Lived experience and the social model of disability: conflicted and inter-dependent ambitions for employment of people with a learning disability and their family carers

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Accessible Summary
- In the UK very few people with learning disability and/or autism and their family-carers have a paid job although a lot of them may wish to work. National plans from the Government have not helped to change this.
- This article talks about a consultation we did on adults with learning disabilities and/or autism who attend day centres and their family-carers. We asked about their current situation, their employment and the barriers to work.
- We found out that very few people with learning disabilities and/or autism or their family-carers were employed. We found that there were lots of things stopping people with learning disabilities and/or autism and family-carers from being able to work.
- We conclude that disability theories like the “social model of disability” need to go back to looking at inclusion, citizenship and independence, based on the real life experience of people with a learning disability. The government needs to provide strong plans to help people with learning disabilities and/or autism and family-carers get into work. “Co-production” networks should be set up between people with learning disabilities and families to support employment.

Abstract
Background: Only 5.9% of working adults with a learning disability are in paid employment and their family-carers are similarly likely to be unemployed, as they continue to take on an extended caring and advocacy role as the welfare state retreats. Despite social policy efforts to stimulate employment for people with a learning disability, there has been little or no progress. Changes in the language of welfare benefit departments seek to use the words once heralded as success for the Disability rights activists and proponents of the social model: such as Inclusion, independence and citizenship. A new definition of the social model of disability utilising Hannah Arendt needs to redefine the “private” sphere of the lived experience of people with a learning disability to allow for a better understanding of the inter-dependencies that exist between people with a learning disability, their family carers and a wider support network.
Materials and Methods: Empirical data were collected in a mixed methods study while undertaking a consultation on the future of day services for people with a learning disability in a Local Authority in the north of England, UK.

Results: The results reveal high levels of inter-dependence between people with a learning disability and their carers, combined with the continued financial struggle as a lived experience of caring. The study found that barriers in providing care and support restrict the rights of people with a learning disability and their carers to secure employment.

Conclusions: There is a need to reconceptualise the social model of disability to more closely resonate with the lived experiences of people with a learning disability and their carers. A newly revised theoretical approach should incorporate the "private" sphere of live acknowledging the inter-dependent, co-produced relationships, between people with a learning disability and their carers to support and enable employment for both people with a learning disability and their carers under the Care Act 2014 (Department of Health, 2014).

Keywords: autism, empowerment issues, family carers, health, learning (intellectual) disabilities, lived experience, social care policy and practice, social model of disability, supported employment

## INTRODUCTION

Throughout the UK, just 5.9% of working age adults with a learning disability are in paid employment (Hatton, 2018; Robertson et al., 2019) a figure that has fallen from 6.6% (2010/11) to 5.9% (2018/19) (British Association of Supported Employment, 2019; Department of Work & Pension & Department of Health of the UK, DH, 2017; Foundation for People with a Learning Disability, 2019b).

People with a learning disability continue to have ambitions to be employed (Beyer & Kilsby, 1997; Melling et al., 2011; Rustad & Kassah, 2020) supporting the evidence that having a job is associated with a greater sense of autonomy, improved self-reported well-being, reduced depression and anxiety symptoms (Robertson et al., 2018). Social policy initiatives have sought to influence more opportunities for employment (DH, 2001, 2007, 2009a, 2009b; HM Government, 2010). Despite these government initiatives, there has been little or no progress in the numbers employed (Blamires, 2015; DH, 2009b; Hatton, 2018). Employment was a key objective of the national learning disability strategy “Valuing People” (DH, 2001–2010) which aimed to “ensure that more people with a learning disability find appropriate employment, including supported employment, which makes the most of their talents and potential” (Valuing People, 2001). There had been some reported growth in employment opportunities during this time where 28% of people with mild-to-moderate learning disability and 10% of people with a severe learning disability were reported to be in some form of employment (Emerson & Hatton, 2008). However, with a new coalition government formed in 2010 in England, Government Ministers felt that the “Valuing People” strategy was no longer a priority and the national strategy was decommissioned (Greig, 2018).

