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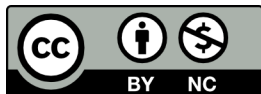
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ORIGINAL ARTICLE

"Everyone has a story to tell": A review of life stories in learning disability research and practice

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Accessible summary

- This paper considers what we know about the life stories of people with learning disabilities.
- It was inspired by one of the authors sharing his own life story.
- It explores what a life story is.
- It discusses how life stories help us to understand more about people's lives and history
- It reviews what we know about how people with learning disabilities can record their stories, including people with high support needs
- We know life stories can help people to get good support and person-centred care
- But we found that people's stories are often lost when there are big changes in their lives
- We found that staff may not have the skills or confidence to support people to tell and record their stories
- We think it is important to find out how life stories can be used to support better care for more people.

Abstract

In this paper, the authors review life stories in learning disability research and practice since the 1960s. Although there is consistent evidence of their value in giving people a voice and an identity beyond the service label, they are not widely used in the provision of health and social care. This is despite long-standing policy commitments to person-centred practice. The paper explores possible barriers to the use of life story work and what further research is needed if they are to be more widely and effectively used in practice.

KEYWORDS
health, history of learning disability, learning (intellectual) disabilities, literature review, social care policy and practice

1 | INTRODUCTION

This paper reviews life stories in learning disability research and practice since the first known autobiography written by a person with learning disabilities, Nigel Hunt, was published in 1967. It considers evidence of their capacity to bring about positive social change both on an individual (Atkinson, 2000; Young & Garrard, 2015) and societal level (Ledger et al., 2020) and asks why there has been only limited progress in embedding their use in practice, despite a long-standing commitment to personalisation in care. We were prompted to write the paper following self-advocate Ian Davies' trip to Japan in November 2019, where he shared his life story with social work students. He is co-author of this paper, and his reflections on why life stories matter are provided in direct quotes throughout.

2 | WHAT IS A LIFE STORY?

> "I was really proud of myself when I saw my life story written down. It made me realise how much I'd done in my life and how much I'd achieved. When I told my story at a conference, people congratulated me on being brave enough to tell my story. They also congratulated me about all my achievements. That made a big difference." (Ian Davies)

Atkinson (1997) defines life stories in the field of learning disabilities as people's accounts of their lives or past experiences as told to another person or persons at various points in time. An entire life story is rarely told. Instead, the life story may act as a foundation, fragments of which are then recounted in a series of oral narratives, told throughout life (Linde, 1993). This sharing of stories plays a role in enabling people to build relationships (Grove, 2015) and rapport (Kaiser & Gaughan, 2012).

The recording of biographical details to serve bureaucratic purposes is ubiquitous in health and social care. Atkinson and Walmsley (1999) term these "biographical fragments," to be distinguished from self or collaboratively authored autobiographical accounts. They note that the most celebrated life stories in learning disability, including those of Nigel Hunt (1967), Joey Deacon (1974) and Mabel Cooper (1997), have not been compiled to have an impact on care, but to celebrate a life. In these accounts, the person is telling their story and choosing what to tell – and what to omit.

McKeown et al. (2006, p.238) recommended the term Life Story Work (LSW) to distinguish the use of life stories in health and social care practice:

> A form of intervention carried out in health or social care practice, … encompassing a range of terms/interventions, for example biography, life history, life stories. It is usually undertaken to elicit an account

of some aspect of a person's life or personal history that goes beyond a routine health assessment undertaken to plan care and treatment, and aims to have an impact on the care the person receives … and usually results in a "product," for example a story-book, collage, notice board, life history/biography summary, or tape recording.

Meininger (2006, p.183), in a learning disability context, expands on McKeown's definition, arguing:

> a life story may resemble an (auto) biography that charts the entire life. It may also be a varied collection of small stories … The most important aspect … is that the individuality, the who, of the person is expressed.

The extent to which the life story represents what the individual wants to share is critical (Atkinson, 2001).

