not as agile and I'm much slower than I was so I feel that the time that I spend with her/him umm... I think that s/he is disadvantaged by it - you know - the fact that s/he has not got to another place. Really what s/he needs - you know - what s/he needs at the age of 34 - you know - s/he needs - s/he has for years since s/he was about 18 wanted her/his own home and s/he was given a placement which didn't work out and I guess this is because you know s/he was only there a few months and I guess this is the sort of thing - the settling in business and you know it was too far. It was in [name of location] and so I wasn't able to be there you know because it took me about half an hour to get there and you know by then any problems they had, had been passed and that was unfortunate and of course [loved one] has been eager to try again but there has been nothing since and that was in 2011 so from April to November we have had nothing since although s/he would still like to try again and especially since Christmas day 2009 my [spouse] died and so that has left loved one] feel very anxious because now s/he only has one person to care for her/him and I guess I am getting older and any problems I have become an extra anxiety for her/him."*(009)

*"Well I always say that we can't take her/him to things like discos and things like that which s/he absolutely loves you know - I told you s/he is a social person - but we can't sort of get to places and when we go on holiday we feel a bit stupid you know going onto the dance floor at our age [both over 85 years old] - but there we are, we do try and I always feel that [loved one] could do with having a companion who would be available to take her/him, I suppose to replace my daughter in law as that is the role she plays and she is happy to go out to places like a disco and all the events that come with her employment - and they have social evenings especially at Christmas."*

As stated earlier, two-thirds of adults with learning disabilities now live with their families – mainly parents (NICE 2017). Given the depletion of day-service provision, it is likely that Mencap's (2012) estimate that 1 in 4 adults with learning disabilities is spending less than one hour a day outside of their homes is a reality. As people with learning disabilities get older, it is reasonable to expect that they may wish to engage in different, more older-age-appropriate activities (Wilson et al., 2010) than they did when they were younger. At the

same time, as shown in both of the cases above, the ‘generation gap’ can be an issue whereby the interests of the family carer are not necessarily going to coalesce with those of the person with a learning disability which can be awkward for both parties to deal with.

### **Subtheme: Hidden impacts of caring**

Having a life that revolved around the timetable of someone else invariably left little flexibility for holidays (as already mentioned) or ad hoc social events for family carers. Apart from a couple of exceptions, most reported that there were few friends or relatives that they could call on to help them accommodate changes in their rather stifled weekly enforced timetables. In part, this supports Iacono et al.,’s (2016) argument that family coping becomes more difficult as the family member with a disability ages, due to social support network shrinkage over time. Whilst some families in this study reported that their immediate family members (other sons and daughters in particular) offered a lot of support in the here and now, perhaps as a reflection of more pejorative attitudes towards disability (which did not begin to change until the 1980s), others continued to receive very little informal support from extended kin. Some participants reported that limited social networks led to feelings of loneliness and isolation:

*“I just do everything around her/him ... I have got family around that I can call on in desperation. I can’t think that they were able to provide support though (003)*

*“...No support from anyone“ (007)*

*“No, 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 s/he has and my fun loving [name] has disappeared - the standard of care is difficult.” (016)*

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

Since feelings of isolation often develop from a sense of being invisible and forgotten about (Cairns et al., 2013; Chadwick et al., 2013), services which adopt a culture which embraces, values and celebrates the work that informal caregivers provide would help.

### **Subtheme: The need for ‘respite’**

The term respite may mean different things to different people depending on their own situation. Generally, respite refers to an opportunity for temporary rest or reprieve from duties of life. It also describes a service that provides a caregiver with temporary, intermittent, and substitute support services (Reinhard, Bemis and Hubtala, 2005:2). In this study, *participants* referred to ‘respite’ in the context of a ‘break’ or relief from the stressors of caring. Whilst <sup>33</sup>HCC provide respite services “for people who live in the family home”, as mentioned earlier in theme one, all of the study participants, regardless of whether or not their loved one resided in the family home or elsewhere - felt some level of on-going stress.

None of the families who were caring for their loved ones at home had received *routine* respite from their caring duties for some years at the point of interview; this type of service appearing to them, to be one of the first to ‘go’ in the run of service cuts (as demonstrated in the first two quotes below). This further thwarted the chances of carers organising their own short term breaks or holidays: :

*“No respite... [name] used to have it when there was a house in [name of service]. A room at the back you [loved one] could stay there [for] up to 2 weeks and [name] absolutely loved that and it allowed us to have a holiday on our own but umm there has been nothing since - then we haven’t had that for years and years. It would be a holiday for [name] as well....Also, respite we occasionally need... we always take [name] with us on holiday. It would be rather lovely to go on holiday and not think about a 3rd person. We have booked up to go to [ holiday destination] in [month] but [loved one] will go with us - but there it is” (019)*

*“We were doing quite well with Direct Payments and I’d never had respite until three years ago – purchased respite care – they took her/him away to a caravan. But [they*

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<sup>33</sup> Personal communication HCC 21 Oct 2019

*have] just had another round of funding cuts. They cut his/her direct payments. They still think I have enough. The social worker cut back the expenses. Officially at the panel [they said they] was spending more on a caravan and there must be a cheaper way.” (018)*

Lack of respite care is not extraordinary to the New Forest sample; Dilllenburger and McKerr’s (2011) study of 28 older parents finding the same deficit in service provision. In the current study, even when a family carer was able to arrange a holiday, the preparation needed beforehand to organise care could be immense:

*“...but going away - it is such a work up - you get two bits of paper and you have to put [loved one] on [their] list and you go to the bank and you get all the little bags for the money and ‘this is money for Monday’ because if I just gave it to [loved one] s/he would just spend it on CDs so you have to have money for Monday and a £1 and then £2 for Wed and you have to go to the bank and get cash for a start then ..Then I leave it all on the side and I have to leave it with the carer and I say ‘right s/he needs that with her packed lunch’ and I still do all the packed lunches because that’s like having a child as well. It is still just like having an overgrown child - that is the only way I can describe it really and there is no any light at the end of the tunnel because as things are, they are only going to get worse”. (001)*

It is hardly surprising then, that for those few who had *occasionally* been offered some form of respite (in the case below, the adult with a learning disability being offered a week away in a residential care home) the task of organising it proved to be too much of a daunting prospect:

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

For those carers whose loved ones were not living at home, and who had been able to organise a ‘break away’ from their caring role, again, there was a sense that they could never really escape their caring responsibility:



*“We are very lucky in that we can get a break if we want for a few days but it never leaves you – [loved one] phones when we are away” (008)*

*“We have this thing that we are not entirely free” (014)*

What was evident was the resilience of all of the individuals interviewed – this linking to the long held ‘adaptation hypothesis’ (Seltzer and Krauss, 1989; Grant and Nolan, 1993; Grant and Ramcharan, 2001) which suggests that individuals adjust to care-giving over time, acquiring skills which enable them to cope, even in the absence of social support:

*“Well I just do it, I just do it...s/he is quite able... it is mostly I am his/her taxi driver and I have to take her/him... I mean s/he has a much better social life than me” (001)*

Yet the impact of this on their lives was evident, especially for those who had been or were caring for more than one person in their household:

*“I work, I look after my [loved one] I do the shopping, I shower [other older family member], I organise the carers. oh and I [do my own activity] about once a week. I don’t know what a normal life is. I can’t imagine what you do when you go home from work at night.” (020)*

*“I’m just so used to it because I cared for both my parents... I’ve almost forgotten what it’s like to do something for me. I’ve spent years looking after elderly parents doing that. I’ve only just been able to sit down and have a glass of wine at night without feeling guilty - or am I going to have to get up at 1am and pick somebody off the floor?” (001)*

*“That’s my style - both of us really -when you try and explain to people, you know, you try and explain that you have these problems... you can never both be down at the same time – one of you has to be up if the other is down. Sometimes you want to pick up the ball and start running with it again. You can never give up because if you do, the authorities will just not do anything. That is our experience” (010)*

The experiences described above are not extraordinary to carers of people with learning disabilities. A growing proportion of the UK population is now experiencing more than one ‘care-giving period’ of their lives including looking after a child and subsequently a parent

and then a spouse (see <sup>34</sup>Carers UK, 2019). What is different and remarkable for these family carers is that their role is protracted –lasting up to 56 years for some parents. It is not surprising then, that participants said that they did not feel that they could retire:

*“...in terms of getting older and changes in our health etc. umm you know and one of the things that is facing us is that when all of these things keep changing as rapidly as they do my [loved one’s] dependence on us is constant and grows at a point when s/he should be becoming more independent. My husband retired last year and since he retired he can’t really move anymore. You know... carer’s calling back, my [loved one] calls him back even if he goes shopping now so [loved one’s] dependence on us grows. I would like to retire. The trouble is s/he gets anxious quite a lot so things like holidays and umm 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)

The quote above resonates with previous research (notably Pryce et al., 2015) whereby family members can feel their own lives, including needs and aspirations, restricted by their caregiving role which, for most of the sample, resembled a ‘perpetual parent’ role (Todd and Shearn, 1996). Perlick et al., (2010) found that physical health difficulties, and lack of social support resulting in feelings of being ‘burdened’ were the main factors associated with carer self-reported depression and although measures of depression were not part of this study, it is likely that if protracted for much longer, the situations participants were in could easily lead to both physical and mental ill health. The chance to have some kind of respite was welcome, but only if it did not mean more work, stress and anxiety organising it. Clearly for most of the individuals in this study, retirement was <sup>35</sup>‘on hold’.

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<sup>34</sup> [https://www.carersuk.org/images/Facts\\_about\\_Carers\\_2019.pdf](https://www.carersuk.org/images/Facts_about_Carers_2019.pdf) [Accessed 30/09/19]

<sup>35</sup> See Carer’s Trust (2016) Retirement on hold: supporting older carers, London, Carer’s Trust

## Theme two: Care Act 2014 – is it happening, is it working?

A summary of the Care Act above outlined the breadth of the legal duty local authorities are under to protect and care for people with disabilities and their carers. The subsequent subthemes provide an indication of how the Care Act is working in practice for the participants in this study.

