

# Becoming an adult



Transition for young men with  
Duchenne muscular dystrophy

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Duchenne muscular dystrophy

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# Foreword

**Living with Duchenne muscular dystrophy is hard.** This may seem obvious when talking about such a serious, life-limiting condition, but many of the issues that are important to those affected are not medical. Often they are sociological – the consequences of society’s ill-informed attitudes towards disabled people. At other times the issues that most directly affect young men with Duchenne are related to the services and support provided by the state.

Certainly this is true in my case. As a 27 year old with Duchenne I rarely spend time thinking about my health or what will inevitably be my premature death. Instead my thoughts focus on my social isolation, my exclusion from the full adult relationships enjoyed by other people my age and my lack of access to employment. Uppermost in my mind is a general feeling that my life is not going anywhere and that my potential is being wasted. Just like any other young man my aspirations are to have a good job, friends, a partner and a family.

As this report shows, I am not alone in having these feelings. Given that the responses come from very different young men and families, it is perhaps surprising just how similar they are. All those questioned have experienced difficulties with services, often resulting in the same problems. What comes through most strongly is that in the period that shapes a person’s future – transition from childhood to adulthood – there is not enough information for those affected by Duchenne and what information there is does not get through to those who need it. Too often young men are being dismissed as difficult to help and unlikely to reach adulthood anyway, despite the great advances in treatment which have markedly extended our lives.

This has to change. Our society must begin to realise that even the most severely disabled people have something to offer and that with the right support they can be a full part of that society.

**Stuart Reid**  
project group member

**This report expresses the concerns and frustrations faced by parents and young people living with Duchenne on a daily basis.** It reflects on how legislation and government policies are directed at improving the transition process; however legislation alone cannot deal with the fundamental points that actually make a difference.

My son has Duchenne and will be celebrating his 18th birthday soon. The issues I have faced and my worries about the lack of opportunities for him in the future are covered in this report. The transition to adult services seems to put into sharp focus all the worst elements of service provision.

Prior to the diagnosis we had ‘normal’ expectations and hopes for our son’s future – these aspirations have never changed. We realise they cannot be achieved in the usual way however they are still possible. Health issues need to be put into context with having a fulfilling social life. At 18 most young men look forward to the enjoyment of independence, employment and leaving home, while doors open for the majority, doors slam shut for our sons.

This report has captured the spirit of many families. It does not view us as people who complain unjustly or as victims, but as a resilient group of people who have managed to keep our sense of humour and warmth in difficult situations. We value those professionals who understand our situation and try to help – these qualities do not require legislation or big budgets!

Families will be grateful to David Abbott and Professor John Carpenter for bringing this topic to public attention. It is clear that considerable time has been spent with families and clinicians from the neuromuscular community and this has resulted in a thorough, perceptive report. I would like to see this report as a resource for every transition team. I don’t want it to sit on a shelf collecting dust, but to be read, understood and used to improve the everyday practice of professionals whose job it is to support our families.

**Sharon Kitcher**  
mother of a young man with Duchenne muscular dystrophy

# Acknowledgements

The research project was designed with the help of the Duchenne Family Support Group (DFSG) a carer-run organisation which provides a national helpline and regional support groups.

The Muscular Dystrophy Campaign, the only organisation fighting Duchenne on all fronts – research, care, support, information and campaigning – remained active supporters of the research throughout.

Support and advice were also offered by Action Duchenne, who campaign and support families living with DMD, also offered advice and support at different stages of this project.

The study involved a project advisory group comprising:

- professionals in the field of Duchenne spanning health education and social care
- members of our partner organisations
- policy leads in the field of transition
- an independent academic and researcher
- and a young man who has Duchenne.

Two other young men with Duchenne acted as consultants to the project.

We are grateful to the Department of Health Policy Research Programme for funding this study as part of the Research and Development Initiative on Long Term Neurological Conditions and particularly to Carol Lupton and Maggie Winchcombe for their support. The views expressed here are not necessarily those of the department.

Our gratitude goes to the young men, their brothers, sisters, mothers, fathers and step parents who gave their time to take part in the research. We hope that we have represented their views and experiences accurately.

# About Duchenne muscular dystrophy

**Duchenne MD is one of more than twenty types of muscular dystrophy, all of which result from faulty genes and cause progressive muscle weakness.** The Duchenne type affects only boys (with extremely rare exceptions) and the faulty gene involved affects the protein in muscle fibres called dystrophin.

It is named after Dr Duchenne de Boulogne who worked in Paris in the mid-nineteenth century and was one of the first people to study the muscular dystrophies.

Most affected boys develop the first signs of difficulty in walking at the age of 1 to 3 years and can't run or jump like their peers, struggle to climb stairs and need to use a banister for support. Rising from the floor can also be difficult.

By the age of 13, boys with Duchenne have generally lost the ability to walk independently and by the mid-teens there can be other complications like curvature of the spine, respiratory difficulties and cardiac failure. For young men with Duchenne, the years between 15 and 20 may mean further spinal surgery and decisions about the use of assisted ventilation for respiratory management.

As the condition progresses, boys are unable to walk as far or as fast as others and may occasionally fall down – some may also have learning or behavioural difficulties at this stage. By age eight to 11, boys may be unable to walk and by their late teens or twenties the condition can be severe enough to shorten life expectancy. The many forms of management which are now available have changed the outlook and can help with complications of the condition in most cases.

During the last few years there have been significant improvements in the ways Duchenne is managed. In particular, teenagers who have been using nocturnal home ventilation to support their breathing can expect to live to around 27 (Eagle *et al*, 2007).

Young men with Duchenne are likely to continue to live longer as more effective spinal surgery and better detection and treatment of cardiac complications impact on the current generation of teenagers. The more recent introduction of use of corticosteroids in the early phase of Duchenne is expected to delay the onset of complications, especially in respiration and improve life span further. It is anticipated that most of these adolescents will reach adulthood.



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'Lots of people round us makes it easier for you to handle things.'

# Introduction and summary

**This report is about the lives of young men with Duchenne muscular dystrophy and the affect on their families.** These young men want to live ordinary lives and do ordinary things, often in extraordinary and challenging circumstances.

During the past few years there have been significant improvements in the ways Duchenne is managed. As a result young men with Duchenne are now living longer than ever before and face a particular set of challenges as they reach adulthood. Those aged over 15 who are the focus of this study, have reached or are reaching stages of adulthood that were at the time of their childhood largely unexpected and unplanned. Given increases in life expectancy young people with Duchenne should be looking forward to living independently with appropriate support, as adults.

## About this study

This research was carried out by David Abbott and Professor John Carpenter at the School for Policy Studies (University of Bristol). Data was collected between October 2007 and November 2008. The research focussed on the transition from childhood to adulthood for young men with Duchenne – how it affects their families and the key professionals who support them. It explored transition in two senses:

- firstly the social and psychological aspects of this major life stage and
- secondly the transition from one set of services to another.

### The key objectives of this study were:

1. To investigate from their own perspectives, how the health and well-being of young men living with Duchenne and that of their parents, can be maximised, particularly at the transition to adulthood.
2. To consider the potential contribution of the National Service Framework for Long Term Neurological Conditions for this group of people.

### The research comprised:

1. A postal survey of parents with a son with Duchenne aged 15 or over living in the South West, West Midlands and North East of England.

*'When I'm older I want to do mechanics and stuff like that. I'd really like to do a car up - a race car or something... get my hands dirty and mess with cars and stuff like that.'*

Young man living with Duchenne aged 15

2. Face-to-face interviews with 40 young men, their parents and siblings about growing older with Duchenne, and the issues they faced at transition.

## Summary of research findings

### 1. Postal survey

Thirty percent of the parents living in the three regions (38 out of 121, mainly mothers) completed an anonymous postal questionnaire.

### Family circumstances

Eighty percent of the young men with Duchenne were living in a family with married or cohabiting parents. Most mothers reported a high level of support from their partners however more than 80 percent reported clinical levels of anxiety and depression. Most had been woken by their son every night of the previous week (average 4.6 nights a week). Fifty percent were looking after the family full time but more than 30 percent were in full- or part-time paid employment.

Disposable family income was comparable to the general population, but this does not take account of the greater additional expenditure incurred in looking after a young disabled person – it is estimated to cost three times as much to raise a disabled child compared to a non-disabled child. Take up of social security benefits was high but only a quarter used a direct payment. Sixty percent owned their own homes and most considered their accommodation suitable.

All families had their own car or van (in most cases adapted). Travel by public transport was difficult. In sixty percent of families the young man's pain and discomfort was a significant obstacle to going out.

‘Everybody perceived him as a sick and dying boy and I keep saying to people, ‘No he’s a burger and chips boy and he’s doing a GCSE in Art.’

Mother of a young man with Duchenne

More than 50 percent of parents were able to have a break from caring from their son as often as needed, in most cases when their son stayed in a hospice. Some did not get sufficient breaks and others had chosen not to use them. Around 25 percent were using, or had used a support group and 50 percent did not use a support group by choice.

### Services

Most families had been in contact with a large number of professionals in the previous six months. Up to 50 percent had been to a specialist medical clinic including respiratory and cardiac clinics and muscle services but only 25 percent had a key worker or care coordinator, usually a social worker.

Overall 50 percent of parents recalled that some form of transition planning had taken place at school, but more than 30 percent did not think this had happened. In most cases parents considered that their sons had played an active part in planning his future.

Sixty percent of parents had insufficient information about options for what their son did next in his life, the services that were available to support him, the roles and responsibilities of professionals and support available for them as parents.

## 2. Interviews with young men and their families

### Education and work

Fifty percent of the young men interviewed were, or had been, in a mainstream school although their families sometimes had difficulty in persuading a school that they could meet their son’s needs.

#### Positive experiences of school included:

- particularly helpful teachers or staff
- opportunity to be involved in out-of and after-school activities
- schools with accessible buildings and on-site services such as hydrotherapy.

#### Negative accounts featured:

- bullying
- difficulties with transport
- some “difficult” Special Education Needs Coordinators
- problems accessing buildings (and thus the full school curriculum)
- experiences of being excluded from activities outside and after school.

Most families were unclear about the process of formal transition planning (required by government guidelines). Key professionals were often absent and there were few examples of young people being actively involved.

Parents felt the onus was on them to ‘sort things out.’ Almost all the young men saw college as the next step although a few were not sure they really wanted to go. There was often not very much choice of college because of problems with access. Some were directed towards residential college.

Most of the young men were positive about college, saying it gave them the chance to join an adult environment and make friends. However, some found making friends harder at college. Some felt that their academic capabilities were not taken seriously and that staff did not have enough understanding and expertise about disability in general and Duchenne in particular. Problems with access to college buildings and out of college activities effectively barred them from some subjects, social events or fieldtrips.

Most young people remembered getting advice about what they should do next but this was often not specific enough about local options. Some gave up on college when they got tired of having to deal with access problems. Five were at, or had been at university, which had involved much planning. Experiences were positive, but there were difficulties in organising reliable and sustainable care and support.

Only one person had had a paid job. Those who had tried to find jobs faced insurmountable difficulties related to employers’ attitudes, access problems, and a lack of specialist and useful advice. The older young men in the study thought they were unlikely to get jobs and that they were probably not well enough to work.

At the time of the interviews, about 30 percent of the young men had been at home during the day and not doing any kind of education, training or work for between a few months and seven years. Their social lives were very restricted (see below).

### **Families' experiences of services**

All but three of the families characterised their overall experience of services as problematic. Getting their son's needs met involved repeated 'battles.' Young men with Duchenne were often aware of these disputes and found them upsetting and stressful. There were very few examples of professionals acting as effective care coordinators for families, who felt that most things were down to them to sort out. The most common problems concerned: the provision of care/support packages; decisions about residential education; obtaining equipment including wheelchairs; and housing and adaptations.

Those families, which were positive about services in general, stressed the importance of factors such as good coordination (through a muscle clinic), planning ahead, and long-standing relationships between the family, the young man, and helpful professionals.

Almost all families in the North East attended a muscle centre where the specialist knowledge and expertise of staff were greatly appreciated. The centre was available for young men of any age with no transfer to adult services – this was greatly valued. In the West Midlands, most families saw a consultant paediatrician in childhood about whom they were very positive. However, some families were unsure about transfer to adult services – who they would be seeing and why. Others said that they were given a lot of notice and that there was some flexibility. In the South West there were no adult neuromuscular consultants. Families were confused and anxious about transition pathways and a few relied very much on their GPs.