3 | LIFE STORIES IN HISTORICAL PERSPECTIVE

Life story research can be traced back to sociologists Thomas and Znanieki, working at the Chicago School, USA, in the 1920s (Plummer, 1983). Its growth was supported by oral history, which gained academic ground from the 1960s. Perks and Thomson (2016, p.xiii) claim that:

> The most distinctive contribution of oral history has been to include in the historical record the experiences and perspectives of groups of people who might otherwise be "hidden by history", perhaps written about by social observers or in official documents, but only rarely preserved in personal papers or scraps of autobiographical writing.

The earliest known life story authored by a person with learning disabilities was *The World of Nigel Hunt* published in 1967. Hunt writes about his life, family and friends, travels abroad and his interest in music. He presents as an educated man with interests and relationships, as opposed to a patient with Down syndrome. L.S. Penrose, Professor of Eugenics at University College London, wrote the foreword:

> This autobiographical essay written spontaneously by someone who has a serious mental handicap is remarkable. It is also of considerable scientific interest …Nigel has been able to give an account of the world as he sees it. He is thus, as it were, able to speak on behalf of thousands of similarly affected people who are either less gifted or who have had less opportunity than him. (Hunt, 1967, p.9)

In the same year, Robert Edgerton's *Cloak of Competence* was published (Edgerton, 1967). It traced how individuals released from the Pacific State Institution in the 1950s were faring. It is based on life stories; a unique insight into the challenges and triumphs of deinstitutionalisation. Joey Deacon's autobiography *Tongue Tied* (1974), was written collaboratively inside St Lawrence's learning disability hospital with the help of friends Ernie Roberts (who could understand Joey's speech), Michael Sangster (who wrote the words longhand) and Tom Blackburn (who taught himself to read and write in order to type the story). It was the subject of a BAFTA award-winning television documentary. The income enabled the authors to move to a bungalow in the hospital grounds.

Since that time, many life stories have appeared in print (Barron, 1996; Burnside, 1991; Cooper, 1997, 2008; Patka et al., 2020), conference presentations (Docherty, 2009; Kearney, 2009), online archives (for example, Unlocking the Past: the Royal Albert project; the Lennox Castle Hospital project) and websites Mencap Here I Am Campaign, 2016. Mabel Cooper's life story (Cooper, 1997, 2008) inspired a museum exhibition, learning disability history workshops and immersive theatre productions (Ledger et al., 2020).

Autobiographies and life experiences have been published in collections such as "Know Me As I Am" (Atkinson & Williams, 1990), stories of deinstitutionalisation (Traustadottir & Johnson, 2000) and achievements of learning disabled professionals working in sport, the arts and politics (Salman, 2020).

Life story methods have enabled more nuanced understandings of the lives of people with learning disabilities in their socio-historical context. Walmsley (1995), used "biographical interviews" to understand women with learning disabilities' experiences of caring. Other publications shed light on experiences of institutional life (Atkinson, 1997; Holman, 1998; Hreinsdottir et al., 2006; Potts & Fido, 1991; Stefánsdóttir & Traustadóttir, 2015), hospital resettlement and community living (Atkinson, 1997; Atkinson et al., 1997; Hamilton & Atkinson, 2009), community care (Welshman & Walmsley, 2007; The Camden Society, 2010), family-based care (Rolph et al., 2005), parenting (Booth & Booth, 1994), gender (Atkinson et al., 2000; Traustadottir & Johnson, 2000) and sterilisation (Tilley et al., 2012). Life stories have enabled people with learning disabilities to be included in the historical record and to challenge mainstream accounts (Atkinson & Walmsley, 2010; Tilley et al., 2020) including negative stereotypes (Stefánsdóttir, & Traustadóttir, 2015).