### **Subtheme: Frustrations with the needs assessment process.**

Experiences of needs assessment were fraught with frustrations with the majority of the sample stating that they had experienced difficulties with the needs assessment process. One participant (008) stated that their adult offspring had received “*no assessment under the Care Act*”. Another parent recounted how they and their adult child with a learning disability and autism had moved location within the previous year and six months later, they were still waiting for the previous local authority needs assessment to be transferred to the new local authority. In the meantime, there was no additional care apart from that provided by the parent, who was over 80 years old:

*“[loved one] had a Care Assessment – nothing came out of that. Hertfordshire still hasn’t sent [loved one] details to Hampshire.” (016)*

*“No assessment under Care Act – the face-to-face social worker rings her employer and says ‘how is she going on?’ – just rings – doesn’t go and see her. (010)*

It also appeared that the time lag between the request for a needs assessment and its completion went far beyond the ‘reasonable time frame’ of around four to six weeks, as specified in the Care Act for a number of participants:

*“It took me a year to get a SS assessment” (015)*

*“I said ‘I want an assistant from Hampshire to talk with me’. It took five months to get a social worker then to start the process. Then the social worker went silent – no Carer’s Assessment – mainly need for care to be available but I can see from their point of view [loved one] manages rather well” (011)*

Others reported how they had been involved with their adult children's needs assessment, but that it had been implemented inadequately:

*"[Loved one] has had a [needs] assessment and it really worries me and I can't say we noticed much difference once we had had it. They said 'you are not getting enough care but saying this, we can't afford it'. The social worker said this - they would put him/her on a waiting list as a first step and if something comes available we would be notified" (O18)*

*"I look forward, so if I look at care plan at the moment which is almost non-existent actually because we have lots of things on the care plan - none of them fulfilled - but if I look at the care plan it is an ambition, it is not a care plan, it is an ambition" (O05)*

Of the few participants (n=5) who said that their loved one had received a needs assessment, none were totally satisfied with the way it had been carried out, especially in relation to appropriate communication formats with one parent stating:

*"[Loved one] told us s/he was due to have an assessment -we weren't involved, we have never been involved and they told her/him but s/he can't read and s/he sends it to us. But under the Data Protection Act, they send it all to her/him but she can't read".*

In general, there was little evidence of innovative practice by assessors to undertake more accessible assessment styles using alternative and augmentative communications such as Talking Mats. Instead, despite the huge advances in this area, traditional paper-based assessment processes were still being used.

A new Integrated Personal Commissioning (IPC) programme (introduced in 2014 by NHS England) stipulating that health and social care services had to work together, was launched in Hampshire as one of nine *pilots* across England. The overarching aim of the programme was aligned to the Transforming Care agenda of enabling people with complex needs to reside at home rather than spending long periods of time in hospitals/treatment and assessment centres. Renaming the IPC <sup>36</sup>'My Life My Way', (MLMW) the idea is for learning disabled people with additional complex needs, their parents, carers, HCC Adults

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<sup>36</sup> <https://www.hants.gov.uk/socialcareandhealth/adultsocialcare/learningdisabilities/mylife> [Accessed 30/9/19]

Health and Care department and the five Hampshire CCGs as well as the Hampshire Advocacy Regional Group (HARG) to work together to provide one individual life or person-centred support plan that all parties can use. They should also work towards producing one personal budget (even when a person cannot get a Direct Payment). Through this scheme, funding is provided if a person is assessed as having eligible needs, which cannot be met in any other way. A central aspect of MLMW is for people with disabilities *and their family* to be supported to make a support plan about how they would like to achieve what is in the plan (more details are provided in the web link provided below).

Whilst almost all of the participants' loved ones in this research had additional needs, at the time of study just one participant reported that they had been aware of this programme: The following extensive quote reflects a) the participants' willingness to adopt the new programme upon learning about it b) their disappointment when, like their experience of previous 'programmes', it is not realised, and c) the consequences of programmes not being clearly explained to carers by the local authority or CCG, leading to carer misunderstandings and anxiety:

*"My Life My Way came along - because of the Transforming Care agenda - which is a brilliant agenda - absolutely I couldn't be more supportive. So [loved one] is a candidate as s/he would be in a treatment and assessment centre so s/he would be a candidate for Transforming Care so they told me.... So...we did it with a social worker who didn't know [loved one] so [loved one] wouldn't speak to her [social worker] and so [the social worker] was doing it with me. And I never get anything back... So we were applying for continuing care mainly because both funding would mean we could pay staff more. And actually, we need to. We didn't have joint funding as we never got that far because they [MLMW programme] stopped us. The first one was done by a social worker who marked [loved one] down. As it's A.B.C., isn't it? And you have to get 4. As [the social worker] marked [loved one] down as a C. But she didn't know her and [loved one] didn't ever look at [the social worker] when she was in the room. Sometimes [loved one] doesn't allow them [social workers] in the room or sometimes s/he puts his/her headphones on and just ignores them and... umm... again people come to our house and they see there are two parents. They see what makes them feel comfortable and they don't see [loved one] as an individual and so [the social worker]*

*marks him/[he] down as a C and I didn't know that. And that became part of the complaint and I didn't even see the outcome of that and I said 'come on, you know s/he's got high anxiety'. Anyway, the second person came out and said 'what?' and marked her at 4 - partly because [loved one] was really challenging when she came into the room and I think [the social worker] was a bit frightened of her/him. S/he is actually like a gentle giant. S/he will throw things and s/he would never hit anybody or hurt anybody as long as s/he wasn't that frightened... I suppose she's never been tested. S/he does throw things and s/he does shout and s/he is big and people can feel very intimidated. Of course anybody who knows her/him wouldn't feel intimidated by that but if you don't know her/him umm and so eh they immediately marked her/him down as A so we said 'Thank God for that'. Then the CCG called us and said 'well we are not going to continue with this because s/he's on the Transforming Care pathway. So for two years we have been pursuing that Transforming Care budget and I thought that, given that Transforming Care is the only policy in town - we don't do anything else apart from getting people out of hospital - umm then that's right. It must be. And I do a google search now and again and I know there is funding as it is the only funding in town then that must be right. I've only recently found out that there isn't a funding stream so after two years we have started again and that is a month ago and they said we would hear within the week and we've not heard and this time I went to the head of the CCG and the head of social care and demanded a meeting and they communicated on a telephone call and the head of CCG didn't turn up on the call and the head of social services did and they absolutely made a commitment to initiate continuing care funding immediately and get a new social worker.'" (005)*

The experience recounted in the quote above corroborates Bowey and McGlaughlin's (2006) findings of limited information provided to family carers which can cause unnecessary confusion that is also time consuming; the MLMW programme has no scoring system, but the carer did not know this. A lack of accessible information concerning the programme therefore led to unintended negative outcomes. It also reveals a lack of what might be termed 'process continuity' to enable comprehensive assessments and subsequent right support for individuals to be realised.

Whilst two of the participants stated that their family member had challenging behaviour, many more of those interviewed described behaviour that could be regarded as challenging, yet none of the participants recalled ever having been offered functional assessments or

positive behaviour support plans. Given the body of evidence showing that a lack of comprehensive needs assessment and interventions for challenging behaviour can impede the wellbeing of both the cared for and the carer (see Baker and Osgood, 2019), getting needs assessments wrong appears to be an example of perverse common sense. The way information is transmitted by professionals to informal carers is also clearly important in order to avoid caregivers experiencing attitudes that they perceive as deliberately non-transparent regarding service provision options, especially in relation to accommodation (Grey, Griffiths, Totsika and Hastings 2015). Hamilton, Szymczynska, Clewett, Manthorpe, Tew, Larsen and Pinfold's (2016) study of the role of family carers in the use of personal budgets by people with mental health problems may be useful here. They found that whilst family carers may be pivotal in terms of initiating, pursuing and maximising the level of support available to their loved ones, tensions can easily erupt between carers and practitioners over decision-making. Family carers in their study also felt that personal budget funding may have been reduced because practitioners assumed that carers were willing and able to provide support. Alternatively, enhanced understanding by practitioners of the motivations behind carers' wishes to be involved in decision-making can bring mutual benefits since the fundamental objectives are common to both.

### **Subtheme: Carers Needs Assessment**

As already stated, the Care Act 2014 also provides for the needs of carers, matching their rights to a needs assessment with those of the cared for person; the carer being entitled to support if they meet the national eligibility criteria. Whilst local authorities can choose to charge carers for services they might receive, including respite care so that they can have a break, it is generally thought that most local authorities do not charge for such services since it is not in the interest of the carer, the disabled person or the wider community to do so. However, they may charge the service-user for the service which directly benefits the carer.

The participants in this study reported the struggle they had with a) receiving a carer's assessment and b) its implementation:

*“I said ‘I really want to request not only an assessment for my [loved one] but also an assessment for me as [their] carer. So this goes through to the advisers and you phone them and then they put you through to social services... So I got the same person from social services who came back to me and said ‘Oh you’ve been on the phone again’ so she said ‘twice’, so I said ‘errm I’ve not been on the phone again twice’. I said ‘I have been on the phone once. The advisor who I spoke to said that because I was requesting an assessment for myself then they said that... umm... that she would send them two different emails’ so anyway she said ‘[loved one] is on the list and now you will go on the list’. So, [laughs] that was the way she said it. I did understand what she said... they take people in order in priority or whatever and you either go up or down depending on your circumstances and ‘now you will go on the list’. But when I spoke to the advisor she said... what the advisor asked me was when I said about the assessment as a carer she said ‘Oh where did you hear about that?’ and I said ‘well I heard it at a Mencap meeting’ and umm so she said ‘Oh’ I said ‘I have previously asked for a carers assessment’ and I was told that ‘they don’t do them’ and this was the same person who said ‘Oh we don’t do them anymore’. So when I told the advisor that she said ‘Oh - they don’t want to do them because it involves money’.” (009)*

Unfortunately, the experience the carer above reflected a general perception that local authorities are somehow trying to stonewall carers due to funding cuts, even if this is not the case. In practice, the absence of any needs assessment meant that local authorities were unable to provide or purchase services to enable carers to continue in their caring role. The Care Act 2014 stipulates that local authorities must identify the needs of a carer, placing their wellbeing equitably with the cared for, and taking into consideration the impact of providing regular, substantial support to a disabled person, but this did not appear to be routinely happening for the participants in this study. Where carers had received a Carers Needs Assessment, the desired outcomes under the Act as listed above did not appear to have been achieved:

*“I did a carer’s assessment about a year ago but we never get anything because we don’t have any continuity now. I know I could say to them ‘the only reason I had a carer’s assessment is that I thought we could get support for [loved one]’ but nothing works umm so err...I just never heard from them and we’ve never [had] a visit since and I said ‘my husband needs it more now because although I am the main carer he is doing it’ (005)*



*“I am his sole carer. I had a Carer’s Assessment a couple of years ago. [Loved one] hasn’t got a social worker it was ‘just call the ‘on call’ social worker if you have any problems’. I just do everything around him. I am 71 but I feel 90 some days.” (003)*

*“I think I had one with the LD team about 2 years ago but as I say the one I had back in December I wouldn’t say that was a review it was just oh I can’t be arsed with this. So no I don’t get anything. I don’t get anything no I earn too much.” (007)*

Whilst the Care Act 2014 aims to impact positively on the lives of carers and those they care for, the accounts provided above indicate little evidence of the ‘whole family approach’ that needs assessments are supposed to be based on. Consideration therefore both conceptually and practically, of both the needs of the person with a learning disability, and the impact of providing for these needs on the life of the carer – in other words, taking a more holistic whole family approach as advocated by Grant and Ramcharan (2001) would be helpful. Combined ‘cared for and carer’ needs assessments would be the optimum which could potentially provide a more positive experience of the assessment process. Seddon et al., (2007:1335) also discussed the limited contribution of health service staff as well as family members to needs assessments leading to confusion over eligibility. Partly due to poor assessor training, what Seddon et al., (2007:1335) were advocating in 2007 still holds today but is rarely implemented - that is, ‘an evidence-based framework for good practice that helps distinguish between carer needs, service provision and carer outcomes’ and which enables practitioners to engage with carers as partners in the needs and care process (Seddon et al., 2007:1335).

