

The changing face of parent advocacy: a long view

1. Introduction

For the future, I wish I could be confident. I know that when I'm no longer around, Hillingdon will take charge and Steven's life will change dramatically. He may still end up in that hospital in Wales.

(Mark Neary 2014a)

Neary, a parent and campaigner, echoes a fear that has haunted families for a century or more, that without constant vigilance, their relative will find themselves in an institution, far from friends or family (Sanctuary 1981, Fitzroy 2015). Although it is well documented that families are not always motivated by the best interests of their relatives (see Rolph and Walmsley 2006 for historic examples), recent reports (for example Mazars 2015, Fitzroy 2015, Bringing Us Together 2016) illustrate graphically that despite considerable changes over the past century, society continues to exclude, neglect and frequently damage people with learning disabilities. Hence the continued need for families to advocate on behalf of their relatives.

In the paper we argue that parent and wider family advocacy in the UK¹ has been at its most dynamic and powerful at periods of immense perceived challenge. The heyday of parent advocacy was in the immediate post war era, with the founding of parent-led campaigning organisations. In the UK, the organisation which later became Mencap (England and Wales) was founded in the 1940s and Enable (Scotland) in 1954. The purpose then was to argue for the right to education for those labelled 'ineducable' and the setting up of services in the community. Once those ambitions were partially achieved, the movement fragmented. The energy and passion of collective parent advocacy has revived since austerity measures began to impact on social care after 2008 and to threaten the gains, in part attributable to parent advocacy, made since in the twentieth century:

¹ We use the term 'parent advocacy' in this article for consistency, but appreciate that other family members, have often been at the centre of the movement also.

As the economic crisis unfolds it seems that the process may come full circle, and disability will again become a 'private trouble'. The work of parents of disabled children in the Global North is in danger of being undone' (Runswick-Cole 2012,1045).

Advocacy is a daily task, for most families with relatives with learning disabilities, most of the time. Every study of families, every interview, points to their perception that they need to FIGHT for their relative, from sorting personal budgets (Neary 2014b), to getting a teenage son's death investigated (Ryan 2015a); from challenging assessments; to arguing for same sex carers on overnight shifts (Walmsley 2015). This type of advocacy has long taken place at the individual level. However, collective family campaigning was given additional impetus when BBC Panorama's shocking revelations about Winterbourne View in 2011² provided a sharp reminder that while institutions were in theory consigned to the past, in fact they were flourishing – and the Westminster Government appeared powerless to halt this (NAO 2015). Indeed new institutions, for example St Andrews Northampton, were being announced at the same time as plans were trumpeted to 'transform care' by bringing people in Assessment and Treatment Units back to their communities (NHS England 2015).

This paper explores the changing face of parent advocacy for people with learning disabilities over the past century. It was written at a time (2015-2016) when the need for parent advocacy was starkly and tragically highlighted. The inquest into the untimely death of a young man, Connor Sparrowhawk, known as 'Laughing Boy', in an NHS Short Term Assessment and Treatment Centre in Oxford, England had laid bare through a live Twitter feed from the Coroner's Court the casual institutional practices which led to his death, contributed to by 'neglect' (Ryan 2015a; Ryan 2015c). It was followed by the Mazars Report (2015) which highlighted a failure to investigate the deaths of people with learning disabilities, many under 50, in the NHS Trust where Connor died.

² The BBC broadcast a programme in 2011 which had been filmed undercover at a residential care home near Bristol, England. In it care workers were shown routinely physically and emotionally abusing residents, all of whom had a learning disability. Eleven care workers were subsequently sentenced after admitting 38 charges of neglect and abuse.

Methodologies: Taking the long view

The paper analyses a wide range of evidence, both contemporary and historical. Contemporary sources drawn upon in this paper include blogs by parent campaigners, social media, interviews, service evaluations, and personal communications, as well as a wider literature on learning disabilities, families and advocacy. Historical sources include archival evidence and oral histories that capture the experiences of the families of people with learning disabilities and the work of local voluntary groups. Much of this data comes from research conducted over a long period by the Open University's Social History of Learning Disability Research Group³ (Rolph 2002; Rolph et al 2005; Tilley 2006) of which the authors are members. The paper's scope stretches back beyond the thirty-year framework of the special issue, to the mid twentieth century, as that was the period when collective and public parent advocacy began to take shape.

The paper builds upon a rich tradition in disability studies that has sought to both obtain and share the narratives of people with learning disabilities and their families. The Social History of Learning Disability Research Group has worked inclusively with individuals, families, self-advocacy groups and service providers over a 20-year period to explore the ways in which the past and present interact with and shape one another. In its historically focused research, members have reflected on both warnings and potential insights from the past and considered how these might be used to help improve the lives of people with learning disabilities in the future. Through the development of innovative participatory research methods (Ledger 2012, Graham et al forthcoming), coupled with careful historical investigations (via archival work, oral histories and analysis of material culture) group members have aimed to shed light on the tangible ways in which laws, policies, structures, institutions, discourses and attitudes have impacted upon the lived experiences of people with learning disabilities and their families (Walmsley et al 2000, Rolph et al 2005, Tilley et al 2012). In the current context of austerity, alongside the rise of new forms of institutions (Bringing us Together 2016), and the apparent drive to silence

³ <http://www.open.ac.uk/health-and-social-care/research/shld/>

dissenting voices, particularly those of parents (Neary 2016) the need to reflect on the past to inform the future is more pressing than ever.

In this paper the authors contemplate what constitutes the 'past' in the 'present' and explore what this means for parent advocacy and for the lives of people assigned the label of 'learning disability' more generally. The research undertaken by and through the Social History of Learning Disability Research Group has both contributed to and been shaped by wider radical movements that have sought to argue that institutional forms of the past in the present (including archives, museums, and research projects) should include ordinary people's everyday lives (Tilley and Graham 2016). More specifically these movements have claimed that the experiences of working class communities, of Black Britons, of women, of the LGBT communities and of course disabled people should be part of this public record, recognized as significant by all as part of our collective history (Sharpe 2002, Scott 2002). These movements have built the political and moral case for including personal experiences in the public record. In the context of disability studies, a strong argument has been posited that the long-term and ongoing exclusion of so many disabled people from the mainstream makes it especially important for personal and 'everyday' narratives to be captured and represented in the public domain. This has particular ramifications for people with learning disabilities who have not always been well integrated into the disabled people's movement, a point publicly acknowledged by veteran disability campaigner Baroness Jane Campbell at the launch of Learning Disability England in 2016 (quoted in Walmsley 2016).

Mabel Cooper, a prominent self-advocate, argued passionately for the importance of history and personal stories in raising awareness about the hidden and marginalised lives of many learning disabled people. She believed that sharing knowledge about the past was a crucial component in enabling wider society to reflect on contemporary attitudes towards disability. She argued that knowing about the past and sharing stories could help make things better for people in the future (Cooper 1997). While the authors take a critical and reflexive approach to the relationship between past, present and future and problematize the ways in which history itself can be used to legitimise or challenge powerful and entrenched discourses and social categories, our work in this field continues to be inspired by activists like

Mabel Cooper. Taking the 'long view' is a vital political act that contributes to discussions about imagining and articulating a different and better future for people who continue to face oppression in the present.

