

Aspiration, Austerity and Ableism: To what extent are the SEND reforms (2014) supporting young people with a life-limiting impairment and their families to get the lives they want?

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## **Introduction**

In 2012 the European Commission noted that too few children with Special Educational Needs and Disability (SEND) were leaving school with qualifications or moving on to employment across Europe (European Commission 2012). In England, many similar concerns were highlighted in a series of reports between 2009 – 2011: the Lamb Review on Parental Confidence in SEND (2009) reported tense and broken relationships between parents, schools and Local Authorities; the Ofsted report ‘A Statement is Not Enough’ (2010) amongst other things discussed the lack of destinations post-19 years for young people with SEND and their lack of outcomes; the Green Paper, entitled ‘Support and Aspirations’, indicated that young people and families needed to have far more control over the process of identifying and achieving their aspirations and that support should be put in place early and quickly (Department of Education 2011). Therefore, the introduction of legislation that Edward Timpson, the then Minister for Children and Families (2014) suggested would bring about ‘the biggest, most ambitious and most aspirational reforms to Special Educational Needs provision in more than 30 years’ could be viewed as long overdue (Department for Education 2014).

The aim of this paper is to explore to what extent young people who have the life limiting impairment Duchenne Muscular Dystrophy (DMD), have found the new SEND legislation helpful in supporting them to achieve the lives they want. DMD is a rare genetic muscle-wasting impairment that affects one in three thousand five hundred male births (Emery and Muntoni 2007). As it is caused by a fault on the dystrophin gene which is on the X chromosome, it affects predominantly males who on average lose the ability to walk by the age of 12 years, and historically have had a mean life expectancy of 19 years (Bushby et al 2010). DMD can be viewed as a neuro-developmental rather than simply a physical impairment (Ricotti et al 2015). Young people are at higher risk of experiencing specific learning difficulties such as dyslexia and Attention Deficit and Hyperactivity Disorder (ADHD), and a higher than average proportion have diagnoses of Autism Spectrum Condition and Obsessive Compulsive Disorder, and experience internalising and externalising behaviours (Hendriksen and Vles 2008; Hinton et al 2009; Ricotti et al 2016).

Like young people with other life limiting impairments, those with DMD are now living longer due to a range of treatments such as cardiac management and ventilation, enabling

some men to live into their thirties and forties (Eagle et al 2007; Hastie and Chapman in Hoskin (ed) 2017). Despite longer life expectancy, continued low expectations have meant that adults with DMD have been referred to as ‘marginalised’ and ‘unanticipated’ with little planning through Transition to Adulthood because nobody expected them to still be alive (Schrans et al 2013; Rahbek et al 2005). In interviews with 40 young adults with DMD and their families in the UK between 2007 - 2009, Abbott reported the Transition to Adulthood process to be problematic for the overwhelming majority, with planning, services and support inadequate and yet to catch up with the improved life expectancy in DMD. Men with DMD that he interviewed were overwhelmingly living at home with their parents, and only one person had experienced paid employment; most experienced very little social contact with people outside their immediate family. The impact of living with DMD negatively affected families, with 80% of the parents meeting levels of clinical depression (Abbott, Carpenter and Bushby 2012). Therefore, young people with DMD would certainly benefit from a SEND system that could help them to have higher aspirations in the context of extended life expectancy, whilst supporting the physical, emotional, and learning needs associated with their impairment.

It could be anticipated that the new Special Educational Needs and Disability Code of Practice with its focus and new chapter dedicated to Transition to Adulthood would eradicate some of the problems that adults with DMD have reported (Abbott, Carpenter and Bushby 2012). It is now a statutory duty to consult all young people with SEND aged between 14 – 19 years about their future – the sort of education and employment they would like to achieve; where they want to live and the type of housing they want to explore; their community inclusion and friendships and finally their health care. Young people should not have blanket decisions made about them – they must be listened to (Department of Education & Department of Health (2015) s 9:16). The emphasis on outcomes such as employment in the SEND Reforms has led to a renewed emphasis on initiatives like work experience, apprenticeships and the introduction of supported internships which are structured study programmes based primarily at a workplace which enable a young person with SEND aged 16 – 24 years to develop the skills needed to obtain a job (Department for Education 2017).

As well as gaining employment, having independence in living arrangements has been reported as key to quality of life and choice for disabled people everywhere (Morris 2006). In Denmark, where there is increased state support for disabled people, adults with DMD live

independently in their own apartments and employ Personal Assistants. This has been described as 'dependent independence' (Dreyer 2010), where the adult with DMD is able to make choices although is dependent on a personal assistant to support him with most day to day activities. Support to live independently has become more prevalent in the UK over the last few years as life expectancy increases (Hastie and Chapman in Hoskin eds 2017). In Japan, where there is very limited state support for disabled people and no national health service, adults with DMD still choose to live independently with personal assistants rather than live in much safer sanatoriums because they value choice and independence above safety. This has been referred to as 'self-reliant independency' (Yamaguchi & Suzuki 2013).

Some question whether the focus on getting work or a place to live is appropriate for young people and adults with chronic conditions. Priestley argues that the ideas of 'transition' and 'adulthood' are socially constructed and do not consider variables such as disability, gender or other difference (Priestley 2003). Research with adults with DMD in Canada has criticized the 'normalised' ideals of adulthood that views employment and residential independence as indicators of success, and puts pressure on people to live up to something they will struggle to attain (Gibson et al 2013; Hamdani 2014). Gibson and colleagues report from an interview with an adult with DMD saying he would rather spend the little time he has left with family and friends rather than looking for a job. They also argue that those who do manage to gain employment remain marginalized (Gibson et al 2013).

Nevertheless, others argue for the rights of disabled young people to gain access to real work opportunities. In her review of Disability Employment Support in the UK, Sayce argues that being able to work is not only important for income and social status, but also for your health and ability to develop and keep relationships (Sayce 2011). Along with others, she reports that disabled sixteen year olds have similar aspirations to stay in education and find fulfilling careers as their non-disabled classmates. (Sayce 2011; Burchardt 2005). Similarly, in interviews with disabled children Connors and Stalker reported that children they spoke to always talked about their similarities with, rather than their differences to, their non-disabled peers suggesting that they did not have dissimilar goals or ambitions (Connors and Stalker 2007).

## **Implementation of the Reforms**

On the surface, and initially perhaps, the changes in legislation did appear to be, ‘aspirational reforms’ : A single Education, Health and Care plan from birth to the age of 25 years replaced the Statement of Special Needs to be funded by Education, Health and Social care services thus removing the lack of accountability that families had complained of ; a ‘Local Offer’ through which every Local Authority by law must advertise what is available for young people and families in their local area; the introduction of personal budgets to introduce an element of choice, and a chapter on Transition in the Special Educational Needs Code of Practice placing an emphasis on post-19 outcomes and destinations (Department of Education and Department of Health 2015). The legislation stresses accountability of every teacher in providing high quality first teaching for all children regardless of SEND, and a national report on Initial Teacher training published the following year highlighted the importance of SEND training for all pre-service teachers (Carter 2015). Above all, the overriding philosophy of the reforms was that families and young people were now, as the Special Needs and Disability Code of Practice states ‘at the heart of the process’ (DoE & DoH 2015 s.9).