## Theme three: Challenges with social care services: continuity, expert, and attitudes

Overwhelmingly, the older carers in this study stated that they had spent their lives battling with social care services. Yet they reported that their struggles had become much more difficult in the last few years. Issues included not having a social worker or key/consistent person to deal with their son/sibling/daughter's case, and perceived lack of expertise and pejorative attitudes of staff which threatened carer-social worker trust:

### Subtheme: Lack of continuity of social workers

Around two thirds of the study group reported that their loved one had been allocated a social worker, which in essence was welcome. The perceived benefit of this provision was evident by the fact that the remaining <sup>37</sup>third felt that this would provide very beneficial support. Nevertheless, the two thirds mentioned that the effectiveness of the provision was reduced because the social worker they had was not in post long enough to establish a strong relationship with their loved one:

*"I mean that the thing with social services is that we just don't seem to get past it - is we have a social worker but not a permanent one, you know, they just seem to allocate different ones."*(009)

*"I did get in touch with Hampshire Social Services... I told them about [loved one] when we moved here and asked how I would go about getting a social worker for [them] and if [they] could be put into the system if anything happened to me. But I didn't get any reply. Nothing."* (015)

Changes in named social workers added to the burden of carers, who would have to repeatedly narrate their loved one's needs to the new social worker; some of whom appeared to be inaccessible:

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<sup>37</sup> e.g. "has no social worker." (006) "I mean s/he hasn't got an allocated social worker." (010)

*“Everyday I am expected to type things for social workers – they change all the time.”*  
(016)

*“...and once you are allocated a social worker it is up to them whether or not they give you their number otherwise you have to keep going back to this call centre 0303 number so whoever you speak to you have to go through all that.”* (007)

In the following quote, a carer recounts their experience whereby their loved one was in need of additional support due to a bereavement. The death of a carer can result in additional changes including the loss of accommodation and support. A lack of tailored bereavement counselling for people with learning disabilities during these times of transition can lead to clinical depression, resulting in challenging behaviour (see Forrester-Jones and Broadhurst, 2007), yet the response from social services in this particular case was far from rapid:

*“At the time of the tragedy [loved one] hadn’t had a social worker for about four years. Umm...and when this happened s/he was given a short term social worker and I didn’t get to see her until June and she wasn’t particularly good I didn’t think. And she was very unprofessional and then... when I... I must admit I did complain as she did some very naughty things in as much as she never took any notes and nothing was ever put on file... umm and then we got someone else and she had been a [other related profession] and I don’t know why she wanted to be a social worker and she said ‘Oh I will only be [their] social worker until we find [them] somewhere to live’ and as soon as that happened, you know, it is almost as if, you know, the case is closed. And I had told her at the time about this problem with [loved one’s] eyes. It was almost as if, you know, ‘[they are] in a home now so we can forget about it’. I did get a named social worker after complaining - yeh - but as I say, once [loved one] was in the house, that was it ‘I’m not going to be [their] social worker any more.’”* (007)

The account above highlights the difficulties carers have when there are long stretches of time when their loved one either has no allocated professional to contact or interact with, or an allocated professional who, due to the nature of their fleeting tenure, is difficult to form a relationship with (similar findings are written about in Gant and Bates, 2019:436). In the case above, the individual missed out on bereavement counselling (a health commissioned service) which they could have been signposted to. Understandably, the

negative impact of this general lack of continuity of social workers in the lives of people with learning disabilities and their carers both in terms of their perceptions and in practice, was acute:

*“..umm social workers come and go - learning disability nurses come and go and of course life happens but nothing is standing still for my [loved one] and it makes for a very scary world for him/her I would say.” (005)*

*“I mean I... we haven’t seen our social worker for two years now umm but if I say to the social worker because they do phone occasionally umm ‘what about housing?’ for example - we are not a priority because we are not about to make [them] homeless and that isn’t right is it because no one else in society would be told ‘you are not a priority because you are not homeless’ would they? You would have some sort of status as regards housing wouldn’t you? Because their needs are so high, they do need one- to-one constantly and they do have challenging behaviour. I probably should have said that earlier – [loved one] does have challenging behaviour partly because s/he doesn’t understand the complexity of the world, but it is not that s/he, you know, is destructive or anything you know.”(005)*

*“And also, I understand [loved one] very well, and s/he is quite a difficult person to understand, and that is one of the problems I have had with social services because they take everything as face value and especially now – it used to be different years ago but I’m afraid in the last 10 years or so it has got worse and worse and worse. I remember when the social worker would come round and have a cup of tea with you and she would know your [loved one] because she had been the social worker for ever and you never bothered the social worker unless you had a problem but at least you had somebody and I don’t think that until they bring back a local care structure - it is not, never going to change.” (012)*

The frustrations with short-termism of service structures described above are also shared by social workers themselves (see Ferguson, 2012 and Pearson and Ridley, 2017) who call for radical transformation of current social care models). Lack of engagement with social workers and social services led some carers to adopt their own measures:

*“Well the only contact I have with social services now is when they ask how much money I can give back because they know I can’t spend it. So how immoral is that? They give me a care package but they won’t allow me to spend it on anything other*

*than day services and there aren't any day services. They phone so in order to try - and this is going to sound really pathetic - but in order to get social services interested in [loved one] and s/he's, you know, how they do their criteria, from critical is the highest, and s/he is critical on every score -so in order to get them interested in [loved one], every so often I phone up and say (because we always have an allocated social worker because they are not allowed to unallocate one, it's just that we never see them), umm and so I will phone them up and say or email and phone, you know, "You need to come and see us because there is money to give back". (005)*

Similar to the findings of Gant and Bates (2019) whilst the participants in this study appreciated the need for working with professionals and were motivated to do so, the lack of continuity in personnel, especially social workers, left the goal of successive legislation of 'family-professional partnership working' still an aspiration.

### **Subtheme: Perceived lack of social worker, assessor, and 'gatekeeper' expertise**

Carers' problems also included feeling that they had been given little or no information about what services might be available by social workers, difficult communications with 'service gatekeepers' (which might include service receptionists perceived by carers as unknowledgeable and confrontational but who were nevertheless, the 'face' of the service) as well as paid needs assessors. These experiences are reflected in the quotes below:

*"...and as an example that I find incredibly... when s/he moved to where s/he is now, we tried to get his/her hours cut - thinking we were doing social services a favour. But what a carry on. We had to go and meet with them -we wanted to give his/her hours back as 46 hours were enough. It took months. S/he had 46 and a half hours - it was too much. There were three young ladies [paid carers] - it was too much [as] there was someone almost there all the time. There was no time for [loved one] to be on his/her won. And all they did was just sit there and read a book and fill in their form and that is all they are expected to do so we tried with the manager but he would only create a tick form. He was very helpful". (010)*

*"I had someone on the phone once and umm to do some sort of... oh when I had complained about the lack of support we were getting, she said 'Oh when did [loved one] catch Down's Syndrome?' I don't know... I was on the phone and I don't know if she was in some sort of call centre which had been out-sourced because when you go on*

*the website of Hampshire County Council you just get their phone number and that is definitely a call centre.” (007)*

For the following participant, the skills and expertise expected of the social worker to appropriately help them was felt not to be evident:

*“...you know the last time I had a social worker round trying to get more support the first thing she said was ‘well s/he gets nearly three hours support a day already’. Well it isn’t three hours a day because 14 into 7 doesn’t go three times or 7 into 14 doesn’t go three times!...just getting more support for him to do things he likes to do - you know - I really can’t believe...” (020)*

*“And then when the bloody social worker comes round and says ‘oh you should do this’ and ‘you should do that’ and ‘you should do the other’. Yeh - go and do one! Umm there’s... I’m sure there’s loads of things [loved one] could be involved in that I don’t know about... umm... You know it amazes me because every time the social worker comes they say to me ‘Oh are you part of the Prince’s Trust?’ and they pass me a piece of paper about it and I say ‘Yeh I know this much about it because every time you come, you give me one of these [leaflets] and I don’t have time to get involved in it as I’m too involved in other things.’ Don’t tell me all these things I could do because I know most of them. I just don’t have time to do it - yeh. And yes there are, I’m sure there are lots of things out there that I would like to know, but I just need help to do them and I guess it is tough because you don’t know what I already know and what I don’t know but I’m not going to shout at you for telling me something I already know but what I will get annoyed about is if you just tell me ‘do this do that do the other’.” (020)*

### **Subtheme: Social Care attitudes**

Rather remarkably, all the participants said that they understood that, as a result of ‘austerity’, it was difficult for social services and the health service to provide care and they sympathised with this situation. They also felt very strongly that the work support staff did was difficult since they were a) not paid enough and b) not trained properly:

*“To be fair to the staff, if you look at their job description, it probably doesn’t say anything at all about training and then....then they charge £14.20 per hour and that is*

*what the company are charging so the staff can't be getting much after the company is taking its slice.” (010)*

Despite this understanding, some of the attitudes they felt that they were subjected to by social services could cause emotional turmoil. In part, this reflected an on-going patronising or pathologizing of family carers by social services, reported elsewhere (Chadwick et al. 2013):

*“Social workers have been patronising to me. I am very capable and competent...”*  
(016)

*Everything boils down to the fact that they are in a funding crisis and they - you know what they are doing? They are putting up the barriers. They are not there to help you. They pull up the draw bridge because we have now become the enemy at the gate. This is what it is like from their point of view. You can imagine they are being told by the top that ‘Oh what are you doing about this that and the other? ‘We can’t have this or that and what initiatives are you’re going to come up with?’ so they have it from all angles so you know, I mean this is government policy you know” (009)*

Given that once broken, trust is very difficult to recapture, the risk of such experiences is that family carers think (also found by Grey et al., 2015) that services prioritise ‘crises’ and are not really interested in the long-term well-being of either carers or the cared for.