Many parents and young men did not like the way that appointments in later childhood and early adulthood focussed on charting their deteriorating health. Even if clinicians thought it was important to monitor health status, young men and their families did not find this motivating.

Physiotherapy was seen as one of the first and most significant losses following the transition to adult services. There was wide variation in the

support obtained from occupational health in relation to equipment and adaptations.

Just less than 50 percent of families interviewed had contact with children's social care and most of these were critical of the nature and level of support they received. Others said their social worker was very supportive. Social workers' involvement at transition tended to focus on paperwork and meetings rather than outcomes or support. There was no on-going relationship with a named social worker following transition to adult care and they were dealt with by a duty social worker instead.

Many families used their local hospice for short breaks and were overwhelmingly positive about the nature and quality of support received. Some young people were no longer able to attend their local hospice as they grew older and in some cases there was no suitable alternative. In two of the three regions, neuromuscular care advisors provided information and support which was highly regarded.

### **Young people's social lives, independence and support**

Young men at school or college generally had adequate social lives and enough friends but most who had finished education were leading restricted lives. TV, computer games and going out with close family members occupied their time but most said that they would like to do more.

Parents had mixed views. Some were worried that their son's potential was being wasted but were anxious not to pressurise them. The main obstacles to doing more during the day were:

- lack of information about local options which accommodated the young person's health and impairments, transport and support needs
- the availability of other people to do things with.

It was hard to gain independence from their parents because they relied on them for transport and care. Few families were using direct payments to pay personal assistants to support their son's leisure activities.

Four young men at college had girlfriends, which was easier for those living away from home. Others wanted a relationship but worried that it might be difficult to find a partner.

## Support and care

External support for the young men varied from a couple of hours a day to a 24-hour package of care, even for those with similar levels of need. Most parents were still very actively providing care.

It could be difficult for parents and their sons to have enough physical and psychological space from each other. Some families, concerned about privacy, declined external carers. The quality of external care varied enormously and its inflexibility could impede the young person's independence.

About 30 percent of parents were using a direct payment. Recruiting reliable carers was difficult. Some were confused about their entitlement and how they could be used. Others felt 'pushed into' direct payments and found the organisational responsibilities onerous.

## Living with Duchenne and becoming an adult

Families dealt with Duchenne in a whole range of ways, which changed in response to events such as a decline in health, a major medical intervention, or the death of friends who also had Duchenne.

Young men tended not to think about living with Duchenne, although it was always at the back of their minds. It was hard to stay positive if they thought about it too much. However, some valued the chance to talk to people they trusted. Parents tended to resist outsiders suggesting that they should talk about Duchenne and its consequences or how they should talk about it.

Some parents thought that their sons tried to protect them by not talking or showing their emotions. Nonetheless, young men identified their parents as their main support for questions or concerns. Parents were not always sure what their son knew about Duchenne and were unsure what to say given changing medical technology and increases in life expectancy. A small number of families discussed their emotional needs in relation to living with Duchenne.

Families tended to say that they 'lived for the day' and found it difficult to look very far ahead because they felt uncertain and apprehensive. But they did plan ahead – for holidays, what to do once school or college was finished, care for the future.

Parents struggled with deciding how much pressure to put on their sons to get qualifications, think about work and living away from home, and with expectations for their futures. Some felt their son's life expectancy was such that there was no point in having expectations and that professionals used this to ration services.

There were very strong emotional bonds between parents and their sons, mutually supportive and often characterised by warmth and humour. But this closeness meant that some young men did not feel able to develop independence – a concern shared equally by some parents.

Duchenne, however significant, was just one aspect of family life. Households had other siblings, busy work lives, domestic work, socialising, and all the ordinary business of family life.

Some said that Duchenne dominated family life – appointments with professionals, fighting for services, caring responsibilities and so on. In addition, parents disliked professionals treating their son as if he had no identity other than Duchenne. Some parents got involved in support groups and with other families affected by Duchenne; some did the opposite, choosing not to get involved because they did not want the frequent reminders of living with Duchenne.

Young men with Duchenne were adversely affected by disabling societal barriers like poor physical access, discriminatory attitudes and services which did not meet their needs. In addition the physiological affects of Duchenne restricted their independence. Pain was frequently mentioned as a source of distress. Medical interventions, such as spinal surgery, could dramatically affect their lives.

Many of the findings of this study are directly applicable to any group of young disabled people with long-term conditions, complex health care needs and life-limiting illnesses. It confirms previous research about transition to adulthood for young people and the very many obstacles they face, and shows that while advances in health care have increased life expectancy this has not been matched by increased support at home and in the community.

The challenge posed by young men with Duchenne and their families is to ensure that their shorter lives are no less valuable and just as fulfilling as any others in our society.

# 1. Duchenne and transition to adulthood

**This chapter summarises research on the transition to adulthood of young disabled people in general and how this relates to young men with Duchenne.** It also draws on research about transition and young people with complex health care needs and/or life-limiting illness which is directly relevant to young men with Duchenne and their families.

## The transition to adulthood for young disabled people

There is a significant body of research concerning the transition from children's to adults' services for young disabled people. Recent studies have highlighted that this period in a young person's life is often characterised by uncertainty, inconsistent approaches to transition planning and a lack of meaningful choice about post education options. In 2007 the Commission for Social Care Inspection (CSCI, 2007) described the transition for young people with complex needs from children's to adult services as a 'nightmare.'

Transition planning for disabled children is a statutory duty. The primary statements of policy are the SEN Code of Practice and SEN Toolkit (Department for Education and Skills, 2001). These emphasise that transition planning should be participative, holistic, supportive, evolving, inclusive and collaborative. Section 10 gives the regulations that a transition plan must be prepared for all young people with a statement of Special Education Needs (SEN) following the Year 9 annual review and then updated at least annually.

## The Transition plan

This plan should draw together information from a range of individuals within and beyond school to plan coherently with the young person for their transition to adult life. It must be designed for and with each young person and the formal duty for ensuring the transition plan is drawn up rests with the head teacher at the young person's school. Social work assessments should be carried out alongside SEN procedures and social workers should identify and attend Year 9 reviews of

young people eligible for assessment under the Disabled Person's (Services, Consultation and Representation) Act (1986).

There are a number of other statutes, policy documents and good practice guides which set out how young disabled people can be supported at transition. The most comprehensive and up to date at the time of writing is 'A transition guide for all services' (DCSF *et al*, 2007).

However, Morris's overview of transition issues for young disabled people may be as relevant now as it was when it was published in 2002. In it she highlighted:

- poor liaison between professionals
- large numbers of young people with no transition plan at all
- failure to involve young people in planning
- failure to cover issues important to young people
- a lack of accessible information
- insufficient assessment of communication needs
- a lack of choice/expectation about training, employment, and housing
- a lack of real post 16-19 options (especially in relation to paid work)
- a lack of significant community involvement, citizenship, choices about friends, relationships and a social life.

Other researchers have described service transition as a 'systems failure' and wondered why, when there is so much evidence about what needs to be done, things are still so bad. Given the plethora of service-led processes that families are exposed to, parents' lack of clarity about transition processes is not really surprising. A study by Tarleton (2004) showed that parents were often unclear about the language and terms used in relation to transition, what was supposed to happen, and who was supposed to do what.

Other research has shown scant evidence of routine compliance with legal duties at transition. Heslop and colleagues (2002) found that a fifth of young people with learning difficulties had left

school without a transition plan and for those who did have a plan the topics covered were often very different from the young person's own priorities. In addition, whether or not these young people had a plan seemed to make very little difference to what actually happened to them.

Hudson (2006) asked why things are still so frustratingly not working. Two of his points are particularly worth noting here:

- One is the **lack of a whole systems approach** – there is still rarely someone with ownership of and responsibility for 'getting things done' in relation to transition. Instead transition remained, in Hudson's words, 'everybody's distant relative'.
- The second point concerns **what transition is and what it is for**. He wrote, '*Ultimately an effective transition serves as a bridge – from adolescence to young adulthood. What lies at the end of this bridge is critical, for a 'good transition' will count for nothing if there are no real choices about future transition.*'

In the absence of choices at transition Hudson suggested that many young disabled people stay in further education. But when this comes to an end, all the legal and formal apparatus of transition has gone.

There is evidence that a poorly planned service transition can have adverse effects on young people's *health*. An Australian review by Wedgwood and colleagues (2008) concluded that poor transition processes result in worse mortality outcomes, long term prognosis and physical wellbeing – as well as educational attainment and social circumstances. Forward planning combined with good communication, self advocacy and management by the young person of their own condition are all very important.

### Young men with Duchenne at transition

All the issues relating to youth transitions and transitions for young disabled people apply to young men with Duchenne. If there are differences, they seem to arise from the fact that this generation of older teenagers with Duchenne is an 'unanticipated' adult population (Rahbek *et al*, 2005). This is a situation shared with other groups

of young people with complex health needs who are also now living longer as a result of advances in medicine and health care.

Research which has investigated services and transitions for young people with complex health care needs and life-limiting/ threatening conditions, have been consistent in its messages (Soanes & Timmons, 2004; ACT *et al*, 2001). Young people need:

- continuity and familiarity
- to be prepared for change
- any new service to be flexible and account for individuality
- good quality support along with staff showing that they care (with kindness, or understanding, for example).

A survey of 850 people living with muscle disease carried out by the Muscular Dystrophy Campaign showed that 60 percent rated their transition from child to adult services as 'poor' or 'very poor' (Muscular Dystrophy Campaign, 2008).

This survey followed a Muscular Dystrophy Campaign report which highlighted the variation in life expectancy for young men with Duchenne between an average age of death of 30 in the North East compared to age 18 in the South West. The report showed that people living with muscle disease did not receive appropriate, specialist care from adult health services (Muscular Dystrophy Campaign, 2007).

As young men with Duchenne get older, how their families communicate about and cope with changes – in prognosis, health and end of life – all become very important. Parker and colleagues (2005) suggested that families were reluctant to talk about the end stages of the condition and that this could create difficulties for professionals who wanted to support them.

Young and colleagues (2003) considered that young people with life threatening illness used their parents as a 'resource to manage communication' – mainly because they often felt uninvolved in the 'talk' that went on between professionals and parents. Consequently, differences in opinion between young people and their parents in perception, knowledge, or the desire for information may go unexplored – it is easy to assume that everyone in the family thinks the same.

Beresford and Sloper (2003) found young people with chronic illness reluctant to raise sensitive topics with health professionals. They also tended not to bring up emotional issues partly because they did not feel that health professionals were interested in them as 'whole people' with day-to-day social needs and concerns - as well as health ones.

The importance of addressing the psychosocial needs of young people with long term conditions was highlighted in the interim standards of care for Duchenne muscular dystrophy drawn up by TREAT-NMD (2008). According to these standards, at times of crisis or changing need (including key transition stages) every family should receive support to address their social and psychological needs through information, advocacy and advice.

Support in dealing with sexuality and relationships is also a priority for young people as they grow into young adulthood and this is often overlooked for disabled people in general. Writing in *The Guardian* (Wallis, 2007) a 22 year old man with Duchenne explained why he thought he would need to pay for sex to experience it. '*Sexuality and disability is swept under the carpet*', he wrote, adding that although he had managed to access higher education without too many barriers, social relationships were much harder to forge:

"I continue to hope that I may be able to establish a relationship with the right person. The same as any other 'dude' I want to be able to hold hands with someone, to love and be loved."



'Health issues need to be put into context with having a fulfilled social life.'

## 2. Parents and carers

**The first stage of the research involved a postal survey.** In accordance with a procedure approved by the Multi-Centre Research Ethics Committee, a questionnaire was forwarded to all 121 parents with a son aged over 15 on the databases of the clinical services in the three regions in England. It was accompanied by a letter from the consultant responsible for the medical care of the young man with Duchenne muscular dystrophy outlining the study. The information sheet emphasised that whether or not the parents chose to participate in the research would have no influence on their son's care and treatment.

The questionnaire was based on one used by Beresford (1995) and subsequently by Chamba and colleagues (1999) to survey the social, demographic and financial circumstances of families with a disabled child. We added a checklist to estimate their contact with and knowledge of service agencies. After a reminder, 38 responses were received, representing a response rate of 32 percent of all families in the three regions.

### Relationships and support

Over 80 percent of the respondents were married or living together as married and of these, nearly 50 percent were looking after the family full time. There were seven single or separated and divorced parents, five of whom were looking after the family full time. One was in education and one was working full time. Three of the respondents said that they themselves were disabled and one of these was single.

