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International perspectives on best practice when working with family carers of people with an intellectual disability from across the life course

“Cautiously Optimistic” Older Parent-Carers of Adults with Intellectual Disabilities response to the Care Act 2014.

Abstract:

This paper discusses potential opportunities for best practice in the UK that may be brought about by the Care Act (2014). This Act gave new rights to UK carers for assessment and aimed to provide a structure for a more personalised approach to care and support.

Offering a discussion of potentials within the Care Act in addition to drawing on a small study involving older parent/carers for sons or daughters with intellectual disabilities this paper explores potentials for best practice and the extent to which such parents of adults with intellectual disabilities were aware of the details of this piece of legislation and the potential impact it may have on their lives.

Semi-structured interviews were conducted with five parents over the age of 60 of sons or daughters with intellectual disabilities in North West England. The study adds to the body of knowledge and understanding about parents of adults with intellectual disabilities and explores and gains a deeper understanding of parents' experiences of the implementation of this legislation and their perception of the relevance of it. Findings include the identification of some optimism and that in general parents in this study were aware of the legislation. However they were less clear about the specificities and the implications for them and/or their sons or daughters with intellectual disabilities.

Key Words: Older Parent Carers; Social Work; Support; The Care Act.

Introduction:

It is known that adults with intellectual disabilities continue to live longer in an increasingly ageing population (Bigby, and Haveman, 2010; Emerson and Baines,

2011), and for the first time, such individuals are now living into old age in significant numbers. Within the UK the majority of people with intellectual disabilities continue to live with their families (Cairns, et al. 2013; Gant, 2010). Adults with intellectual disabilities are less likely to have a spouse/partner or children who may be called upon to care for them in later life (Ryan et al, 2014), and family carers (usually parents) are themselves experiencing continuing longevity. Such demographic changes mean that the number of carers is increasing and as Carers UK (2010) note, the intensity of the caring role is also increasing. According to the figures supplied by the Foundation for Learning Disabilities, quoted in Pryce et al, 2017 in the UK there are approximately 29,000 people with intellectual disabilities who live with a family member over the age of 70.

This paper offers a discussion of the implications of a relatively new piece of UK legislation The Care Act (2014) punctuated with findings and comments obtained from a small scale qualitative research project with 5 older parents of adults with intellectual disabilities. The aim of this project was to obtain their thoughts and feelings about the Care Act (2014) UK legislation that appears to have potential for significant (positive) impact upon their lives and those of their offspring. Exploring aspects of a particular piece of social care legislation and capturing the understanding a small group of carers of adults with intellectual disabilities have of this extends understanding and offers for debate the relevance of such legislation. Such research is timely as in the UK the demand for care is increasing, it has been anticipated that 3 out of 5 adults in the UK will become a carer at some point in their lives (Carers Trust, 2018).

Understanding the role, perspectives and experiences of carers is beneficial in many ways. Using this information in order to monitor, inform and enhance practice supports professional understanding and raises the profile of a small but increasing minority of carers-those of adults with intellectual disabilities. Understanding carers perceptions about the relevance to their own situation of current legislation, including how it is explained and introduced to them and their offspring, is important in order to develop systems for future information provision, as well as providing a functional platform to enhance working together to support the health and wellbeing of the person in receipt of care services. Recognising carer perspectives, and developing ways of supporting them may offer practitioners (and carers themselves) a range of

potential benefits: emotional, practical and, not least given the current economic situation, financial (Jordan and Drakeford, 2012).

As the number of carers increases so too has legislation and policy aimed at supporting the role of family carers. Developing apace particularly over the last 3 decades, carers are now seen as a service user group in their own right (Clements, 2012) making the relevance and understanding of legislation affecting this group of people highly significant.

For the purpose of this paper the term 'Carer' is taken to mean a family member or friend who supports (unpaid) an individual who would have difficulty managing without such care.