## Theme four: Fears about the future

### “Future? – just carry on really as long as I can.” (003)

Similar to previous research (e.g. Bowey and McGlaughlin, 2007), all the family carers talked about their fears for the future. This mainly centred on what would happen to their disabled loved ones if they were to die. For most participants who had spent a lifetime ‘managing’ care as well as doing the practical tasks of caring, the question of who would take over their role was pressing and yet no explicit plans had been made, corroborating findings of Taggart et al., (2012). There was a sense that individuals were ‘tolerating uncertainty’ about the future (as also found by Pryce et al., 2015):

*“Well, it’s the same for everybody - who is going to look after [loved one] after I’m gone? And that isn’t the financial bit as my [other child] is a very wealthy man and I know he would pay for someone to look after [loved one], but it is - who is going to supervise the financed care ahh it isn’t quite the same is it?” (012)*

*“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 [loved one] could live with her but life gets in the way... [loved one] doesn’t need help with the washing yet. S/he shops, goes to the barbers on her/his own. I wouldn’t like her/him to go further afield as I wouldn’t know how far s/he would get.” (015)*

In the light of dissatisfaction with other service options available, some preferred to provide support as long as possible (also found by Davys and Haigh, 2008). Others reported that they had made various plans:

*“I have made a will in the hope that someone in the family will sort things out for [loved one] and I have done power of attorney for health and finance but that was part of when her/his father died and left her/him the money and it went into the courts. So I have to do the accounts for her/him. I have to make sure that the money is used for her/him. So I would want someone else to do that if anything happened. My brother and sister and nieces would do that. S/he would probably live with one of them hopefully but who knows? No one knows...” (003)*

*“I hope [loved one] goes [dies] before me. We have organised her/his funeral...I was ill earlier this year and so I am anxious. Funeral and service is all planned.” (014)*



*“Yes, obviously we have thought a lot about this and again curtesy of Mencap we attended in 2014 or 2015 probably, we attended a Mencap seminar on wills and trusts etc. And we learnt a lot principally because the way we had set up our will would have been a financial disaster ehh for [loved one]. And we then engaged the lawyer to re-do our wills accordingly and also to set up a Trust which doesn’t have much money in it but it is there and ehh and when we snuff it eventually [loved one’s] inheritance will go into that settlement ehh and s/he has her/his brothers - one of them lives locally and they are getting quite involved with [loved one] which is nice.”(002)*

Others wanted to start to make plans in the event of no longer being able to care for their loved one – but both the idea of this, and the practicalities of preparation could be challenging:

*“I don’t really think about it [future] too much but I expect I will have a massive stroke or heart attack or something and [loved one] will have to go into care. Really I would like to start sorting something now. It will take about a year for the process to work and they are aware at the [care agency] because they have houses and [they are aware] that I would quite like [loved one] in one if one became available. Umm... Because what I don’t want to happen is that I drop down dead and [loved one] loose me, and their home. [Loved one] would be much better off going into care and me visiting her/him and s/he get into the routine before something happens to me. So that part of it is a worry really but because s/he gets so distressed every time I talk about her/him leaving home only because s/he doesn’t know what it would be like I think – s/he has no concept. S/he has been to tea at these places but s/he come back and said ‘it’s too noisy’ - s/he doesn’t like noise so if somebody is there screaming and shouting that upsets her/him but most of his/her friends now are in supported living or something you know...” (001)*

The quote above exemplifies both the emotional and practical difficulties (including the length of time to organise new housing) of making future plans. Even raising the subject of ‘future plans’ with their loved one was hard to deal with in this case and the parent was alone in having to broach it. Avoidance of talking about the future was the inevitable default position for many carers, which could in the long run unwittingly stymie the opportunity of the cared-for to think about new possibilities for their lives (see Allen, 2011:30 in Pryce et al. 2015). Yet the same participant above also highlighted what others

(including McConkey 2005, Ryan et al., 2014) have called ‘mutual interdependence’ of the parent-adult child relationship, both financially (it is generally easier to make one dinner for two than two separate meals) and emotionally:

*“I am sure I would be lonely and would miss her/him as we are a bit like Darby and Joan you know and s/he is a reason to get up in the morning....but s/he’s there and for that reason I have to stay in really but yes. I do, I need, I do need to do it [make plans] but because I know s/he will hate it and because I know I will miss her/him and I will definitely miss he/him financially. Its like ‘oh well we are just plodding on’ you know but I do need to do something constructive about her now” (001)*

Gant and Bates (2019:438) argue that ‘personalized approaches and individual budgets can provide opportunities for pooling of resources to meet the needs of multiple people living within a family unit’ and it is understandable that losing this opportunity could be a difficult prospect for some care-givers. At the same time, participant 001 above also helps us to comprehend their reluctance to relinquish a role which mediates feelings of life satisfaction and self-worth (Bibby, 2013; Gant and Bates, 2019). In this scenario, it is important for services to be sensitive to inevitable perceived and real losses tied up with finance and emotion when helping caregivers to plan for the future. Guidance for services in relation to avoiding ‘crisis care’ can be found in both the government’s <sup>38</sup>Carer’s Strategy (DoH, 2008) and <sup>39</sup>Caring for our Future (DoH, 2012).

Other participants (mainly those in their 80s) were becoming resigned to the fact that they simply could not continue to provide the same level of support, and so the question was – who would take over?

*[Loved one] could not manage [if we were not here] and really and truly we should be at this point trying to find what I call ‘umbrella care’ for her/him. As far as I am*

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<sup>38</sup> DH Carers at the heart of 21<sup>st</sup>-century families and communities 2008

[https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/136492/carers\\_at\\_the\\_heart\\_of\\_21\\_century\\_families.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/136492/carers_at_the_heart_of_21_century_families.pdf) [Accessed 30/09/19]

<sup>39</sup>DH Caring for our future: reforming care and support 2012

[https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment\\_data/file/136422/White-Paper-Caring-for-our-future-reforming-care-and-support-PDF-1580K.pdf](https://assets.publishing.service.gov.uk/government/uploads/system/uploads/attachment_data/file/136422/White-Paper-Caring-for-our-future-reforming-care-and-support-PDF-1580K.pdf) [Accessed 30/09/19]

*aware in this area (and I wouldn't want her/him to move out of this area as s/he has got a huge network), there is only one place that has the sort of accommodation for me, for us, where they have a block, little bed sits with a living room, kitchen bathroom. But on the same site they also have a home for very severely - which means that there would be 24/7 oversight....I can see that this cannot go on because I am finding it more and more stressful to function at this level of support and live something of a normal life. And as I say, the only thing I can think of is that we try and find her/him some kind of accommodation". (011)*

*"As we are getting older, if anything happened to her/him...recently s/he injured her/his leg and if that had been any worse, s/he might have been confined to home for a long time so then you do need someone to keep an eye on [her/him]." (010)*

*"As I get older...there is nothing I can do - I do my best. All I want is to see [her/him] well treated. My aims are modest. I just want her/him to be safe, healthy and happy but s/he is none of those at the moment." (016)*

*"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)*

For these participants, there was a recognition and concern that other family members would end up taking the responsibility:

*"Well it has always been our worry you know I mean I hate to say it but it has always been our worry that our [loved one] would outlive us but you know the medical care they get is absolutely fantastic at Southampton. I feel that [loved one] will outlive us but I am always trying to make her/him as independent as possible. I've got two other [children] and I don't want them to think that they have to be responsible for [loved one]. But with the [service provider] they are very ahead thinking and they are sort of keeping it on a back burner that 'yes these people are getting older' and we are going to have to look at providing more support but for a group of people, you know, of the same age and I mean in [loved one's] house they are all in their 40s apart from two who are in their 50s and you know that is really good because in residential homes for people with learning disabilities you could have someone in there who was 20 and someone in there who was 50, you know, and the interests are not the same." (007)*

The importance of family members, especially siblings in relation to the current support they provided, and in terms of their possible role as subsequent carer was highlighted in

almost all of the interviews, though, as Heller and Arnold (2010) found, there was no expectation that other kin would replicate carer's own hands-on support:

*"So we are very fortunate that our daughter in law is fantastic she loves her/him like a brother/sister. She takes her/him to gateway club every week you know... all her social events - she takes her/him too"*

Yet, as also found by Weeks et al., (2009) and Eley et al., (2009) the expectation of siblings taking on the caring role was more of a 'hope' than a concrete plan:

*"Umm we have a son in the UK and the other one is in [abroad], and our son/daughter is very good. S/he doesn't live nearby but we can trust that if we are not around, s/he will make sure that [loved one] is cared for ...so yes you try and plan ahead as much as you can but you realise that [loved one] could be on her/his own. Yeh, you know, we sort of work as a team. With our [other children] - we don't burden them. [But] friend and family, I've only got a brother/sister and s/he is a lot younger than me and your family [directed at spouse] have never been supportive."*  
(004)

For other carers, there was a kind of inevitability about the future:

*"We have wills obviously but you know all our friends and everything are our age. And we do have other family but they don't want to know. They run for cover."* (006)

Even the best made plans can change, depending on fluctuating health, finances, and family situations and this was no different for the families interviewed for this study. 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.

The fact that siblings and other family members outside of the nucleus household were involved in the caregiving process for many of the families in this study adds weight to the argument for a more holistic family approach to needs assessment and planning. What was evident in the above quotes was that parents clearly recognised the possibility of outliving their sons/daughters; 'the first generation to face this statistical likelihood' (Jokinen and

Brown, 2005:792). Whilst some siblings are willing to assume the caregiving role beyond the lives of parents, others will not wish to or be able to. Given this reality, the lack of future planning input from social services is stark. Writing in 2007 (pp. 41-42), Bowey and McGlaughlin stated that: “a failure to meet the planning needs of service-users living with older carers represents a serious contradiction to the principles of the Department of Health’s (2001) White Paper, *Valuing People*” which requires that services produce a secure plan for all service-users living with older carers. This was reinforced by the subsequent consultation paper *Independence, Well-being and Choice* (DoH, 2005) and the *Improving the Life Chances of Disabled People* final report (Prime Minister’s Strategy Unit, 2005). The findings in this study show that 12 years on, future planning is not in place, risking situations whereby local authorities will end up responding to crises (e.g. where parents die) leading to inappropriate placements of people with learning disabilities, unresolved grief causing in some cases clinical depression and challenging behaviour (Forrester-Jones and Broadhurst, 2007; Forrester-Jones et al., 2017) as well as negative impacts on individuals’ quality of life (Thompson and Wright, 2001).