Ferguson-Wormely and Jonathan Evans represent Speakup, a self-advocacy organisation in the north of England who were also part of the Valuing People national subgroup on employment (2001–2010). It is from this context and experience that Speakup have witnessed a stark decline in the numbers of people with a learning disability in employment across England. When Speakup were asked by a local authority to co-design and co-create a Public Consultation on the future of learning disability services in 2016–2017, they recommended the inclusion of three specific questions regarding employment which were to identify the aspirations of people with a learning disability and their carers towards employment, to explore attitudes to work and finally to identify opportunities for employment. These three questions were developed as part of a mixed methods study where Speakup were fully engaged in the co-design, implementation and analysis of the research data with the local authority with a demographic above average for socio-economic deprivation (Table 1).

This article is a case study drawing upon empirical survey data from both people with a learning disability and family carers on their views relating to employment as part of a Public Consultation to inform future service provision. This study is unique in that it generated data from people with a learning disability and family carers (not necessarily related to each other). Few studies have examined the inter-dependent relationship between people with a learning disability and family carers in relation to aspirations, attitudes and opportunities for employment. What is known is that there is an economic consequence for carers in their support role, with mothers frequently taking on the extra demands of care giving which can result in a drop in familial income (Heller et al., 2007; Young et al., 2017) and many carers face continuing unemployment which is associated with family socio-economic disadvantage (Institute
This local authority is ranked in the lower quartile in the Index of Multiple Deprivation (IMD) worksheet in England having a very high proportion of Lower-layer Super Output Areas (LSOAs) in the most deprived 10% nationally (Government of UK 2015). Life expectancy is around five years less than the national average.

of Education, 2017). This is the lived experience reported by many carers of people with a learning disability and reported through research narratives (Chappell, 1998; Walmsley, 1997, 2001; Walmsley et al., 2017) yet this lived experience is not currently captured by the social model of disability that has otherwise made significant gains to advance the human rights of people with a learning disability. The social model of disability was founded on the political and social aspects of life and failed to address the "private" sphere of life defined by lived experience. However, changes introduced in the Care Act, 2014 have opened up an opportunity to revisit the "private" sphere of life through the inter-dependent relationship between people with a learning disability and their carers by introducing the concept of "co-production" which has been defined as: "a means to deliver public services in an equal and reciprocal relationship between professionals, people using services, their families and neighbours. Where activities are co-produced in this way, both services and neighbourhoods become far more effective agents of change" (Boyle et al., 2010; Boyle & Harris, 2009; Boyle et al., 2010). It is through the concept of co-production that it will be argued that the social model requires revision to encapsulate the "private" aspect of human life if we are to address the structural barriers to employment for people with a learning disability going forward (Arendt, 2003; Owens, 2015).

There are laws to protect employment rights and interests of both people with a learning disability and family carers. "Parties recognise the right of persons with disabilities to work, on an equal basis with others; this includes the right to the opportunity to gain a living by work freely chosen or accepted in a labour market and work environment that is open, inclusive and accessible to a person with disabilities" (United Nations General Assembly, 2006). At the same time, the Universal Declaration of Human Rights states: “Everyone has the right to work, to free choice of employment, to just and favourable conditions of work and to protection against unemployment” (Article 23.1).

However, both laws are conflicted as there is a lack of recognition of the inter-dependent relationship and support role carers take on when supporting their adult sons and daughters to achieve employment (Young et al., 2017). It is the lived experiences of people with a learning disability that are so intertwined with the lived experiences of parents and carers, as parents will work together to help each other, sharing experiences to help their son or daughter find stable, permanent and long-term employment (Young et al., 2017).

Parents and carers cope with cuts to government welfare entitlement and support that threatens to consign people with a learning disability and their families to self-help or neglect (Walmsley et al., 2017).