The self-advocacy movement opened further new avenues for life stories (Noll & Trent, 2004, p. 16). In response to the challenge "Nothing About Us Without Us" (Aspis, 2000), self-advocacy groups encouraged members to speak up about their lives, not as "cases" but as experts in their own lived experience, capable of communicating what they want and of critically reflecting on systems that result in exclusion and limited life opportunities. Life story research with self-advocates gave insights into self-advocacy's meaning and significance (Atkinson, 2004; Atkinson & Walmsley, 1999; Goodley, 1996, 2000). French and Jones (2019) used a life history approach to share Jones's experience of setting up her own business, "Positive You." Caldwell (2010) facilitated life story interviews to identify factors associated with leadership amongst self-advocates. The company Openstorytellers (Grove and OpenStoryTellers, 2017) adopted life stories to include people with complex learning disabilities in political work, lobbying against cuts to mobility payments. And co-author Ian Davies' story was, as narrated above, used to share his experiences in Japan (Tilley et al., 2020).

Walmsley and Johnson (2003) identified life stories as a key method in enabling inclusion in research (Cooper, 2008; Hewitt, 2003). Self-advocate and researcher Ellen Jones (French & Jones, 2019) asserts that life stories have historically provided a way for people with learning disabilities to contribute to research journals, by, for example, sharing their employment stories and so creating new positive role models.

4 | WHY DO LIFE STORIES? WHAT WE KNOW FROM RESEARCH

> "The reason I recorded and shared my life story was to raise awareness that people with learning disabilities can do this. People think we can't, but we can. Telling our stories helps other people to understand us. You can't just read academic journals to learn about people with learning disabilities. You need to find out about people's lives, in their own words. Some people can do their own life stories by themselves, other people need to work in partnership with someone else to do this." (Ian Davies)

There is a strong message in the literature that life stories give voice to people with a learning disability. Atkinson (2010), reflecting on her research into the social history of learning disability, concludes that the opportunity to tell one's story is important because people have often been silent, or silenced, while others – families, practitioners, historians – speak on their behalf. Life stories can begin to redress that balance (Stefánsdóttir & Traustadóttir, 2015), in contrast to deficit-focused documents characteristic of services (Gillman et al., 1997). It is argued that autobiographical accounts capture the lived experiences of individuals whose lives and perspectives are often represented in stereotypical ways by more powerful others (Ledger et al., 2020). Goodley et al. (2004) draw attention to the power of life stories to give voice "to people whose stories are often not documented, publicised, listened to and afforded significance" (p.87). They argue that the "hallmark of a good life story is that it should prompt 'positive social change'" (p.107).

In the self-advocacy movement, the sharing of life stories has supported members to celebrate achievements (French & Jones, 2019), create training vignettes (Sunderland People First, 2020) and evidence the impact of policy on their own lives (Atkinson, 2010). In the absence of a life story, people vulnerable to marginalisation or exclusion are at risk of being defined by their diagnosis, behaviour or living situation. Westerhof et al. (2016) reflect on how "problem-saturated" labels and accounts can become dominant in professional decision-making, reinforced by stereotypes.

Despite legislation emphasising the right to be treated as equal citizens (UK Human Rights Act, 1998; United Nations, 2006), failure to consider personal life story information remains commonplace in services, a barrier to the delivery of person-centred, safe and skilled support (Care Quality Commission, 2020; Flynn, 2012; Heslop et al., 2013).

Research has highlighted that people are at particular risk of losing their life stories during periods of transition or crisis, for example, the sudden death of a family carer or following placement out of area (Towers, 2017). This is often compounded by a loss of connection with people who knew their past history (Kaiser & Gaughan, 2012; Mansell et al., 2007). People with high support needs are particularly vulnerable to the loss of their personal histories (Sense, 2018). For this reason, methodological developments that enable people with complex disabilities to share their personal stories are of particular significance. These are discussed in the next section of this paper.

A transdisciplinary evidence base consistently indicates the potential value of life story work to learning disability practice. Yet, research supporting their introduction and embedding in health and social care remains limited and predominantly drawn from case studies or small samples (Crook et al., 2016), with few larger randomised control studies reported. Findings from a small number of researchers employing quasi-experimental designs add support for further use of life stories. Bai et al. (2014) employed a quasi-experimental design with 60 older adults with learning disabilities assigned to experimental or control life story work groups. Findings indicate the potential of life story work to prevent loss of interest and pleasure and to enhance socialisation skills. Beernink and Westerhof (2020) also used a quasi-experimental research design with one group ($n = 32$) following a My LifeStory intervention and the other a matched control condition ($n = 30$ care as usual). When compared to the control group, participants following the My LifeStory intervention improved more against measures of psychiatric condition, well-being, life satisfaction and purpose in life.