## 6. Next Steps: What might 'good' support look like?

At the end of each interview, participants were asked what they thought might help to support them, what 'good' support might look like and how New Forest Mencap could input into this support: The following bullet points and accompanied quotes summarise the ideas carers had:

- Investment in specialist housing – “there is a focus on getting people with learning disabilities out of long stay hospitals and going ‘home’ but when we asked about the new flats, they said they were given to people ‘with a local connection’ but none went to anyone living with learning disabilities locally – we want funding for night supervision.” Ummm unless they can come up with something to do with housing it seems to be everyone’s probe every mum I talk to it is housing.
- A definitive source of information and a local specialist learning disability team - “with a co-ordinator with experience of learning disability so they could help people directly.”
- A specialist plan of services for older carers - “I think we are all worried about getting older...well with regards to planning ahead not just our kids getting older but us getting older. Well umm have a plan ready in any event of emergency cropping up because there are still a lot of parents in the New Forest a lot older than me who are still looking after their youngsters with them and their youngsters have never been away from home and they should be the priority”.
- Weekend social care and activities - “perhaps a job share for someone who would do things with individuals at the weekend.”
- A dedicated social worker who will do needs assessments and reviews: “well the one thing I think that is a real shame is that local authorities don’t have reviews anymore unless there is a real crisis and I think they should have reviews every six months, you know, together with all the providers and the family but also I think that the local authority should want to make sure that all this money that is being paid out - that the service users are getting value for money. But also a lot of the service providers have stopped doing the reviews as well I think probably because they got

so fed up with inviting social workers and they never turned up or said they couldn't come."

- "Only thing I would like is if there was someone there who I could get on to if I needed anything. I don't want anyone to think that I am going to be a burden and want things. Just that [son/daughter] would be known that kind of thing – known to services. I don't think that is asking too much. I know we haven't been in the area for long but I at least thought that a social worker would have been in touch. I contacted them and sent a letter."
- More carers who are better paid. "It is a job to get in full time carers –agency staff last year they started. Staff should be paid more."
- The use of technology. "I feel that there is a great future for chat for people like [our son/daughter] as s/he could come in and have a long conversation with her Alexa. It is the future for vulnerable people. I would like [her/him] to have something like that but it is the Wifi element that concerns me –s/he would be on to all sorts of things – I don't think s/he would because s/he couldn't but it's not just the ordinary, it's the access etc. I think it is an area that has expanded very quickly without any control whatsoever so probably if you could have close circuit with Wifi that would be great".
- Respite for all carers. "Respite at [care provider] is only there for carers who have people at home – but we will need help, need respite so it can be arranged for older carers".
- A register of older carers: "I don't know what will happen if we fall off our perch. Then social services will pick it up but I don't like to think that's what it might be. They might say s/he has to go further away. I suppose social services would provide something, find a cheaper [place] to keep [her]him] in their flat and provide extra support for less money. There is no forward planning. Do they have a register of the ages of parents? If they don't then how can they provide care?" (O11)
- A need to start with the individual when providing care: "I just don't understand why we don't problem solve and make a difference. I just don't know why we don't just all sit around and there are several things: this tick box one size fits all just

drives me mad because nothing ever fits [son/daughter] so unless we start planning from [their] perspective rather than from 's/he doesn't fit in.

## **New Forest Mencap**

- Acting as a pressure group. “putting pressure on social services” - “use case studies to inform social services rather than just statistics - that is very powerful when you say what people are having to put up with”.
- Working towards gaining appropriate transport to help “get people around and about the New Forest area”.
- Seeking more publicity concerning what MENCAP does and what it can do.
- “Every time there is a meeting, it should be advertised in the local paper. Make sure that people knows so that they can come to the LIG meetings...as well as having meetings in Ringwood and use the community centres there”
- Localised New Forest Mencap meetings: “It is quite nice to speak to people who are in the same boat. So I have been to carers meetings and because there are times when you think ‘I am the only one doing this and then you speak to others... and I say oh I’ve been to the doctor to get more cream and [they’ll] say ‘Oh yeah, and she’s the same and she has the same battle with the weight and you know so you think to yourself “I’m not the only one doing this and if nothing else it is nice. I used to go to a carer’s meeting at the New Forest but they moved it to Winchester or Andover and so I stopped going because by the time I had got there I’d have to turn round and come home”.
- Helping to support family carers to be less isolated. “MENCAP are a wonderful agency and I would say umm I think one of the things that we suffer from as parents and I’m sure you are hearing this from everybody is that we are all so isolated. So they tell me recruitment is so difficult but then I speak to someone that I know in [place] and they are in the same position and we are all so isolated that they point the finger at your situation and say it is your situation.”



## Discussion and conclusion

Increased longevity of people with learning disabilities is to be celebrated; individuals can now enter the retirement phase of life just like the general population. Care policy and practice for people with learning disabilities and/or autism have also moved in a positive direction over the last 20 years, with personalised support and individual budgets replacing block grants and conglomerate care provision. Policies such as Valuing People, Valuing People Now and Transforming Care mean that many people with a learning disability and/or autism can now experience the majority of their lives cycle in their own homes in the community. For many this means living with their families, or living close to their families, so that family support is readily available. Family members (particularly parents) therefore increasingly play an extended caregiving role - this role stretching into their retirement stage of life. Whilst the proportion of ageing adult carers is growing rapidly, research, policy and practice, which specifically consider the needs of older carers of people with learning disabilities have been slow to catch up. The purpose of this study was to map, describe and provide in-depth analysis of the caring roles of older family carers, with a view to bringing about positive change for this population's caring experiences.

The research was carried out in the New Forest, a predominantly rural area of Hampshire. This fitted the remit of the research commissioner (New Forest Mencap) and the funding provided (Lottery – Awards for All). The sample was small, but appropriate for a qualitative study using interpretative phenomenological analysis. The target sample of 21 older carers was hard to get. Whilst data sets exist for people with learning disabilities in the Hampshire and New Forest area, these are incomplete and provide estimates only. HCC (2018:11) states that *'there is no central register of people with a learning disability across health and social care'*. There is also no readily available register of older carers. Investment in an integrated system whereby more precise figures of people with learning disabilities *and* their carers are logged with the local authority and health service, and which are shared with designated charities such as Mencap, would be helpful for targeting those who already have, or who may be at risk of having support needs. It would also possibly save service provision cost in the long-term. That said, the intended study sample was realised, mainly due to the older

carers themselves, who, having seen the New Forest invitation to participate, were proactive in ‘wanting to help’ inform both New Forest Mencap, HCC and SH about their lives as carers. Many of them also saw the invitation to participate in the research as a means to make contact with a charity that might be able to help them. The response rate for this study is highly encouraging for study replication in other areas and regions of England.

Whilst the prevalence of people within the BAME groups is generally lower in Hampshire than regional and national averages, this is increasing. The Foundation for Learning Disabilities and the Department of Health suggest there could be specific difficulties for people with learning disabilities from BAME groups particularly in more rural areas where small numbers could make them less visible to services and even more vulnerable to social isolation.<sup>40</sup> Only a more expansive study would capture this population. Nevertheless, the experiences recounted by the study group were not dissimilar to those found in Hubert’s (2006) study of 29 older parents of people with learning disabilities from BAME groups in a south London borough. In Hubert’s study, parents reported feeling isolated and anxious, and worried about the future, stating that they needed support to start making viable plans for future care provision of their offspring. This usefully demonstrates the transferability of the findings from this study, illustrating that the issues faced by family carers may not necessarily be unique to one particular group of the population or another. Yet, Hubert’s study only included parents rather than other family members, and both Hubert’s and this study analysed the emic or insider’s view of carers only. A larger, more comprehensive UK-wide study which qualitatively interviews the experiences of both older people with learning disabilities *and* their carers across the UK is recommended (currently only one study by Gant and Bates 2019, has approximated this, but the sample size ( $n=5$ ) in their study significantly limits the scope for generalising the findings). Mapping of services already being provided in similar rural regions would also enable local services to adapt existing provision, or introduce new support to address the issues that longer life expectancies of both people with learning disabilities and their carers are creating. Few studies also exist that look specifically at gender differences in

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<sup>40</sup>Learning Difficulties and Ethnicity: Updating a Framework for Action. Foundation for People with Learning Disabilities and Department of Health, London (2012)

relation to older carers. Carers UK's (2019) recent press<sup>41</sup> estimates that more carers are women (58% women vs 42% men). Whilst the majority of the carers *interviewed* for this study were women (76%), it was clear that a sizeable proportion of partners of those interviewed were *also providing* substantial amounts of care. A broader study would enable capture of issues specific to gender, including LGBTQ.

The accounts documented indicate the huge capacity, energy and resilience of family carers to provide the best possible quality of life for their loved ones as they enter old age. Yet four main themes were delineated from these accounts which highlight the changing needs of carers as they grow older and, inevitably, frailer. The themes comprised: transition to retirement - a misnomer; the Care Act 2014 – is it happening, is it working?; challenges with social care services: social worker continuity, expertise, and attitudes; and fears for the future.

Health deterioration (a natural consequence of the aging process) of both the person with a learning disability and their carer impacts hugely on the day-to-day functioning of family life. Age-related health and medical issues, in addition to those associated with the person's learning disability, result in the older carer's role gradually becoming extended, more intense and more complex (Carers UK, 2010); including arranging transport for their loved one to get to and from GP and hospital appointments, administering additional medications, and adjusting weekly timetables including liaising with support workers and other professionals. Such tasks are made more cumbersome when older carers are experiencing age-related health difficulties and a depletion in skills (e.g. no longer being able to drive). The accounts also reveal a risk that their willingness to continue caring whilst not being supported goes hidden within an overall system of inertia. In this scenario, formal care is provided only at the point of crises, which can lead to more long-term demands on health and social services. The use of technology and home adaptations that could address individual's changing needs as they get older and which might pre-empt crisis have been recommended by <sup>42</sup>NICE (para 1.4.7).

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<sup>41</sup> <https://www.carersuk.org/news-and-campaigns/press-releases/facts-and-figures> [Accessed 30/09/19]

<sup>42</sup> <https://www.nice.org.uk/guidance/ng96/chapter/Recommendations> [Accessed 30/09/19]

The problem seems to lie within the premise of ‘roles’. In the absence of an ‘informal carer job description’, paucity of information (Cairnes, Tolson, Brown and Darbyshire, 2013) of available support, and scepticism over the standard of formal services (Hubert, 2006, Pryce et al., 2015) family carers appear to be taking on parts (or in some cases all) of the roles that would ordinarily belong to formal paid carers and care managers. For example, Hampshire County Council (2018:5) states that *‘it is important to ensure that people with learning disabilities can lead healthy lifestyles and are empowered to make health choices to minimise preventable conditions’* and there is a need to *‘ensure strategies are in place across the organisations supporting adults with learning disabilities to cater for the level of need as the population of adults with learning disabilities ages’* (HCC, 2018:7). Invariably however, it is family members who are enacting this, either directly or indirectly, by ‘checking up’ on support workers to make sure that tasks are carried out properly, or ‘keeping an eye on’ their loved one and arranging services. In some cases, the onus was put on family carers (who are tired and have very little spare time) by professionals to ‘look up information’ themselves using toolkits, and do tasks that the professional could do much more efficiently. One participant stated, *“it feels like we have to know everyone else’s job [care professionals] [but] they only have to know about us”*. Clearer remits of the roles and responsibility of care managers and support workers (which encompassed information-provision around ageing and learning disability and helping carers to navigate the system, as well as doing some bureaucratic tasks for them) would help ameliorate the impact of the caring role on the wellbeing of older carers. Well co-ordinated and appropriate respite, to enable carer’s to have a ‘night off’ and/or longer stretches of time to rest, and enable life goals to be realised would put carers on a more equal footing with non-carers who are enjoying retirement.