Background:

This paper offers a discussion and consideration of research literature in relation to the Care Act, it also draws on findings from a small scale empirical project for which the following information is pertinent:

After obtaining ethical approval from a University Ethics Committee a small sample ($n=5$) of parents over the age of 60 caring for individuals with intellectual disabilities at home was purposefully selected via a support organization for carers. The criteria included having cared for individuals at home for most of their lives. People with intellectual disability vary significantly in their ability, so the criteria for selection was that they were unable to support themselves independently, and that parents have elected voluntarily to continue to care at home. Potential participants were suggested by an intermediary who worked for the support organization and had mentioned the project to her contacts informally. All 5 were approached by letter that detailed the aims and objectives of the study as well as practical details including where, when and how information might be obtained. Signed consent was obtained from all participants. The intention was to keep the project relatively small given practicalities, and to potentially use it as a base for a large-scale research project in the future.

4 interviews were carried out in participants' own homes, one took place at participants request in a public place (a quiet café). 4 of the interviews were audio recorded and transcribed, and one participant requested that no audio recording was made but was happy for written notes to be taken which they verified. Data was analysed with a thematic approach following Braun and Clarke (2006) and when coded produced a number of interesting themes. Of the themes identified some have

been discussed elsewhere (Gant, and Bates 2017, Gant, 2017). For the purpose of this paper the theme identified as carers being 'Cautiously Optimistic' regarding the implementation of the legislation will be discussed, in particular with relation to three areas:

- Carer's needs assessments
- Reciprocal Care
- Wellbeing as it relates to older carers

Discussion:

Much of what is offered in the duties and priorities of the Care Act 2014 formalises previous best practice and policy for adults who have intellectual disabilities and their carers such as Valuing People (2001), Carers (Equal Opportunities Act 2004) and Valuing People Now (2009). In particular, evidence of this can be seen in the area of assessment.

In the UK in order for local authorities to begin to provide or purchase services for people it is necessary to identify their needs through carrying out an assessment. Assessment for parent-carers under the Care Act (2014) should establish their willingness to continue caring as well as considering what the impact is on them, and what they want to achieve in their day-to-day life. Providing regular support to someone who could not manage without it means carers have the right to have their needs assessed by their local authority, this is the case even if the person for whom they care has refused support services or an assessment of their own needs. The Carers Needs Assessment (as assessment under the Care Act is known), in this instance explores with parent-carers whether they have eligible needs for care and support in their own right. Such an assessment explores the impact of caring and also considers challenges faced by parent-carers how (and if) they manage them, as well as supporting parent-carers to articulate what they want to achieve in their day-to-day life. If a parent-carer is found to have eligible needs for care and support the assessor (in many cases a social work practitioner) will discuss available options.

Traditionally assessments had been carried out by professionals with carers and service users face to face, however professionals now utilize a range of assessment methods including telephone and Skype or Facetime and there have been significant

increases in the number of self-assessments. Tracing the history of carer assessments in the UK it is possible to see statutory requirement for such assessments became significant with the implementation of the Carers (Recognition and Services) Act, (1995) introducing the new concept of a carers assessment (Clements, 2017). This stated that in order to receive an assessment of needs, carers should be providing substantial amounts of care on a regular basis although 'substantial' was open to interpretation. This was a significant Act of Parliament as family carers, one of the main providers of health and social care in the UK, were now starting to become recognized as skilled and experts in their own settings. It is important to note that an assessment is seen as a critical intervention as that is the point where key information is gathered. The 1995 Act was seen as a starting point for the legal recognition of carers and for future policy developments. There were caveats however; within this legislation access to assessment for carers varied depended on a number of factors, not least geographical location and availability of workers to undertake such assessments, and subsequently on the amount of support offered. The 1995 Act was the first major piece of legislation to recognise fully the important role played by carers. It is noteworthy that within the 1995 Act carers assessment only occurred if the person in receipt of care was also being assessed for community care services. It was not until 2000 with the advent of the Carers and Disabled Children Act that carers had the right to an assessment independent of the person they cared for. Within this Act local authorities also had mandatory duties to support carers by providing services to them directly and were empowered to make direct payments to carers. The 2004 Carers (Equal Opportunities) Act further extended the rights of carers in the UK by placing a duty on local authorities to inform carers, in certain circumstances, of their right to an assessment of their needs. The 2004 Act provided that when assessing a carer's needs, local authorities must take into account whether the carer works or wishes to work, undertakes or wishes to undertake education, training or leisure activities, these were seen as significant and important factors when this legislation, the forerunner to the 2014 Care Act was enacted.