Why focus on families?

Families are the most consistent individuals in the lives of most people with learning disabilities. The majority of people with learning disabilities live with family (Foundation for People with Learning Disabilities 2012). This has been the case since before (Andrews 1998) and after the implementation of the Mental Deficiency Act in England and the Mental Deficiency and Lunacy (Scotland) Act 1913. Even at the height of institutionalisation, in 1969, more than 50% of people with learning disabilities lived outside institutions, most with family (Shennan 1980; Walmsley 2000). Historically families have had to fight for support and resources (Rolph et al 2005) and this has changed little according to contemporary family testimony collected through research, blogs, Twitter, project evaluations and conversations (Walmsley 2014, 2015). The third author, herself a parent, gives this example:

L's support has been in the process of being reviewed for a year now. This involves a stop/start series of meetings with care managers and seniors. The bottom line is a cut in her hours but with no clear justification or assessment. An assessment was undertaken in the spring and it was called an 'outcomes focussed assessment'. The only outcome however was a reduction in support from 35 hours per week (too much as everyone agrees) to 7 hours per week. The only reason given was that L is 'independent'.

We robustly challenged this 'assessment' and it ended up (eventually) with a senior council officer declaring it inadequate and the whole sorry process started again. Only yesterday we had an email from yet another care manager saying that L's support would be reduced to 'take account of her outcomes' (as yet not known or documented).

We have been asking about self-directed support for a year now. Each time we're told it 'will be considered' but nothing happens. It is as if a legal requirement is in the gift of an individual agency or worker. In fact an

individual service user or carer needs to have a 'referral' to a social worker before the local authority will even look at SDS, or so we've been told, and without this no progress can be made. So the status quo is that we identify opportunities for L, for example to continue her riding and horse volunteering, and provide her with support to access them.

Although it is not de rigeur in disability studies to include the voices and experiences of family members alongside those of disabled people (Walmsley 2016), for those people like L, whose voices may go unheard, or for those who do not speak at all, and in the absence of consistent advocacy, families can be an important route to publicising their concerns and needs. For these reasons this paper gives voice to and focuses on parents and families.

2. Understanding why and how parents advocate

The argument posited in this paper is that the reasons families advocate have remained remarkably constant over time. The changes in discourses about learning disability over the past century, in language, in aspirations, and in policy rhetoric have been dramatic (Johnson and Walmsley 2010) but it is salutary to note that the issues facing families have changed much less. Recent literature on families caring for adults with learning disabilities demonstrates clear continuities with the past. For example, in the twenty-first, as in the twentieth and earlier centuries, families act as the first and last resort for care (Prosser 1997; House of Lords and House of Commons 2008; Dumbleton 2013; Foundation for People with Learning Disabilities 2012). One possible reason for this is that families describe a lack of confidence in current and future service provision, particularly what will happen when parents die (Bibby 2013; Davys et al. 2014; Fitzroy 2015; Neary 2015a). Families also report problematic relationships with professionals, and difficulty in getting the family's knowledge of the person taken into account (Michael 2008; Bibby 2013; Jingree and Finlay 2012; Davys et al 2014; Ryan 2015a; Ryan and Runswick-Cole 2008). Lastly there is an enduring challenge of achieving a balance between autonomy and protection (Foley 2012; Tilley et al, 2012; Ledger et al, 2016) in which families are often considered risk averse.

Families do not trust the state to provide safe, consistent care for their relatives (Bibby 2013; Davys et al .2014; Neary 2015a). They have good reason to be suspicious. Professional care has too often failed people in spectacular ways - the Winterbourne View scandal in 2011, the death of 18 year old Connor Sparrowhawk in 2013 due to neglect in NHS care, the deaths of Thomas Rawnsley and Stephanie Bincliffe in Assessment and Treatment Centres being but recent examples of many serious cases of abuse of learning disabled people. Oversight by families is an important, though not always adequate, safeguard against abuse or neglect. In the complex world of service provision, families are the people who know their relatives. Service providers change frequently. The information families hold matters, and can be the difference between life and death. Investigations into failings in healthcare consistently point to a failure to heed families' concerns and advice (Mencap 2007; Michael Report 2008; University of Bristol, 2013) or to inform and involve them (Mazars 2015). Families need a very loud voice to be heard.

Both the literature and contemporary social media point to an intensely problematic relationship between families and care providers. Eugenic inspired legislation in the early twentieth century was premised upon a belief that learning disability was inherited (Jones 1986; Jackson 2000). Hence the impetus to prevent parenthood, the segregation of the sexes in institutions, and the close surveillance of families whose disabled children remained within the family (Rolph and Walmsley 2002). Families were deliberately kept at a distance from their relatives in institutions. Institutions were frequently in remote places, with limited public transport, visiting was restricted to one or two days in a month, post was censored; and families were not permitted to meet relatives in the wards, rather were directed to official visiting rooms, hence they did not get a picture of their relative's life (see for example Keilty and Woodley 2013).

In the post war era families came to be seen as people who deserved support and sympathy. This was accompanied, at times, by cooperation with families (Rolph 2002). However, despite frequent rhetorical pleas for 'partnership' (for example Partnership Boards set up in England in the wake of Valuing People 2001), the practice of keeping families at a distance has continued, often justified on the

grounds that parents restrict their adult offsprings' independence. Parent academics Sara Ryan and Katharine Runswick-Cole cite this example:

a case study of a disabled young man called Ray, identified the normalizing gaze of Ray's mother as a key factor contributing to the lack of independence Ray experienced within his life. For Veck 'Ray's ability to take control and to direct his life seemed to be diminished by professionals and his mother' (Veck 2002 537, quoted in Ryan and Runswick-Cole 2008 p. 204).

Ryan and Runswick-Cole argue that parents threaten professionals because parents are the true experts in their relatives' care. So professionals seek to diminish parents:

The competence of the mothers is constantly under surveillance and, in some cases, challenged
(Ryan and Runswick-Cole 2008, p. 204).

Family advocacy has fluctuated over the past century. Much of the time, it has principally involved families fighting for their rights, and those of their disabled relative. At other times, collective campaigning has emerged alongside individual actions. In the early twenty first century these boundaries are more fluid. Skilful and consistent use of social media enables the private troubles of families to be shared, and to become a voice of collective protest (Ryan, 2015a; Ryan 2015b; Neary 2016).

In the first half of the twentieth century family advocacy was individualised. Families were isolated partly due to the stigma associated with having a child with learning disabilities. People had no means of knowing there were others in their situation, except by chance (Rolph 2002). Families were allowed to care, if they could satisfy the demands of the authorities and meet surveillance requirements – such as preventing their relative consorting with the opposite sex (Rolph and Walmsley 2002). Archive records show that some families did indeed fight the system to keep their sons and daughters out of institutions, or to get them out (Thomson 1998), but there were few mechanisms by which families could know of others in their situation, hence no collective voice.