In carrying the role of managing care for their loved ones, family carers are having to navigate multiple and complex pathways which may involve providing duplicate information, or require needs assessments that produce plans that are not implemented. Whilst it is generally agreed that the Care Act 2014 is a positive piece of legislation (the central premise on which it is built being that the individual including the carer is best placed to judge about their own well-being), the duty of the local authority to undertake

comprehensive needs assessments (under s5 of the act) appears not to be routinely or adequately performed. Where needs are identified, provision is not necessarily implemented, despite the Care Act stipulation that a) each person has a right to an assessment with expertise, b) that the assessor should understand eligible criteria and have competence and expertise, and c) the local authorities (and health where appropriate) should meet eligible needs irrespective of costs. The Care Act lays out the potential for best practice, joined-up working and creativity in service provision (Gant 2019), providing a framework that skilled professionals may use to mediate the wellbeing of those they work with. Whilst some participants had the benefit of independent sources of information including carer's networks, others did not. Information sharing concerning the Care Act directly aimed at family members by local authorities would enable them to know more about it in order to challenge decisions they may feel have been taken without regard to it. In particular, services need to allow people with learning disabilities and their carers to have meaningful involvement in plans for their futures well before the need arises (also found by Pryce, Tweed, Hilton and Priest, 2015). This would mean that services also need to give greater cognizance to the status of the older carer as someone who may well have lived through a period when institutionalisation of people with learning disability was generally recommended, who have experienced recurrent patterns of funding crises over the years, and have had to battle with services for most of their lives to get even the minimum of support for their loved one. They have much experience (often much more than the care manager) and they constitute the first generation who face the real possibility of their son/daughter/sibling outliving them. Yet they often feel that they are not listened to (a finding also by Pryce et al., 2015) and end up coping on their own. Services need to be mindful and sensitive to these facts, not only in terms of their day-to-day interactions with older carers – there is a need for more empathetic listening to establish trust - but also when developing services.

The adults with learning disabilities cared for in this project generally did not have a spouse/partner or children who they might rely on to help them in later life, as mirrored in other studies (e.g. Ryan et al., 2014). Their parents and other family members are therefore vital to their worlds in every way and these relationships are frequently characterised by

mutual interdependence. More family-system engagement which facilitates integrated co-production would help find appropriate solutions and interventions that fit the family circumstances in order to reduce distress, enhancing their well-being and quality of life and at the same time, help shift any pejorative attitudes carers and professionals have of each other. In particular, discussions with families around future planning should be made much earlier than they seem to be at the moment (NICE, 2018). The literature (e.g. Knox and Bigby, 2007; Taggart et al., 2012) points out that having two care-givers who are both in relatively good health (this applied to a sizeable proportion of the study sample) risks putting planning on hold since there is an inherent expectation that at least one of the parents or siblings will be in a position to continue in the caring role, thus reducing the need to make concrete plans. Carer's assessments need to take these aspects of family caring into consideration.

There is also a need for learning disability services to adapt their provision to age-related changes, particularly in relation to long-term living arrangements. This population segment is no different from the general population in wanting to downsize, or move on to age-appropriate living accommodation, as people get older and more infirm. The ability of residential services for older adults to meet the needs of adults with learning disabilities who are aging is currently questionable (Forrester-Jones et al., 2017) and there is a need for social services to think strategically in terms of commissioning appropriate accommodation for older people with learning disabilities. Commissioning should also be more astute to specialist providers who have the *right* skills, and monitoring (including CQC monitoring) should routinely include the commissioner actually seeing the person with a learning disability and their family in person. In rural areas such as the New Forest, special attention should be given to thinking about how best to provide services - due to its geographic and demographic situation and as mentioned, the difficulty in finding support staff in numbers who would need to travel distances without suitable and affordable transport provision. In January 2019, the NHS Long Term Plan published goals for the next ten years. For adults with learning disabilities and autistic people, these include 'increasing the investment in community support including investment to provide community care which is more

personalised, thereby reducing inpatient admissions’. This of course is predicated on health and social services working together.

Carers are beginning to be seen as a service-user group in their own right (see Clements, 2012 and the Consultation on Carers: provision of support for adult carers’ guidelines which are expected to be published on 22 January 2022). Ways that charitable organisations can help are first to enable advocacy and self-advocacy of parents; second, act as lobbyists to policy makers, and, third, provide accessible information and advice about local provision within a legislative framework.

## **Main recommendations for practice, policy and research**

### **Clinical and professional practice**

1. An integrated system whereby more precise figures of people with learning disabilities and their carers are logged and shared between the local authority and health service, and which are also shared with designated charities such as Mencap - to target those who have health and social care needs.
2. Clearer remits of the roles and responsibility of care managers and support workers and their relationship to health provision, including direct tasks - to help ease the burden of the family carer’s role.
3. Co-ordinated and appropriate respite, to enable carer’s to have a ‘night off’ and/or longer stretches of time to rest, and enable life goals to be realised - putting carers on a more equal footing with non-carers who are enjoying retirement.
4. Combined carer and cared-for assessments which acknowledge mutuality and interdependence, and which are more family-oriented in approach; with assessors who understand and consider the ageing process.
5. Greater and more varied ‘appropriate’ specialist housing options with on-going updates of availability as part of a wider information sharing and communication strategy across health and social care services.
6. A way of organising designated social workers which allows for social care relationship continuity.

7. A family approach to assessing the need for and provision of adaptations including the use of technology to address changing needs of both people with learning disabilities and their carers to ease the growing older phases of their lives.

#### **Policy recommendations**

8. More emphasis and clear guidance for family members on the duty of the local authority to undertake comprehensive needs assessments (under s5 of the act) - with plans co-produced in terms of a whole family approach. This should include planning for future needs - to pre-empt crises.

#### **Research recommendations**

9. A larger, more comprehensive UK-wide study which qualitatively interviews the experiences of both older people with learning disabilities and their older carers, as well as practitioners specifically in relation to the Care Act 2014.

## **Postscript: impact of the study findings**

### **Academic impact**

An interim summary report<sup>43</sup> was provided to New Forest Mencap in April 2019. Summary findings were then presented at the Westminster Health Forum Keynote Seminar: Learning disabilities and autism care in England in London on 12 June 2019, chaired by Baroness Jolly. A peer-reviewed poster depicting summary findings was also presented at the International Association for the Scientific Study of Intellectual and Developmental Disabilities (IASSIDD) World Congress in Glasgow, 5-9 August 2019. A brief oral summary of the main findings was also provided to a Legal Strategy Meeting at Irwin Mitchell offices, London (20 September, London) organised by the Challenging Behaviour Foundation in association with Irwin Mitchell Solicitors and this was followed by discussions around how best to support older carers in terms of service provision. Internationally, the findings were discussed at a Policy Lab (Cairo 28-29 October 2019) concerning social protection policies

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<sup>43</sup> All of the findings presented at seminars and conferences were anonymised.



for people with learning disabilities as well as other disabilities who live in the Middle East and North Africa (MENA) region, including Egypt. The policy lab was attended by academics, representatives from NGOs and charitable organisations, and government ministers. A peer-reviewed presentation of the study findings also took place at the 4<sup>th</sup> MENA Social Policy Network Conference, (Cairo 30-31 October 2019) where the experiences of older carers in England were discussed in relation to older carers in the MENA region. Various agencies and funding bodies from the region have expressed interest in the research and how it can be applied to the situation. Finally, feedback of the results are being presented to participants and relevant stakeholders at an event organised by New Forest Mencap on 20 November 2019.

## Practice Impact

Hampshire County Council, whilst not agreeing with all of the study findings and requesting some amendments, have nevertheless already begun to address some of the issues raised, stating that <sup>44</sup>*‘the research has extremely valuable content’* and *‘the quotes themselves provide valuable insights into the experience of carers’*. They have also stated that as an organisation they are *‘committed to addressing the very clear issues for carers’*.

Actions have already included checking on the welfare and situations of carers via New Forest Mencap, in order to identify further areas for investigation and arranging information and advice ‘drop-in’ sessions in the New Forest for carers. One of these has already taken place with others planned. They include sessions for adults with learning disabilities. As part of the implementation of Hampshire’s Joint-Carers Strategy, HCC Learning Disability Team are developing a How to Support Older Carers of People with Learning Disabilities in Hampshire guidance for Social Workers. Implementation is planned in 2020. This work stream is to be co-produced with carers and other interested parties, and HCC now wish to work with NFM to improve information and advice to carers. Hampshire County Council state *‘we remain committed to take the more constructive findings of*

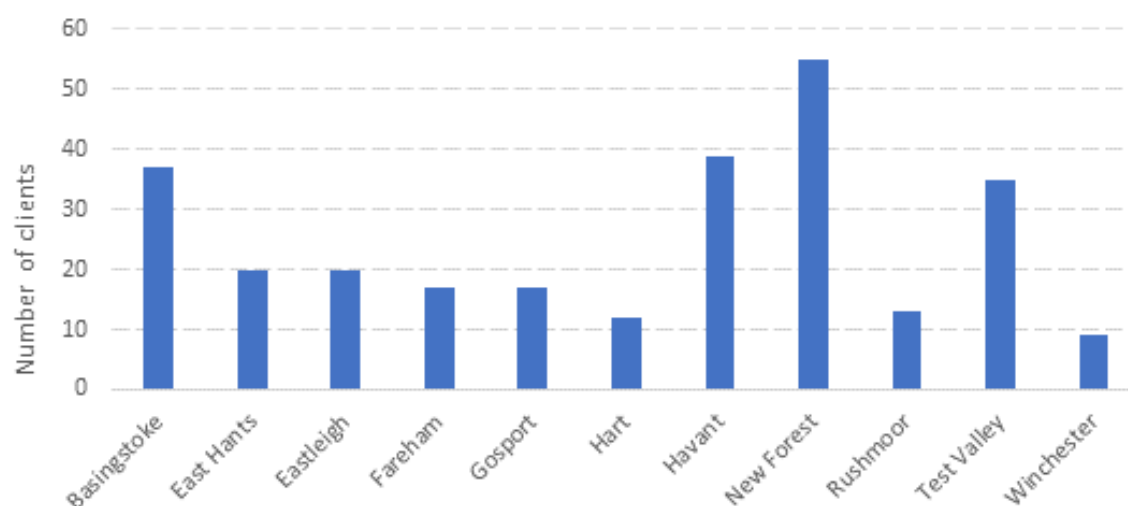
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<sup>44</sup> Letter and response to Report, HCC 21/10/19