The proportion of married and cohabiting respondents was noticeably higher than the 60 percent of respondents in Beresford's (1995) survey. Seven said that they shared their son's care equally, ten that their partner 'helped a lot' and eleven 'helped a little'. One reported that her partner did not help at all and two chose not to answer this question. Forty-five percent of respondents considered that their partner shared the care of their son or 'helped a lot' compared to Beresford's respondents where the proportion was only 20 percent.

In response to a question about the emotional support they received from their partner, 61 percent said that they 'supported each other equally' and a further three said that their partner gave them 'a lot' of support. Seven were considered to provide only a little support and one provided no support at all.

Siblings could be a source of support. Twenty-five of the respondents reported that they had other children; seven said that their other child or children 'helped a lot' in caring for their brother with Duchenne and a further fifteen said that they 'helped a little'. One child was too young to help and two were said 'not to help at all'.

### Work and money

Half of all respondents who had, in most cases identified themselves as the main carer in the family, were looking after the family full time. Beresford (1995) similarly found a majority of main carers looking after their child full-time. Three respondents, with adult sons with Duchenne, were working full time and a further 11 were working part time. In all more than 30 percent were working full or part-time.

Eighteen percent said that having a son with Duchenne had not affected their employment, presumably because they had not intended to work outside the home. Twenty-six percent reported that they had had to leave work to care for their son and a further 24 percent said that they had not been able to return to work for the same reason. Of those who were working, five said that they could not work as many hours as they would have liked and one said that she had to work extra hours because of extra costs of having a disabled son. Four considered that they had not been able to progress as far in their job as they had hoped.

Of the 16 respondents who were in work, 10 were allowed to take time off from work when their son was ill, had appointments or was in hospital. Four respondents were self-employed and could make their own decisions and two reported that they could not afford to take time off work. Of those

allowed to take time off only two could do this without difficulty or loss of pay and the other eight either lost pay or had to take the time off as leave.

## Income

There were quite wide disparities in income. The average disposable weekly household income in the UK in 2007 was estimated by the Office of National Statistics as being £534 (ONS, 2008, Table A47). Nine of those choosing to reply to the question had a weekly disposable income of less than £300 per week placing them in the bottom half of the general population. Twelve respondents reported earnings of over £500. Eleven preferred not to divulge this information. There was no apparent association between disposable income and relationship status in this small sample.

Direct payments are local council payments for people who have been assessed as needing help from social services, and who would like to arrange and pay for their own care and support services instead of receiving them directly from the local council<sup>1</sup>. Only around a quarter of the young men (or in the case of those under 16, their parents) were receiving a direct payment although all presumably met the eligibility criteria of their local authority. The reasons for this were not sought in the questionnaire but were explored with some of the families who chose to be interviewed in the second part of the study.

## Housing

Sixty percent of the families lived in their own home and the remainder rented from the council or a housing association and in one case from a private landlord. Only four respondents considered that their accommodation was unsuitable. All gave the same reason – not enough room for the extra equipment that their son needed. These findings show an improvement when compared to the four in ten parents in Beresford *et al.*'s, (1995) survey who considered their housing to be unsuitable.

## Son's day activities

Survey respondents were caring for sons aged between 15 and 34. Fifty percent of the young men had reached the age of 19, the life expectancy without nocturnal ventilation (Eagle, 2007). Until recently, their parents could not have expected still to be looking after them at this age.

Eleven of the young men were of school age, with six attending mainstream school, three at a local special school, and one at a mainstream college of further education. One was at home and not taking part in education- the reason for this was not given.

Ten of those between 17 and 20 were still in education and three were at home 'doing nothing'. Of those aged over twenty-one only three had continued in education, two were attending a day service and nine were 'doing nothing'.

## Taking a break

Nearly 60 percent of the respondents considered that they were able to have a break from caring for their son as often as needed and; in 13 cases this was when their son went to stay in a hospice. Other breaks were provided by a paid carer coming into the family home to look after their son. Three respondents said that their son was away at college, one commented that the family was 'delighted' to see him when he came home.

Seven respondents who were using short break services (hospices in five cases and paid carers in the other two) said that these breaks were not as often as they needed. Two respondents said that they were not getting a break because they thought that no such services were provided locally. Five respondents said that they knew about short break services but chose not to use them. One mother, who shared her son's care equally with her husband, wrote that they looked after their son themselves, but felt that she did not have a break as often as she needed. The other four mothers in this group also did not feel that they could have a necessary break, two of them writing that the reason for this was that their sons did not like to be left with other people. One wrote: 'My son gives me a hard time when I get back'.

## Sleep

Thirty-three respondents answered a question about the number of nights they had been woken by their son during the previous week. The average number of disturbed nights was 4.6. Sixty-one percent of respondents had been woken every night, but 25 percent had not been disturbed at all. There was no association between the son's age and parent's disturbed nights. A study by Meltzer and Mindell (2006) found similar results for the

1. [www.direct.gov.uk/en/DisabledPeople/FinancialSupport/DG\\_10016128](http://www.direct.gov.uk/en/DisabledPeople/FinancialSupport/DG_10016128)

prevalence of sleep disruptions in 52 percent of mothers caring for ventilator-dependent children. This was significantly higher than a matched sample of mothers of healthy children. These authors also found an association between sleep disruptions and depression.

### Anxiety and depression

All 38 respondents completed the Hospital Anxiety and Depression Scale (HADS). HADS is a widely used self-report screening measure for anxiety and depression. Eighty-four percent scored above the clinical thresholds for anxiety and depression. The remaining six respondents scored within the 'normal' range. There was no statistically significant correlation between the main carers' scores on the HADS and the age of the son.

### Services

The extent of contact with a range of professionals is shown in Table 1, which also summarises the numbers reporting whether they were satisfied or dissatisfied with these contacts. The highest proportion of families in contact with a professional in the last six months was the 60 percent who had seen their GP. Forty-two percent of families had been to a muscle clinic and a similar proportion to a respiratory clinic; nearly 50 percent had attended a cardiac clinic in the previous six months.

Fewer than 50 percent of families reported having seen a social worker occupational therapist or physiotherapist. Eight respondents reported contact with a psychologist, psychiatrist or counsellor. More than 30 percent had had contact with a community nurse or community based palliative care.

**Table 1. Contact with services and professionals in last six months (total 38 families)**

| Professional/Service              | Number of families | Satisfied | Not satisfied | No response |
|-----------------------------------|--------------------|-----------|---------------|-------------|
| GP                                | 25 (66%)           | 16 (50%)  | 1             | 8           |
| Muscle clinic: child/young person | 10 (26%)           | 5 (42%)   | 2             | 3           |
| Muscle clinic: adult              | 6 (16%)            | 3 (50%)   | 2             | 1           |
| Cardiac clinic                    | 18 (47%)           | 12 (67%)  | 1             | 5           |
| Respiratory clinic                | 15 (39%)           | 9 (24%)   | 1             | 5           |
| Orthopaedic                       | 12 (32%)           | 4 (33%)   | 1             | 7           |
| Physiotherapist                   | 16 (42%)           | 8 (50%)   | 0             | 8           |
| Occupational therapist            | 17 (45%)           | 6 (35%)   | 2             | 9           |
| Educational psychologist          | 2 (5%)             | 0         | 1             | 1           |
| Clinical psychologist             | 2 (5%)             | 1         | 1             | 0           |
| Counsellor                        | 1                  | 1         | 0             | 0           |
| Genetics service                  | 0                  | –         | –             | –           |
| Social worker                     | 17 (45%)           | 12 (71%)  | 2             | 3           |
| Connexions                        | 5 (13%)            | 1         | 2             | 2           |
| Community nurse                   | 4 (11%)            | 4 (100%)  | 0             | 0           |
| Community palliative care         | 9 (24%)            | 2         | 0             | 7           |
| Psychiatrist                      | 3 (8%)             | 3         | 0             | 0           |
| School nurse                      | 8 (21%)            | 2         | 0             | 6           |
| Wheelchair services               | 22 (58%)           | 10 (45%)  | 2             | 10          |
| Orthotics                         | 6 (16%)            | 2         | 0             | 4           |

Overall, of those respondents expressing an opinion, 90 percent gave a 'satisfied' rating. The number of those who said that they were not satisfied were very low (however, many chose not to respond to some of these questions). The highest expressed 'satisfaction rates' were for community nurses, followed by social workers and the cardiac clinic.

Respondents were also asked whether they had a key worker, link worker, case co-ordinator or 'named person'. Nearly 50 percent did not answer this question and two said that they did not know. Of those that did respond, all but one of those with a key worker or equivalent considered that this person was very helpful. Five who did not have a key worker said that they would like one. Only two respondents gave a negative response. Most of the key workers were identified as social workers, but a physiotherapist, community physician, GP and 'lifetime nurse' were also mentioned.

**Support groups**

Around 25 percent of the parents were using, or had used a support group (in many cases the Duchenne Family Support Group) but some used support groups attached to local hospices or to carers' services. In comparison, Beresford *et al.* (1995) reported that 30 percent of her sample used a support group. Reasons mentioned for using support groups were:

- finding out about local services and benefits
- finding out about how to plan for the future
- having someone to talk to who is in the same situation
- having the chance to go out and have a social life
- giving my son the chance to meet other disabled young people
- giving my son the chance to meet other non-disabled young people.

Of those not involved with a support group, three parents, all in the West Midlands, said they did not know what a support group was, six believed there was not one close by and 50 percent said that they did not use one by choice. Beresford (1995) reported that 30 percent of her sample had chosen not to belong to a support group. The reasons for and against using support groups are explored in the interviews with parents reported subsequently.

**Transition planning**

As noted in the previous chapter, for some years there has been an expectation that when young disabled people reach the age of 14, schools, along with other agencies, will begin planning for their future. Respondents were asked whether, as far as they knew, there was or had been any such planning at school for their son's future. Overall 50 percent recalled that some planning had taken place, but more than 30 percent did not think this had happened and five parents said that they did not know.

**Table 2. Sufficiency of information (37 respondents)**

| Have enough information on:                                                      |     | Region     |               |            | Total    |
|----------------------------------------------------------------------------------|-----|------------|---------------|------------|----------|
|                                                                                  |     | North East | West Midlands | South West |          |
| Options for son's future                                                         | Yes | 4          | 5             | 2          | 11 (29%) |
|                                                                                  | No  | 7          | 14            | 5          | 26 (68%) |
| Availability of services for son                                                 | Yes | 3          | 6             | 3          | 13 (34%) |
|                                                                                  | No  | 9          | 12            | 3          | 24 (66%) |
| Roles and responsibilities of professionals who can support son as he gets older | Yes | 1          | 4             | 4          | 9 (24%)  |
|                                                                                  | No  | 11         | 14            | 3          | 28 (76%) |
| How son's condition will develop in future                                       | Yes | 9          | 14            | 7          | 30 (79%) |
|                                                                                  | No  | 3          | 5             | 0          | 8 (21%)  |
| Support for you as a parent                                                      | Yes | 3          | 7             | 2          | 12 (32%) |
|                                                                                  | No  | 9          | 12            | 5          | 26 (68%) |

## Information

Parents were asked whether they had enough information about their son's future and the support which was available (Table 2 below). While more than 75 percent believed that they had enough information about how their son's condition would develop, 60 percent considered that they had insufficient information about options for what their son did next in his life, the services that are available to support him and the roles and responsibilities of professionals. A similar proportion replied that they did not have enough information about the support available for them as parents of a disabled young person.

Parents' sources of information about their sons' condition included doctors, the Internet, the Muscular Dystrophy Campaign, the Duchenne Family Support Group (DSFG), other families, medical books and leaflets.

Those parents who considered that they had had enough information concerning their son's future reported receiving it from a variety of sources, including their son's school, college or university, social workers, family care officer, Connexions, and the Internet. Information about support available to parents themselves came from the Muscular Dystrophy Campaign and the DSFG, social workers, a carers' centre and hospices.

Respondents were asked whether they had received information about their son's needs on becoming an adult. They were presented with a list of topics suggested by the researchers in consultation with the DSFG.

Twenty-nine respondents answered this question indicating first whether the topic had been covered and then whether they wanted more information (see Table 3). According to the parents, the topics which had been least frequently addressed, and on which they required further information were:

- leisure and social opportunities for their son (discussed with fewer than 25 percent of parents but with almost 75 percent requiring further information)
- career and longer term employment (less than 25 percent and 62 percent respectively).