Parent advocacy was muted and personal. We find in the archives plaintive pleas like this from a man requesting that his sister be allowed home for a holiday:

I am the only one who goes to see her. I thought a change would do her good to being in there. She has never had a holiday.

[Bedfordshire Mental Deficiency Papers 1937 Vol. 23 22/4/1937]

This is a rare voice of human concern in the dry records of the management of 'mental defectives' in the early twentieth century. His request was refused as the Visitor found the home to be dirty. Some families resorted to law, or to contacting their MP (Bromham Joint Board Papers 1944), but there was no collective parent organisation.

The second half of the twentieth century saw a massive growth in parent advocacy. From the later 1940s, families were gradually rehabilitated in public discourse. They were increasingly portrayed as burdened; deserving of both sympathy and practical support (Walmsley 2000; Rolph 2002; Castles 2004). 'Little Stephen', Mencap's then logo, exemplified this shift. The pathetic child replaced the menacing 'other', although the paternalism implied by the image has since been dismissed as incompatible with a contemporary discourse of equal citizenship.

Arrangements for community care slowly developed, in part as a result of campaigns by newly emboldened families who drew on a discourse of the 'perfectly normal and blameless family that had the misfortune to produce children with mental retardation (sic)' (Castles 2004, 356). Although until the final decades of the twentieth century parents were frequently told to put their children away and forget about them (Rolph et al 2005), increasingly it became accepted that disabled people deserved support from the state (Roulstone 2015), and that it should provide resources and services in the community which could foster a more ordinary life, both for the person with a learning disability, and their family (Johnson and Walmsley 2010, 94).

Collective parent advocacy in the second half of the twentieth century was characterised by three functions – mutual support, the provision of services in local communities, and campaigning (Rolph 2002). Initially it comprised small energetic local groupings, working on behalf of, rather than with, people with learning disabilities. Their early efforts were focussed on building their own services and

supports – such as holiday chalets, nurseries, residential homes, occupation centres, training volunteer welfare visitors (Rolph 2002). Some of these initiatives remain in the form of large provider organisations like Hft and MacIntyre, both started by parent activists in the 1960s, looking for alternatives to large institutions. At the same time they collectively campaigned at a national and local level for the state to offer more support, and to alter legislation. Notable landmarks, in part attributable to effective campaigning, were the 1970 Education Act (England and Wales) and the Education (Mentally Handicapped Children) Act 1974 in Scotland which gave all children the right to an education for the first time; and the 1971 White Paper Better Services for the Mentally Handicapped (England and Wales) and Scotland's Services for the Mentally Handicapped (1972) which both made commitment to expand residential and day provision, in 'the community' (Welshman and Walmsley 2006). Similar processes have been recorded in the USA (Castles 2004), and in Denmark (Bylov 2006).

The late twentieth century saw the development of ideas associated with ensuring equal citizenship for people with learning disabilities. Deinstitutionalisation was a banner around which many different interests could coalesce (Ingham 2013). The problem of people with learning disabilities was recast as the challenge of closing institutions, countering stigma and reducing barriers to participation, under the influence of the social model of disability (Johnson and Walmsley 2010, 93). There was a sense that families were one of these barriers, being over-protective and unnecessarily restricting autonomy and independence:

Before the publication of *Valuing People*, many families felt that the overarching culture in adult learning disability services saw families as a barrier to progress and a problem that needed to be managed (Cooper and Ward 2011, 46).

The interests of families and people with learning disabilities came to be seen as in conflict (Dumbleton 2013). Unlike in Denmark, for example, where, Bylov (2006) argued, self-advocacy was initially nurtured by a parents' organisation, in the UK self-advocacy saw itself as challenging family claims to speak for people with learning disabilities (Buchanan and Walmsley 2006). Self-advocates challenged the idea that parents or professionals knew best and instead constituted an alternative champion

for people with learning disabilities. Parent organisation Rescare campaigned in the 1980s to retain institutions, while self-advocates and their allies made increasingly vocal demands for independence, choice and equal rights (Williams and Schoulz 1982, Simons 1992). Dumbleton reflects that as a care worker in the 1980s she and colleagues

had a suspicion that, if only they [families] would be less risk averse, protective and interfering, their adult children would be leading much more rounded, satisfying lives (2013, 286).

Simultaneously, Citizen Advocacy developed, and based its claims on the argument that adults with learning disabilities require an independent advocate, who can help them to voice their choices and assert their rights (Simons 1992). Families were cast as a barrier to people with learning disabilities' enactment of adult roles. The split was enshrined in the two representative organisations set up in the wake of Valuing People (2001), the National Forum of People with Learning Disabilities and the National Valuing Families Forum.

For a brief period policies such as The Same as You? (Scottish Executive 2000) and England's Valuing People (2001) promoted the idea that young disabled people could and should, like non disabled young people, leave home in their early twenties, rather than spending their lives in their family of origin (Welshman and Walmsley 2006). For some this heralded important new freedoms, but the marginalisation of the parent-carer voice was also problematic because in practice they continued to provide the bulk of care and oversight, not only in childhood, but throughout life (Foundation for People with Learning Disabilities 2012).

The early twenty-first century witnessed contradictory developments which impacted upon parent advocacy. On the one hand there remained a commitment to personalise services, using devices such as Direct Payments and Individual Budgets (Glendinning et al 2015) so that 'citizens can become actively involved in selecting and shaping the services they receive' (Scottish Government 2009, 10). In theory, this was a victory for disabled people. It assumed that families had a minor part to play in a world where budgetary control was seen to equate to true independence, but in practice these new forms of funding placed considerable responsibility on families who were increasingly called upon to manage the budget, purchase

services, and act as a bulwark against exploitation and abuse (Glendinning et al. 2015; Neary 2015a). As Harkes et al note,

Self-Directed Support will prove difficult for people with intellectual disabilities who lack capacity and have no close family or friend. (2014:175)

At the same time pressure on the resources available to disabled people, and their families, as a result of welfare reform and reductions in Local Authority budgets, risked undermining the principles of Self Directed Support, pushing families back into providing the care their relative needs:

The increasingly common practice of only attending to the needs of those at a critical or substantial level strongly contradicts recommendations for early social work intervention, designed to prevent crises (Mencap 2002). In practice, this means that families failing to meet the criteria for social care find themselves signposted to universal services (Bibby, 2013).

In the post war movement, the focus of parent advocacy was on creating community services where none existed. In the twenty-first century, the focus shifted to new campaigns such as defending community services at threat of closure (SASH 2015); taking on the responsibilities of managing an Individual Budget (Anonymous Family Carer 2008; Neary 2015a); bringing people in out of area institutions back to their own communities (HealthWatch Oxfordshire 2014; NAO 2015) or fighting individual infringements of rights and life (Ryan 2015a, Justice for Nico 2015).