Schepens et al. (2019) identified life story work as a key factor in their systematic review of support strategies to improve the quality of life of older people with learning disabilities. McKeown et al. (2006) systematically reviewed the literature on life stories in health and social care practice across all client groups, including people with learning disabilities. This review indicated that life story work can make a positive contribution to care: to challenge attitudes and assumptions; provide a basis for individualised, person-centred care; contribute to assessments; assist with transitions; and help to develop relationships and understanding between care staff and families. Further scoping reviews have examined the effectiveness of narrative therapy and reminiscence in a learning disability context (McParland, 2015; Van Puyenbroeck and Maes, 2008), raising methodological issues and highlighting a need for larger scale and more robust research and evaluation to explore and build the evidence base.

5 | HOW TO DO LIFE STORIES: METHODOLOGICAL INNOVATION

> "I knew I wanted to do my life story and I asked Liz to help me. I knew the important things I wanted to talk about like being born with sight impairment, and going to a special boarding school, and I needed someone to help me tell the story by asking me questions. We met twice and we did stuff over the phone. She helped me put it into a presentation for a conference." (Ian Davies)

There has been considerable methodological innovation in learning disability life story research, though there is little evidence that these methods have been more widely adopted in day to day service practice. Many life stories have been told through a "mixed method" approach, drawing on the techniques of oral history, life history and narrative inquiry (see, for example, Potts and Fido, 1991). They may be told on a one-to-one basis with the interviewer/researcher being the audience, or in a group where researcher and group members provide an audience (Atkinson, 1993; Atkinson et al., 2000; Cooper, 1997).

To facilitate the telling of stories by people with more complex disabilities, Kennedy and Brewer (2014) replaced interviews with thematic analysis of songs, photographs and scrapbooks to enable people to share aspects of their life stories. Sanderson (1998) and The Sensory Objects Project (2015) collected objects to represent events and people or places from the past to help people share their stories. Hewitt (2006) found memory boxes helpful with people who are visually impaired. Boxall and Ralph (2010) argued that photovoice methods (Berg, 2004; Wang & Burris, 1997) have considerable potential. Slater and de Wit (1997) accompanied people with "no life story" on file, to visit places they had lived and documented these memories – by collecting objects, photographs or maps. Ledger (2019) used mobile interviews to re-visit places where participants had lived. Images and memories on maps provided a life summary. These approaches have helped some people to re-connect with family, former friends, neighbours and faith communities.

With the advent of digital media, opportunities to create and share image and video have become commonplace. Not only does multimedia technology support the development of interactive life stories, but advances in accessibility enable the person to navigate their way through their life story, interacting with any elements they wish to explore further (Kwiatkowska et al., 2012). An app, Our Story, was "helpful in facilitating sequential arrangements" of media, its design "harnesses the learning potential of story-sharing and story-creating" (Critten & Kucirkova, 2015, p.2).

Multimedia Advocacy, developed by Rix Research & Media, used a simple web platform to provide participants with "a virtual space for creating knowledge, and sharing their experiences and views of life and work with others" (Kwiatkowska et al., 2012, p.363). In evaluating it, McCormack (2017, p.59) wrote:

The nature of its design created opportunities for shared interpretation and the development of dia-logic relationships. In addition, the "life story" and one's participation and engagement in it was organic and open to change and growth.

Though early to be certain, the COVID-19 pandemic also appeared at the time of writing to have boosted the use of technology to record life story snippets. Examples were to be found on at least two websites, Surviving through Story (England)[1] and All Wales People First members' stories (Wales).

6 | POLICY INTO PRACTICE?