In addition to careers, employment and leisure opportunities, the other striking information need reported was for emotional advice and support for the family including the young man with Duchenne – 60 percent of parents wanted further information on this topic. Overall, further information was required by at least 30 percent of parents on most of the topics mentioned.

## How might these needs for information best be met?

The survey questionnaire suggested a range of sources. It was notable that no one single source was preferred. Some parents identified just one preferred source and others multiple sources. The most popular suggestions were:

- a named professional key worker
- the Internet
- written materials (e.g. leaflets)
- a support group such as the DSFG.

The Internet was frequently mentioned in addition to other sources, but a minority preferred written information and three parents thought that videos on Duchenne and services would be helpful.

**Table 3. Parents' information needs (n=29)**

| <b>Topic</b>                                                       | <b>Has been addressed</b> | <b>Would like more information</b> |
|--------------------------------------------------------------------|---------------------------|------------------------------------|
| Careers and employment post school/college                         | 10 (34%)                  | 16 (55%)                           |
| Career and employment longer term                                  | 6 (21%)                   | 18 (62%)                           |
| Further/Higher education                                           | 18 (62%)                  | 9 (31%)                            |
| Transport                                                          | 13 (45%)                  | 13 (45%)                           |
| Transfer to adult health services                                  | 16 (55%)                  | 11 (38%)                           |
| Hospice or respite care                                            | 19 (66%)                  | 10 (34%)                           |
| Obtaining aids or equipment                                        | 18 (62%)                  | 8 (28%)                            |
| Access to emergency medical care                                   | 9 (31%)                   | 12 (41%)                           |
| Managing pain                                                      | 8 (28%)                   | 10 (34%)                           |
| Transfer to adult social services                                  | 16 (55%)                  | 11 (38%)                           |
| Changes in social security benefits                                | 14 (48%)                  | 11 (38%)                           |
| Future housing options                                             | 9 (31%)                   | 13 (45%)                           |
| Leisure and social opportunities                                   | 6 (21%)                   | 21 (72%)                           |
| Managing money                                                     | 12 (41%)                  | 9 (31%)                            |
| Relationships, sex and sexuality                                   | 13 (45%)                  | 9 (31%)                            |
| Direct Payments                                                    | 18 (62%)                  | 12 (41%)                           |
| Independent Living Skills                                          | 11 (38%)                  | 10 (34%)                           |
| Sources of emotional advice/support for my family including my son | 10 (34%)                  | 18 (62%)                           |
| Support for me to talk to my son about his future                  | 9 (31%)                   | 11 (38%)                           |

## 3. Education, work and beyond

### The next four chapters draw on data from the second, qualitative stage of the research.

One hundred and two members of 40 families, including 37 young men with Duchenne (age range 15-33) accepted an invitation to be interviewed about their views and experiences. Thirty-four mothers, seventeen fathers and seven brothers and sisters were interviewed. They were given the option of being seen separately or together. Thirteen of the young men were at school, 10 at college and two at university; the other 16 were at home for most of the day. Two families were from a minority ethnic background; the other 38 were white British.

This chapter focuses on what young people and their families said about the milestones in their life in relation to education, work and beyond. It also discusses how young men and their families negotiated between different stages and were supported (or not) to make choices about them.

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### Secondary school

The young men interviewed were fairly evenly divided between those who were, or had been in a mainstream school, and those who had been, or were at special school. Families had different reasons for favouring one option over the other.

### Making a transition from secondary school: what next and why?

In common with their non-disabled peers, the overwhelming majority of the young men, either still at secondary school, or who had been through secondary school, saw college as the inevitable next step and most were happy enough with this. This trajectory was probably least problematic for young people in mainstream schools who had sat GCSEs. One young person explained 'I didn't really have anything in mind other than just to do that really.'

Several young people were also able to stay at school until they were 19 years old, including one who stayed for an extra year, as one mother described:

*'He loved the school so much he didn't want to leave. He stayed there till they kicked him out and he put in an extra year.'*

'Staying on' at school post-16 was described as the least problematic option, which is true for most disabled and non-disabled young people of that age. However for some families it seemed to be a way of putting off future uncertainties.

*'He would like to stay on at school. So the best option is that he stays at school till he's nineteen- he has a community of friends, the support he needs, it's a safe little bubble.'*

Most young people who were at, or hoped to go to college, felt that college was a positive step because it could offer a more adult environment. This included the possibility of having a better social life, or making new relationships. One young person suggested: *'I'd like to go to college. I could perhaps get a girlfriend if I went to college.'*

As with the choice of secondary school, young people were influenced by where their friends were going. Several wanted to go to the same college as their friends or their siblings.

Three families said that they felt steered by the Connexions service to look at special residential colleges as the next step after school. One mother said it was presented to them as the only option: *'That's all we got bombarded with - residential colleges. Wore us down a little bit you know 'cos it wasn't what personally me and my husband wanted, because obviously we're a close family and we wanted to sort of be together. I felt a bit bullied by this, you know, residential college thing.'*

Three families were interested in special residential college. In two instances Connexions were supportive but in another, the mother said that Connexions were telling her that it was highly unlikely that funding for such a placement would be agreed.

This mother considered that the local mainstream college would be fine academically but would leave her son socially excluded – *'He'll come home at 4.30 and there'll be nothing after.'*

In contrast, the residential college they had been to visit offered, she believed, a much wider range of social and personal development opportunities: *'My son's really sociable and he wants an environment that he's included in. I was stunned by [residential college] – nothing was impossible. It's independent living. I want my son to have a life after school. And I want him to leave home!'*

In terms of which college to go to, there were restrictions relating to physical barriers and access problems. Consequently choices were few. One mother said that Connexions gave them two choices, neither of which they were very happy with: *'I think that's where we started to feel a bit let down really. The only options seemed to be ... go straight to [x] college that was wheelchair friendly and do like a life skills course, wasn't it? Or go to residential.'*

One young person half joked that his choice of college would be reliant on access:  
Interviewer: *'What would you want to know about the college to make you feel, yeah, I think I will come here?'*  
Young person: *'Well if I can fit through the doors.'*

Six young people were not sure that they really did want to go to college. Some of these were looking ahead to college and some looking back at their experience. However there seemed to be little else on offer:  
Interviewer: *'Had you decided that you wanted to go to college?'*  
Young person: *'Not really. I just went didn't I?'*  
Mother: *'Yeah. Nobody sort of sat down with him and said, 'Well, what would you like to do?''*

One father said his son had 'no choice' but to go to college when what he really wanted was work experience. One other young person also wanted to leave and get work as a mechanic but was persuaded to go to college instead. Another said: *'I didn't want to go to college, I wanted to do something else but it was the only thing I could think of – college.'*

Finally, another young person felt whilst further study was not for him, the alternative presented to him – a day centre – was not appealing either: *'Don't like them. I know people that are in them and I don't like it. It's like putting someone in a home really.'*

## The processes of transition

We heard very few examples of structured transition planning following national guidelines (see DCSF *et al*, 2007) and starting at the age of 14.

Given that these regulations have been in place for twenty years, every young person in this study should have been involved in transition planning. The following quote typifies families' responses to questions about transition planning – here is a family in which the son was, at the time of interview, a month or so from finishing secondary school:  
Interviewer: *'Has there ever been a transition plan?'*  
Young person: *'No, actually.'*  
Mother: *'Not as such, no. I mean it's been talked about in a round about way you know, but not as such, no.'*

When review meetings took place parents often did not explicitly know if transition was the focus: *'Well I don't think anybody ever ... the transition, something went wrong with that anyway, didn't it? They just did an ordinary review, 'cos nobody turned up for it anyway I think, so ...'*

In other instances key professionals were absent – often social services and Connexions staff – or parents said the meetings were badly organised. One parent said that her SENCO had not invited any key professionals to reviews, including the transition review, because she thought it was the parents' job:

*'I spoke to the local community paediatric consultant and he went through the file and found out that the last time anyone from his department had been invited to a review was at primary school. And SENCO's words were, 'I thought Mum did it', and there was a stunned silence.'*

We did not hear many examples of young people being actively involved in transition reviews. Many did not attend. One that did attend his high school reviews remembered being unhappy that when it came to deciding what he was going to do after secondary school, the subject of money seemed to dominate.

*'I think now I do understand money a bit more. But still, it was almost like money was more important than people's feelings or what could be done, I think.'*

The absence of planning exacerbated what was already quite a stressful time. Families felt that on the whole school years had been relatively settled but that they were now beginning to face more uncertainties. Gaps in information or planning were seen as making that worse, as one mother explained: *'The most important thing to me now is the transition into adulthood. I've been to plenty of meetings, but apparently there's no literature at all about the transition into adulthood. So I'm not quite sure what's happening there. It's just been a talk shop really, 'cos nothing's happened, and nobody's sent me anything to read and we don't seem to be getting any further forward.'*

One mother said that she did not remember any formal transition planning. However, she added that she did not feel that this had been a loss: *'I don't feel I've had anything. But actually I'm not too concerned about it because it's more paperwork, more people and actually talking to people who are a few steps ahead – well, there's very few options first of all. Secondly, it'll be the case that you pretty much find it and sort it out for yourself and then you pursue it.'*

There was one exception to this generally bleak picture. One mother said that everything that should have been done had been done and that her son had made a smooth transition from school to college and later, to university: *'I mean we had reviews really a couple of times a year anyway. So that was always ... all the way through his school life. All the reviews were taking place with all the appropriate people there and everything just worked out beautifully.'*

Most families had felt largely unsupported at this time of transition and remarked that the onus

was on them to 'work it out.' 'Connexions' was mentioned by about 50 percent of the families; about 50 percent of them found Connexions useful and the other 50 percent said they had been very unhelpful. One family said that Connexions had been 'brilliant'. They had faced great uncertainty when their son was two days away from finishing school without knowing what he was going to do next. Connexions helped the family organise a place at a local college, with which the family were pleased. It was not clear why Connexions had not been involved before the mother made the last minute call however. Families who were critical of Connexions mentioned that they were often absent from key meetings and decisions, or seemed to know very little about DMD – or disability in general.

Parents lamented the lack of specific help, information and advice about real life choices, as opposed to generalist advice, as one mother described: *'I think we wanted a bit of advice. That's what we was missing out on. I think we just felt a bit helpless, like what do we do from now. All of a sudden we was out on our own type of thing, and we didn't know what to do.'*

## College

Almost all the 28 young people who went to college or who were at college at the time of interview, had been prepared. Preparation had included visits, 'taster days', interviews, and looking at the Internet or promotional booklets or DVDs.

There was a wide range of practice relating to issues like transport to college and learning or personal support whilst at college. Some institutions clearly offered more support than others. Most of the young people were positive about college, highlighting the opportunity it gave them to inhabit a more adult environment and make friends but some young people found making friends harder at college. Some felt that:

- their academic capabilities were not taken seriously enough
- the college staff did not have enough insight into or expertise concerning disability in general and Duchenne in particular
- there were several examples of young men not being able to access parts of the college buildings or take part in external activities such as social events or fieldtrips.

The majority of young men were studying in further rather than higher education. They were working towards A levels, foundation degrees and Higher National Diploma in a wide range of subjects, although with a bias towards life skills, IT, art and design.

### Making a transition from college

The majority of young people at college, or who had left college, could recount getting general advice and information about life after college from the college staff or Connexions, although not all could. Those who were, or had been, at specialist, residential, FE college were the most likely to say that they received a lot of information and guidance on what to do in the future.

Young people who were planning to go to university generally received appropriate and helpful information, perhaps because it was an established trajectory for young people of this age. The main issue to resolve was where the young person would live – away at university or at home – and then sorting out the subsequent transport and support issues.