History teaches us that the personal can become political. Individual family fights transform into more generic campaigns. Rene Harris, a founder member of Luton and District Mencap in the 1950s, recalled that when her son entered Bromham Hospital ‘that is when I threw myself into Mencap, heart and soul. I thought “I must fight ... because perhaps parents won’t have to undergo this trauma in the future if we can improve services”’ (Harris 2005, 50 - 51). Contemporary examples mirror this. In the case of Connor Sparrowhawk, for legislation to assert people’s rights. In the case of Nico Reed, persuading the regulatory and inspection body for England, the Care Quality Commission, to extend its remit to Supported Living (Justice for Nico 2015). In the case of Finola Moss, combatting the impact of the Mental Capacity Act legislation which was being used to deny her, and other families, a say

in the lives of their relatives, on the grounds of enabling adults to make their own decisions:

At 18 it is 'inappropriate' for you to make decisions for him, and you have no right to do so.

(Moss 2015)

Mutual support has been key to effective parent advocacy. In the post war era, this was achieved through local 'Societies' under the auspices of the National Association for Parents of Backward Children (NAPBC), later Mencap, (in Scotland the Scottish Association of Parents of Handicapped Children founded 1954, later Enable) which created a sense of an often-embattled community (Walmsley 2000). The need was great. Families could be incredibly isolated with their disabled children (Rolph 2002; Harris 2005).

We never saw a soul. We just had them at home. There was nothing. Nothing at all ... it was a very dim period really for us in those days (Rolph 2002, 52).

Such stories were common, until the advent of local groups, and the establishment of services. The Societies formed in the period after World War 2 were motivated by the perception of exclusion. The response was to create something which would sustain a sense of belonging. The stories told by parents about their coming together have a strong theme of transformation.

Suddenly we realised we were not on our own ... It was a great relief, we thought we must be the only parents struggling like that ... It did seem miraculous that we were going to these little functions where we were welcome, and our daughter Wendy was particularly welcome (Rolph 2002, 45).

Similar transformative stories are found in the US, where the rise of the National Association for Retarded Children (NARC) mirrored the growth of the NAPBC. Wrote one father of the first meeting of an NARC branch:

They were reticent, brooding tragedy haunted parents ... They were diffident and cautious at first, even with each other. Then slowly they began to thaw out. ... One by one they rose and cast aside the usual feelings of guilt and shame to tell a familiar story of bafflement and despair (Castles 2004, 358).

There are more recent examples. Oxfordshire Family Support Network's Changing Scenes initiative 2012 - 2015, funded by a charitable fund, was aimed at older carers. Through setting up groups in small towns in the largely rural county, it created small communities of carers of adults with learning difficulties, which in some respects mirrored the self-help groups of the 1950s onwards, though led by a paid coordinator, not a volunteer. The participants spoke warmly of how it had helped them get connected, and fight for a better life for their sons and daughters, and themselves (Walmsley 2015).

However, social media opened the way for more diverse alliances, across the country and across the world. Sara Ryan's campaign, conducted largely through Twitter and an online blog (Ryan 2015a) was supported not only by other parents, but also by self-advocates, academics, and other allies, including some politicians (Ryan 2015a), and contributed to the creation of the Learning Disability Alliance coordinated by The Centre for Welfare Reform (Learning Disability Alliance 2014).

Contemporary Concerns and social media

The day to day fight to defend their relatives continues for families, intensified because austerity and reforms to welfare benefits are facing people with reductions in the support they can expect (Neary 2015a; Dumbleton 2013). When it comes to campaigning, perhaps the most significant difference in parent advocacy in the early twenty-first century is the means through which it is expressed. Whilst in the 1950s and 1960s it was characterised by close knit local groups, coffee mornings, fund raising and setting up services (Rolph 2002), more recently its most visible manifestations have been through Twitter, and blogging. The rise of social media has enabled some family members to bring the private trouble that is parenting a disabled child into public sight. Blogs, tweets and Facebook posts give insight into

day to day concerns, which highlight both despair and determination (for example Neary 2015a; Ryan 2015a; Moss 2015), although the practical issues they face vary. For people who live with family or independently, there is the challenge of getting timely help; and the need for a family member to manage an individual budget, to supervise staff, and to account for expenditure, in the face of unhelpful bureaucracy and budgetary constraints (Neary 2015a). In this blog, Mark Neary noted the real impact of managing an individual budget after his son's payment was delayed, incurring an overdraft charge:

So this is where we are personalisation wise. You either accept a commissioned service which does not cover the assessed needs because the Local Authority aren't prepared to pay the rates the provider charges. Or, you accept a personal budget. Become a manager. Become an employer and have to deal with the taxman. And then you are reliant on an antiquated system clunking into life (Neary 2015b).

For people whose relatives have been damaged in the care system, there is the challenge of holding organisations to account (Ryan 2015a; Justice for Nico 2015). At times individuals cross the boundary between both having to use services while simultaneously challenging what was offered – as when Steven Neary was (illegally) kept in residential care by the London Borough of Hillingdon Council after a spell in respite (Neary 2014); and as when Sara Ryan's appeals for help in managing her son's increasingly fractious behaviour led to his admission to the Short Term Assessment and Treatment Centre where he later died (Ryan 2014a).

The threats to the wellbeing of people with learning disabilities, and their families, from the twin forces of austerity leading to cuts in Local Authority budgets, and Welfare Reform, both placed more responsibility with families, and spawned a renewed energy in parent advocacy. The energy and enthusiasm for collective services on the part of previous campaigners now appears to be invested in achieving more individualised lifestyles, with more reliance placed on social media, rather than face to face interaction in local groups.

3. Examining parent advocacy as a force for change

Assessment of what parent advocacy has achieved is problematic. Had this paper been written in 2005, it might have been possible to cite the creation of alternatives to hospital provision in community based services. But these began to close, under the twin imperatives of cost saving and 'inclusion', a preference in the minds of policy makers, at least, for mainstream provision. The energy with which family campaigns were being waged in 2015 - 16 indicated the continuing need for advocacy, as community services closed, and austerity began to bite; and in response to a series of serious abuses (Mazars 2015).

Co-produced services were undoubtedly an achievement of the earlier parent movements. Families were instrumental in setting up services in the community, using their own resources, and money raised by fund raising to found nurseries, welfare visitors, even residential homes and Day Centres (Rolph 2005a and 2005b). Many of these early initiatives to set up services in the community - examples of co-production before the term had been coined - were taken over by Local Authorities over time (Rolph 2005a, b, c), and family influence over them waned. Ann Prior describes in her life story how families in Wantage, Oxfordshire persuaded Oxfordshire County Council to build a day centre in the town. It opened in 1983. The centre was managed by paid staff, but there was an equal number of volunteers. It was actively supported by a local group, Friends of the Charlton Centre. Trainees worked in the well equipped gardens, or the kitchens. A café was opened and staffed by trainees. Open days were held at which plants and shrubs were sold to the local community. Thus, she described, 'This ... brought the local community into the Centre and they were very supportive and got to know the trainees' (Prior 2015). More recently she writes with some apparent regret, attitudes have changed to family involvement:

The Centre is now mostly used as day respite care for those with difficult behavioural problems ... because it is a much cheaper option. Consequently, the more able people are just offered a day or two a week, and the sense of community is lost (Prior 2015).