Family carers have taken on additional responsibilities with the implementation of “Direct Payments” which offers individualised care to adults with a learning disability by offering them and their carers direct commissioning of services through fundholding. This increases the responsibilities of family carers who often assume the responsibility of identifying, accessing and managing services as well as providing cover for absences (Petriwskyj et al., 2016; Selepak, 2008). Over 50% of 1.4 million adults with a learning disability in the UK live in a family house, depending on 0.84 million family carers causing significant physical, emotional and financial burden to them (Carer Trust, 2019; Carers UK, 2019a, 2019b; Foundation for People with a Learning Disability, 2019a; Mencap, 2019). Family carers supporting people with a learning disability are under significant financial hardship. The informal unpaid care provided by 8.8 million family carers is valued at £132 billion (2015); however, nationally only 39% of them were in paid employment (Carers UK, 2019a). Among all UK employees, 1 in 7 carers regularly juggles work with caring responsibilities; 2.6 million had to give up work and 2 million had to reduce their working hours (Carers UK, 2019b). Scarcity of health and social care support during a global economic crisis has increased poverty among adults with disabilities. Family carers are forced to spend money from their own finances and around 2 in 5 carers are struggling to make ends meet (Carers UK, 2019a). The current economic climate and austerity means that people with a learning disability and/or autism who would like to work may not be able to hold down a full time or part-time job and may be less likely to want to lose benefits they fought so hard to get.

It is often carers who have to forgo their right to work to provide care to their adult sons and daughters with a learning disability while also becoming involved in collective family campaigning and parent advocacy when services neglect and fail people (Walmsley et al., 2017). A lack of a national strategy to support the employment

| TABLE 1 The characteristics of the local authority and demography |
|----------------------------------------|------------------|
| Characteristics                        | National average |
| Total population (approx.)             | 250,000          |
| Total adult population                 | 220,000          |
| Employment rate                        | 69%              |
| Skill set (NVQ 4+)                     | 26%              |
| Percentage of adults receiving personal independence payment | 8.5% |
| Estimated population with learning disabilities and/or autism among adults: | 1.1% |
| Adults with learning disability known to support services | 870 |
| Prevalence of specific learning disability among primary school children | 30% |
| Diagnosis of autism among primary school children | 10.6% |
| Diagnosis of autism among secondary school children | 15.5% |

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of people with a learning disability results in significant geographic variation among local authorities with most people working less than 16 hr per week, with employment rates higher for men than women (Hatton, 2018). People with a learning disability are usually poorly paid which, in conjunction with the increased cost of living attributed to disability, increases their isolation and impacts upon their quality of life (Disabled World, 2019; The World Bank, 2019a). The UK Government (2017) has pledged action under the “Improving Lives—The Future of Work, Health and Disability” initiative (Department of Work and Pension and DH of the UK, 2017) to address the barriers to employment. Similarly, the World Bank has adopted ten commitments in their Global disability summit 2018 (Department for International Development, 2019). Its impact is yet to be noticed and without recognising the co-produced, inter-dependent relationship between the person with a learning disability and their carer, it is unlikely that any solution will be sustainable over the long term.

The inter-dependent relationship between people with a learning disability and others in their lives has been described as a support network by people with a learning disability as they describe the quality of perceived supportiveness and inter-dependency that is critical in defining the quality of these relationships. In one research study, these “support networks” included people with a learning disability, families, friends, and neighbours as well as support workers and others in a professional relationship with them (Strnadova et al., 2019). Strnadova et al., (2019) used the term “peer support” to describe “emotional and practical” support, clarifying that the way the support was given was important. Their study revealed that people with a learning disability are able to define the standard of support required in an inter-dependent relationship giving examples such as “a good peer supporter is respectful, non-judgemental and not imposing their own views and perspectives when giving support.” Less important is “who” gives support but more important is how it is done. The inter-dependencies between carers and service users may be overlooked in the assessments of service users, but carers have their own needs too under the Care Act 2014 (Department of Health, 2014; Brooks et al., 2015) and are often asked about their willingness and ability to continue caring and not necessarily about their own needs (Brooks et al., 2015). In addition, there may be an over-reliance on family carers who may lack support to either make choices for themselves or ensure choices for the people they support (Beresford, 2012; Brooks et al., 2015). The co-dependent relationship between people with a learning disability and/or autism and their family carers needs to be examined and explored further to recognise and balance both.