Initially, impact of the new legislation looked promising. An evaluation in areas that were ‘Pathfinder’ local authorities (those areas that had trialled the reforms from 2011-14) which included 698 families and 31 local authorities suggested that the new system was addressing many of the limitations of the old one. For example, 84% of parents reported greater satisfaction with the process and reported that plans were achieved in a timely way (Department for Education 2015). Similarly, a small scale project reported on how families preferred the new emphasis on person-centred planning (Department for Education 2016). Research published by the Department for Education and Ministry of Justice in 2017 indicated of 13,000 families contacted, 66% of parents and young people reported as being satisfied with the new SEND procedures (Department for Education and Ministry of Justice 2017).

However, more recently, complaints from families to the Local Government Ombudsman (LGO) about Education Health and Care plans doubled between 2015/16 and 2016/17, and in a report of the first 100 cases, the Ombudsman revealed that many councils were unlikely to meet the legal deadline of April 2018 for transference to Education Health and Care Plans from the old system of Statements of Special Educational Needs; and those plans that were

being created were often not within the 20 week deadline (LGO 2017). In some cases, this meant that children with SEND were unable to start school on time. In just under a third of the 30 Local Authorities they inspected between 2017-18, the Office for Standards in Education (Ofsted) and the Quality Care Commission (CQC) reported significant concerns about whether the local area was meeting its duties or securing better outcomes for children and young people with SEND (Ofsted and CQC 2017). Some of the other criticisms highlighted in these reports were the lack co-ordination of services, lack of proper assessment, input of therapy, support from local Children and Mental Health Services and the lack of young people's voices in the SEND process amongst other things (Local Government Ombudsman 2017; Ofsted & CQC 2017). As the Ombudsman's report noted '... we have seen some families having to push, persist, and go well beyond the call of duty just to confirm the type of support they should receive, and to get it provided.' (Local Government Ombudsman 2017 p1).

It can be difficult not to view the changes in legislation as a consequence of neo-liberal thinking and cost-cutting. In a critical discourse analysis of the 2014 SEND Code of Practice, Burch suggests that that the new legislation with its focus on employment and independence has been developed as a tool of the Government to support their national economic and political demands, rather than to address the unique needs and aspirations of young people with SEND (Burch 2017). Norwich warns of the 'rhetoric' of the new legislation, arguing that in fact very little has changed and that the Children and Families Act does not represent a 'radically new system' (Norwich 2014 p422). He views the changes as reflecting a wider social policy that is driven by economic austerity policies rather than the needs of young people with SEND. For children and young people with more complex care needs, the roll out of personalization in social care with the use of personal budgets has coincided with the global programme of Austerity. As Pearson and Ridley (2016) ask with regard to the implementation of the personalization agenda for social care in Scotland, is this bad timing or was this always part of the plan? (Pearson and Ridley 2016)

### **Timing of the Reforms and Austerity**

Undoubtedly, the SEND Reforms were introduced at a time of great financial precarity across Europe. The Great Depression of 2008 caused by the banking crisis, led Governments across Europe and the UK to make decisions on strategies for financial savings. Under the guidance

of the European Commission and the International Monetary Fund, by 2010 many countries such as the UK, France, Portugal and Spain and the US launched programmes of Austerity making severe cuts to public services. However, according to Stuckler and colleagues, Austerity was not an inevitable consequence, and those lucky enough to live in countries like Germany or Denmark which have stronger social protection systems have not experienced the same level of cuts (Stuckler et al. 2013).

Across Europe, Austerity has caused untold damage to certain sections of the population, particularly those depending on state welfare support, and studies have shown high levels of poverty, decreased public health, links between austerity and increased suicide rates, a rise in homelessness, as well as lack of services that have negatively affected those with SEND (Karanikolos et al 2013; Loopstra et al 2016).

In the UK, disabled people and those with SEND have been disproportionately affected, and research shows that rather than share the burden of cost, these cuts have been directed at the most severely disabled and have served to increase the divide between the most wealthy and least wealthy postcodes (Duffy 2012; Fothergill and Beatty 2016). Research published as early as 2012 reported that 81% of local authorities in England set care eligibility thresholds at “substantial/ critical only”; over 50% closed a disability support service, and in some areas charges to service- users rose by 400% (Wood 2012). The Independent Living Fund, a national funding body set up in 1988 to provide funding for severely disabled adults to live independently at home was shut down in 2016. Recently, ideas such as ‘warehousing’ disabled people have re-emerged, with many disabled adults fearful of being institutionalised because Local Authorities view this as a cheaper alternative to independent living (Brown 2017). Perhaps it is little wonder that in 2016, a United Nations inquiry concluded that policies introduced into welfare and social care by the UK Government amounted to “systematic violations” of the rights of disabled people. (United Nations 2017).

It is not only disabled people and their families who have struggled under Austerity. Savage speaks of a rise of a new class, the ‘precariat’, who depend on zero hours’ contracts, live in temporary accommodation and who lack permanence and consistency (Savage 2013). This group of people, may often include those who care for and support disabled children and adults, and whom disabled people need to recruit, train and manage. An ongoing struggle is thus not always only in receiving appropriate budgets to live independently as a disabled

person, but in recruiting and maintaining consistent care staff (Ferguson 2007; Sims & Whisker 2015). The focus on independence and social inclusion in the SEND Reforms could therefore feel unattainable given the social context in which they have been introduced.

Looking at the experience of children and young people in education specifically, reduced budgets to Local Authorities have meant a lack of specialist support for young people with SEND in schools and in the local community. This includes trained and experienced staff who can facilitate and conduct Education Health and Care planning meetings as well as develop the plans themselves. Schools themselves have seen direct cuts to funding, and according to the Education Policy Institute (2018) the new National Funding Formula does not meet the pressures on schools budgets, with around a third of local authority secondary schools currently in deficit (Education Policy Institute 2018).

‘High Needs’ funding, which is Government funding allocated to Local Authorities for children with the most complex Special Educational Needs and Disability, has been described as insufficient particularly now that plans are continuing to the age of 25 years (Association of School and College Leaders 2018). Indeed, Freedom of Information requests have shown that combined high needs education budgets in England increased from £61m in 2015-16 to £195m in 2017-18 indicating that Local Authorities have had to use funding from other areas such as mainstream and early years education to cover the shortfall ([Jayanetti & Savage 2018](#)).

Austerity measures have also been blamed for the large numbers of children with Education Health and Care Plans who are currently not in educational provision (National Education Union 2017) and waiting lists for Child and Adolescent Mental Health services show these services unable to meet growing demands, (Children’s Commissioner 2017). Over all it is difficult to see how young people with SEND could hope to be aspirational or improve their life outcomes when the very services and resources that could support them to do this are being drastically reduced or removed.