The legislation described above is a small but highly significant element of relevant legislation for older parents of adults with intellectual disabilities in the UK, and it can be seen that prior to the introduction of the Care Act (2014) understanding relevant legislation for carers involved in many instances picking through a patchwork of

confusing and somewhat convoluted Acts of Parliament and policies. Any change to simplify and streamline this process was seen to be welcomed and long overdue, particularly for parent carers of adults with intellectual disabilities, who may have been providing high levels of care for decades.

Regarding assessment of needs, the Care Act places carers on an equal footing with the cared for individual, and an assessor has the scope to complete a detailed assessment in order to gather the information necessary to understand the situation and the impact on a parent-carer's well-being. The Care Act 2014 highlights that it is important to look at a person's life, considering their needs and agreed outcomes in the context of their skills, ambitions and priorities however - what this may mean for older parents of adults with intellectual disabilities is debatable. With the assessment process continuing to be one of the most important elements of the care and support system it remains essential that it is a collaborative process involving the person concerned.

The Act's encouragement to utilise innovative practice suggests that practitioners may well have the scope and freedom to undertake assessments in ways that deviate from tradition. This may be of benefit to those with intellectual disabilities and their parent(s) for whom engaging with traditional paper based assessment processes and indeed timeframes may not be effective. Individuals with intellectual difficulties may need more time to complete an assessment for example when utilising a specific method of communication to work with an individual to complete an assessment, such as intensive interaction (Nind and Hewitt, 2012), a longer time frame might be required, if combined assessments are undertaken additional time may be advantageous for parent-carers also. Within the research project none of the carers said they had experienced a combined assessment, however one participant was keen to explore the idea for any future assessments.

It is of significance that the Act states that an individual must be given information about the assessment process in advance – although only wherever practicable. This potentially enhances the assessment experience and process and may enable parents of individuals with intellectual disabilities to potentially better prepare for assessment as well as considering in advance what they want from the process and what wellbeing means to them.

The importance of correctly assessing, and recording an individual's articulation of well-being is key to ensuring a successful assessment for all those involved in the process. Assessing the needs of an individual takes skill, knowledge and professional discretion, and may require the fashioning of 'raw information into a useful piece of work' (Dyke, 2016: 8). It is essential that the needs of both the adult with an intellectual disability and their parents are acknowledged, validated and planned for holistically in order for the assessment to be seen and experienced as a meaningful process. Assessments and interventions must systematically identify all elements of need within the whole family-based situation as discussed below, with clear implications for practice at a number of levels.

Having a legislative framework to support assessments and recognising that an individual is at the centre of this process as well as being best placed to judge their own well being with regards to care and support, may be seen as an innovative and positive way of working from the perspective of parent carers and their offspring.

One of the keys to developing and understanding assessments of adults with intellectual disabilities and their parents is an appreciation of the co-support that often exists between them. Such reciprocal care and mutual dependency are acknowledged in the Care Act within the whole family approach. This is a positive feature for parent carers of adults with intellectual disabilities in particular, as this goes some way to recognise the significance of the family unit as a whole, as opposed to seeing the carer and person in receipt of care independently. Feldon, (2017), notes that the intention of the whole family approach is for local authorities to take a holistic view of the person's needs and to identify how the adult's needs for care and support impact on family members or others in their support network. This is particularly significant when considering the lives of adults with intellectual disabilities as research highlights the mutual interdependence between their lives and that of their parents (Knox and Bigby, 2007; McKenzie and McConkey, 2016; Ryan et al, 2014) and the fact that this legislation can be interpreted as recognising this, to some extent, is to be positively acknowledged.