*this report and work in partnership with New Forest Mencap and carers to form a strategic action plan to comprehensively address issues identified.”*

Following ‘*helpful insights of NFM*’, HCC have also undertaken a review of the shared support community day services, planning to grow this model and develop independence pathways. In relation to the lack of carers’ assessments identified in the report, HCC has said that as part of the Carer’s Strategy work, it has been reporting Carers Assessments numbers and outcomes to the Carers Strategy Group which includes carers and that members of this group are setting up a Carers Partnership Board. HCC would welcome carers of people with learning disabilities in the New Forest to participate in the work of this Board. Finally, just before this report went to press, <sup>45</sup>HCC provided information pertaining to their older carers strategy work. They have very recently completed analysis of people with learning disabilities over 35 years living at home with family and friends which demonstrates that the New Forest has the highest rate in the county as demonstrated below:

Figure 2: Learning Disability clients aged 35+ living with parents, family and friends, 2018/19



Source: HCC Public Health Analysis (unpublished) 01/11/2019

It is hoped that this current drive to work with New Forest Mencap will ameliorate the wellbeing of older family carers of adults with learning disabilities.

<sup>45</sup> Personal communication HCC 01/11/19



## References

- Abbott, S., & McConkey, R. (2006). The barriers to social inclusion as perceived by people with intellectual disabilities. *Journal of intellectual disabilities*, 10(3), 275-287.
- Audit Commission (2004). *The Effectiveness and Cost-Effectiveness of Support and Services to Informal Carers of Older People*, London, Audit Commission
- Axmon, A., Höglund, P., & Ahlström, G. (2017). Chronic respiratory disorders and their treatment among older people with intellectual disability and/or autism spectrum disorder in comparison with the general population. *Healthcare*, 5(3), 40.  
doi:<http://dx.doi.org/10.3390/healthcare5030040>
- Baker, P. A., & Osgood, T. (2019). *Understanding and responding to behaviour that challenges in intellectual disabilities*. London, Pavillion
- Ballard, C., Mobley, W., Hardy, J., Williams, G., & Corbett, A. (2016). Dementia in Down's syndrome. *The Lancet*, 15, 622-636
- W.M. Bjornson-Benson, W.M., Stibolt, T.B., Manske, K.A., Zavela, K.J., Youtsey, D.J., Buist, A.S. (1993) *Monitoring recruitment effectiveness and cost in a clinical trial*, Control. Clin. Trials, 14 pp. 52S-67S
- Bhardwaj, A. K., Forrester-Jones, R. V., & Murphy, G. H. (2018). Social networks of adults with an intellectual disability from South Asian and White communities in the United Kingdom: A comparison. *Journal of Applied Research in Intellectual Disabilities*, 31(2), 253-264.
- Bibby, R. (2013). 'I hope he goes first': Exploring determinants of engagement in future planning for adults with a learning disability living with ageing parents. What are the issues? A literature review. *British Journal of Learning Disabilities*, 41(2), 94-105.
- Bigby, C., & Beadle-Brown, J. (2016). Culture in better group homes for people with intellectual disability at severe levels. *Intellectual and developmental disabilities*, 54(5), 316-331.
- Bigby, C., Bowers, B., & Webber, R. (2011). Planning and decision making about the future care of older group home residents and transition to residential aged care. *Journal of Intellectual Disability Research*, 55(8), 777-789.

- Bischoff, K. E., Sudore, R., Miao, Y., Boscardin, W. J., & Smith, A. K. (2013). Advance care planning and the quality of end-of-life care in older adults. *Journal of the American Geriatrics Society*, 61(2), 209–214. doi:10.1111/jgs.2013.61.issue-2
- Bowey, L., & McGlaughlin, A. (2006). Older carers of adults with a learning disability confront the future: Issues and preferences in planning. *British Journal of Social Work*, 37(1), 39–54.
- Cairns, D., Tolson, D., Brown, J., & Darbyshire, C. (2013). The need for future alternatives: an investigation of the experiences and future of older parents caring for offspring with learning disabilities over a prolonged period of time. *British Journal of Learning Disabilities*, 41(1), 73–82.
- Carers UK (2013). *Missed Opportunities: The Impact of New Rights for Carers*, London, Carers UK.
- Carers UK (2015). *Facts about carers*. London, Carers UK
- Chadwick, Darren D., Hasheem Mannan, Eudene Garcia Iriarte, Roy McConkey, Patricia O'Brien, Frieda Finlay, Anne Lawlor, and Gerry Harrington. "Family voices: life for family carers of people with intellectual disabilities in Ireland." *Journal of Applied Research in Intellectual Disabilities* 26, no. 2 (2013): 119–132.
- Coolican, H. (2017). *Research methods and statistics in psychology*. Psychology Press.
- Davys, D., & Haigh, C. (2008). Older parents of people who have a learning disability: perceptions of future accommodation needs. *British Journal of Learning Disabilities*, 36(1), 66–72.
- Dementia Action Alliance. (2017). *Meeting the challenges of dementia for people with learning disabilities: roundtable discussion briefing paper*. London: Dementia Action Alliance
- Department of Health (2001). *Valuing People: A new strategy for learning disability for the 21st century*. UK Department of Health.
- Department of Health. (2009). *Valuing people now: A new three-year strategy for people with learning disabilities*. Department of Health.

Department of Health (2012). Transforming Care: A national response to Winterbourne View Hospital. London: DH publishing.

Department of Health & Social Care (2018a). Care and Support Statutory Guidance. London: DH & SC.

Department of Health and Social Security (1971). *Better Services for the Mentally Handicapped*. London: Her Majesty's Stationery Office

De Winter, C. F., Van den Berge, A. P. J., Schoufour, J. D., Oppewal, A., & Evenhuis, H. M. (2016). A 3-year follow-up study on cardiovascular disease and mortality in older people with intellectual disabilities. *Research in developmental disabilities*, 53, 115-126.

De Winter, C. F., Echteld, M. A., & Evenhuis, H. M. (2014). Chronic kidney disease in older people with intellectual disability: results of the HA-ID study. *Research in developmental disabilities*, 35(3), 726-732.

Dillenburg, K., & McKerr, L. (2011). 'How long are we able to go on?' Issues faced by older family caregivers of adults with disabilities. *British Journal of Learning Disabilities*, 39(1), 29-38.

Dillman, D.A. (1991) The Design and Administration of Mail Surveys, *Annual Review of Sociology*, 17, 225-249

Eley, D. S., Boyes, J., Young, L., & Hegney, D. G. (2009). Accommodation needs for carers of and adults with intellectual disability in regional Australia: their hopes for and perceptions of the future. *Rural and remote health*, 9, 1-13.

Emerson, E., & Hatton, C. (2008). People with learning disabilities in England. Retrieved from

[http://www.lancaster.ac.uk/staff/emersone/FASSWeb/Emerson\\_o8\\_PWLDinEngland.pdf](http://www.lancaster.ac.uk/staff/emersone/FASSWeb/Emerson_o8_PWLDinEngland.pdf)

[Accessed 19/04/19]

Evans, T. (2010). *Professional discretion in welfare services*. Aldershot: Ashgate

European Association of Palliative Care. *European Association of Palliative Care Palliative Medicine*, 30(5), 446-455. <https://doi.org/10.1177/0269216315600993>

- Ferguson, I. (2012). Personalisation, social justice and social work: a reply to Simon Duffy. *Journal of social work practice*, 26(1), 55-73.
- Forrester-Jones, R. (2014). Loss and people with autism. In S. Read (Ed.), *Supporting people with intellectual disabilities experiencing loss and bereavement* (pp. 165-173). London: Jessica Kingsley Press
- Forrester-Jones, R., Beecham, J. K., Barnoux, M., Oliver, D., Couch, E., & Bates, C. (2017). People with intellectual disabilities at the end of their lives: The case for specialist care? *Journal of Applied Research in Intellectual Disabilities*, 30(6), 1138-1150.
- Forrester-Jones, R., & Broadhurst, S. (2007). *Autism and loss*. London: Jessica Kingsley.
- Forrester-Jones, R., Carpenter, J., Coolen-Schrijner, P., Cambridge, P., Tate, A., Beecham, J., Hallam, A., Knapp, M. & Wooff, D. (2006). The social networks of people with intellectual disability living in the community 12 years after resettlement from long-stay hospitals. *Journal of Applied Research in Intellectual Disabilities*, 19(4), 285-295.
- Forrester-Jones, R., Gore, N., & Melling, K. (2010). How many people with intellectual disability are employed in the UK? *Tizard Learning Disability Review*, 15(1), 56-58.
- Fyffe, C., Pierce, G., Ilsley, B., & Paul, P. (2015). Improving policy and practice: Adults with intellectual disabilities and their families. *Research and Practice in Intellectual and Developmental Disabilities*, 2(1), 73-78.
- Gant, V. and Bates, C. (2014). "‘Cautiously optimistic’: Older parent-carers of adults with intellectual disabilities—Responses to the Care Act 2014." *Journal of Intellectual Disabilities* 23.3 (2019): 432-445.
- Grant, G., & Nolan, M. (1993). Informal carers: sources and concomitants of satisfaction. *Health & Social Care in the Community*, 1(3), 147-159.
- Grant, G., & Ramcharan, P. (2001). Views and experiences of people with intellectual disabilities and their families.(2) The family perspective. *Journal of Applied Research in Intellectual Disabilities*, 14(4), 364-380.