### **Austerity and Neo-liberalism**

Austerity is cleverly linked to the ideals of neo-liberalism where families are encouraged to be self sufficient with minimal input from the state (Goodley 2011). Neo-liberalism champions the rationality of the market and celebrates the ‘ideal citizen’ who is an ‘economic maximiser’ (Lynch 2006 p 3 ). This citizen has what Campbell describes as ‘a particular kind



of self and body' that is 'perfect and species typical' (Campbell 2001 p 44). Although unattainable to all, this ableist ideal serves to support the binary discourse of 'us' and 'them' which others have argued is intrinsic to neo-liberalism (Ramilow 2006; Runswick-Cole 2014): those who are unable to work are depicted as 'them', in contrast to 'us' the hardworking, non-disabled population who contribute to the economy. Goodley explains that neo-liberalism provides an 'ecosystem for the nourishment of ableism', which he terms 'neo-liberal-ableism' (Goodley et al 2014 p981). Austerity plays an important role in neo-liberal-ableism, celebrating concepts of individualism, decrying dependency on the state, and helping to normalize low wages, budget cuts and precarity (Bates et al 2017).

Although DMD is a rare impairment, numbers of children with complex and life limiting impairments are rising. An analysis published in 2012 reported that the true prevalence of children living with a life limiting condition has increased annually in all areas over the past decade and is now 32:10,000, which is double the previously reported estimates . (Fraser et al 2012). It is therefore hoped that findings and discussion from this small-scale study will highlight some of the key the issues relating to changes in SEND support for many children with life limiting and complex impairments who are looking to local services in a time of Austerity to support their aspirations and improved outcomes.

### **Method and Methodology;**

After gaining ethical approval from the University of East London, information letters were sent to the national charity Action Duchenne who advertised the project through their newsletters and social media. Six families self-referred to take part in the project and 5 schools gave their consent. One school declined to be interviewed. Pupils varied in age from 6 years to 17 years. Schools varied from a state maintained primary (School 1), to Catholic primaries (School 4 and 5), a specialist secondary school for ages 11- 19 years (School 2), and a recent secondary school member of a Multi-Academy Trust (School 5). Table 1 includes demographic information about all participants.

Table 1 Participants: Parents, Children and young people, and teaching staff

The research questions for all participants were exploratory: How, if at all, was the new SEND process supporting the young person and his family to get the lives they wanted? In order to ascertain their views about the SEND Reforms, all participants took part in semi-

structured interviews. Those involving children and young people used age appropriate language. All interviews were recorded. All teacher interviews took place in school in a quiet space; all interviews with children and young people took place at school apart from participant 6 who was interviewed at home during a free lesson from his timetable; parent interviews took place at home or at a quiet space chosen by the parent, for example a coffee shop.

Talking to parents and young people themselves was a key aspect of this project. Too often in these times of neo-liberal-ableism, the family of a disabled child is viewed through a lens of tragedy, and regarded as an object of pity. Disabled children themselves are often seen as passive, the object of conversations, rather as 'social agents and co-constructors of their social worlds' (Brady et al p174). Following principles of disabled children's childhood studies, and the sociology of childhood, in this study steps have been taken to place the voice and experiences of the disabled child or young person and his family at the centre (Curran and Runswick-Cole 2013; James and Prout 1997).

Furthermore, as DMD is a life-limiting and life-threatening impairment that can bring with it many challenges, the researcher was keen to discourage participants from focussing solely on difficult aspects of their medical prognosis. The risk of making parents 're-live' difficult times has been highlighted in DMD and other life-limiting impairments (Eakes et al 1993; Poysky et al 2009; Stevens 2010). Similarly, Oliver has criticised the ways in which some interviews can cause disabled people to feel demoralised and disempowered and serve to reinforce the idea that their difficulties are caused by their own 'personal inadequacies or functional limitations' (Oliver 1990 p8). Therefore it was important to ensure that participants did not feel like objects of research but rather as the experts of their own lives. In order to achieve this, questions used a solution-focused approach using concepts from Solution Focused therapy (De Shazer & Dolan 2007), so for example, young people, parents and schools were asked to think about their best hopes of the new SEND legislation and how they were currently using it to achieve the lives they/ the young person wanted. What did it look like when it was working? This in no way meant that challenges and barriers were not discussed, but it did enable participants to view these barriers from a position of control rather than feel overwhelmed by them. In addition, as the researcher was the parent of an adult with DMD, it was easier to establish rapport and trust with participants who did not view her as an 'outsider' with no understanding of the challenges they faced (Stevens et al

2010). A small group of adults with DMD offered support through a steering committee to ensure that questions were appropriate and to advise on any omissions (French and Swain 2003).

The data was interrogated for themes and followed Braun and Clarke's six step approach to identify and analyse them: from becoming familiar with the data, generating initial codes, finding themes, reviewing them before naming them and writing the report (Braun and Clarke 2006). The researcher was self-reflexive, returning to the data regularly once the initial themes had been identified. This was particularly important in this case as the researcher was a parent of an adult with DMD and was keen to ensure she was aware of any preconceived views. Four themes were identified: embracing the new person-centred philosophy and the focus on outcomes; the survival of the 'warrior parent'; lack of knowledge about DMD amongst professionals and finally the impact of the programme of cuts or Austerity.

## **Findings:**

### **Theme 1: Young people and parents embrace the new person-centred philosophy and the focus on outcomes**

The first theme supports the positive findings about the Education Health and Care system from early users of the new system and the Pathfinder (pilot) evaluations (Department for Education 2014; 2015; 2016). All parents and young people reported that they preferred the new person-centred approach associated with the SEND reforms from the old SEND system. Three of the other mothers (3,4 and 6) had taken part in transition projects or pilots about the new legislation and were positive about its philosophy. In particular, all participants reported that the new legislation had offered the opportunity to hear the voice of the young person and to enable them to think about their aspirations. Most children/young people reported that they felt listened to about their plans for the future. C/YP 6 said of the new process:

'I think it's useful to be able to plan what you want to do in the future'

and others compared this favourably to the previous SEND system in which they often were not invited to either attend their annual Special Educational Needs review meetings or to speak. Parents and teachers appreciated the focus on the young person's views and hopes, and felt that the process was more up to date than focusing on early diagnostic information.

'...he's grown and he's thought yeah I have got a voice and I can speak up for myself' .  
They (school in the EHC meetings) always ask about his aspirations now.' (M2)

All parents were positive about direct payments and personal budgets, and either were using direct payments already or liked the idea of being able to buy in the support when they needed it.