Parent advocacy appears to have been ineffective in resisting the closure of the facilities previous generations worked hard to create. Closure of day services revealed differences between families, some of whom welcomed the opportunity offered for inclusion in mainstream services, but was resisted by many others who argued that their closure deprived their relatives of daily occupation, and deprived them of valuable time free of caring responsibilities (Mencap 2012, SASH 2015). Mary Langan, like Sara Ryan an academic with an interest in disability issues, and mother of a son with autism (Langan 2011) led a campaign against closure of local authority funded services in Haringey, London (Save Autism Services in Haringey (SASH)). In a speech to the All Party Parliamentary Group on Autism she argued,

It is impossible to reconcile the interests of people with autism and the current scale of cuts in adult social care. Current policies will inevitably result in more scandals and horror stories, but the real burden will be borne by people like James and families like ours (SASH 2015).

Although it appeared following the closure of the last NHS Learning Disability Hospital in 2009 (Goldring 2009), that - in part because of parent pressure - institutional detentions were a thing of the past, in practice much contemporary parent advocacy is focussed on the detention of relatives in Assessment and Treatment Centres (ATUs). Perhaps the most prominent of these was the Laughing Boy campaign. The family, energetically supported by a constellation of organisations (Ryan 2015b) and individual academics and campaigners, successfully fought for an inquest in which the jury found that the man's death had been contributed to by neglect. Like many families before them, this family's concerns that their son's epilepsy was recognised and the risks managed had been systematically ignored by staff (Ryan 2015b). Following the inquest, the family continued to fight for a change in legislation (the Laughing Boy or LB Bill⁴) using crowdsourcing and social media; and for independent investigation into the deaths of other people with learning disabilities in the NHS Trust where LB had died (Ryan 2015a).

⁴ <http://justiceforlb.org>

One of the most significant achievements of parent advocacy has been to influence the way people with learning disabilities are portrayed, as people rather than as 'other'. Brenda Nickson, whose son was born in 1955, was an early member of Bedford Mencap. She typifies the challenge, expressing the work of 'the Society' as

To try and get the children ... recognised as people (Nickson 2005 p. 78)

Langan describes how parents of people with autism in the UK contributed to a move to respect and celebrate difference, rather than seek for a cure (2011), although this appears to differ from parents involved in autism movements in Canada (Orsini and Smith, 2010) and Sweden (Bertilisdottir Rosqvist et. al 2015). Contemporary bloggers share this emphasis on portraying their relatives as fellow humans. Sara Ryan nicknamed her son as 'Laughing Boy':

Some people suggest that LB (17) has various labels like autism, learning disabilities, epilepsy and Klinefelter's Syndrome. I just think he is one crazy dude who loves Eddie Stobart, drum and base and going to London (Ryan 2015a).

Mark Neary described his son's ordinary day, and contrasted it with what might be, if he had remained in an Assessment and Training Unit:

I sat with Steven (son) and ran through the plans he's made for today. They were: go to Ranjit's shop for a Flake; have a Fawlty Towers marathon; search YouTube for the clips he wants for his radio show on Monday; go swimming at our local Mencap pool. If Steven was still in the ATU, he would not be able or allowed to do any of these things (Neary 2015).

However, how many of the changes to legislation and services achieved in the latter twentieth century are attributable to parent advocacy is open to debate. There was, as Roulstone (2015) points out, a cross party consensus that disabled people were entitled to support, albeit with paternalist overtones. A constellation of forces, of which campaigning by families and organisations representing them was one, led to

discrediting of institutions and the setting up of community based services. Research and academic critiques, economic forces making large institutions too expensive, challenges of recruitment to often remote locations, and a series of scandals (Welshman and Walmsley 2006, Donges 1982), all contributed to the decision to close mental handicap hospitals. Even so, closure was a long time coming, and institutions under new names, run by private companies, charities and by the NHS, survived the official closure programme, with Government apparently unable to change this (NAO 2015).

Families, as both the academic research and blogs cited in this paper show, continue to have to fight to establish even an acceptable life for their relatives. At a policy level, advocacy and campaigning by families in the past certainly contributed to changing the public perception of people with learning disabilities, though sometimes into objects of pity rather than fellow citizens. Families did achieve a right to education for children previously labelled 'ineducable'. Community services were achieved, but later under threat of closure. Co-produced services gave way to professionally controlled services. And, in the second decade of the twenty-first century, campaigns to retain the gains of previous generations, and to finally put an end to detentions in institutions for people who are difficult to house in their own localities have met with very mixed success (NAO 2015).

4. Conclusion: a time for new alliances?

This paper has sought to demonstrate the passion and vitality of parent advocacy, particularly at times of significant change and challenge in the support available to people with learning disabilities; and the abuse of rights, particularly for people detained in institutions. The campaigning battleground has largely moved from local Societies fighting their corner to the global reach of social media. But the daily grind of fighting for services, to be heard continues. The challenges remain: to be taken seriously, to protect vulnerable relatives, to ensure that they are viewed as fellow citizens, to secure the future after families are no longer able to care.

Advocacy is exhausting. On top of the challenge of caring for or supporting a son or daughter with learning disabilities, it is sometimes too much to become a crusader for people's rights. In late 2016 Mencap, to publicise its 70th anniversary, reported that parents of children with learning disabilities still fear public reaction to their child. Seventy percent of parents polled had felt unwelcome in public and a fifth have been asked to leave a public space due to their child's behaviour, heightening their sense of isolation⁵. Families cannot relax their guard, as support is eroding at the time of writing, with more stringent eligibility criteria meaning that fewer people 'count' as disabled (Roulstone 2015, Hatton 2015); and the Government commitment to ending placements in out of area institutions had not been met (NAO 2015). These battles cannot be left to families. A key message from this account is that presenting the interests of families and people with learning disabilities as in conflict is at best over simplistic, and at worst, positively harmful. Families can be over cautious, and they can also be abusive. But they are people's most consistent allies, and particularly at times when other support is unreliable, vital to people's wellbeing. It is time, as Robin Jackson has argued (2015) to recognise that a divided movement is unhelpful when combatting threats to services and income – and in some cases, to life (University of Bristol 2013, Mazars 2015).

Arguably the greatest contribution to change made by parent advocacy was that it contributed to changing the discourse about learning disability, from a condition that was essentially unalterable, where people with the label represented a threat to society to one where people were recognised as fellow human beings, and, more prominently, their families became regarded as burdened and worthy of support (Castles 2004, Walmsley 2000). This change of narrative opened the way, not only for closure of institutions, but for the provision of services which alleviated that burden of care, because families with a disabled son or daughter were 'people like us'.

Parent advocacy has been a constant since the post war era, although it has shifted in response to the wider social landscape that shapes the lives of people with learning disabilities. The earlier parent movement achieved its goals of universal

⁵ <https://www.mencap.org.uk/press-release/almost-two-thirds-parents-miss-social-engagements-due-fear-public-reactions-their-0>

entitlement to education, and the provision of community services. But these successes revealed underlying tensions, particularly disagreement over deinstitutionalisation, the need to represent special interest groups (Tilley 2006) and the right of people with learning disabilities to have their own voice through self-advocacy (Jackson 2015). These tensions were compounded by the advent of free at the point of delivery community services and more generous financial provision, which meant that need, and the motivation to work collectively, reduced (Johnson and Walmsley 2010).