- Grey, J. M., Griffith, G. M., Totsika, V., & Hastings, R. P. (2015). Families' Experiences of Seeking Out-of-Home Accommodation for Their Adult Child With an Intellectual Disability. *Journal of Policy and Practice in Intellectual Disabilities*, 12(1), 47-57.
- Heller, T., & Arnold, C. K. (2010). Siblings of adults with developmental disabilities: Psychosocial outcomes, relationships, and future planning. *Journal of policy and practice in intellectual disabilities*, 7(1), 16-25.
- Heslop P, Blair P, Fleming P, Hoghton M, Marriott A, Russ L. (2013). *Confidential Inquiry into premature deaths of people with learning disabilities (CIPOLD): Final report*. Bristol: Norah Fry Research Centre, University of Bristol
- Hirst, M. (2014). Transitions into and out of unpaid care, Social Policy Research Unit, Working Paper No. CUK 2644, Heslington, University of York Heslington [accessed 17 September 2019] <https://www.york.ac.uk/inst/spru/pubs/pdf/CUK2644.pdf>
- Holman, A. and Bewley, C. (1999) Funding Freedom 2000: People with Learning Difficulties Using Direct Payments. London: Values into Action UK.
- Howe, D. (2017). Empathy, social intelligence and relationship-based social work. *Zeszyty Pracy Socjalnej*, 22(1), 1-12.
- Hubert, J. (2006). Family carers' views of services for people with learning disabilities from Black and minority ethnic groups: a qualitative study of 30 families in a south London borough. *Disability & Society*, 21(3), 259-272.
- Iacono, T., Evans, E., Davis, A., Bhardwaj, A., Turner, B., Torr, J., & Trollor, J. N. (2016). Family caring of older adults with intellectual disability and coping according to loci of responsibility. *Research in developmental disabilities*, 57, 170-180.
- Johnson, K., & Walmsley, J. (2010). *People with intellectual disabilities: Towards a good life?* Policy Press.
- Jokinen, N. S., & Brown, R. I. (2005). Family quality of life from the perspective of older parents. *Journal of Intellectual Disability Research*, 49(10), 789-793.



- Kelly, K., Clark, B., Brown, V., Sitzia, J. (2003). Methodology Matters. Good practice in the conduct and reporting of survey research *International Journal for Quality in Health Care* 2003; Volume 15, Number 3: pp. 261–266 10.1093/intqhc/mzg031
- Kenny, L., Hattersley, C., Molins, B., Buckley, C., Povey, C., & Pellicano, E. (2016). Which terms should be used to describe autism? Perspectives from the UK autism community. *Autism*, 20(4), 442-462.
- King's Fund (1980). *An Ordinary Life: Comprehensive Locally-Based Residential Services for Mentally Handicapped People*, King's Fund Centre, London
- Larkin, M., Henwood, M. Milne, A. (2018). Carer-related research and knowledge: Findings from a scoping review, *Health and Social Care in the Community*, 27, 55-67
- Learning Disability Mortality Review (LeDeR) (2019). *Annual Report 2018*, Bristol, Norah Fry Centre for Disability Studies, University of Bristol, HQIP [accessed 17 September 2019]
- Lipsky, M. (1980). Street-Level Bureaucracy. "Dilemmas of the individual in public services." *New York: Russell Sage Foundation* 71.
- Lyotard, J.F. (1991) *Phenomenology*. Albany, SUNY Press
- McConkey R. (2005). Fair shares? Supporting families caring for adult persons with intellectual disabilities. *Journal of Intellectual Disability Research* 49, 600– 612.
- McVilly, K. R., Stancliffe, R. J., Parmenter, T. R., & Burton-Smith, R. M. (2006). 'I Get by with a Little Help from my Friends': Adults with Intellectual Disability Discuss Loneliness 1. *Journal of Applied Research in Intellectual Disabilities*, 19(2), 191-203.
- Mencap (2012). *Stuck at Home: The Impact of Day Service Cuts on People with a Learning Disability*. Mencap, London.
- National Health Service and Community Care Act 1990 London HMSO
- Newton, J., & Browne, L. (2008). How fair is fair access to care? *Practice: Social Work in Action*, 20(4), 235-249.
- NHS Digital. Health and care of people with learning disabilities, experimental statistics: 2017 to 2018. (24 Jan 2019). <https://digital.nhs.uk/data-and->

[information/publications/statistical/health-and-care-of-people-with-learning-disabilities/experimental-statistics-2017-to-2018](#). [Accessed 19/04/19]

Nolan M., Grant G., Keady J. (1996). *Understanding Family Care: A Multidimensional Model of Caring and Coping*. Open University Press, Buckingham.

Palinkas, L.A., Horwitz, S.M., Green, C.A. Wisdom, J.P., Duan, N., Hoagwood, K. (2015) *Administration and Policy in Mental Health and Mental Health Services Research* 42, 5, 533-544  
<https://doi.org/10.1007/s10488-013-0528-y>

Parker R. (1981). Tending and social policy. In: *A New Look at the Personal Social Services* (eds E. M. Goldberg & S. Hatch), pp. 17 – 33. Policy Studies Institute, London.

Pearson, C., & Ridley, J. (2017). Is Personalization the Right Plan at the Wrong Time? Rethinking Cash-for-Care in an Age of Austerity. *Social Policy & Administration*, 51(7), 1042-1059.

Perkins, E. A., & Haley, W. E. (2013). Emotional and tangible reciprocity in middle-and older-aged carers of adults with intellectual disabilities. *Journal of Policy and Practice in Intellectual Disabilities*, 10(4), 334-344.

Perlick, D. A., Miklowitz, D. J., Lopez, N., Chou, J., Kalvin, C., Adzhiashvili, V., & Aronson, A. (2010). Family-focused treatment for caregivers of patients with bipolar disorder. *Bipolar disorders*, 12(6), 627-637

Power, A., Bartlett, R., & Hall, E. (2016). Peer advocacy in a personalized landscape: The role of peer support in a context of individualized support and austerity. *Journal of Intellectual Disabilities*, 20(2), 183-193.

Priestley, M., Jolly, D., Pearson, C., Ridell, S., Barnes, C., & Mercer, G. (2006). Direct payments and disabled people in the UK: supply, demand and devolution. *British Journal of Social Work*, 37(7), 1189-1204.

Pryce, L., Tweed, A., Hilton, A., & Priest, H. M. (2017). Tolerating uncertainty: Perceptions of the future for ageing parent carers and their adult children with intellectual disabilities. *Journal of Applied Research in Intellectual Disabilities*, 30(1), 84-96.

- Reinders, J. S. (2002). The good life for citizens with intellectual disability. *Journal of Intellectual Disability Research*, 46(1), 1-5.
- Reinhard, S., Bemis, A., & Huhtala, N. (2005). *Defining respite care*. Discussion Paper. New Jersey: Community Living Exchange.
- Riddell, S., Pearson, C., Jolly, D., Barnes, C., Priestley, M., & Merce, G. (2005). The Development of Direct Payments in the UK: Implications for Social Justice. *Social Policy and Society*, 4(1), 75-85. doi:10.1017/S1474746404002209
- Ryan, A., Taggart, L., Truesdale-Kennedy, M., & Slevin, E. (2014). Issues in caregiving for older people with intellectual disabilities and their ageing family carers: a review and commentary. *International journal of older people nursing*, 9(3), 217-226.
- Sango, P. N., & Forrester-Jones, R. (2017). Intellectual and Developmental Disabilities, Spirituality and Religion: A Systematic Review 1990–2015. *Journal of Disability & Religion*, 21(3), 280-295.
- Seddon, D., and Robinson, C. (2001). Carers of older people with dementia: Assessment and the Carer's Act, *Journal of Health and Social Care in the Community*, 9, 3, 151-8
- Seddon, D., Robinson, C., Reeves, C., Tommis, Y., Woods, B., & Russell, I. (2007). In their own right: Translating the policy of carer assessment into practice. *British Journal of Social Work*, 37(8), 1335-1352.
- Seltzer, M. M., & Krauss, M. W. (1989). Aging parents with adult mentally retarded children: Family risk factors and sources of support. *American Journal on Mental Retardation*.
- Shearn J. & Todd S. (1997) Parental work: an account of the day to day activities of parents of adults with learning disabilities. *Journal of International Disability Research* 41 (4), 285–301.
- Sitzia J, Wood N. (1998). Response rate in patient satisfaction research: an analysis of 210 published studies. *Int J Qual Health Care* 10, 311–317.
- Smith, J. A. (2010). Interpretative phenomenological analysis: A reply to Amedeo Giorgi. *Existential analysis* 21, 2, 186-193
- Stancliffe, R.J.; Wilson, N.J., Gambin, N, Bigby, C., Balandin, S. (2013). *Transition to Retirement. A guide to inclusive practice*, Sydney University Press

- Taggart, L., Truesdale-Kennedy, M., Ryan, A., & McConkey, R. (2012). Examining the support needs of ageing family carers in developing future plans for a relative with an intellectual disability. *Journal of Intellectual Disabilities*, 16(3), 217-234.
- Thompson D., Ryrie I. & Wright S. (2004). People with intellectual disabilities living in generic residential services for older people in the UK. *Journal of Applied Research in Intellectual Disabilities*. 17, 101– 108
- Todd, S., & Shearn, J. (1996). Struggles with time: The careers of parents with adult sons and daughters with learning disabilities. *Disability & Society*, 11(3), 379-402.
- Tuffrey-Wijne, I., (2015). Cancer and intellectual disability. In: D. Wyatt and N. Williams (Eds), *Cancer and cancer care*. London, U.K. SAGE pp143-158 ISBN 9781446256282
- Tuffrey-Wijne, I., McLaughlin, D., Curfs, L., Dusart, A., Hoenger, C., McEnhill, L., Read, S., Ryan, K., Satgé, D., Straßer, B. and Westergård, B.E., (2016). Defining consensus norms for palliative care of people with intellectual disabilities in Europe, using Delphi methods: A White Paper from the European Association of Palliative Care. *Palliative Medicine*, 30(5), pp.446-455.
- Turner, S., and Bernard, C. (2014). *Supporting older people with learning disabilities: a Toolkit for Health and Social Care Commissioners*, Birmingham, BILD
- Yoong, A., & Koritsas, S. (2012). The impact of caring for adults with intellectual disability on the quality of life of parents. *Journal of Intellectual Disability Research*, 56(6), 609-619.
- Walker, C. M., & Hayton, J. W. (2017). Navigating austerity: balancing ‘desirability with viability’ in a third sector disability sports organisation. *European sport management quarterly*, 17(1), 98-116.
- Walker, R., & Hutchinson, C. (2018). Planning for the future among older parents of adult offspring with intellectual disability living at home and in the community: A systematic review of qualitative studies. *Journal of Intellectual & Developmental Disability*, 43(4), 453-462.
- Weeks L.E., Nilsson T., Bryanton B. & Kozma A. (2009). Current and future concerns of older parents of sons and daughters with intellectual disabilities. *Journal of Policy and Practice in Intellectual Disabilities* 6, 180–188

Wilson, N. J., Stancliffe, R. J., Bigby, C., Balandin, S., & Craig, D. (2010). The potential for active mentoring to support the transition into retirement for older adults with a lifelong disability. *Journal of Intellectual and Developmental Disability*, 35(3), 211-214.

World Health Organisation. (2011). *World disability report*. Retrieved from [www.who.int/disabilities/world\\_report/2011/report.pdf](http://www.who.int/disabilities/world_report/2011/report.pdf)