"I told my life story on a visit to Japan. I spoke to so-cial work students at a University. There were a lot of people in the room, about 100 students. Afterwards, they had to fill in a form about my presentation. I couldn't believe it when I saw what the students had said. They were so positive and supportive. Some students said they would like to help other people in Japan to tell their stories. I think it made a really big impact." (Ian Davies)

Ubels (2015) argues that caring for people must involve connect-ing to their unique story and their storytelling capacity. Kaiser and Gaughan (2012) emphasise the role of life story work in supporting people with learning disabilities to play an active part in designing their support by both "looking back to the past and forward to fu-ture hopes and plans." Dennison and Mee (2011, p.1) state that "truly listening to personal narrative should underpin person-centred plan-ning". Despite this the integration of life story work into practice has been slow and inconsistent (Grove, 2015). The literature indicates that life stories are rarely used in learning disability practice settings, although they are more embedded in dementia care (see Gridley et al., 2020). This is surprising as the literature we have reviewed indicates their potential to significantly strengthen the person-centred practice long advocated in UK policy (Department of Health, 2001, 2009; Jay, 1979; LGA/ADSS/NHSE, 2015).

Person-centred care as a policy objective has almost as long a history as life stories. Person-centred planning (PCP) (also known as Individual Programme Planning or Shared Action Planning) began to be advocated in the 1970s (CMH, 1973), initially to support hospital resettlement. It gained momentum in the 1980s and 1990s (Blunden, 1980; Brechin & Swain, 1986; O'Brien & Lyle O'Brien, 1988; Mount, 1995; Sanderson et al., 1997; Sanderson, 1998; Pitonyak, 1997). Person-centred support was central to the ambitious policy aspira-tions of the early 21st century, for example Valuing People (England

and Wales, 2001) and The same as you (Scottish Executive, 2000) albeit with a subtle acknowledgment that it was not yet embedded:

Services will *start* (author emphasis) to use a "person centred approach" (Department of Health, 2001, p.18).

Legislation and policy supportive of the use of life stories is strongly evidenced in contemporary practice guidance. The Care Act (England) requires that all assessments must be person-centred throughout (The Care Act, 2014). Article 8 of the Human Rights Act asserts the right to respect for private and family life. Care Quality Commission (CQC) key lines of enquiry include "Do staff know and respect the people they are caring for and supporting, including their preferences, personal histories, backgrounds and potential?" (Care Quality Commission, 2015, C1.4, p.17). Core and essential service standards for supporting people with profound and multi-ple disabilities (Doukas et al., 2017) include the importance of staff knowing the person's history (p.35) and opportunities for story sharing (p.30). Planning guidance for families of adults with learning disabilities (Towers, 2017, p.55) recommends:

Sharing life stories and memories can help people with learning disabilities to develop and affirm their sense of identity … These memories become even more important when the person moves away from the family circle, for example, when leaving home, or when their parents die. One way of doing this is to create a memory book or box with your relative.

The Learning Disabilities Good Practice Project (Department of Health, 2013) selected a life story project as a clear example of "what good looks like" in practice. The Positive Behavioural Support (PBS) Coalition UK's Framework (2015) identifies "The person's individual history, including their family and social context" as key "need to know information" for direct care staff and managers seeking to implement PBS academy standards, a point reinforced by NICE guidance on chal-lenging behaviour (NICE, 2018). We could continue.

And yet, reports on the use of life story work in practice indi-cate that it is far from straightforward without the help of research projects or similar initiatives. Life story work was adopted by the All Wales Strategy in 1983 as a way of individualising services, yet proved slow to take off, with only 11% of families reporting that their relative had a life story after 8 years (Felce & Grant, 1998). Shared Action Plans (Brechin & Swain, 1986) placed emphasis on "Getting to Know You," and were recommended for use in residential and day care settings, with an aspiration that the content of such plans would then inform and drive forward strategic local planning linked to people's life goals. The Rediscovering Our Histories programme was a three year Department of Health funded action research project which aimed to show how life stories could be integrated into a wide range of existing person-centred planning tools and

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[1]www.survivingthroughstory.com

included individual pilots, group activities and training. Evaluating this programme, Slater and de Wit (1997) report that re-establishing connections to the past informed individual planning and choices. Harwood (2011) implemented a three-year Storysharing project – modelled closely on how people collaboratively share personal anecdotes in daily life – with adults with learning disabilities across eight residential homes and a day centre in Somerset. Findings indicated a positive impact in terms of increases in communication, participation, relationship-building and decision-making.