For one carer in the research:

'I am hopeful that this new legislation will bring about greater appreciation of me as a carer, and also recognises the help my son does give to me now I'm getting older '

The reciprocal, or mutual care reported in the literature (See for example Fyffe et al, 2015; Knox and Bigby, 2007; Perkins & Haley, 2013) that is seen as highly significant to many families is finally recognized in policy via the whole family approach. Individuals with intellectual disabilities living with older parent-carers can and do provide many hours of supportive care and personalised approaches and individual budgets can provide opportunities for pooling of resources to meet the needs of multiple people living within the family unit.

The Care Act can be seen as providing opportunities for the development of relationship-based practices these are usefully re-contextualised as now having a statutory/legal underpinning. This may also align itself constructively with the potentials for better assessment practice(s) leading to greater accuracy in identifying service and support needs with the concomitant benefits of better outcomes and higher levels of wellbeing. Furthermore there is emphasis on the intended collaborative nature of assessment under the Act with guidance with a new duty to provide access to advocacy where there is substantial difficulty with communication. Given the prevalence of communication issues amongst individuals with intellectual disabilities, approaching this new responsibility with cautious optimism would seem appropriate in terms of considering such experiences and the support that may be offered by parent-carers.

A partnership approach is evident within The Care Act (2014) this puts carers on the same footing as those they care for, with support for families and the notion of the whole family approach being one of its key elements. Within this approach the significance of any other family members for whom the carer has responsibilities is therefore recognised, for example many older carers take responsibility for grandchildren, and for some care of their spouse is also relevant. If both the person in receipt of care and the carer agree, a combined assessment of their needs can be undertaken, although it is worth noting that in the case of a combined assessment, both parties still need an opportunity for a private conversation with the assessor.

One participant in the study described how they felt changes were happening as a result of the Care Act implementation:

‘So you see for example one or two changes are already taking place.... things are gradually beginning to kick in with the Care Act –just in the last couple of weeks, I found out from (son’s) Social Worker there has been some new guidelines for Social Workers to follow up with carers-surely this can only help.’

Reciprocal care between adults with intellectual disabilities and their older parents has been noted elsewhere in the literature (Baumbusch et al, 2017; Bowey and McGlaughlin, 2005; Iacono et al, 2016), however to see such an acknowledgement noted in legislation is a positive recognition of the situation many adults with intellectual disabilities and their parents are in. For example one carer noted:

‘Well, he (son) helps me in ways you wouldn’t even think of-he’s very sociable and makes me get out of the house and do things. That keeps me going I suppose.’

Mutual helping and co-dependency might be something to celebrate alongside the use of strengths-based assessment considering the holistic nature of well-being, and there is potential here to develop trust and faith in professional intervention if this can be communicated effectively to older parent-carers. It may also be possible to see positives of reciprocal care utilising Duffy’s Seven Keys to Citizenship, more specifically around the areas of ‘purpose’ and ‘help’ (Centre for Welfare Reform). Furthermore, the complexities of significant relationships can now be acknowledged as they are reflected within the area of well-being ‘maintaining family and other personal relationships’ and therefore, if there is a significant detrimental impact upon this area of well-being, there is potential eligibility also. Highlighting the role of parent-carers and the presence of reciprocal care-giving also allows practitioners and policy makers to respond more pragmatically to real need, rather than assuming that such relationships are normative and therefore not requiring of support and maintenance.

Changes that affect one family member had an impact on others. The scenario of parent-care-giver and adult care-recipient is not mutually exclusive. As Fine and Glendinning (2005) have suggested, care is not a situation where an active care-giver performs an activity on a passive and dependent recipient. Although only a

small sample, the majority of people involved in the research project appeared to adopt both care-giving and care-receiving roles.