Furthermore, the emphasis on improved outcomes for the future, in particular with regard to issues such as employment for young people with SEN, was seen as an important change. Teacher 2 talked about the change of focus in his special school due to the legislation for post 16 opportunities, and the introduction of new initiatives such as supported internships:

'I would say the Green Paper inspired our head teacher ....we always had this cliff edge when they finished 6th form a lot of students were either going on to college and it was just not working then they were dropping out and then going on to benefits and their life expectancy and their aspirations were just shot'. (T2)

This was confirmed by parents who all talked about their sons' plans for working in the future. It was assumed by parents and young people that getting a job would be part of their future and none of them suggested that not working would be a better option. One said the new focus on employment and work experience was helpful, saying:

'they've (their young people with DMD) got to learn that you've got to help yourselves, we're not there all of the time...that's what we're trying to tell them, I hope they've listened'.  
(P2)

On the other hand, feedback from teachers about the aspirational and person-centred aspect of the legislation was more mixed. Two of the teachers who were Special Educational Needs

and Disability Coordinators (SENDCOs) and held senior management positions were very supportive of the changes with one explaining that she had only just completed her SENDCO training and had never experienced any difference. Two of the schools felt the ideas were good but were still reticent to believe that without any extra funding major changes would happen. One school stated that it 'could not see any difference' from the old system (T4). One teacher felt that the student in her school who had severe dyslexia as well as DMD had too many barriers to learning for her to feel aspirational for his future. When he suggested he would like to be a car designer in the future she felt that this would not be possible because of the multiple barriers in his way : 'If it was just dyslexia then it would be different'.

A key finding worth noting was the disparity between this first theme which was predominantly positive – young people and families really valuing being listened and being central to the planning process - and the other themes, which at times appeared to contradict this finding. In other words, there appeared to be a marked difference between the philosophy of the new legislation and its implementation.

## **Theme 2: The continuation of the 'warrior parent'**

In his 2009 report on Parental Confidence in Special Educational Needs, Brian Lamb referred to the emergence of 'warrior parents' who were placed in a situation of conflict with their child's school over required support and intervention (Lamb 2009 p 2). The new emphasis in the legislation of placing the parents and child 'at the heart of the process' (DoE and DoH 2015 s 9), was intended to end these battles. However, it would appear from these interviews that the struggles between families, schools and local authorities are ongoing.

For example, Teacher 5 who when asked about how the SEND Reforms were supporting a young man with DMD, he replied:

'the drive of the mother has overridden any process if you like, so any success that the young person's had, you know, achieving things or gaining things, has not been through going through the process.... the success is wholly driven by the mother's tenacity to make it happen.'

Teacher 5 was very clear that the process 'per se' was not what had enabled the young person to do well at school and to access the support that he needed. He cited other young people with SEND at his school who had not been able to do this, and was adamant that the input of his mother was the defining feature of the young person's success.

Parents reported battles with school, and those who had older boys felt that they had to fight for social care even though their boys were not ambulant and therefore should qualify for social care support to help with personal care (for example getting up and going to bed) and for short breaks funding (for example funding to enable a young person to go out independently with an assistant). Parents also talked about a lack of support from local health authorities who were difficult to get hold of, attend meetings or contribute to the Education Health and Care process without prompting.

Half of the parents were well informed about the SEND reforms having benefited from a range of training and support. One mother had been part of the Pathfinders pilot (Pilot project for SEND Reforms from 2011 – 2014) and another had been part of a charity-led Transition to Adulthood project that had given training to parents about the new legislation (Takin' Charge Action Duchenne). Another parent was involved with her local Parent Forum group (parent led organisation existing within local authorities) and had attended many of the free training that had been offered by Local Authorities about the new SEND legislation. Although she reported often disagreeing with her son's school over issues regarding his support she repeated several times 'it's working with, not working against school' and was keen to focus on supporting her child's ambitions rather than being involved in conflict. However, in practice, school reported that her 'working with' them was often confrontational, and sometimes felt that her expectations were not realistic, in terms of what her child could accomplish with the resources available.

### **Theme 3: Lack of professional knowledge and understanding of both DMD and the new SEND system**

Linked to the theme of the 'warrior parent', is the lack of awareness and training that professionals have with regard to both DMD and the new SEND system.

Parent 1 talked about her relationship with school, saying:

‘..they’re asking the parents for advice. And we’re looking to them for advice..’

Specific learning difficulties such as dyslexia are a common co-occurrence in DMD yet parents reported having to fight for assessment and diagnosis even though their sons presented with literacy difficulties. One mother, whose son was in the late Juniors and was still unable to read fluently, talked about her struggles to understand why:

‘He doesn’t fit any categories and that’s really hard but, I wonder, you see, I always wonder now he’s hit 9 (years) whether he is dyslexic on top of everything else but I don’t know how you go about testing that or whether it’s just the learning.’

Presumably school would have been aware of the high risk of co-occurrence of such impairments, yet the parent was ‘wondering’ and her emphasis of the phrase ‘on top of everything else’ indicating that she felt she was making too much of a fuss looking for extra labels for her son.

As well as lack of knowledge of DMD, parents also reported that schools were not aware of changes that the new legislation had introduced. For example, one parent described a SEND Review meeting she had attended at school where there had been a discussion about her young person applying to university the following year:

‘So basically when we had the review of the plan last year nobody in that room except for me knew that plan didn’t carry on to university. So they’re all sitting there going ‘Really?’ And I said : No!’.

Similarly, the lack of knowledge from those working in social services was mentioned by both mothers 3 and 6, whose sons were both non-ambulant and who depended on Direct payments from Social Care to fund domicillary care and short breaks. According to the Children and Families Act (2014), the new Education Health and Care plans bring services together to jointly support the outcomes that each young person and their family have

identified. Parent 3 described a home visit from a social worker who met her son who had been non-ambulant for seven years:

‘The woman that came (from social services) she was like, reading off an ipad and she kept asking B the same question but in a different scenario of how far he can walk, and can you get out of your chair? Then B lost his rag.’

Again, due to the rarity of DMD, professionals are often unaware of its implications on physical health. Most young people will attend a tertiary centre, for example Great Ormond Street Hospital, if they are living in North London, where they have bi-annual meetings with a Neuromuscular consultant and physiotherapist; in addition they receive local health input from their local Community Care Giver (CCG), which can involve appointments with a community paediatrician, physiotherapist, occupational therapist and sometimes local Children and adolescent mental health service. Lack of knowledge of local professionals about a rare condition as well as poor lines of communication has been highlighted as problematic (Abbott and Selby in Hoskin ed. 2017).