Co-production has contributed very little to the policy agenda for employment for people with a learning disability despite the concept informing collaboration with co-dependents defined within the Care Act, 2014 (DoH, 2014). One of the problems with how co-production is incorporated in the Care Act 2014 (DoH, 2014) is the limited ways citizenship and capacity are understood and defined by UK law. In contrast to the UK, Canada has the British Columbia Representation Agreement Act (1996) which provides a means for individuals to formally recognise one or more persons as their representative for routine health, personal care, financial decision making and legal affairs. The British Columbia Representation Agreement Act (1996) changes the way capacity is viewed and understood. Rather than a simple common law test of capacity to determine whether one can formally express an understanding, meaning and consequences of a given decision as is done in the UK, the Act relies on expanding the traditional concepts around communication and the quality of the relationship (Stainton, 2005). In the UK, people with a learning disability are made “wards” if they are deemed not to have capacity, fated to remain society’s passive beneficiaries (Leydet, 2017). Leydet (2017) argues that being a “passive beneficiary” has been contested and that people with a learning disability should be treated as “citizens.” Leydet (2017) argues that “to the extent that individuals act in ways that can be construed as expressing approval, acquiescence or dissent with the laws and regulations that affect them, they can be described as acting politically and as displaying a form of democratic agency” (Leydet, 2017). The current definition of co-production in the Care Act 2014 (DoH, 2014) does not go far enough to outline power and accountability in the relationship between people with a learning disability and their carers and a “communication profile” of the person with a learning disability is a recommended way of describing the nuanced and personalised form of communication preferences of the person with a learning disability (Aylott, 2009, 2010).

2 | METHODS

“Co-production” formed the underpinning approach to the design of a mixed methods approach to combine the use of a survey questionnaire and focus groups to maximise participation and engagement. Ethics permission was not required as this work was in line with government guidance on undertaking Public Consultations (Local Government Association, 2020; NRES, 2009). The approach was designed to be inclusive and participatory to engage all stakeholders including service users, carers, members of staff and the public. In order to do this, a mixed methods approach was used to combine the use of a questionnaire (either online or a paper version) and several focus groups. The focus groups were one off events and separate focus groups were organised for people with a learning disability and for parents/carers. A power point presentation was prepared for all focus groups, and data were collected using a data capture sheet. Although there were some responses that related specifically to employment in the focus groups, the responses to employment were analysed from the three questions included in the questionnaire. The questionnaire was approved by the local authority in-house services to meet the legal requirements of consulting with service users and the public if a change in service provision is planned for. The questionnaire was developed into four separate formats to target specific audiences to ensure the best accessibility format for each of the four groups. For example, an easy read questionnaire was designed for people with a learning disability with words and “easy read” pictures from pictorial software; a carers questionnaire was designed with an additional aim to connect to carers to provide
greater communication and discussion about future care options; a staff questionnaire was designed to support accessibility through the main local authority website and members of the public were invited to participate in a questionnaire through promoting this at various sites across the borough. The consultation was also based on The Gunning principles that are: (a) a consultation must take place when the proposal is still at a formative stage; (b) sufficient reasons must be put forward for the proposal to allow for intelligent consideration; and response; (c) adequate time must be given for consideration and response.

2.1 | Data analysis

Hard copy completions of questionnaires were manually inputted into an Excel spreadsheet so that three of the questionnaires (person with a learning disability/autism; family carer and member of the public) could be analysed collectively. The staff questionnaire was generated through a Google online form and exported into an Excel spreadsheet. This process was completed by the local authority in-house services. Two independent researchers, Prosenjit Giri and Jill Aylott, undertook an independent analysis of the data by using descriptive statistics and thematic analysis, coding inductively across the four surveyed groups. There were however some missing data across three of the questionnaire formats and a hand search was required with the local authority’s in-house services to extract the demographic data to enable an accurate level of analysis. The second challenge with data analysis was that the same questions were not asked consistently across all four stakeholder groups. Our initial plan to analyse the data across the total sample had to change and focus on separate stakeholder analysis for each group. Codes generated from the inductive data analysis were then compared across the four stakeholder groups. After completion of this first stage of analysis, key themes from the data were then discussed with all authors to reach consensus and agreement.