The promotion of the whole family approach within the Care Act goes some way to recognise the significance of the family unit as a whole. Seeing the adult with intellectual disability and the parent/carer independently as well as any other family members for whom the carer has responsibilities by its very nature discounts the experiences of so many families. Individuals with intellectual disabilities living with older parent-carers can and do provide many hours of supportive care (Fyffe et al, 2015; Knox and Bigby, 2007; Perkins and Haley, 2013) and to see an opportunity for this to be recorded is positive. Additionally, there is potential for personalised approaches and individual budgets to provide opportunities for pooling of resources to meet the needs of multiple people living within the family unit, this could include older parent carers and their offspring with intellectual disabilities. (Whole Family Approach, 2015).

Whilst the concept of well-being is one with a degree of subjectivity, it provides a greater breadth of opportunity for an assessor to capture the individual carer's realities in terms of what is meaningful to them.

'The general duty of a local authority, in exercising a function..... is to promote that individual's well-being' (The Care Act, 2014, c23, Part 1 Promoting Individual Well-being).

The Care Act's focus on well-being has the potential to offer significant improvement on previous provisions for parents of individuals with intellectual disabilities, as well as adults with intellectual disabilities themselves and sits alongside an enhanced emphasis on prevention and integration of services together with consistency of assessment and eligibility.

The Care Act 2014 includes a duty to meet need in a way that contributes to well-being and not just a duty to provide services. In this sense it has the potential to allow practitioners, individuals and families to be more creative and focus on areas of the individuals' lives beyond the previous basic priorities of personal care that were felt to be 'critical or 'substantial' need under previous legislative and policy frameworks (NHS and Community Care Act 1990 and Fair Access to Care Services 2010).

Understanding and assessing an individual within a framework of well-being provides more flexibility for assessors to consider the individual's life in an holistic way and draws on previous key elements from within UK policy – Valuing People (2001) and Valuing People Now (2009) such as paid work, housing and community relationships – all of which can now be considered when exploring with an individual what well-being means to them, but that were topics that did not necessarily feature as part of previous assessments under the NHS and Community Care Act, 1990 and the FACS criteria (Fair Access to Care Services) .

As noted the Care Act 2014 places carers on an equal footing with those for whom they are caring and establishes a legal obligation to meet carers' needs in a similar way to those for whom they care. For parent carers of adults with intellectual disabilities a move away from assessing the number of hours they spend caring, towards the more holistic approach offered by the well-being principle within the Care Act might better take account of the extent of their responsibilities not always quantifiable. Research (Iacono, 2016; Shearn and Todd, 2000) suggests that it is not necessarily the number of hours a carer spends caring that creates a sense of responsibility and associated potential detriment for the carer, but rather the knowledge that the cared for person is reliant upon them. With the Care Act highlighting “the importance of beginning with the assumption that an individual is best placed to judge the individual's well-being” (DoH, 2014, p9), practitioners will have the scope to focus more on an individual carer and their experiences in terms of its impact on their life in an holistic way as opposed to the number of hours they are caring for.

Planning for the future care of people with intellectual disabilities is cited in the literature as being an area of major concern for older parents (Bowey and McGlaughlin, 2006; Cairns et al 2013; Pryce et al 2017) and for many professionals working with families it is a relatively new area to consider (Ryan et al 2014). Changes in the life expectancy of adults with intellectual disabilities means that many more people are out-living their parents, this is still a relatively new phenomenon and one which many practitioners may not have experienced. For parent carers there are clear barriers to planning for the future (Walker and Hutchinson, 2017), including lack of information and availability of preferred options. Whilst the Care Act does not

make specific powers towards developing future planning for any client group, professionals, by recognizing and using the perceived potentials within the 2014 Act creatively, may be able to support carers both in the (day-to-day) caring role and assist them in planning for the future – both their own and that of their son or daughter with intellectual disabilities- as it is important to recognize the paths of each may not be the same.

Parent carers of adults with intellectual disabilities recognize that they do need support from professionals, however for many this is lacking (Cairns et al 2013). It is important to note that recognition by carers of their own support needs does not necessarily equate to them having a stressful caregiving experience. For some carers there are many benefits of being a carer (McConnell et al, 2015; Pakenham et al, 2007) these include life satisfaction as well as feelings of worth and positivity. This needs to be placed against a discussion of shared responsibility and support networks that extend beyond that of the immediate family and are planned for in a meaningful and realistic way.