In light of the current crisis facing many people with learning disabilities, it seems there is a need once again for families to fight for change. The movement of the 1950s and 1960s was driven by a sense of profound desire to bring private family experiences into the public domain. It was propelled forward by new connections being made by parents both nationally, and internationally and the creation of networks to share knowledge and understanding. With the advent of social media, and the growing confidence of self-advocates (despite ongoing cuts to their support and funding), it seems reasonable to believe there are now opportunities for new connections and alliances to be made. The advent, in 2016, of a new organisation called Learning Disability England (<http://learningdisabilityengland.org.uk/index.html>), seeking to be led by people with learning disabilities and including family carers, academics and provider organisations in their membership, may be significant. Building on the work of the Learning Disability Alliance England, the organisation aims to a forge partnership between different groups, on the basis that 'for too long, we have been working separately and our voices have not been strong enough on our own to make change' (<http://www.centreforwelfarereform.org/news/learning-disand-launched/00285.html>). While international research has highlighted the tensions inherent in some social movements that purport to be inclusive of both disabled people and their families (Orsini and Smith 2010; Bertilsdotter Rosqvist 2015), Learning Disability England is the product of a different time, and a different context. If it can successfully harness the energy of earlier disabled people's and parents' movements in a way that is genuinely integrationist, there is real potential to challenge the current discourses and policies that are affecting people's lives in such acute ways.

Perhaps the greatest challenge to a contemporary movement is to coalesce around a set of ideas which can unify disparate allies behind a banner for change, as effectively as the post war parents' movement gathered behind the need for education and for community services to support family care. The way forward is unclear. It is perhaps tempting to hark back to a previous era of segregated services, those now closing, yet those services were too frequently of low quality and low aspirations (Power, Bartlett and Hall 2016). But the prevailing individualism and Government's (mis)use of concepts associated with the disabled people's movement, such as independence (Roulstone 2015), to cut entitlements to welfare and support, threaten to consign people with learning disabilities and families to self help or neglect. Terms such as inclusion, independence, citizenship have been taken to mean changing the person to fit into society, equipped with tools, like individual budgets, which seek to put them on an equal footing with other citizens (Johnson and Walmsley 2010). But there are problems with this, not least that individualising support erodes collective resistance, something which does not serve people with learning disabilities well at a time of reductions in funding.

Are there other ways to think about this? Winance argues that

One does not integrate disabled people into society; one simultaneously builds the normal person and the collective in which he/she will be included. And this work on the norm transforms everyone (with or without impairments) involved
(Winance 2007 p. 634).

In other words, she argues that the challenge is to get rid of the binary which divides us. Sara Ryan expresses something similar, with great eloquence:

My beyond wildest dreams would be that – we are not going to achieve this in a million years – but would be that we didn't even have to talk about learning disabled people, because, because there wouldn't need to be that division, because everybody would have a right to live where they choose, everybody has an imagined future, and the distinction between being learning disabled

and being non-learning disabled would become sort of irrelevant because it isn't an issue. That, that I suppose is my wildest dream, but whether that will happen or not, I, I don't know, so we'll reach for the stars and see what happens. Coz I think Connor's up there. (Ryan 2015a)

Achieving this is too important to be left to families alone. Certainly, fighting for Sara Ryan's wildest dream is a job for all of us.

Word count: 7910

References

Andrews, J (1998) Begging the question of idiocy: the definition and socio-cultural meaning of idiocy in early modern Britain: Part 1. *History of psychiatry*, 9(33), pp.65-95.

Anonymous Family Carer (2008) In Control? Making sure we're not out of control! Some issues for people considering a direct payment or individualised budget *The Journal of Adult Protection*, Vol. 10 No.3 pp. 14 – 22

Barnes, M. (2006/2010) 'Caring and Social Justice', in *Have Families been Rethought? Ethic of Care, Family and 'Whole Family' Approaches*, eds. L. Murray & M. Barnes, Social Policy and Society, Vol. 9, no. 4, pp. 533–44.

Beadle-Brown (2006) *Person-Centred Approaches and Quality of Life* Tizard Learning Disability Review Vol. 11 Issue 3 pp 4-12

Bedfordshire Mental Deficiency Papers Vol. 23 22/4/1937

Bertilsson Rosqvist, H., Brownlow, C. and O'Dell, L. (2015) 'An Association for All'—Notions of the Meaning of Autistic Self-Advocacy Politics within a Parent-Dominated Autistic Movement, *J. Community Appl. Soc. Psychol.*, 25: 219–231 (2015) Published online 7 October 2014 in Wiley Online Library (wileyonlinelibrary.com) DOI: 10.1002/casp.2210

Bibby, R (2013) '*I hope he goes first*': *Exploring determinants of engagement in future planning for adults with a learning disability living with ageing parents. What are the issues?* *British Journal of Learning Disabilities* Vol. 41, No. 2 pp 94-105

Blackburn, L. and Gallagher, J. (2012) *Quarterly Report on the Scottish Innovation Forum: The delivery of personalised care* Scottish Affairs Vol. 78 (First Series) No. 1

Bringing Us Together (2016) *Stronger Together Report*
<http://bringingustogether.org.uk/wp-content/uploads/2016/07/Stronger-Together-June-2016.pdf> [accessed 5 August 2016]

Bromham Joint Board Papers (1944) Bedfordshire Library, Archives and Records
JBV 14/i

Buchanan, I. and Walmsley, J., 2006. Self-advocacy in historical perspective. *British Journal of Learning Disabilities*, 34(3), pp.133-138.

Bylov, F., 2006. Patterns of culture & power after 'The Great Release': the history of movements of subculture & empowerment among Danish people with learning difficulties. *British Journal of Learning Disabilities*, 34(3), pp.139-145.

Cairns D, Tolson D, Darbyshire C, Brown J (2012) The need for future alternatives: the experiences of older parents caring for offspring with learning disabilities over a prolonged period of time *BJLD* 41, 1 73-82

Castles, K., 2004. 'Nice, Average Americans': Postwar Parents' Groups and the Defense of the Normal Family in Noll, S. and Trent, J., 2004. *Mental retardation in America: A historical reader*. NYU Press. 351-368

Cooper, V and Ward C (2011) Valuing People: Family Matters Ten Years On *Tizard Learning Disability Review* 16:2 , 44-48

Davys D, Mitchell D and Haigh C (2014) Futures Planning: Adult Sibling Perspectives *BJLD* 43 219-226

Department of Health (2009) *Valuing people now: a new three-year strategy for people with learning disabilities* London, HMSO

Donges, G. (1982) *Policy making for the mentally handicapped* (Aldershot: Gower Publishing Company Limited)

Dumbleton, S (2013) Goodies and baddies: equivocal thoughts about families using an autoethnographic approach to explore some tensions between service providers and families of people with learning disabilities *Ethics and Social Welfare*, Vol. 7 No.3 pp. 282 -292

Fitzroy (2015) *Who will care after I'm gone: an insight into pressures facing parents of people with learning disabilities* online <http://www.fitzroy.org/wp-content/uploads/Who-will-care-after-im-gone.pdf>