One young person said his transition from college to university had been smooth and that he had been given good advice by his teacher:

*'I remember first seeing it [information about the University] actually on a board at school and I asked my teacher, and that's when it all started really. And then I went to [university] and we had various meetings and I pretty much decided I wanted to go there straight away really. So ... it all went really smooth to be honest.'*

A small number of families said they did not know what was going to happen when college finished or who would be able to help them. One mother said she felt 'all at sea' and unsure where the responsibility lay. For a number of young men the transition from college was hurried and unplanned. Mostly this was due to the severe decline in health and increase in impairments associated with the

condition, but sometimes because of persistent access issues and problems. In these cases there had not been time for any planning and the young person often did not return to college or any other day time educational or training activities:

Interviewer: *'Did college come to an end for any particular reason?'*

Father: *'Yeah. Just couldn't cope with it, there was nothing else for him to do anyway.'*

Interviewer: *'Right. So what happened next?'*

Mother: *'Nothing.'*

Interviewer: *'And were the college talking to you about, you know, he could do this, he could do that? Connexions weren't involved or the careers or ...'*

Mother: *'No, nobody. Nothing.'*

Interviewer: *'So at that time what were you thinking would happen next?'*

Father: *'Enjoy life and get on with it (laughs).'*

One young person left college after an illness led to him using a ventilator 24 hours a day. His parents were worried that if he went back to college there would be a problem with his ventilator. They rang his support workers at college who said the staff would be prepared to get training in how to use and look after it. However, their son seemed not to want to go back and they decided that the choice had to be his: *'He's quite happy ... we're not happy ... he's quite happy just sitting here and he watches the telly, will go to the football matches, he'll go on his brother's computer ... or they'll go out to the shopping centre, whatever ... he's just quite happy to do that. We're not happy that that's what he's doing, but at the end of the day he is 21 now and he has to make these decisions.'*

### University

Five young people were at, or had been at university. Organising going to university involved a lot of careful planning and families' experiences of support varied. University had positive aspects for all those young men who had experienced it, especially in relation to the social opportunities it offered and the adult learning environment. There were some difficulties in organising a reliable and sustainable package of care and support though. Those young men who lived at home and went to university, rather than living away from home, said that their opportunities for making friends were limited.

Getting support organised was a major concern. There was a range of experiences – some said the university (and in particular the disability advisor) took a helpful lead. Others said they had to organise most things themselves, including transport, and that the disability advisor was not very helpful.

One young person had had his 24 hour package of care organised by an independent company which had hired undergraduate students to provide the support. At the time of interview he had a team of five support workers, all students his own age. He had been supported in carrying out the interviews to pick his own support workers. They stayed overnight on the sofa bed in the living room. He was very positive indeed about how this had worked for him:

*'...you'll make friends with them and get on with them. They're not just there to like care and then turn up and then leave. I look for people... [who are] encouraging you to do things ... people who are quite energetic...they look for things that'll be better for me... they'll make me go out places ... I'll meet their friends and things like that.'*

The decision to live at home and commute or move out of home was significant. As discussed, one young person had his accommodation and support already arranged. Another person also moved away from home into accessible accommodation provided by the university, and another who was in the process of applying intended to do the same. The two others lived at home and commuted. One of those wondered whether that might change in the future: *'I think back then I wanted to stay at home, but ... I think maybe going away would have been good but ... but I'm happy with it as the way it is at the moment, so ... yeah. I just don't think I was ready to move away from home at that age really.'*

## Work

At the time of interview, only one person had had experience of paid work. Employment was identified as a priority for information and advice in the postal survey. Several interviewees did not

know who to talk to about employment and in this excerpt, the interviewer ends up volunteering some information:

Young person: *'I'd like to work but I don't know what I could do really.'*

Interviewer: *'I wonder, if you wanted additional advice on work, whether they could find out who your local disability employment advisor is.'*

Mother: *'See I've never heard that word. You know ... these are the things we don't know. And really you just don't know where to start. That's what we need, yeah ... so that's ... disability ... I'd better write it down.'*

Young person: *'Yeah you should.'*

Mother: *'Disability ... '(writing)*

## Views and aspirations concerning work

The young people at the older end of the age range were sceptical about work – their ability to do it, or the possibility that they would find it – or, had not given it much thought. Here a young man who was at home and not doing anything much during the day is pressed, gently, by his mother to think about doing something:

Mother: *'Even if it's like a work environment or something like that.'*

Young person: *'I wouldn't want a work environment. I never thought about working before.'*

Mother: *'Cos I suppose really it's like ... would he be able to like kind of thing'*

Young person: *'There's no jobs I like anyway'*

Mother: *'It's like ... there's going to be a new Tesco...'*

Young person: *'I'd probably get bored too easily. There wouldn't be much for me to do. I couldn't be packing all the bags.'*

Most young people who spoke about work thought that there would be big barriers to face: *'I've heard that it's quite hard for people who are disabled to get jobs. It might be difficult to get a job.'*

Others, often the younger men, and their families, did aspire to work for all the reasons mentioned above – money, fulfilment, and independence. One of the youngest planned to apply for part-time work at 'McDonald's' when he was sixteen and hoped to work as a mechanic in later life. His mother talked about something that came up in several interviews – a tension for parents between being supportive about work, whilst worrying that it may prove too difficult to find: *'I would love to see him go out and get a job, mix in with other people. But you kind of, you don't want to sort of like dash his*

hopes, and we do talk about you know 'when you get a job'. But in the back of your mind you think, 'I don't know whether you're going to get a job.' It's a very difficult one.'

Ultimately, nearly all parents who discussed work said that the choice would, in the end, be their son's. Another difficulty identified in thinking about work for young people with Duchenne by one mother was that her son had not had enough experiences of increasing adulthood, separation from family, or disabled role models to make choices or decisions about something as 'grown up' as work:

*'That's why I think it's difficult for him to make a choice about a career. When you've never caught a bus on your own and your mother's still following you around and your mother washes and dresses you - they haven't taken the steps which gives them any control. And then suddenly aged sixteen everyone is saying, 'What do you think?' and he's, 'Well what are you asking me for?'*

One young person who felt socially isolated explained that he had hoped that work might help him expand his social networks in the 'ordinary' way in which most non-disabled people meet colleagues and form friendships: *'I mean most people find friends and they don't even remember where they met, they're just friends. If you've got a job you meet people and you become friends. Then you go out after work and maybe you meet their friends; it's not a deliberate thing like, 'I'm going to find some friends'. The main reason I don't have friends is that I don't go out to work and I don't go out and meet people, so it just doesn't happen.'*

### **Experiences of trying to find work and being in work**

For many young people, expectations about work are shaped by early episodes of work experience organised in their school years. However, many had been excluded from school work experience apparently because placements could not be found which could accommodate their access and support needs or because there was not the same expectation that they would do it that existed for the other students.

Mother: *'Work experience! That was a laugh. We had to go on the internet and find him something to do. Well I didn't bother, thought well that's just ridiculous, you know.'*

Young person: *'They said if I wanted to do work experience I should stay in the school and do it and I said I don't want to, cos everybody else isn't.'*

Four young people had put a lot of time and effort into trying to find work – with very little success. Both faced similar problems when trying to access sources of advice like job centres and both faced a lot of barriers. Here are their summarised accounts. First a young person who had left school after his GCSEs: *'I was looking for like stuff in offices, stuff in like shops. I just assumed that I'd be able to get something. I sent lots of things like ... application forms and things like that, and I didn't really get many interviews for a while, so I decided to stop putting that I was like ... sort of disabled or anything on them. And I got a lot more. I got some interviews. And ... one of them, I couldn't believe they actually did this ... but one of them I went to, they turned up and went, 'Oh you're disabled!' They said that like at the start. They said, 'You didn't put that on the form'. It was just an absolute nightmare. The Jobcentre, they sort of like treated me like every other person and just went about the process in terms of just trying to get a job. But ... you need somebody to find places that would be interested in taking wheelchairs, and things that you can do. They didn't really keep in contact much at all, so I just stopped going in.'*

The second young person who put a huge effort into finding work had been at residential college, and then, for a time at university. He returned home when that did not work out and looked for work: *'I was looking into getting some work so I made an appointment to see the Disability Employment Advisor at the job centre, but she wasn't much good to be honest. She pretty much said straight away that there wouldn't be any work that I'd be able to do. I was hoping for a bit more of a positive approach than that! I thought it'd be the other way around – that they would be telling me it is possible when I think it's not. It wasn't even a case of looking, she just didn't even try. I also contacted people through New Deal for Disabled People 'cos they wrote to me. So I got in touch back and the guy said he would put me in touch with a job broker. But I never heard anything back from him either, so that wasn't very encouraging.'*

Finally, two brothers aged 17 and 19 who had given up college were trying to find out about getting jobs. The two young men and their mother described what had happened so far:

Mother: *'Their social worker was off sick so we hadn't had a visit in twelve months. So I thought – 'work'. I got in touch with the disability careers officer. She came out, totally unprepared, no ideas. So we went for this appointment at the careers office 'cos she said they should come in and do a test about what jobs would suit them best. But when we got there she wasn't there. So I spoke to another woman who said she didn't know anything about it. So then we went another time instead and they told them to sit at two computers to do the test but the desks were too low, they couldn't get to them with their chairs. I had to run home and get their trays to put the computers on.'*

Young person 1: *'You can see why we've got no confidence!'*

Young person 2: *'So my test said I should do gardening! I hate gardening.'*

Young person 1: *'And mine said work in an office or factory.'*

Mother: *'So the careers woman says what about working in a charity shop. Can you imagine it, two young lads in a smelly charity shop! Can't they show any more imagination than that? You can see why people are put off. It ain't as if you don't try.'*

One young person had been helped by his college to get a full-time job as a civil servant. His college had assigned him a job coach to work on the practical issues that would make work viable. Transport to and from work was paid for by the local authority. His health deteriorated and he moved to part-time work for four years before deciding to end work. He had support from 'access to work' and said that his own support needs were catered for. Looking back, his view was that on balance, it had been a good thing to do.

## Young men at home during the day

About a third of young men were at home during the day. They had got to that point in a number of different ways: leaving college or university because it ended, or because they weren't well enough to continue, or because they could not find work. The amount of time spent at home ranged from just a few months to seven years.

Young men at home for all, or most of the time, tended to say that they watched TV, played on their computers if they could, went out with close family members to places like the shops and the cinema. Parents often mentioned that their sons were becoming a bit 'nocturnal' and worried that they seemed withdrawn. One mother explained: *'You know he goes to bed late and doesn't get up till late. He keeps a lot to himself. He won't come out here very often. He spends a lot of time in his room, watching the telly and watching the videos.'*

These young men expressed a range of views. Some, especially those who felt they had 'over-stayed' their time at college said they were happy enough to be at home – but even these young men tended to feel less happy about it as the time went on: *'For the first year it was all right. But ... gets boring then. Only time I go out is when I go to the football matches, or when I go to respite [care].'*

Some were not happy with the situation and wanted to do more. One had investigated doing a foreign language class, but it was only offered in the afternoons when he needed to be on his ventilator. Another wanted to train to be a DJ. Another, who was interested in creative writing, had written a novel:

*'Writing is on my own, but at least it's good to be doing something.'*

Day centres had been explored by six young men and their families but were mostly disliked because the other users were much older and had learning disabilities.

Parents generally had quite mixed views about their son's being at home. They were worried if their son did not seem to have enough to do and were anxious that their potential was being wasted, but did not want to pressure them. Some seemed resigned, although not in a particularly positive sense, but because other options had been exhausted and they were very conscious that their son's condition would deteriorate: *'I think all of us [parents] just think, 'Well, he's in the best place. Make him as comfortable as possible. He's in his comfort zone – he's not going to go anywhere now.'*

Three sets of parents and two young people said that being at home had adversely affected their confidence:

Mother: *'You know ... that's how life should go, that you start to make your friends and have your outside interests away from your mum and dad. I just wish he could have ... for his sake, I wish he could have more of that you know. Because it is a confidence thing as well, his confidence has dipped hasn't it?'*

Young person: *'Yeah.'*

Here is an example, borne of concern and frustration, of a parent wishing that more was possible for her son who had left college:

Mother: *'What annoys me and his Dad is they've got so much potential and so much to give – why waste it? I mean you wouldn't would you? But having said that we aren't in his position. To me and his dad from our generation, it's just a complete waste. The whole waste of all this intelligence and knowledge that they've got and ... but it's like they say, if it's what [son] wants to do, well that's fine, but it just sometimes niggles you a bit... but they don't want to do it. And it's like as if they're giving up and you just want to shake them and ...'*

Young person: *'Well I wouldn't mind doing stuff with my intelligence, but sometimes...'*

Mother: *'It gets too much. We do understand ...'*

*we understand that. It's just when me and your Dad are having conversations with you and you're so knowledgeable about this and that and the other, you can understand from the parents' point of view. So you can understand we've a frustration that you've got so much to give. But we understand if that's the way you want to be. We don't mind, I don't mind about you being in the house and doing what you want to do, if this is where you feel comfortable. It's just, we feel that you have got so much potential, and it's just being wasted.'*

One of the main impediments to change seemed to be a lack of information and choices about what a young person who was at home could do, taking into account their impairments and current health, their access and support needs, transport, and of course their personal interests and the availability of other people with whom to do things.