For one carer in the study:

'I see my responsibilities as caring for L. I see the council's responsibility as helping me to care. I want to take care of my daughter as long as I can and hopefully this legislation will help'.

The Care Act is to ensure the individual, whether that be a carer, or an adult with intellectual disabilities, is best placed to judge their own well- being. There is a clear statutory concept behind this and in practice it should work to the advantage of individuals.

This notion is a familiar one to many practitioners working in partnership and from a strengths based perspective (Howe, 2017) with carers and adults with intellectual disabilities. Establishing a working partnership is seen as a positive factor (Hothersall and Maas-Lowit, 2010) and the duty is on the practitioner to have regard to the wishes and preferences of an individual. It cannot be emphasised enough that attention needs to be paid to placing the individual at the centre of any decision made about them, and ensure they are at the heart of the process.

As with all legislation, knowing of its very existence and understanding aspects of it are key to understanding the scope it has to impact on ones life. All participants

involved in the study said they had heard of the Care Act, and three participants said they had discussed elements of it at carer support meetings they attend, although they were less clear about the specifics. Similarly the extent to which its implementation may support them in their caring role was less clear, 4 participants said they had received a carers needs assessment in the past 12 months which they linked directly to the implementation of the Care Act, whereas 1 participant said they were unsure if or when they had received such an assessment. Interestingly all participants acknowledged that they were carers as well as parents, (literature around carers indicates that many carers do not recognize themselves as such, see for example Greenwood et al 2015) although all noted how it was not always an easy transition or self-acknowledgment, for example:

'I do think we are carers, but know a lot of other parents who wouldn't even consider they were anything other than parents. For me it came about years ago when I was advised by a Social Worker to apply for Carers Allowance-I thought 'ok so that is what I am is it?'

For parents of offspring with intellectual disabilities the extension or differentiation between 'caring' and 'parenting' may be subtle and nuanced and one that has developed incrementally as their son or daughter ages. Regardless of title all parents interviewed for the research project said they provided a range of support for their offspring above and beyond that which they provided to their other adult offspring, and above that of the support any of their friends provided to offspring of similar ages without intellectual disabilities. Participants noted that on many occasions their own needs were subsumed by their caring roles and how at times this became an expected pattern.

'I don't think about myself at all really-as long as he (son) is ok that's all that matters. I fit all my activities in the days he's out with the support worker anyway.'

One of the most significant aspects of the Care Act (2014) is that it places carers on an equal footing with those for whom care is provided and it emphasises 'the importance of beginning with the assumption that the individual is best placed to judge the individual's well-being' (DoH, 2014 p9). There appears to be scope within

the Act for practitioners to appropriately (and necessarily) shift the focus away from (simplistic) calculations of hours of care provided onto a considered appreciation of an individual carers experience of caring in terms of the impact on their life- (as may have been the case with previous legislation). This however requires that both assessors and carers are aware of this. In the project 3 carers said they had heard or read about the personal impact of caring and how this may be used to guide services, however 2 carers were less sure. For the 3 carers who were aware of the 'impact' factor they cited 'effective relationships' (Gant, 2010) with professionals as being a significant factor when planning future care arrangements.

For carers involved in the study, some support and information given by professionals throughout the life-course of their son or daughter was recognised although this was set against a recognition by parents of increasing case loads and cuts to budgets; for this participant accessing appropriate individuals was at times problematic:

'Once you break it down a lot of the professionals are really good a lot of the time, but you are facing hurdles to get to them. Take receptionists, part of their job is to stem the flow. Hopefully the Care Act will make a difference with that.'

The ethos behind the Care Act is to ensure the individual, in this case the parent carer, is best placed to judge their own well-being. There is a clear statutory concept to this and the implications for those being assessed are significant. The importance of professionals asking appropriate questions and being skilled at analysing responses is key. Correctly assessing, and recording an individual's articulation of well-being is essential in ensuring a successful assessment. By an assessor obtaining detailed information options may be more readily available for support and agreement given for financial backing for these options at local authority funding panels.