Such lack of understanding is illustrated in the case of C/YP 2 whose mother reported on intervention from the local physiotherapist who advised school on her son’s toileting needs. Instead of using a bottle to pass urine, as is standard advice for young people with DMD once they are no longer able to stand independently (Abbot & Selby in Hoskin ed 2017), staff were advised that due to health and safety concerns the child was to be hoisted onto the toilet at certain intervals throughout the day, even when he hadn’t expressed the need to use it:

‘And then he used to kick off because he was being hoisted to the toilet when he didn’t want to go....because one of the TAs refused to use that bottle...and the busybody physio got involved and said that health and safety was to be used when he goes to the toilet because they thought he was going to fall out of his chair when he leans forward’ (P2)

However, it was not only the parents who reported frustration with this lack of understanding. Professionals also reported that they were often left to get on with it with no specialist support. Teacher 1 reported that as a SENCO in a mainstream school she often felt isolated and lacked the opportunity to meet other teachers of children with rare conditions. In addition, very little training was available for impairments that were rare.



#### **Theme 4: The role of Austerity**

Austerity interlinks and underlies earlier themes. Austerity has introduced and justified cuts to many local services including social care and education services, and anxiety regarding funding emanated from all conversations with parents and teachers and with older boys.

Parent 6 explained that her son's secondary school included many young people with Education Health and Care Plans in comparison with other schools in the area. It had become a Multi-Academy Trust and had cut the role of SENCO in order to save money:

'They were looking at resources within the school and they decided that they could deliver SEN provision differently and differently meant getting rid of that person and basically using a SENCO who is in a different school 10 miles down the road who has limited experience of SEN' (P6)

This was confirmed by Teacher 5 who said:

'when there's a school like us with 14 or 15 EHCPs there's an enormous job to keep them all moving forward....I'm an Inclusion manager, we're now part of an Academy Trust so we don't have a SENCO in school any more, we have a SENCO across two schools,'

The ongoing restructuring and cutbacks to Local Authorities has had a key impact on the SEND process in schools, not only in the structure of schools but also in making experienced professionals' roles redundant who in the past may have provided support and training to teachers.

This is illustrated by Teacher 2 who said of his Local Authority:

'The problem is when the cuts came in and they made the decision for redundancies or to move people to different departments it's not just the people it's the skill set that was lost. So even when people are brought back on board it's the training - it's getting people up to the required level.'

In England, Personal Health budgets have been offered to young people and adults living with complex health needs alongside social care support through National Health Service Continuing Care funding. The threshold for this funding is high, and offered according to severity of health need. None of the participants in this study were told they qualified for this funding except C/YP 6. However, just before the interview with the researcher, C/YP 6's personal health budget was stopped due to financial constraints on the Local authority. As Parent 6 explained, this 'top-up' to funding and resources could mean avoiding a much more expensive future health crisis that could result in a young person being hospitalized.

'For goodness sake....How ill do you have to be?' she demanded.

The cuts have led families in this project to view the future as precarious. As Parent 3 said:

'we've got to think that much quicker now, like they might not need it til next year but then I'm thinking , well we'd better start the process'

This also affected young people's choices about where they went to university as the chance of support breaking down was viewed as a likely risk. C/YP 6 had achieved extremely high results in his GCSEs, and for most young people this would mean the choice of any university in the UK. However, his plans for the future were being made with regard to the possibility that funding or support may not be available when needed:

'I think I'd prefer that (not to go to university too far from home) then if I get any problems then I'm close enough to home for someone to help'.

## **Discussion**

The findings from this small scale study have shown a mixed response to the SEND Reforms from those affected by life limiting impairments and their families and schools. The

importance of focusing on improved outcomes and the voice of young people with a life limiting impairments cannot be underestimated. With reports of such poor outcomes and social isolation of adults with DMD in the past, the chance to be in a work place and have a social life is a step forward (Abbot, Carpenter and Bushby 2012). No young person or parent suggested that they couldn't have serious plans for the future because of their debilitating condition; in fact having a job and thinking about living arrangements seemed to be very important to them and something to be celebrated. Parents agreed, but also shared their ongoing experiences of battling for adequate support in order to achieve this. Therefore although others have warned against the pressures of normalizing the lives of young people with DMD and unfairly placing expectations on them for employment and residential independence, the young people and their families in this study themselves viewed these as indicators of positive aspiration and success (Gibson et al 2013;, Hamdani et al 2014). Furthermore, parents and boys tended to view them as rights they needed to fight for so that boys with DMD had the same opportunities as their peers.

In their analysis of the lives of people with learning difficulties during the time of the Coalition Government in England between 2010 - 2015, Goodley and Runswick-Cole utilize Berlant's theory of 'Cruel Optimism' (Runswick-Cole & Goodley 2015). This theory suggests that despite deteriorating social and economic conditions, people remain attached to 'clusters of promises' even when these are in fact injurious to them (Berlant 2007). Between 2010- 2015, David Cameron's 'Big Society' ideology promised citizenship and employment to people with learning difficulties which often remained 'tantalizingly out of reach' thus raising people's hopes for a fairer society which in fact could not be realized (Runswick-Cole and Goodley 2015 p 178). In some respects, Berlant's ideas could equally be applied to the SEND Reforms in England: espousing high aspirations and a focus on post-19 employment and independent living at a time when a brutal programme of Austerity has meant support and resources to reach these goals are minimal.

Indeed, it is not possible to explore the impact of the new educational and social care legislation since 2014 without regard to the role of Austerity. Face to face services, layers of trained professionals as well access to individual budgets and training have been removed over the past 8 years all of which have affected the lives of people with SEND, and those with complex impairments like DMD particularly (Wood 2015).

Personal budgets and direct payments, although on the one hand supporting the idea of choice and control, have enabled some services to disappear and costs to be cut.

Media narratives of austerity and ‘the need to tighten our belts’ have helped to enable these cuts: reports of disabled people as ‘skivers’, as opposed to hard working ‘strivers’ have been prevalent, and research has shown the rise of disabled hate crime (Bates 2017; Burch 2018); focus has been taken from the tax avoidance and fraud, even though the latter has been a substantially larger problem than, for example, benefit fraud (Duffy 2012) in an environment of ‘compulsory able-bodiedness’ (McRuer 2002 p93). In this project, precarity has tended to trump aspiration in family and people’s decision-making, indicating a clear lack of confidence that resources would remain in place.

Those families and schools who had the opportunity to learn about the legislation and use it to fight for their young people have, to some extent, ‘troubled’ the challenges caused by austerity measures. Through using the new focus on improved outcomes, they have, in some measure, been able to achieve support for university, opportunities for internships and work experience, as well as highlight the need for appropriate health and social care support in their plans. By drawing on the ‘aspirational’ spirit and language of the reforms, families and schools have succeeded in using the law itself, as other campaigners have done in other fields, to achieve what E P Thompson refers to as ‘an unqualified human good’ (Thompson 1975 p 267), indicating perhaps that it is not the legislation itself that is the problem but the context and time in which it has been introduced. The promotion and achievement of raised aspirations for disabled young people in times of Neo-liberal-ableism could be seen as both contradictory and novel, particularly in times when austerity has normalized low wages, precarity and a lack of aspiration.