Two brothers with Duchenne echoed comments from other families that they found it hard to make choices because they 'didn't know what was out there.' The brothers said there was no particular shortage of professionals coming to their house and saying, 'What do you want to do?', but they struggled to answer because they did not know what they could do. One of the brothers suggested that professionals sometimes appear to get frustrated with them when they seemed unable to answer.

Families in this situation did feel that there probably was a lack of choices that were age appropriate, accessible and enjoyable. One mother said: *'I don't know what there is really for ... I don't know what he would do. What do they do in other areas? If they don't go to college, what is there for young people to do? We haven't got anybody we can sit and discuss it with.'*

The young people themselves wanted to be with people of their own age doing things they enjoyed. One young man said: *'I'd like to go to like a place where... like a youth club where they MC (Master of Ceremonies) and stuff like that. I'd go and listen and watch.'*

## 4. What happens to services at transition?

**In this chapter we describe families' accounts of their interactions with services in general, but perhaps more importantly, families' accounts of what happens to services, their availability and their relationships with them once the young person with Duchenne reaches a 'transition age'.**

We know from previous research (outlined in chapter one) that there have been major concerns about what happens to families and young disabled people when they get to a certain age, in terms of the discontinuity of statutory service provision.

Some families had, by their own admission, a very limited idea about what would happen to the services they received and the professionals they saw: *'I would just like more information on transition and exactly ... how it goes. I mean is it [adults' services] just as good as the childrens' services? I mean why can't it be? Just because he's turned into an adult, why should the services change? Or why should they become more difficult to get'*

A young person agreed and suggested that part of the issue was that, post childhood, services did not actually seem to care that much what happened: *'It does seem to be that before you're sixteen there is a plan – this happens then that happens, and it's smooth. Then you get to a certain age and no-one's thought about what happens next. It's like, 'We've done our job now, it doesn't really matter what happens next just find out for yourself.' Once you've done with school it's like, 'OK, well you've got your benefits you can sit at home and do nothing and that's fine.'*

This young man's mother felt that some services had simply not expected her son to be alive: *'[Son] will be twenty-five this Christmas and it's as if some people think, 'Oh you're still around, you shouldn't be, we don't know what to do with you'. And I'm sure there's more and more boys lasting longer.'*

Most people mentioned the 'suddenness' of the service changes at transition typified by one mother's description of abandonment: *'...all of a sudden we was out on our own and we didn't know what to do.'*

### Families' experiences of services and transition

As background, all but three of the families characterised their overall experience of service provision as problematic. It was extremely common for families to describe having to prove their needs over and over again. Getting their son's needs met often involved 'fights' and 'battles.' Young men with Duchenne were often aware of these disputes and found them upsetting and stressful.

There were very few examples given of professionals acting as effective key workers or service coordinators for families. The parents felt that most things were down to them to sort out. This uncoordinated approach, and difficulty in getting needs met, was most commonly experienced in relation to:

- the provision of care/support packages
- decisions about residential education
- equipment including wheelchairs
- and housing and adaptations.

Those families which were positive about services in general stressed factors such as:

- good coordination through the Muscle Clinic in the North East
- planning ahead
- long-standing relationships between the family, the young man and 'helpful' professionals.

### Health services at transition

In relation to hospital based professionals, families in the North East almost all attended the Muscle Centre. The specialist knowledge and expertise at this centre was regarded by most families as very valuable, especially the fact that staff were 'under one roof.' Members of staff were widely regarded as pleasant and accessible. Some families complained that they sometimes had to see different staff members when they attended and expressed a preference for seeing the same person.

Most families in the West Midlands saw a consultant paediatrician in childhood, about whom they were very positive. In the South West clinical services for families and experiences of

clinicians were very varied. There were accounts of some positive relationships between families and services, but overall there was confusion about the structure and organisation of health services that were relevant to their son's needs.

The nature of transition from child to adult health services varied between and sometimes within regions. In the Peninsula area of the South West, some families were seeing local paediatricians and making a transfer to local adult consultants who usually specialised in respiratory or cardiac services. One young person had been through this transition just before the research interview took place: *'I think I've moved on to adult there now haven't I? It took me a long time to want to swap really. I seem to fit in so well with all the nurses and that on the kids ward, 'cos I've known them for a long time, so ... I felt I could trust them quite a lot, you know, and I didn't really want to swap over. But in the end I think it sort of automatically happened. But yeah, the last appointment was all right wasn't it?'*

Another family in this area described how their respiratory consultant in children's health services ran an 'adolescent clinic' and over time introduced their medical colleagues in adult respiratory care – *'so that he gets used to seeing him.'*

However the mother in this family did not know about neuromuscular adult health professionals and was worried after reading the Muscular Dystrophy Campaign's report (2007) on inequalities in access to adult health services in the South West: *'As far as the adult neuromuscular, I've no idea. I don't want to think about changing to adult – after reading that report!'*

Another family in the South West was facing an imminent transition from child health services. It had been suggested that their GP would become their primary health professional and they were very anxious about this:

*'It seems to have come all of a sudden – he was a child – now all of a sudden everyone's pulling out and disappearing and those that haven't yet are sort of saying 'Well get used to being on your own'. So it is just dawning on me that I need to get myself organised. Without some sort of guidance it's really scary.'*

Yet another family in the South West had made a transition from children's health services to their GP but not in a planned or deliberate fashion. Rather, they felt that they had fallen through the net: *'So, we still carried on seeing [children's consultant]. And then this particular day we was up there and he said, 'He's an adult now so he's got to go to adult services. So we said, 'Yeah, fair enough'. We seen someone and they said, 'See you in twelve months' time.' So we said, 'Yeah all right', and we're still waiting for the letter, and that was what, four, five years ago?'*

One young man expressed his concerns about his forthcoming transition to adult health services: *'What is adult services? I don't have a clue. They deal with adults crappy compared to children. I mean you just hear these stories that when you go into adult services you don't get things as quickly as ...'*

In the West Midlands, families who saw the consultant paediatrician said that they were given some leeway and quite a lot of notice about moving to adult health services, and what that would entail. One mother recounted: *'In fairness she said at the last meeting, 'Are you happy to move in March?' 'cos if you say you are, then we'll move you then.' But she inferred that if he wanted to stay a bit longer then it wouldn't be a problem.'*

Another parent explained how this 'leeway', and slight delay in transferring to adult service, had worked well for them: *'[Consultant] just said, 'Oh well perhaps we'll see you again in another six months'. Yeah, and then he was bad so she said, 'We won't kick you out just yet 'cos you're very bad' ... till the last time and then she said, 'I'm ever so sorry, I'm afraid we're going to have to hand you over now'. We have seen the new man and he was very nice.'*

In the North East, families who planned to stay in active contact with the muscle centre valued the fact that in this region, unusually, there was no discontinuity of service; the centre saw adults as well as children so care would remain constant throughout and beyond the transition to other adult services. One mother explained: *'It is a sort of difficult time, and those people that you've trusted are suddenly not going to be there [anymore], probably when you need them most. Fortunately, at least we've got [muscle clinic consultant] who will continue with us. We're not going to suddenly lose her.'*

## Social services at transition

Just under half of the families said that they had any contact with children's social services departments, either now or in the past. The majority of those who did have contact were critical of the nature and level of support they received. Contact was often intermittent and unsatisfactory. However, six families said that their social worker was supportive and carried out, what sounded to us, to be a coordinating role.

For those families who were able to make a comparison between child and adult social services and to describe how the transition worked, the significant difference was the end of the named relationship with a child social worker, replaced instead with a duty social worker system. One mother described it this way: *'If you want something, once you've turned eighteen, you have not got a social worker that would come and visit you on a monthly basis. You phone the civic centre and you're allocated a social worker that'll deal with the problem at hand and then it's gone. Then the next time you want one you get another one.'*

The effect of this kind of change was that families felt less supported, as another mother explained: *'I found that a bit difficult once he went over to adult. I found that they took less notice of you. It took longer to get things done, where they're [social workers] falling over themselves when they're children.'*

Another mother said that the transfer to adult social services led to an assessment which had concluded that the three nights a week care that the family had received from social services for several years was going to end. She commented: *'I'd say it's all changed since he's gone over to the adult services. I mean it was fine when he was in children's you know, 'Here have this, have this, have this.' Now it's, 'Taking that away, we're taking that away.' It was just a bombshell they dropped at the end, you know. Tick these [forms] ... and I thought, 'Oh it'd be all right. And then she said, 'Oh he doesn't meet the criteria.' And I thought I hadn't heard her right.'*

There was no easily identifiable pattern in the nature or age of transition from child to adult social services. In one family, contact with children's social services stopped at aged 16 and for the next two years there was no contact with social services.

Then, when the son was aged 18, an adult social worker initiated contact. There was, in effect, no transition: one service stopped and then after a while, another started. His mother found this disconcerting:

*'... between sixteen and eighteen there was nobody responsible for him really. He was in between, it's a very grey area.'*

Five families described an adult social worker coming 'to do the transition to adulthood'. However it was not clear to them what this meant. It often included an 'assessment', but it was not obvious what happened as a result. It was not clear why social workers involved with transition were being introduced to families at the age of 17 or 18 when they might be expected to be working with families at an earlier age. One mother said that her son was 17 before anyone in social services made themselves known to them, at which point the topic of transition was introduced:

*'[Children's social worker] was saying you know [son] should really be referred to this 'transition team'. But of course we've never had any dealings with social services, never had a social worker or anything. So maybe they were a bit slow, I don't know, but she was saying, 'Really at his age they should be involved. They should be planning.' So another social worker came out to do the assessments and then she goes. So then they send another social worker. So we've got to go through the thing again!'*

Three parents said that children's social services had provided a social or leisure service with which their sons would not be able to continue after service transition. One young person went to an outdoor activity group and another had a befriending service. The third had access to what he called a 'buddy'. However this ended when he was 16. One year on he said that he missed it: *'I did have a buddy but the money ran out. I do wish I had the buddy again sometimes though 'cos I get bored at the weekends. I did have a really good one but he disappeared. When it stops is when you need it the most, 'cos I couldn't do so much like... [my old] school friends are all over.'*

## Access to physiotherapy and hydrotherapy at transition

Some services received in childhood pretty much disappeared at transition to adulthood – hydrotherapy and physiotherapy being the most commonly cited, as one father of a 20 year old man reviewed with his son: *'You had your hydro pool once a week, you had physiotherapy once or twice a week. And that seemed to just stop. I mean you haven't had anything like that for years, have you?'*

There was a general lack of knowledge about why physiotherapy often stopped altogether at a certain age and if people had a right to physiotherapist in adulthood. One 22 year old said: *'Like physio, you get it till sixteen and then no idea what happens next. I don't get it anymore.'*

One family had a long standing relationship with their son's physiotherapist, who apparently decided to carry on coming to the family home to do physio even after he had become too old: She said; *'Technically he's not paediatrics any more' but she said, 'I'm not going to drop him, I've known him all his life!', and so she just came ... I don't know how she arranged it.'*

## Hospice provision at transition

Many families used their local hospice for short breaks and were overwhelmingly positive about the nature and quality of support they experienced. A small number of families said they were put off using their local hospice because of its strong connotations with the end of life.

Historically, young men with Duchenne attended children's hospices and were accommodated there for short breaks until they died. But greater life expectancy has meant that hospices accommodating young men with Duchenne have had to grapple with the difficulties of meeting the needs of an emerging, unanticipated, young adult population. For most young people in the study, reaching adulthood meant the end of their opportunities for short breaks at children's hospices. One mother in the South West, who felt this was just one of the many losses the family was facing at transition, explained: *'There won't be anywhere for him to go once [children's hospice] say he's too old to go there. So again, that's somebody else [who] has finished with him and [there's] nowhere to go.'*

We heard that some hospices had been flexible about applying the usual age criteria to young men with Duchenne. One mother, whose son had been using the hospice together with his friends explained: *'Because they're twenty-five this year, [hospice] can't take them after that age. I know it's like a children's hospice, but because with MD lads, cos they're going beyond their years, that's why they allow it to twenty-five, which is good of them to do that.'*

Some young men were aware that they could no longer, or soon would no longer be able to go to the hospices they had attended as children. A couple had been to see adult hospices and not liked them:

*'I don't really know what to say about it, it's not the same at all. I just don't like going there as much do I?'*

## Muscular Dystrophy Campaign regional care advisor/neuromuscular care advisors

In all three regions, families had – or had in the past – access to a Muscular Dystrophy Campaign regional care advisor, previously known as a family care officer. This post had historically been funded by the Muscular Dystrophy Campaign to provide a kind of coordinator role, which often spanned health and social care and was usually located in the hospital setting.