Planning for the future care of people with intellectual disabilities is identified in the literature as being an area of major concern for older parents (Bowey, and McGlaughlin, 2006; Ryan et al 2014). Within the project carers recognised the relevance of working alongside professionals from a variety of disciplines to support their son or daughter. This combined with the need to know about and consider suitable options for the future care of their offspring were vital. For professionals, by

recognizing and using the perceived potentials within the 2014 Act more creatively, it seems they may be able to support carers both in the (day-to-day) caring role and assist them in planning for the future – both their own and that of their son or daughter with intellectual disabilities- as it is important to recognize the paths of each may not be the same.

All 5 participants in the research project were acutely aware of the need and importance of working successfully with professionals to support their son or daughter, although it was noted this is an area that may be fraught with difficulties. Despite legislation and policies that promote working together practicalities, or some may say realities exist. For example it is difficult to build and sustain relationships with practitioners when there is a high turnover of staff, or periods of not having an allocated or named professional to contact as was the case in this instance:

'We have had so many workers come and go over the years-it's hard for us to get to know them let alone P (son)-when you do get a good worker you try and hang on to them by their coat tails (laughs)-seriously though it does get more urgent as parents get older-there is a need to make sure the future is sorted out, we're ok but I think we're in the minority.'

Conclusion:

In conclusion this paper offered a discussion relating to literature and a small scale research project. These elements highlighted the need to expand research and understanding into the way information is transmitted by professionals and those in the know, as well as the ways in which such information is received and understood by those for whom it is intended. In order to support the wellbeing of parent-carers of adults with intellectual disabilities it is vital that their needs and perspectives are understood. The Care Act 2014 aimed to provide a framework within which personalized care can be conceived of as being realistic and practical (DoH 2014). Examination of the legislation indicates that there is potential for best practice, for joined up working and for creativity in service provision. This is positive, however the reality may differ significantly from the rhetoric. The Care Act does appear in principle to provide a framework that skilled professionals may use to enhance the lives of the people they work with. However rising case loads experienced by many professionals combined with budget cuts to services in an on going climate of

austerity may provide a challenge to creative and flexible work with family carers of all ages (Gant, 2018). For parent carers of adults with intellectual disabilities knowing more about the details of the Act may enable them to challenge any decisions that they may feel have been taken outwith the spirit of the legislation. Information sharing and dissemination of key points relating to legislation is needed, carers groups may provide a useful opportunity to share such information, although ways of contacting those carers unknown to services or who do not attend groups remains an on-going challenge.

It is evident that older adults who provide care (and may have done so for decades) have a significant role to play in the lives of their sons or daughters with intellectual disabilities. It is important that policy makers and practitioners clarify just how much older carers understand the legislative framework that shapes and guides future care and support. The relationship this group of older people have with current legislation has not been explored and this is one of the first studies to report on older carers attitudes to The Care Act (2014).

As noted earlier the population of adults with intellectual disabilities is growing and opportunities for better practice and the utilisation of a more vibrant and creative evidence-base are now visible, although effective knowledge development use, transfer and dissemination for all practitioners needs to be considered as routine if sustainable improvements are to be realised (Heinsch, Gray and Sharland, 2015).

In the same way though, seeing the opportunities within the 2014 Act as an opportunity to value the caring role and to see reciprocal care as a celebration of the positivity inherent within many family relationships should themselves be taken to reflect some of the potentials of the legislative landscape culminating in The Care Act (2014). These are potentials that, if taken seriously, and considered (as they should be) as the appropriate State (collective) response to the needs of its citizens, could see carers being valued in a way previously only hoped-for.

Further research is needed to explore many of the issues raised above in depth, it is still relatively early days in relation to the implementation of the Care Act (2014) and jurisprudence in relation to aspects of it are still developing. There will be a need for further analysis, social, practical and judicial in terms of future provision and understanding of this significant legislation.

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