This suggests the importance of advocacy training and signposting for families and those working in education, health and care services in how to navigate the SEND system and in particular how to support young people with life limiting impairments to do so. It also indicates that young people with life limiting impairments have aspirations that are not unlike their non-disabled peers as others have noted (Sayce 2011). Furthermore, it confirms the need for opportunities to share success stories: where young people with complex impairments and their families have negotiated care packages, organized support for university, achieved successful collaborative working with school and college. In the absence of experienced

Local Authority professionals, this could be implemented by user-led groups such as parent forums and schools who are seeking to share best practice, or through less formal local networks. Against what may seem like enormous bureaucratic barriers, being able to share what works can be powerful and effective for both families and professionals, particularly in the context of DMD where expectations and aspirations have continued to be very low due to its serious prognosis. The person-centred planning process, although deemed overwhelmingly positive by families in this study, is only as good as the resources available, and there is a risk of it becoming meaningless if lack of funding denies the young person the ability to reach the outcomes co-produced on their plan. Therefore understanding how the law can support children with SEND is key and parents should be made aware of national advocacy and legal organisations.

This is a very small scale study of families who self-referred and it is therefore difficult to generalize about the DMD population as a whole. However, uniquely, it does throw light on how the SEND reforms are currently being implemented across England, and on the barriers that can still exist to prevent young people with life limiting impairments getting the life they want, at a time when their life expectancy has increased. It is a significant piece of research as it shares the voices and concerns of young people with life limiting impairments and their families and schools, who are a growing group within SEND (Fraser et al 2010). In the current context of improved life expectancy, it is crucial that not only are young people, families and professionals supported to have higher aspirations for young people with DMD, but that these aspirations can be realized with the appropriate resources and funding.

### **References:**

Abbott, D., Carpenter, J. Bushby, K. (2012) Transition to adulthood for young men with Duchenne muscular dystrophy: research from the UK. *Neuromuscular Disorders* ;22:445–6.

Abbot, L., and Selby, V. (2017) The physical management of DMD in school, college and beyond in ed. Hoskin, J., (2017) *A Guide to Duchenne Muscular Dystrophy Information and Advice for Teachers and Parents* Jessica Kingsley publishers

Association of School and College Leaders Position Statement on Funding October 2018  
available here: <https://www.ascl.org.uk/policy/position-statements/funding.html> accessed on  
February 6 2019 (accessed 10 December 2018)

Bates, K., Goodley, D., & Runswick-Cole, K. (2017) Precarious lives and resistant possibilities: the labour of people with learning disabilities in times of austerity, *Disability & Society*, 32:2, 160-175

Beresford, B. (1994) Caring for a Severely Disabled Child Social Care Research 54 White Rose Research available at : <http://eprints.whiterose.ac.uk/75150/> (accessed 12 June 2018)

Berlant, L. (2012) On her Book Cruel Optimism Cover Interview June 5 2012 Rorotoko  
Available at: [http://rorotoko.com/interview/20120605\\_berlant\\_lauren\\_on\\_cruel\\_optimism](http://rorotoko.com/interview/20120605_berlant_lauren_on_cruel_optimism)

Birnkrant, D.J., Bushby, K., Bann, C.M., Apkon, S.D., Blackwell, A, Colvin, M., Cripe, L., Herron, A.R., Kennedy, A., Kinnett, K., Naprawa, J., Noritz, G., Poysky, J., Street, N, Trout, C.J., Weber, D.R., Ward, L.M., (2018) Diagnosis and management of Duchenne muscular dystrophy, part 3: primary care, emergency management, psychosocial care, and transitions of care across the lifespan *Lancet Neurol.* 2018 Mar; 17(3): 251–267.

Burch, L. (2016) Tackling disability discrimination and disability hate crime: a multidisciplinary guide, *Disability & Society*, 31:10, 1408-1409

Burchardt, T. (2005) *The Education and Employment of Disabled Young People An analysis of the extent to which disabled young people achieve their aspirations for work and education.* Joseph Rowntree Trust

Brown, M. (2017) Disabled people are to be ‘warehoused’. We should be livid. *The Guardian* (online) Available at  
<https://www.theguardian.com/commentisfree/2017/jan/25/disabled-people-disabilities-health-care-homes> [Accessed 6 Jun. 2018].

Bushby, K., Finkel, R., Birnkrant, D.J., Case, L.E., Clemens P.R., Cripe, L., Kaul, A., Kinnett, K., McDonald, C., Pandya, S., Poysky, J., Shapiro, F., Tomezsko, J., Constantin,

C. DMD Care Considerations Working Group. Diagnosis and management of Duchenne Muscular dystrophy, Part 1: Diagnosis, and Pharmacological and Psychosocial Management *Lancet Neurology* 2010; 9(1)

Brady, G., Lowe, P., Lauritzen, S., (2015) Connecting a sociology of childhood perspective with the study of child health, illness and wellbeing *Sociology of Health & Illness* Vol. 37 No. 2 2015 ISSN 0141-9889, pp. 173–183

Braun, V. and Clarke, V. (2006) Using thematic analysis in psychology. *Qualitative Research in Psychology*, 3 (2). pp. 77-101

Burch, L.F. (2017): Governmentality of adulthood: a critical discourse analysis of the 2014 Special Educational Needs and Disability Code of Practice, *Disability & Society*

Burch, L.F. (2018) ‘You are a parasite on the productive classes’: online disablist hate speech in austere times, *Disability & Society*, 33:3, 392-415,

Campbell, F.Kumari (2001) Inciting legal fictions: Disability’s date with ontology and the ableist body of the law. *Griffith Law Review* 10 42-62

Carter, A. (2015) *Carter Review of Initial Teacher Training* Reference: DFE-00036-2015 available at: <https://www.gov.uk/government/publications/carter-review-of-initial-teacher-training>

Children’s Commissioner for England (2017) *Report into Children’s Mental Healthcare in England*

Connors, C., and Stalker, K., (2007) Children’s experiences of disability: pointers to a social model of childhood disability *Disability & Society* Vol. 22, Iss. 1, 2007

Convention of the Rights of Persons with Disabilities (2016) *Inquiry concerning the United Kingdom of Great Britain and Northern Ireland carried out by the Committee under article 6 of the Optional Protocol to the Convention. Report of the Committee\** CRPD/C/15/R.2/Rev.1

Curran, T. and Runswick-Cole (Eds.) (2013) *Disabled Children's Childhood Studies – Critical Approaches in a Global Context* Palgrave Macmillan

Department for Education and Department of Health (2015) *Special educational needs and disability code of practice: 0 to 25 years*. Available at: <https://www.gov.uk/government/publications/send-code-of-practice-0-to-25> (Accessed: 13 June 2018).