Within learning disability services, tools and training packs have been developed to support the introduction of life story work (Aspinall, 2002; Grove & McIntosh, 2002; McCormack, 2020; Slater & de Wit, 1997). The publication *People, Plans and Possibilities* (Sanderson et al., 1997) introduced a number of planning tools that specifically assisted with "recording the person's history" (p.163), accompanied by a range of practice-based suggestions of how this work can be undertaken by staff and circles of support (see for example Sanderson, 1998, pp.165–180). However, sustained and consistent uptake of life story work in practice settings has not been achieved.

7 | BARRIERS TO LIFE STORY WORK IN PRACTICE

> "I didn't know how it would feel to tell my story in public. The first time I told my story to a room full of people, I got through it ok, but at the last bit, which had a difficult memory, it was very emotional. It was a long time coming. But people at the conference supported me, and thanked me." (Ian Davies)

So, with strong research evidence of its value, and legislation and policy which should prompt its use, why has the implementation of life story work in practice settings faltered? In this section, we consider the possible barriers. There has been remarkably little published on this in the learning disability literature. However, there has been considerably more attention on the introduction of life story work in dementia care (see, for example, Cooney & O'Shea, 2019; Gridley et al., 2016, 2020; Kaiser & Eley, 2016; McKeown et al., 2010) which we draw upon to inform our reflections.

McKeown et al. (2006), who reviewed the literature on life story work across all settings, say that although it has potential to be a valuable intervention it is nonetheless complex and should not be implemented on a large scale without a well-thought out strategy. They suggest that protocols for consent, ownership and access to the life story are all needed. They also argue for embedding life story work as part of an overall philosophy to avoid it being seen as yet another task.

The challenges to introducing life story work in care settings can also be seen as part of a wider set of challenges in implementing person-centred care. Care Act (England) guidance states that assessments should be person-centred "throughout" (Department of Health, 2016, p.149). The social care assessment is described as "one of the key interactions" between a person and the local authority with critical importance for care and support (Department of Health, 2016, p.74). Symonds et al. (2019) argue that little policy attention has been paid to translating person-centred practice into adult social care systems. These researchers interviewed staff undertaking Care Act assessments. Findings showed tensions between adopting a person-centred approach, including the collection of life story information, and organisational practices such as fixed recording formats that placed constraints on collecting life story information.

Further barriers to using life stories are time and cost constraints. Working with people to recover and record their life histories requires time (Kinsella, 2000; McCormack, 2017). In research, a classic approach is to work directly with the person who wants to tell their story (Atkinson, 2004; Cooper, 1997). Atkinson's work with Mabel Cooper spanned almost 20 years, something that may be possible in a research context, but more difficult in practice settings. A further barrier is that accessing records requires expertise and confidence, not always readily available (The Inclusive Archive Project, 2015), and that without explicit consent from the person, or their advocates, many records are closed (Walmsley, 2020). This raises important questions about workforce skills, training and resources. It may be arguable that this upfront investment of time is regained at a later stage as the process of life story work supports communication and planning, and in the long term, if it contributes to sustaining social connections, may ultimately reduce reliance on services (Slater & de Wit, 1997). In this respect, further research to document both the costs and benefits of life story work, and the conditions needed to support it, would be useful (Gridley et al., 2016). Furthermore, there is a question about where responsibility for initiating life story work might sit – with key workers, with social work or nursing, or within advocacy contexts (Arigho, 2008).