3 | RESULTS

The four questionnaires returned a total of 487 responses, of this number, 227 adults with moderate to severe learning disability participated comprising: 158 who had a learning disability, 59 who had a learning disability and autism and 10 who had a diagnosis of autism. When asked the question: "should individuals with a learning disability and or autism have the opportunity to work?" for those who replied to this question 167 (92%) said yes, with only 15 (8%) saying no or don’t know. The types of work that people with a learning disability suggested they would like included 14 (26%) work in a bar, café, baker, shop, or library with 6 (11%) wanting to work outside gardening or on an allotment. Others were creative with their ideas saying: "I want to work at the local football club, anything or litter picking" (cu48). In reality only 18 people (8%) were in paid work with 65 (21%) in voluntary work, although among the respondents, 98% (217/227) were in the working age group (18–64 years). When the respondents were asked if they wanted to do voluntary work, the majority 75% said no and 25% said yes. When asked what skills people with a learning disability had, many were able to reply to this question with 95 (48%) stating hobbies including jigsaws, bowling and arts and crafts and 69 (35%) reporting that they are good at people skills, team working and socialising. It appears that seeking employment for many individuals is complex as many depend on a level of support from others to achieve their goals with 134 (65%) needing some support and 72 (35%) needing a high level of support. In addition, three people identified issues and barriers, not directly related to their impairment but to external factors: "I would like people to be more tolerant of my learning disability and autism" (cu67); "If I know people better in my area who are similar to me, but I am a bit of a loner. I feel part of the community when I go to the centre and do things in the community with my friends" (cu69) and "my local paper shop makes me feel worried. The people treat me differently ...it’s a feeling" (cu98).

3.1 | Family carers

Seventy-seven (77) family carers responded. Of this number, 77% (59/77) of family carers were of working age (18–64) compared to 98% of adults with a learning disability. Adults with a learning disability were much younger (70%; 155/227 under 45 years vs. 22%; 17/77 of family carers).

Among family carers, 55% (42/77) were unemployed. More carers wanted to work but their caring commitment had made this difficult to achieve at times: "For the past few years I have not been able to access paid employment due to my caring commitments and I feel I should be supported in this. It is also my view that my daughter should continue on her journey to be less dependent on me, eventually leaving home but to do this gradually" (c46 carer support). Carers reported an economic driver to work due to the cost of caring. The cost of transporting the person they care for in the community was high and sometimes seen as a barrier that prevents the person from doing activities they would like to do "cost of transport to support the activities" (c26); "the cost of transport although mobility allowance is paid at the lower rate, it does not cover the cost of transport to places" (c59); "there is a lack of money to get him to places" (c43).

A high number of carers 74 (86%) reported that the person they care for cannot travel unaided: "he has to be supported all of the time, so he relies on myself or a family member to take him where he needs or wants to go" (c22). In addition, the use of public transport was not practical for many carers who provide support to individuals with complex needs; "always need support to get around" (c2); "sometimes can’t get on public transport with a wheelchair" (c2); "my sister is unable to access buses or other transport options with assistance" (c5); "they have difficulty walking long distances" (c12); "he can’t go out independently, but he does a lot of outdoor activity under supervision" (c21). Generally public transport was not
convenient and sometimes a risk to others: “there have been incidents where he has hit out at the driver on public transport” (c13).

Both the adults with a learning disability, 72% (163/227), and family carers, 50% (35/70), were pessimistic about the employment prospect of adults with a learning disability. Only 25% (29/115) adults with a learning disability had any aspiration to work; however, this is significantly higher than the national average of 5.9% (British Association of Supported Employment, 2019). Poor self-belief; low self-esteem; feeling vulnerable and unsafe and negative societal attitude were blamed for these low expectations.