Department for Education (2014) *Special Educational Needs and Disability Pathfinder Programme Evaluation Thematic Report: The Education, Health and Care (EHC) Planning Pathway for families that are new to the SEN system* Research report January SQW  
Reference: DFE RR326B

Department of Education (November 2014) The Key Conference *Improving the progress of pupils with Special Educational Needs*

Department of Education (2015) *The Special Educational Needs and Disability Pathfinder Programme Evaluation Final Impact Research Report* July 2015 DFE-RR471

Department for Education (2016) *Mapping User Experiences of the Education Health and Care Plan Process: a qualitative study* ASK Research: DFE RR523

Department for Education (2017) *Supported Internships*

Department for Education and Ministry of Justice (2017) Review of arrangements for disagreement resolution (SEND Research Report, London: Crown Copyright DFE-00104-2017

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De Shazer, S. and Dolan, Y., (2007) *More than miracles: The state of the art of solution-focused brief therapy*. Haworth Press

Dreyer, P., Steffensen, B. & Pedersen, B. (2010) Living with severe physical impairment, Duchenne's muscular dystrophy and home mechanical ventilation, *International Journal of Qualitative Studies on Health and Well-being*, 5:3

Duffy, S., (2013) Briefing on How Cuts Are Targeted Centre for Welfare Reform downloaded at: <http://www.centreforwelfarereform.org/library/by-az/briefing-on-how-cuts-are-targeted.html> (accessed 10 June 2018)

Eagle, M., Bourke, J., Bullock, R., Gibson, M., Mehta, J., Giddings, D., Straub, V., Bushby, K. (2007) Managing Duchenne muscular dystrophy—the additive effect of spinal surgery and home nocturnal ventilation in improving survival. *Neuromuscular Disorders* ; 17: 470–75

Employment Policy Unit (2018) School Funding Pressures in England available at: [https://epi.org.uk/wp-content/uploads/2018/03/Schools-funding-pressure\\_EPI.pdf](https://epi.org.uk/wp-content/uploads/2018/03/Schools-funding-pressure_EPI.pdf) (accessed January 2019)

European Commission (2012), ‘Special Needs Children and Disabled Adults Still Getting a Raw Deal from Education, says report’, Commission Press Release (July). As of 30 March 2013:  
<http://europa.eu/rapid/pressReleasesAction.do?reference=IP/12/761&format=HTML&aged=0&language=EN&guiLanguage=en> (accessed 10 June 2018)

European Commission (2013) Employment, Social Affairs and Inclusion Support for Children with Special Educational Needs. Available at:  
<http://ec.europa.eu/social/main.jsp?advSearchKey=Special+Educational+Needs+2013&mode=advancedSubmit&catId=22&policyArea=0&policyAreaSub=0&country=0&year=0> (accessed 10 June 2018)

European Commission (2012) Special Needs Children and Disabled Adults Still Getting a Raw Deal from Education says report’ Commission Press Release (July)

European Commission (2010) *The European Disability Strategy 2010-20* Brussels

Ferguson, I. (2007); Increasing User Choice or Privatizing Risk? The Antinomies of Personalization, *The British Journal of Social Work*, Volume 37, Issue 3, 1 Pages 387–403,

Gibson, B.E., Young, N.L., Upshur, R.E., McKeever, P., (2007) Men on the margin: a Bourdieusian examination of living into adulthood with muscular dystrophy (2007) *Social Science and Medicine* Aug: 65 (3) : 505-17

Gibson, B.E., Mistry, B., Smith, B., Yoshida, K.K., Abbott, D., Lindsay, S., Hamdani, Y., (2013) Becoming men: gender, disability, and transitioning to adulthood. *Health* 2014;18:93 ;112.

GLAZZARD, J. (2011), Perceptions of the barriers to effective inclusion in one primary school: voices of teachers and teaching assistants. *Support for Learning*, 26: 56-63

Goodley, G., Lawthom, R. & Runswick-Cole, K (2014) Dis/ability and austerity: beyond work and slow death, *Disability & Society*, 29:6, 980-984

Hale, R. (2013) The Big Society Fails the Hardest Hit The Centre for Welfare Reform downloaded at: <http://www.centreforwelfarereform.org/library/by-az/the-big-society-fails-the-hardest-hit.html> (accessed 10 June 2018)

Hamdani, Y., Mistry, B., Gibson, B.E., (2015) Transitioning to adulthood with a progressive condition: best practice assumptions and individual experiences of young men with Duchenne muscular dystrophy *Disability and Rehabilitation* Vol. 37, Iss. 13,

Hastie, J. and Chapman, M. (2017) Getting a Life as an Adult with DMD in ed. Hoskin, J., (2017) *A Guide to Duchenne Muscular Dystrophy Information and Advice for Teachers and Parents* Jessica Kingsley publishers

Hendriksen J.G., Vles JS. (2008) Neuropsychiatric disorders in males with duchenne muscular dystrophy: frequency rate of attention-deficit hyperactivity disorder

(ADHD), autism spectrum disorder, and obsessive-compulsive disorder. *Journal of Child Neurology* 2008; 23: 477–81

Hinton, V.J., Cyrulnik, S.E., Fee, R.J., Batchelder, A., Kiefel, J.M., Goldstein, E.M., Kaufmann, P. and Darryl, C., 2009. Association of autistic spectrum disorders with dystrophinopathies. *Pediatric neurology*, 41(5), pp.339-346.

Horne, P., & Timmons, V. (2009) Making it work: teachers' perspectives on inclusion, *International Journal of Inclusive Education*, 13:3, 273-286

James, A., Prout, A., (1997) *Constructing and Reconstructing Childhood: Contemporary Issues in the Sociological Study of Childhood* Psychology Press

Jayanetti, C and Savage, M. (2018) Devastating Cuts Hit Special Educational Needs *The Guardian* (November 10 2018)

Jeppesen J., Green, A., Steffensen, B.F., Rahbek (2003) J. The Duchenne muscular dystrophy population in Denmark, 1977–2001: prevalence, incidence and survival in relation to the introduction of ventilator use *Neuromuscular Disorders* 13; 804-812

Knight, K. (2013) The Changing Face of the 'Good Mother': trends in research into families with a child with intellectual disability, and some concerns *Disability and Society* Vol 28, Iss. 5 2013

Karanikolos, M., Mladovsky, P., Cylus, J., Thomson, S., Basu, S., Stuckler, D., Mackenbach, J.P., Mckee, M. (2013) Financial crisis, austerity, and health in Europe *The Lancet*, Volume 381, Issue 9874, Pages 1323-1331

Lamb, B. (2009) *Lamb Inquiry: Special Educational Needs and Parental Confidence* Annesley: DCSF Publications.

Legislation.gov.uk. (2014). Children and Families Act 2014. [online] Available at: <http://www.legislation.gov.uk/ukpga/2014/6/contents/enacted> [Accessed 11 Jan. 2015].