These roles had undergone quite a lot of change in recent years. In the North East the role was contained within the Muscle Centre and supported all ages. It was not seen separately as a family care officer by families, but rather as a core member of the Muscle Team. In the West Midlands the post had not been filled for the duration of this study, but an appointment was made in January 2009. In the South West, the number of hours available had been reduced and along with it the age ranges of people who could be supported. The post was no longer funded by the Muscular Dystrophy Campaign but had been subsumed within the NHS and re-named a 'neuromuscular care advisor'. In May 2008, a second person was appointed on a part-time basis to cover children in the south of the region. In 2009 following the launch of a

Muscular Dystrophy Campaign report highlighting major deficiencies in care for those with muscle disease in the South West, the NHS committed £1 million to improving services. The new South West 'neuromuscular network' will include dedicated consultants, physiotherapists and care advisors for the area, to help families access the multi-disciplinary services they need.

Fifty percent of the families in the study talked about regional care advisors as having provided positive and significant support. This makes this post the most positively regarded of all professionals from the perspective of families interviewed in this study. Aspects of support which were most commonly valued were: the practical

nature of help given – actually getting things done and sorted out; the co-ordinating role; the extensive contacts and knowledge of the family care officer; and, for some, the emotional support offered by the person in this role. There were only a very small number of families who said that they were currently being supported by regional care advisors, so their accounts were retrospective. These comments from parents were typical: '[x] was helpful – would visit and listen to what we had to say and deal with the practicalities. She was great – she wanted to do things for the families. She would sometimes ring us and just see how we were doing. If there was any problems, no matter what the subject was, she'd be able to go and find out the procedure.'



'They decided to set up a team down here. It's amazing, I love it.'

## 5. 'Having a life': social lives, independence and support

### **We know from the research discussed in chapter one that young disabled people in general can face barriers to participating in society.**

This chapter describes what young people and their parents had to say about their social lives, friendships and relationships. Young men with Duchenne need good, appropriate support to live as full a life as possible. This chapter also outlines their experiences of getting support and the issues raised when that support is inadequate.

### **Young people's social worlds**

The young men who were at home during the day (around a third of those interviewed), had social lives which were almost entirely conducted as part of family activities; they had few independent friends of their own. The others had a wider social network, especially those still at school, at residential college or at university. Indeed, one young man living away at university had a full social life which was entirely comparable to any non-disabled peer. Young men said friends could be a big source of support. One had a well developed and very long standing set of friends with whom he kept in touch, and who kept in touch with him: *'suppose it's why I've always been like positive you know. Loads of people round us, makes it easier for you to handle things.'*

For several of the young men, the absence of friends made it difficult to have a social life. One 22 year old who was at home said: *'I don't really have anyone to go out with or anything.'*

A lack of friends and accessible local amenities meant that one 17 year old's social activities were limited to college. Even so, this was some distance away and he had to leave promptly by bus at the end of the day:

Mother: *'There's nothing round here for him to do.'*

Sister: *'You haven't really got any mates round here have you?'*

Mother: *'But there's nothing here ... all he can do is go bowling.'*

Sister: *'You can't even go cinema and stuff.'*

Mother: *'He can't get into the cinema, he can't go swimming.'*

Interviewer: *'Is the cinema not accessible?'*

Young person: *'No.'*

Mother: *'And he can't go swimming 'cos that's not accessible either.'*

The young people interviewed had a range of interests, hobbies and pastimes. Music, computers, TV, films, cars, cinema and sport featured. Three had season tickets for local football clubs and attended home matches. A number were involved in wheelchair football or hockey, including competitive games with travel across their region and beyond. One young man explained how local parents of disabled children had set up a team: *'It's just a couple of parents of disabled kids found out there was a form of football that we could play. 'Cos they knew that a lot of us love football and we'd love to play it. So they decided to set up a team down here. I mean it's amazing, I love it.'*

As we have seen, after leaving school or college, many young people had experienced a decrease in social lives and friendships and spent more time at home watching TV, DVDs or playing on their computers. Several interviews had a sad sense of friends moving on and the young person with Duchenne being 'left behind'. School friends might go away to university, move away from home, or get partners or marry: Mother: *'And of course he had a friend who came here from the age of about four years old. He used to come here every weekend and everything. And I said to [son] you know, when he discovers girls he's going to be gone. He discovered girls, he's gone.'*

Young person: *'And he's got a job. And stuff.'*

Mother: *'Yeah and of course they move away, they do. So ...'*

School and college trips sometimes necessitated parents to be involved so that their sons could join in. In some families this continued beyond school and college. If young people needed accessible transport, the chances were that their parents would have to take them. Consequently, they were

not able to gain much independence from their parents, who were often instrumental in their social lives as well.

Doing things with your family is not a bad thing in itself, of course, and families spoke with a great deal of pleasure about the enjoyable things they did together. However, this was not always entirely through choice. Sometimes it was due to the lack of other friends, or high levels of support the young person required.

A small number of young people who lived at home were able to exercise greater independence. This was often linked to the availability of accessible public transport locally. One 16 year old was able to go to the nearby city with friends, without any adults. This was important to him – and to his mother: Mother: *'Yeah I mean you do, you have quite a lot of freedom really don't you?'* Young person: *'Yeah, yeah I do have quite a lot of freedom.'*

Interviewer: *'And is that important to you?'*

Young person: *'Yes. 'cos if you don't have much freedom it's just boring isn't it? If you can't do what you want because you've got to be like with your parents and stuff.'*

## Relationships

Four of the forty young men interviewed said that they had girlfriends and felt this had made a positive difference to their lives:

*'It's much better. I've got a much more interesting life now. It's somebody to talk to.'*

A young person at a residential college said it had been easier for him to find a girlfriend there than at home. He said it was 'great' to be in a relationship, but added that he did not feel he always had the privacy he would have liked: *'To be honest with you, I do feel that I'm a bit watched and a bit restricted with the relationship.'*

One young man still needed his mother to help him get to places with his girlfriend. She shared his concern that they did not get as much privacy as a non-disabled teenage couple: *'Her [girlfriend's] Dad and I decided early that we wanted them to have as normal a relationship as possible and embrace it in all its aspects, but we're a bit stuck.'* The interview continued:

Mother: *'When we said embrace all aspects of the relationship...'*

Young person: *'Mum!'*

Mother: *'...we meant all aspects....and his social worker is coming to talk to [son] to about sorting things out and she thought [hospice] would get involved with that, but [hospice] have said absolutely not and [son] was like, 'I can't believe my Mum's had this conversation...'*

Young person: *'I can't!'*

Mother: *'But she said it's about giving [son] a normal a life as possible and I was impressed that they're willing to do that and it's ironic that he can't have a buddy to go ten pin bowling with, but if he wants to have sex with his girlfriend they'll make the arrangements.'*

Young person: *'I wondered when you were going to bring that up! [all laugh].'*

Other young men said that they would like to have a relationship, a desire echoed by some of their parents. One mother said: *'I would love him to get a girlfriend – he'd love to get a girlfriend! I just wish people would see past the chair. Metal casing, but he's quite soft in the middle.'*

When asked, others said it was something that they would like to happen, as in the case of these two young men: *'I ain't in a relationship, no. It's hard 'cos no-one will particularly talk to you 'cos you're in a wheelchair. That's what I think. They kind of ignore you. And we don't know what to say.'* *'At the moment I haven't got one [girlfriend] but there are people I like and stuff. We [friends] talk about stuff like that – girls and stuff like that.'*

## Getting support

We wanted to explore experiences of support and care and see if, for example, close relationships of care between parents and children endured into adulthood. We wondered if these got in the way of 'ordinary' family transitions, where children are expected to develop more separateness and independence from their parents. Most parents and young people said that they did not have enough space from each other, not in an overtly negative way, but with an acceptance that their relationships were more intertwined than in many other families.

There were very differing amounts and types of external support being given to families with apparently quite similar levels of need. The range of support provided included the following:

- A carer coming into the house, 9.00am-3.00pm, five days a week, via a direct payment
- Using a direct payment to pay for housework to free up time for the mother to support her son
- Two carers coming into the house, 5.00pm-7.30pm, every day
- Mother (30 hours a week) and brother (40 hours) providing paid care via direct payment and the Independent Living Fund
- 24/7 nursing care
- A carer coming into the house 10.30pm-8.30am, six days a week
- A carer living in 24/7 – one week on, one week off
- A carer coming in, one hour a day, five mornings a week, paid for by family

There was no one, typical, care package. Very few families had had straightforward experiences of getting the care and support they wanted. The need for additional care sometimes came about as parents got older, or had health problems of their own, especially back pain, possibly as a result of lifting, the young person as they got older and bigger.

Most parents were still providing a lot of support and care at home, either instead of or as well as, paid carers. About one fifth of families had no external care or support but managed it all within the family. A number of reasons were given for this: for most it was a combination of the young person ('we have our mum to do all that') and his parents deciding that it was best for them and sometimes their extended family to do the job. They preferred this to outsiders coming in, as one mother explained: *'We don't want it. Basically [son's] quite happy isn't he with me just caring, you don't really feel ... you know we feel like we cope okay. So just at the moment we're quite happy with the arrangements we've got.'*

Some parents said they wanted to preserve family privacy, for example:

*'...we decided against that because we wanted to keep the house ... you know like a normal family, as private as possible, rather than having people in to give care.'*

Some added that if they could be really confident that they could find people they trusted to offer a comparable level and quality of skilled care, they might re-think their position.

Where parents were providing most of the care-giving and support it had an effect on the parent/child relationship and on the identity of parents, who considered that they had an unhealthy dual role of both parent and carer. One mother said she felt as if she was employed by her son: *'It's like my company is my son and that's my sole purpose in life. It's like if I'm not providing the care I'm organising the care. That is all I do. It is more difficult [as son gets older] because where normally there would be a distance between us. I do more for him now than I did when he was five and it should be the reverse of that. It's been him and me constantly. There's no such thing as him slamming the door and saying, 'Get lost mother!'; because he can't lose me, we're stuck with each other. And he's got no freedom and I've got no freedom. So we're bound together.'*

Another mother had applied to the Independent Living Fund to get more support at home precisely because she did not want to become her son's full-time carer: *'I don't particularly want to give up my job to care for [son] in the day time as well, but equally I don't think it's that healthy for a young man to spend all his time with a middle aged mother. You know it would be good for him to have a carer who's a young man, somebody in his own age group really.'*

In the small number of families where the young person lived away from home, a greater degree of separation had been achieved. One such mother reflected on how this had changed relationships within the family: *'It's strange, I feel happier. I hadn't realised how much hard work it was looking after ... I mean, I did it every day and I didn't begrudge it, I enjoyed looking after him ... but when he actually went away, I found I had a good nights sleep and then I could get up whatever time I wanted and go out without arranging for somebody else to look after him ... I hadn't realised how tired I was! It did me good, but also it's altered his attitude. While I was his chief carer, he was really quite, you know, kind and nice to me! (laughs) ... and now he's really rude and abusive because he knows that he's got his own carers and he's not relying on me for anything ... I don't mean in a nasty way, he's like ... he's become a teenager a bit later on, because he can answer me back! I would have never withdrawn my services*

when I was looking after him, but I think he always ... he could see that I was doing a lot of work for him, so he was, you know, politer to me! (laughs) And now he feels he can say anything ... he keeps saying, 'Oh it's all right, I've got younger more able carers now'. But I quite like that, because it's more of a normal parent child relationship.'

Families that did have external support and care coming into the house described advantages and disadvantages. The support was needed and welcomed, but the effect on family life was disruptive: 'It's stressful – you don't have a private life. I wish there was another way of doing it.'

There were some concerns about the rigidity of care arrangements and the impact of this on the young people's life. In one family with a 19 year old son, support staff came to the house at 9.00pm every night, so he had to be home and ready to go to bed. The young person and his mother were frustrated at the inflexibility of the arrangement which curtailed any social life in the evening. His mother said: 'He's got to be back for nine o'clock for the carers putting him to bed. You can't have a social life, can you?'