Foley S (2012) Reluctant Jailers speak out: parents of adults with Down syndrome living in the parental home on how they negotiate the tension between empowering and protecting their intellectually disabled sons and daughters *BJLD* 41 301-311

Foundation for People with Learning Disabilities (2012) *Learning Disability Statistics: Support* <http://www.learningdisabilities.org.uk/help-information/Learning-Disability-Statistics-/187696/>

Glendinning C, Mitchell W and Brooks J (2015) Ambiguity in practice: carers' roles in personalised social care in England *Health and Social Care in the Community* 23, 1, 23 -32

Goldring M (2009) Hospital Closure marks a milestone available on <http://www.theguardian.com/society/joepublic/2009/may/01/hospital-closure-care> [accessed 30/12/15]

Harkes, M, Brown, M. and Horsburgh D (2014) Self-directed support policy: challenges and possible solutions *British Journal of Learning Disabilities* Vol. 42, No. 3 pp 169-176

Harris R (2005) I don't think I'll give up until I die in Rolph S Atkinson D, Nind M and Welshman J (eds) (2005) *Witnesses to Change: Families, Learning Difficulties and History* Kidderminster BILD pp. 47-54

Hatton C (2015) online blog The Disappeared 2/11/15 <http://chrishatton.blogspot.co.uk/2015/11/the-disappeared.html> [accessed 30/11/2015]

HealthWatch Oxfordshire (2014) *A Local Experience of National Concern* Oxford: HealthWatch Oxfordshire

House of Lords and House of Commons Joint Committee on Human Rights (2008) *A Life Like Any Other? Human Rights of Adults with Learning Disabilities*, Crown Office, London

Hutchison, I. (2011) *Institutionalization of mentally-impaired children in Scotland, c. 1855–1914* *History of Psychiatry* Vol. 22 No. 4 pp. 416–433

Ingham, N. (2013) *Organisational Change and Resistance: An Oral History of a Long-Stay Institution for People with Learning Difficulties* Unpublished PhD Thesis, Milton Keynes, Open University

Jackson, M. (2001) *The Borderland of Imbecility: Medicine, Society and the Fabrication of the Feeble Mind in late Victorian and Edwardian England*. Manchester: Manchester University Press.

Jackson R (2015) Who Cares? Online <http://www.centreforwelfarereform.org/library/by-az/who-cares1.html> [accessed 30/12/2015]

Jingree, T. and Finlay, W. (2012) 'It's got so politically correct now': parents' talk about empowering individuals with learning disabilities *Sociology of Health and Illness* Vol. 34 No. 3 pp. 412-428

Johnson K and Walmsley J (2010) *Towards a Good Life for people with intellectual disabilities* Bristol: Policy Press

Jones G (1986) *Social Hygiene in Twentieth Century Britain* London Croom Helm

Justice for Nico (2015) online blog <http://justicefornico.org>

Keilty T and Woodley K (2013) *No Going Back* Sheffield: Centre for Welfare Reform
Earle S, Chapman R, Tilley E, Townson L, Walmsley J (2015) *Contraceptive choices for women with learning disabilities: Research Report* Milton Keynes: Open University

King's Fund (1980) *An Ordinary Life: Comprehensive Locally-based Residential Services for Mentally Handicapped People*, London, King's Fund Centre.

Langan, M. (2011) Parental Voices and controversies in autism *Disability and Society* 26, 1 193-205

Learning Disability Alliance (2014) Join the Learning Disability Alliance
<http://www.centreforwelfarereform.org/news/join-the-leaity-alliance/00171.html>

Ledger, S. (2012) *Staying local: support for people with learning difficulties from inner London 1971-2007* unpublished PhD thesis, Milton Keynes, Open University

Ledger, S., Earle, S., Tilley, E. and Walmsley, J. (2016) 'Contraceptive decision-making and women with learning disabilities'. *Sexualities*

Mackay, R. (2010) 'Social policy perspectives on empowerment' in Hothersall, S and Bolger, J (eds) *Social Policy for Social Work, Social Care and the Caring Professions: Scottish Perspectives* Ashgate Farnham, Ashgate

Manthorpe, J., Hindes, J., Martineau, S., Cornes, M., Ridley, J., Spandler, H., Rosengard, A., Hunter, S., Little, S. and Gray, B. (2011) *Self-directed support: a review of the barriers and facilitators* Edinburgh, Scottish Government Social Research

Mattison V and Pistrang N (2000) *Saying Goodbye: when keyworker relationships end* London: Free Association Books

Mazars (2015) Independent Review of deaths of people with learning disabilities or mental health problems in contact with Southern Health NHS Foundation Trust April 2011- March 2014 available on <https://www.england.nhs.uk/south/wp-content/uploads/sites/6/2015/12/mazars-rep.pdf>

Mencap (2007) *Death by Indifference* available on <https://www.mencap.org.uk/death-by-indifference> [accessed 31/12/15]

Mencap (2012) Stuck at Home <https://www.mencap.org.uk/news/article/stuck-home>

Mencap (2015) Annual Report 2014-15
https://www.mencap.org.uk/sites/default/files/documents/2015.013%20Annual%20Report_1.pdf [accessed 29/8/2015].

Michael J (2008) *Healthcare for All* London: Department of Health

Mitchell, F. (2015) *Facilitators and barriers to informed choice in self-directed support for young people with disability in transition* Health and Social Care in the Community Vol. 23 No.2 pp. 190-199

Moss, F. (2015) online blog [accessed 12/12/15]<http://FinolaMoss.wordpress.com>

National Audit Office (2015) *Care Services for People with learning Disabilities and Challenging Behaviour* London: NAO

NHS England 2015 *Transforming Care: Homes not Hospitals for people with learning disabilities* available on <https://www.england.nhs.uk/2015/10/30/homes-not-hospitals/>

Neary M (2014a) <https://markneary1dotcom1.wordpress.com/2014/12/09/it-never-abates/>

Neary, M. (2014b) <https://markneary1dotcom1.wordpress.com/2014/12/04/card-games/> [accessed 15/8/16]

Neary, M. (2015a) online blog <https://markneary1dotcom1.wordpress.com/> [accessed 12/8/16]

Neary, M. (2015b) online blog <https://markneary1dotcom1.wordpress.com/2015/09/22> [accessed 12/8/16]

Neary M 2016 <https://markneary1dotcom1.wordpress.com/2016/01/03/mr-submissive/> [accessed 15/8/16]

Nickson B (2005) in Rolph S, Atkinson D, Nind M and Welshman J (eds) *Witnesses to Change: Families, Learning Difficulties and History* Kidderminster BILD pp. National Audit Office (2015) *Care Services for People with Learning Disabilities and Challenging Behaviour* London: NAO

O'Brien, J (2004) If Person-Centred Planning did not Exist, Valuing People Would Require Its Invention *Journal of Applied Research in Intellectual Disabilities* Vol. 17, Issue 1, pp 11–15

Orsini, M. & Smith, M. (2010). Social movements, knowledge and public policy: the case of autism activism in Canada and the US. *Critical Policy Studies*, 4, 38–57.