4 | DISCUSSIONS

People with a learning disability and their carers aspire to be employed; however, both groups are pessimistic about being able to work. There is an overwhelming attitude among people with a learning disability and family carers that people with a learning disability should have the opportunity to work. Eight per cent (8%) were in employment which is slightly higher than the national average figure of 5.9% but nowhere near the 25% of people who would like to work but who are unemployed. Although 21% of people with a learning disability were doing voluntary work, 75% did not aspire to do voluntary work. They recognised themselves as having a high level of skills, but the main barrier perceived by people with a learning disability was in the level of support required from others, with 65% needing some and 35% needing a high level of support. Whereas support was identified as a requirement to seek employment from the perspective of people with a learning disability, the view from carers appeared more complex. The majority were unemployed due to their caring role. However, it was not just the caring role that they provided it was to support the transportation of their adult sons and daughters, when public transport was not appropriate, with many carers 86% stating that the person cannot travel on public transport unaided. It was the cost of caring that was a driver for carers to seek employment as many referred to the additional cost of caring which was found to be challenging. The findings from this research study highlight substantial inter-dependence between people with a learning disability and their family carers.

Our study outcome echoed findings that structural barriers to employment still shape how individuals view themselves and their opportunities for employment outside specialised workplaces (Castaneda et al. 2019). In our study, structural barriers included inadequate transportation, lack of targeted job opportunities and support networks, poor self-esteem and negative societal attitude and discrimination (Carer Trust, 2019; Carers UK, 2019a, 2019b; Castaneda et al. 2019; Disabled World, 2019; Foundation for People with Learning Disability, 2019b; Mencap, 2019; The World Bank, 2019a).

The lived experience of people with a learning disability in an inter-dependent relationship with their family carers needs to be part of the narrative and discourse going forward. Negative societal attitudes; bullying/harassment/crime; lack of access/resources/transport/ training facilities and targeted job opportunities were identified as structural barriers for work by the adults with a learning disability. Family carers highlighted significant emotional and physical strain caused by unrealistic demands from their employers and individuals with a learning disability; increasingly scarce resources and Lack of social/employer’s support (Carer Trust, 2019; Carers UK, 2019a, 2019b).

The social model of disability has had substantial success in challenging structural barriers to employment and positioning the rights of disabled people at the forefront of the social policy and research agenda; however, it has been unable to explain the inter-dependent relationship between people with a learning disability and their carers and the more invisible structural barriers that occupy the realm of private life. The social model of disability’s success has been in the influence of the United Nations Convention on the Rights of the Person with Disabilities (CRPD) “which was one of the most innovative and far-reaching pieces of legislation” (Berghs et al., 2019), but now it is reported that “the disability movement is failing to uphold the rights and entitlements that had been so hard won” (Oliver & Barnes, 2012; Berghs et al., 2019). Berghs et al. (2019) argue that society should and can do better in terms of responsibilities of a social contract to all of its citizens and that “the time has come to think of “what unifies and to reinterpret what the ‘social’ now means” (Berghs et al. 2019). We propose that the social model should incorporate the “lived experience” of people with a learning disability, as it is the lived experience that is so often defined by interconnectedness and inter-dependence between people with a learning disability and their family carers. This can be explained further by drawing upon Arendt’s The Human Condition (2013) and Owens (2015) to develop a conceptual framework for theorising inter-dependence of people with a learning disability and their carers.

Hannah Arendt (2003) sets out three realms to social life: political, social and private (Owens, 2015). While the social model addresses the political and the social, it falls short in explaining the inter-dependencies that exist between people with a learning disability and their carers, which is encompassed within the private realm of life. It is the “private” which Arendt (2003) argues is critical for understanding the lived experiences of those with illness and impairment. Arendt states: “we are all humans, but everyone is exceptional in her or his uniqueness, a uniqueness that he or she actively reveals whenever he or she is willing to act and speak at all, to insert herself or himself into the world and begin a story of her/his own.” The notion of action and speaking suggests collaboration and support in communication and the interconnectedness of human beings. For some people, telling their own story is difficult and Bach (2015) argues that the agency of the person with a learning disability can be communicated through storytelling: “to hear the stories of parents telling how their sons and daughters are experiencing life—the agency of the person resides in the stories of the people that know them best.” He argues that for every human citizen who has their own mind and who can communicate their own identity, then agency resides in the stories told about them which is the space between them and their family and friends.
Arendt made reference to co-dependencies in relationships covered by the “private” sphere of life:

we know from experience that no one can adequately grasp the objective world in its full reality all on his own, because the world always shows and reveals itself to him from only one perspective, which corresponds to his standpoint in the world and is determined by it.