The emotional dimension also requires sensitive consideration. Kaiser and Gaughan (2012) found that life story work is sometimes resisted by staff and managers for fear of upsetting people by reminding them of happier times or of loss. Hamilton and Atkinson (2009) report that their life story participants recalled confinement, coercion, bullying and exclusion alongside more positive memories. These authors acknowledge that introducing life story work to service settings is not straightforward and that support is needed to train and supervise staff. However, Robinson, a self-advocate who recorded his own life story, cautions against staff preventing people from re-connecting with their personal stories in this way, however well intentioned (Ledger & Shufflebotham, 2008). Robinson argues "that your story is what makes you who you are" and can enable people to rekindle contact with key people and places in their lives, so bringing opportunity for new friendships and community connections. Atkinson (1999, p.35) drawing on his experience of life story interviews, commented:

> [...] it is usually not necessary to try to avoid these places in a person's story. People will let you know if they don't want to go there.

Kaiser and Gaughan (2012) from the Life Story Network support this view. They state the need for investment in the right training and support, so staff feel confident in working with more difficult stories (Thompson, 2011). As these authors argue, not communicating about a painful experience does not mean that the person will not continue to experience it. Many people with learning disabilities have encountered significant experiences of rejection and loss and may benefit from being offered the opportunity to share difficult memories alongside happier ones (Beernink & Westerhof, 2020).

The purpose of life story work needs to be clear, but often is not, making research and evaluation activity more complex to undertake. Meininger (2006) highlights terminological vagueness about the intervention and its purpose. Van Puyenbroeck & Maes (2008) identify three possible aims of narrative work (including the use of life stories) with older people with learning disabilities: a critical approach encouraging reflexivity and historical awareness; a person-centred approach, in which reminiscence serves a social purposes; and a clinical approach, where reminiscence is used as a diagnostic instrument or clinical intervention. These contrasting aims require different approaches and evaluation. Research to evaluate the impact of life story work in the field of dementia care provides further insight into potential barriers. Gridley et al. (2016) used a mixed-methods approach to explore the feasibility of a formal evaluation of life story work across health and social care settings for people with dementia. They concluded that it is "a complex intervention" in settings "that are themselves often complex and complicated" (p.102), hence hard to evaluate. They argue for further qualitative research to explore the motivation and "emotional intelligence" of staff to use life stories in person-centred care. These researchers produced good practice guidance for life story work in dementia contexts (Gridley et al., 2016, 2020).

There are also question marks over how to demonstrate that life story work is an asset in care settings. The building of an evidence base is needed to justify more widespread adoption. Gridley et al. (2016) noted that conventional outcome measures proved unable to capture "in-the-moment" (p. xxv) benefits of life story work such as lifting a person's mood or helping a person to feel calmer. During the research, positive changes were reported in staff attitudes to people with dementia, but researchers highlighted that it was hard to determine whether these occurred as a result of training in life story work, implementation or both. Equally, it was difficult to determine whether observed improvements in participant well-being were attributable to life story work or to spending more time interacting with staff. Gridley et al. (2016) recommended the need for further qualitative research into life story work that explores the motivation and "emotional intelligence" of care staff, and further methodological development in assessing quality of life "in the moment" (p.xxvii).

8 | CONCLUSION

In this paper, we have reviewed the literature on life stories and life story work in learning disability. This has a long history in research terms, spawning rich historical data and creating a space for methodological innovation. Life story work also has a long-standing relationship with care practice, although a number of barriers exist to weaken its sustained implementation and research to evaluate its impact has been limited. We have cited extensive evidence that life stories can be valuable for people, contributing to a stronger sense of identity, a way of being known beyond the label, and the building and sustaining of relationships. We have noted that the long-standing policy drive to person centredness sits well with life story work, yet there is scant evidence of its use in learning disability contexts, other than when linked to specific research projects – and funding. As a result, people continue to become separated from their stories in a way that risks dehumanisation and reliance on disability labels to define them. The reasons for this have been little explored in the learning disability literature, but literature from the field of dementia indicates that barriers include vagueness about the purpose, staff confidence, staff training, and issues around consent, not to mention the fear of opening a Pandora's box of unresolved grief. We argue that further research may be useful to explore what conditions allow life story work to flourish within learning disability practice settings.

DATA SHARING STATEMENT

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