Loopstra, R., Reeves, A., Barr, B., Taylor-Robinson, D., McKee, M., Stuckler, D. (2016) The impact of economic downturns and budget cuts on homelessness claim rates across 323 local authorities in England, 2004–12, *Journal of Public Health*, Volume 38, Issue 3, Pages 417–425,

Lynch, K., (2006) Neo-liberalism and Marketisation: the implications for higher education *European Educational Research Journal*, Volume 5, Number 1,

McRuer, R. (2013) Compulsory Able-bodiedness and Queer/Disabled Existence in Davis, L.J. ed. *The Disability Studies Reader* Routledge

Nereo, N., Fee, R. & Hinton, V. (2003) Parental stress in mothers of boys with Duchenne muscular dystrophy. *Journal of Pediatric Psychology*, 28, 473–484

Ofsted (2010). The special educational needs and disability review A statement is not enough. London: Ofsted.

Oliver, M., (1992) Changing the Social Relations of Research Production (1992) *Disability, Handicap and Society* Vol 7 No 2 (1992)

Oliver M., (1990) *The Politics of Disablement* (Basingstoke, Macmillan)

Poysky, J., and Kinnett, K. (2009) Workshop Report Facilitating family adjustment to a diagnosis of Duchenne muscular dystrophy: April 24–25, 2008, Miami, Florida *Neuromuscular Disorders* 19 (2009) 733–738

Rahbek, J., Werge, B., Madsen, A., Fynbo, C. Steffensen B. and Jeppesen J. (2005) Adult life with Duchenne muscular dystrophy: Observations among an emerging and unforeseen patient population *Paediatric Rehabilitation* 2005; 8, 1: 17-28

Ramilow, T.R. (2006) Bodies in the Borderlands: Gloria Anzaldúa's and David Wojnarowicz's Mobility Machines, *Race, Ethnicity, Disability, and Literature*, 31(3) 169-187

Ricotti, V., Mandy, W., Scoto, M., Pane, M., Deconinck, N., Messina, S., Mercuri, E., Skuse, D., Muntoni, F (2016) Neurodevelopmental, emotional, and behavioural problems in Duchenne muscular dystrophy in relation to underlying dystrophin gene mutations *Developmental Medicine and Child Neurology* Vol 58 issue 1, p77-84

Runswick-Cole, K. & Goodley, D. (2015) Disability, Austerity and Cruel Optimism in Big Society: Resistance and “The Disability Commons” *Canadian Journal of Disability Studies* vol 58, issue 1; p 77-84

Runswick-Cole, K. (2014). “Us” and “them”? The limits and possibilities of a politics of neurodiversity in neoliberal times. *Disability & Society*.

Savage, M., Devine, F., Cunningham, N., Taylor, M. Li, Y., Hjellbrekke, J., Le Roux, B., Friedman, S., Miles, A. (2013) A New Model of Social Class? Findings from the BBC’s Great British Class Survery Experiment (2013) *Sociology* Volume: 47 issue: 2, page(s): 219-250

Sayce, E. (2011) Getting in, staying in and getting on Disability employment support fit for the future A Review to Government Department for Work and Pensions

Schrans DG, Abbott D, Peay HL, et al (2013) Transition in Duchenne muscular dystrophy: an expert meeting report and description of transition needs in an emergent patient population: (Parent Project Muscular Dystrophy Transition Expert Meeting 17–18 June 2011, Amsterdam, the Netherlands). *Neuromuscular Disorders* 2013;23:283–6. 14.

Sims, D., & Whisker, J. (2015) Personalisation and disabled people: The rhetoric and the reality. A discussion paper regarding aspects of the transformation agenda. *Social Work and Social Sciences Review* Vol 17, No. 3

Stevens, M.M., Lord, B. A., Proctor, M. Nagy, S. & O’Riordan, E. (2010) Research with vulnerable families caring for children with life-limiting conditions, *Qualitative Health Research* 20 (4) 496-505

Stuckler, D., Reeves, A., Loopstra, R., Karanikolos, M., McKee, M., (2017) Austerity and health: the impact in the UK and Europe, *European Journal of Public Health*, Volume 27, Issue suppl\_4, Pages 18–21

The National Archive. (2011). Support and aspiration: A new approach to special educational needs and disability. [online] Available at: <http://webarchive.nationalarchives.gov.uk/20130401151715/https://www.education.gov.uk/publications/eorderingdownload/green-paper-sen.pdf> [Accessed 6 Apr. 2017].

Thompson, E.P. (1975) *Whigs and Hunters : the origin of the Black Act* Pantheon London

Timpson, E. (2014) Edward Timpson discusses special educational needs reforms. Children’s minister addresses The Key at the Improving the progress of pupils with special educational needs conference available at <https://www.gov.uk/government/speeches/edward-timpson-discusses-special-educational-needs-reforms> (accessed June 2018)

Webb, C. L. (2005), Parents’ perspectives on coping with Duchenne muscular dystrophy. *Child: Care, Health and Development*, 31: 385–396.

Rob Webster, Peter Blatchford, Paul Bassett, Penelope Brown, Clare Martin & Anthony Russell (2010) Double standards and first principles: framing teaching assistant support for pupils with special educational needs, *European Journal of Special Needs Education*, 25:4, 319-336

Weiss, M.J. (2002) Hardiness and Social Support as Predictors of Stress in Mothers of Typical Children, Children with Autism, and Children with Mental Retardation *Autism* Vol 6 Issue 1 cited in European Commission (2013) Employment, Social Affairs and Inclusion Support for Children with Special Educational Needs. Available at:

<http://ec.europa.eu/social/main.jsp?advSearchKey=Special+Educational+Needs+2013&mode=advancedSubmit&catId=22&policyArea=0&policyAreaSub=0&country=0&year=0>

(accessed June 10 2018)

Wood, C., (2012) “For disabled people, the worst is yet to come....” Destination Unknown Summer 2012 Demos; available at:

[https://www.demos.co.uk/files/DestinationUnknownAutumn2011\\_-\\_web.pdf?1322826138](https://www.demos.co.uk/files/DestinationUnknownAutumn2011_-_web.pdf?1322826138)

(accessed May 10 2018)

Yamaguchi, M. & Suzuki, M. (2013) Independent living with Duchenne muscular dystrophy and home mechanical ventilation in areas of Japan with insufficient national welfare services, *International Journal of Qualitative Studies on Health and Well-being*, 8:1

Yamaguchi, M. and Suzuki, M. (2015) Becoming a Back up Carer: Parenting sons with DMD transitioning into adulthood. *Neuro-muscular Disorders* 85 – 93

Table 1: Participants

Participants Parent (P), Child/Young Person (C/YP), Teaching staff (T)	Age of Child/Young Person	Teacher and school status	Location
P1, C/YP	6 years	N/A	South East
P2, C/YP2, T1	10 years	SENDCO of maintained primary school	Welsh Borders

P3, C/YP3, T2	16 years	Deputy Head of SEND Specialist Academy	West Midlands
P4, C/YP4, T3	9 years	Deputy Head and SENDCO of Catholic primary school	North West
P5, C/YP5, T4	11 years	Teaching assistant in Catholic primary school	North West
P6, C/YP6, T5	17 years	Inclusion Manager in secondary school within Multi Academy Trust	East Midlands