(Arendt, 2003, 128)

Arendt’s approach emphasises the co-existence of different relational forms and the multifacetedness of social relations. Arendt states: "If we want to see and experience the world as it really is, we can do so only by understanding it as something that is shared by many people, showing itself differently to each and comprehensible only to the extent that many people can talk about it and exchange their opinions and perspectives with one another.” Leydet (2017) suggests that we are all inter-dependent, relying on others to enable and sustain our capacities for agency.

Reconceptualising the “social” in the social model, by incorporating an “individual” “private” realm of interconnectedness between people with a learning disability and their family carers helps challenge the assumption that people with a learning disability are a homogeneous group (Cluley et al., 2020). Historical sources of evidence by family carers and friends sheds light on tangible ways in which laws, policies and structures, institutions, discourses and attitudes have impacted upon the lived experiences of people with a learning disability and their families in inter-dependent and co-produced ways (Walmsley et al., 2017).

The social model of disability argues for disability to be seen as a collective experience where the collective, results in a political, social and cultural identity (Watson, 1998:160). For people with a learning disability and their family carers, this is a collective inter-dependent identity with stories from non-disabled people as allies, supporters and facilitators (Chappell, 1998; Walmsley, 1997, 2001) who “de-code” or “translate” metaphorical language or understand the meaning of behaviour as communication (Aylott, 2009, 2010).

Recognising inter-dependence through co-production as a core tenet within the social model of disability will require new and innovative ways to support employment opportunities for people with a learning disability while also maintaining their carers in employment. Co-production can only succeed if it is embedded in public policy as a default position (Ersoy, 2017) which has been successfully developed in Scotland (Ersoy, 2016, 2017). Co-production needs to be embedded in a co-production network, which is a long-term commitment to develop capacity within its members (Ersoy, 2017). In Norway, such an approach can offer a new conceptualisation of co-production where experts by experience can be involved as “co-workers” (Andreassen Alm, 2018; Andreassen et al., 2020) in a model of “user-employment.” This is a model of citizen involvement in which citizens are involved as co-workers, co-carers and co-researchers (Andreassen Alm, 2018). This model appears to have spread from the United States to Australia, New Zealand, the Netherlands, Canada and the UK and also to Scandinavian countries, but the model needs to be supported by social policy guidance. Terms used in this model are consultor providers, consumer employees, lived experience workers and consumer consultants. Personal experience as service users and having a health condition, mental health problems, disability or social problems are the important qualifications for this model for services users to be engaged by a service provider or a commissioner in a paid capacity.

5 | CONCLUSIONS

Co-dependence between people with a learning disability and family carers needs to be recognised within practical and structural mechanisms that support co-production within local authorities. Such mechanisms need to include the voice of service users through the use of communication profiles which become the basis for the local authority to build formal co-production networks within the confines of the Care Act, 2014 (Department of Health, 2014).

This study supports the evidence of continued financial challenges to the cost of caring, which raises the question of the immoral state abdication of responsibility for caring for our most vulnerable members of society as it erodes accessibility to welfare entitlements (e.g., Personal Independence Payments) the precise benefits that are designed to cover the additional costs of caring (Roulstone, 2015).

A reconceptualisation of the social model of disability needs to make explicit the “private” realm of the lived experience of disability to account for the inter-dependence between people with a learning disability and their family carers. This redefinition should be grounded in policy and should shape a revised national strategy for people with a learning disability, recognising the ongoing inter-dependency in the lives of people with a learning disability to advance plans to achieve theirs and their carers ambitions for employment.

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DATA AVAILABILITY STATEMENT

The data that support the findings of this study are available on request from the corresponding author. The data are not publicly available due to privacy or ethical restrictions.

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