Oxfordshire Family Support Network (2015) <http://www.oxfsn.org.uk/about-us/aims-and-values/> [accessed 29/8/2015]

Prior A (2015) *Defining Moments* Presentation to Social History of Learning Disability Conference, Milton Keynes, June 2015 available on <http://www.open.ac.uk/health-and-social-care/research/shld/conferences/conference-2015>

Prosser, H. (1997) 'The future care plans of older adults with intellectual disabilities living at home with family carers' *Journal of Applied Research in Intellectual Disabilities* 10: 15–32 cited in Bibby, R (2013) *'I hope he goes first': Exploring determinants of engagement in future planning for adults with a learning disability*

living with ageing parents. What are the issues? British Journal of Learning Disabilities Vol. 41, No. 2 pp 94-105

Power A, Bartlett R and Hall E (2016) Peer advocacy in a personalised landscape: the role of peer support in a context of individualised support and austerity *Journal of Intellectual Disability* 20, 2, 183-193

Rolph S (2002) *Reclaiming the Past: The role of local Mencap Societies in the Development of Community Care in East Anglia 1946-1980* Milton Keynes: Open University

Rolph S (2005a) *The History of Bedford Mencap* MK: Open University

Rolph S (2005b) *A Little Glamour with a Strict Tempo The History of Cambridge Mencap* Volume 1 1947-1990 MK: Open University

Rolph S (2005c) *Captured on Film: The History of Norwich and District Mencap Society* MK: Open University

Rolph S Atkinson D, Nind M and Welshman J (eds) (2005) *Witnesses to Change: Families, Learning Difficulties and History* Kidderminster BILD

Rolph S and Walmsley J (2002) 'The history of community care for people with learning difficulties' in Bytheway B, Bacigalupo V, Bornat J, Johnson J and Spurr S (eds) *Understanding care, welfare and community: a reader* London: Routledge

Rolph S and Walmsley J (2006) Oral History and New Orthodoxies: Narrative Accounts in the History of Learning Disability *Oral History* Spring pp. 81-91

Roulstone A (2015) Personal Independence Payments, Welfare Reform and the shrinking disability category *Disability and Society* 30, 5 673-688

Runswick- Cole K (2012) Review of Social policy and social capital: parents and exceptionality 1974–2007, by Dora S. Bjarneson, *Disability and Society* 27, 7 1044-1045

Ryan S and Runswick-Cole K (2008) Repositioning Mothers: Mothers, Disabled Children and Disability Studies *Disability and Society* 23, 3 199-210

Ryan S (2014) online blog <https://mydaftlife.wordpress.com/category/laughing-boy-tales/death/page/3/> [accessed 30/12/2015]

Ryan S (2015a) online blog <https://mydaftlife.wordpress.com/2015/11/> [15/8/16]

Ryan S (2015b) online blog Summary <https://mydaftlife.wordpress.com/summary/> [15/8/16]

Ryan S (2015c) <http://justiceforlb.org/> [accessed 12/12/15]

Sanctuary G (1981) *After I'm gone what will happen to my handicapped child* London: Souvenir Press

SASH (2015) <http://saveautismservicesharingey.co.uk/2015/11/nas-warns-of-roundway-terrible-loss-ham-high/> [accessed 30/12/15]

Scott, J.W. (2002) Women's History, in *New Perspectives on Historical Writing*, ed. P.Burke 2nd edition. Cambridge, Polity Press. pp.43-70.

Scottish Executive (2000) *The Same As You? A review of services for people with learning disabilities* Edinburgh, Scottish Executive

Scottish Government (2009) *Personalisation: A Shared Understanding/Commissioning for Personalisation/A Personalised Commissioning Approach to Support and Care Services* Edinburgh: Scottish Government
<http://www.gov.scot/Resource/Doc/269193/0080033.pdf> [Accessed 9th April 2015]

Scottish Government (2011a) *Evaluation of Self-directed Support Test Sites in Scotland*, Edinburgh: Scottish Government
<http://www.gov.scot/Resource/Doc/358197/0121078.pdf> [Accessed 9th April 2015]

Scottish Government (2011b) *Self-directed Support (Direct Payments) Survey*, Edinburgh, Scottish Government

Scottish Government (2013) *The Keys to Life Improving quality of life for people with learning disabilities* Edinburgh, The Scottish Government

Scottish Government (2013b) *Our Shared Vision for Independent Living in Scotland* Edinburgh, The Scottish Government

Shennan V (1980) *Our Concern: the story of the National Association for Mentally Handicapped Children and Adults* London: National Association for Mentally Handicapped Children and Adults

Simons K (1992) *Sticking up for yourself: self advocacy and people with learning difficulties* York: Joseph Rowntree Foundation

Simons K (1993) *Citizen Advocacy: The Inside View* Bristol: Norah Fry Research Centre

Sims, D. and Cabrita Gulyurtlu, S (2014) A scoping review of personalisation in the UK: approaches to social work and people with learning disabilities *Health and Social Care in the Community* Vol. 22 No. 1 pp. 13-21

Sharpe, J. (2002) History from Below, in *New Perspectives on Historical Writing*, ed. P.Burke 2nd edition. Cambridge, Polity Press. pp. 25-42.

Thomson, M. (1998) *The Problem of Mental Deficiency in England and Wales, 1913-1946* (Oxford: Clarendon Press)

Tilley E (2006) The Voluntary Sector in Welshman J and Walmsley J (eds) *Community Care in Perspective: Care, Control and Citizenship* London: Palgrave MacMillan pp219-232

Tilley, E., Earle, S., Walmsley, J. and Atkinson, D. (2012) 'The Silence is roaring': Sterilization, reproductive rights and women with intellectual disabilities, in *Disability and Society*, 27(3) pp. 413–426

Tilley, E. and Graham H. (2016) 'Exploring a Living Archive of Learning Disability History' (presentation to the 2016 'Theorising the Mundane' Normalcy Conference, Manchester)

University of Bristol (2013) *Confidential Enquiry into Premature Deaths of People with Learning Disabilities (CIPOLD)* Bristol: University of Bristol
<http://www.bris.ac.uk/cipold/> [accessed 31/12/15]

Walmsley J (2000) 'Straddling Boundaries: the changing role of the voluntary sector' in Brigham L, Atkinson D, Jackson M, Rolph S and Walmsley J (eds) *Crossing Boundaries: Change and Continuity in the History of learning Disability* Kidderminster BILD

Walmsley J (2015) *Final Evaluation of Changing Scenes Oxford Family Support Network: unpublished Evaluation Report*

Walmsley J (2016a) *One Voice Community Living July / August 29, 4, pp?*

Walmsley J (2016b) *Launch of Learning Disability England Community Living (in press)*

Welshman J and Walmsley J (eds) (2006) *Community Care in Perspective: Care, Control and Citizenship* London: Palgrave MacMillan

Williams P and Schoultz B (1982) *We can speak for ourselves* London: Souvenir Press

Winance, M. (2007). Being normally different? Changes to normalization processes: from alignment to work on the norm. *Disability & Society*, 22(6), pp.625-638