A different family had successfully challenged a proposed similar arrangement. The father had told carers that they could not tell their 21 year old son what time to go to bed: 'He'll go to bed when he wants!' One care agency insisted that their staff had to wear uniforms. The young person concerned found this off-putting and said that this inhibited him from going out to social venues with them.

One young man who was living away from home while attending university had a care package of support from fellow students organised by a care management company. He and his parents had confidence about his care and support arrangements and as a result he had a degree of autonomy that stood out from the others. His mother said: 'The good thing is that I feel so confident about it, that if I don't hear from him for a few days, I don't worry that there's anything wrong.'

## Direct Payments

About a third of parents were using direct payments, although no young men aged 16 to 18 had a direct payment in their own right, as they

are now entitled. There were mixed views about and experiences of, direct payments. One family said they had felt a bit pushed into using them, but were definitely 'not interested': 'We had some leaflets but never really did anything about it. We have our mum to do all that.'

Another family applied for direct payments because the parents thought it was time for their son to:

'...have some different faces... it'll give [son] a bit more independence not having to go out with me or his dad all the time. You know at eighteen you don't want to be trailing behind your mum and dad, do you?'

But they were concerned about making direct payments work, especially in recruiting and retaining good staff and had not proceeded. Several families had been successful in sorting out direct payments with the intention of employing support workers, but had then been unable to recruit anyone. Others were put off because they did not think they would find anyone.

Some parents were concerned that having a direct payment would add another layer of responsibility and effort to their already busy lives: 'I don't want to be an employer, I've got enough on my plate', one mother said.

A small number of parents were using the services of third party organisations which acted as brokers and took on the administration of the direct payment including recruiting support workers. However, they involved the family and young person in drawing up a job description and in interviewing applicants, as one mother explained: 'They're going to set up all the interviews and place the advertisements and sort out the pay slips and the tax and the national insurance. So they're just taking all the hard work out of it, and we're just going to do the interviews.'

Most people who knew about direct payments thought that they could only be used to pay for personal assistants for the young person. However, two families were using them more flexibly. One was paying for housework to free the mother to care for her son and another was using it to have the ironing done and to have someone to sit with her son, so that she could go out.

## 6. Living with Duchenne and becoming an adult

**This chapter explores the impact of living with Duchenne and how it might affect the process of becoming an adult.**

### Talking about Duchenne

We were interested in how Duchenne was spoken about within families and with the 'outside world' of professionals. Not surprisingly, families dealt with communicating about Duchenne in different ways. These changed over time, as the young person got older, or had a health scare, or following a suggestion from someone outside the family that an issue should be discussed.

The most common response from young men to our questions about Duchenne was that they did think about it sometimes, but that it was at the back of their minds rather than the front. It would be hard to stay positive about life otherwise, they said. These quotes typify the kind of responses from young men (aged 20, 22 and 33 respectively):  
*'In everyday life I didn't think about it much. I try not to think about it.'*  
*'Sometimes you talk about it and sometimes you don't. I'm not bothered about talking about it though.'*  
*'I've got it everyday. I know what I need to know. I'm not really interested.'*

By and large, families wanted to decide for themselves how they wanted to manage talking about Duchenne. So, for example, one family was very angry when a consultant told them that 'there was nothing more that could be done.' She was upset that her son had been 'exposed' to information which she did not want him to be aware of: *'Nobody's going to say anything to him. I mean nobody knows what the boys know and what they don't know. And our view is [that] what people don't know don't harm them. And unless they come to us, their parents, and ask us a specific question, like 'What happens when I get to twenty-something?' – you leave it. Because some people can hack being terminally ill and some people can't. My son can't. Me and his Dad know that and we act on that.'*

The most common way in which the subject of Duchenne and the course of the condition was discussed was gradually, over time. It surfaced at different points as their child grew up and was presented with different challenges. In general, the parents interviewed said they would always 'tell the truth' if asked, but some volunteered more information than others, as one mother explained: *'He's never asked anything. Not a thing. We've always been on a 'need to know' basis. We never lie, but as each part of the condition's come up he's been told about it. But we've never volunteered more information than he needs to know at that particular time. Like specially as a child. I think if you start instilling in a child, maybe five or six, that they've got this illness that they're maybe not going to live through past a certain age, it's got to have a hell of an effect on them.'*

Four parents said that there was an element of self-censorship; not talking about the emotional aspects of living with Duchenne was linked to protecting others. Two mothers reported that their sons wanted to protect them by not showing their emotions or talking about their concerns:  
Interviewer: *'Who can you talk to?'*  
Young person: *'Do I speak to you Mum?'*  
Mother: *'No, you try to protect me.'*

One young person aged 24, acknowledged that he worried more about how others in his family were affected by his diagnosis than about himself: *'I remember when they told me and the first thing I asked was whether my gran knew 'cos I didn't want her to be upset. I wasn't worried about being upset myself.'*

Nonetheless, most young people said their parents were the people they spoke to most about any questions or concerns that they had about Duchenne. Some also spoke to their friends, but others did not. One young person mentioned that he spoke to his grandmother; there was more privacy at her house than at home where he said his brother was, 'always listening in.' Whoever they spoke to, it was not easy. One young man said:

*'My mum mainly I'd talk to. I don't feel that open with other people ... not even some of my friends I'd talk about it that much, other than sort of my one friend, but I've known him all my life. So, no, there's not that many people to talk to really.'*

Parents were not always sure what their sons did or did not know, or where they got their information from, although they usually thought they had a good idea. One father said:

*'He's known since he was about four and a half that it was terminal, but we still to this day don't know how he worked it out.'*

In one family there was a mismatch between what their 16 year old son knew and what his parents thought he knew. This became clear in the course of the research interview in which mother, father and son took part together:

Mother: *'Although he's really good in computers and everything, he never chose to actually go onto the computer and look up all about Duchenne.'*

Young person: *'No I did ...'*

Father (to Mother): *'Not that you know of! (laughs).'*

Young person: *'I actually did, but I didn't want to talk about it.'*

Mother: *'Oh right, right. So when was this? Is this new then?'*

Young person: *'No it's not!'*

Mother: *'Okay, sorry. Right.'*

One mother said that because medical treatments and interventions were changing along with life expectancy, it was hard to give just one answer to a question about what would happen in the future:

*'We've never told him the ultimate answer but we've always said if he asks we'll tell him. But we're not suddenly going to say, 'Oh by the way... 'Because we've lost four friends in the last two years from as young as 16, we stupidly assumed that he must know. But if he does, he's not saying because he's been spoken to and he just won't discuss anything. And in his head I think he just thinks they were unlucky and had something else wrong as well.'*

A young man considered that his parents had done the 'right thing' by not telling him everything in one go when he was a small child: *'My parents didn't*

*want to scare me too much. They said I had weak muscles. I think they dealt with it in the right way.'*

A small number of young men were clear that they did not have enough information and did not feel that they had people to talk to, as in these examples from interviews: *'No one's ever told me anything, I just sort of found out myself. I don't know if there is a way of finding anything out really.'*

This young person had been part of a group facilitated by a psychologist, which no longer existed. Here young men with Duchenne had been able to talk about anything that was troubling them. He raised an issue which did not surface a great deal in the other interviews, about young people's coping mechanisms, and their behavioural and emotional responses to living with Duchenne: *'I mean a while ago a couple of friends of mine had muscular dystrophy, they were about my same age ... we used to go to this meeting where we'd just go and talk about anything – like if we couldn't talk to mum and dad about. I mean we could talk about a really depressing subject but we'd have a laugh about it. And I'd come out of it feeling loads better. It's not that easy to talk about a lot of things about MD with your mum and dad. It's a shame there's nothing really like that [anymore]. We spoke about everything. How did we feel if something annoyed us or whatever? How did we get it off our chest or whatever. I used to do like weird things, like ram into things and swear at people and stuff. But now ... I don't know really, I just sort of bottle it all up now.'*

Four other families explicitly discussed mental health and emotional well-being in relation to Duchenne. One mother told us that her son had self harmed and had been seeing a psychiatrist. The young person said he had found the psychiatrist useful. Another mother mentioned that both she and her son were on anti-depressants.

In some families, the loss of friends and peers with Duchenne could be a catalyst for sadness and anxiety about the future. One mother believed that she did not need to tell her son about Duchenne and the future because it became self evident when his school friends with Duchenne died. Some young men were at a very young age when they experienced friends dying. As one young person in his early twenties explained, the emotions were complex and involved grief for the lost friend as well as sadness for himself: *'Generally you try not*

*to think about it but when there have been friends passing away then you talk about it with your friends. It's been difficult because when that happens people are upset – upset about it happening. But also when someone dies, because they've got the same condition as you, that makes it harder because you think, well the same thing could happen to me.'*

Most parents understandably found it hard to think about death and other end of life issues. This was evident in different ways: some did not want to be involved in MD support groups, the Duchenne Family Support Group; others tried to avoid all families who had a son with Duchenne; others were wary of hospices. Thus, one father explained why they did not use the local hospice for short breaks: *'[Hospice] is a right downer really ... let's not beat about the bush about it. You know... I went through one door and I was out the other wasn't I? I just couldn't cope with it in there.'*

### Planning ahead amidst uncertainty

When asked about the future, many parents said that they took one day at a time because the future was unknown and uncertain. One mother explained: *'You've got to live in the here and now. You live for today. It's not to deny it's there but you can't dwell on the end else you'd be depressed all the time.'*

A father made a similar point: *'You want to plan a future but you don't ... you're a bit scared to. Yeah. Cos it is uncertain, I think basically that's it ... as they turn into adults, it is ... it's an uncertain world, that's where we live, isn't it?'*

A minority of parents went so far as to say they did not want to even think, or indeed know much about the future at all. In one mother's words: *'We tend not to want to find out anything what's going to happen. You just take it as it comes kind of thing, don't we. Don't want to, like, look into the future.'*

Some young men recognised that the future would be a mix of ups and downs:

*'Generally at the moment I'm thinking it will be quite good, but then sometimes I think, 'Oh it's going to be really bad. I don't really want to go into that next stage'. But generally I think it will be good, but it'll still have this downside.'*

One mother reflected on this tension between living day to day and living an 'ordinary family life' which necessitated planning ahead to a degree: *'We always lived day to day as normal because he is normal in every way other than his disability. When he becomes ill then it changes. You can't worry about it, you might just as well continue as you're carrying on. And you can't change it. You can just be as prepared as you can be. You can't not do things in case you die and that's probably true for everybody. So really, you just hope that he stays well. You can't live each day expecting that this will be your last and that there's no point making any plans. I make endless holiday plans because then you create memories – happy memories – then you've got something.'*

Thinking ahead and about adulthood and growing up, is, of course a dynamic process. Parents spoke about the adjustments they had to make. One mother explained: *'Don't forget that [son] was diagnosed aged five and a half, so I've had ten years to think about this. One of the things is that when he was diagnosed you think there'll be an immediate change and when that doesn't happen it takes a bit of adjustment and then along the way you have major things...'*

An important issue for families was having to revise their expectations. Many of them had sons who had reached an age which at the time the diagnosis had been made was not thought possible. This was not without its psychological complications. One mother explained that the family had been anticipating, and grieving, his death at a much earlier age: *'I feel we've grieved for ten years when we didn't necessarily need to.'*

What went largely unsaid was that thinking about the future was so unpalatable, precisely because it inevitably meant thinking about the death of the young person with Duchenne in the family. One mother tentatively shared her thoughts about her own future, which were linked inexorably with her son's: *'It's not nice to plan ahead, but you have to. We've bought a house in Spain ... if anything happened that's where I'm going. And God willing, that'll be a long, long time, but that's the plan. And you can't really plan. You know like people say, 'Are you going to live there?' And you think, 'Yeah yeah'. Then you think, 'But what's got to come before?'*

A small number of parents discussed how their own and other people's expectations of their son, including how long they would live, had affected their choices and options. One father said:

*'When he was fourteen or fifteen, he wasn't looking in the long term for qualifications. 'Cos he's saying, 'Well it's a waste of time, I'm not going to be around, you know. You can see his point of view. I know he's only sixteen, but you can see his point of view.'*

One mother said that she had been told that her son was not a sufficiently high enough priority for hydrotherapy. She felt that this was giving a message that he was not 'worth it': *'I asked for hydrotherapy and the local physiotherapist actually said, 'There's a waiting list and some of the children on it will actually go into adulthood so we have to make provision for them'. So I said, 'With adequate physio there's no reason why my son can't make it into adulthood.' To me it just said, 'I don't have enough money, I'm prioritising the ones that will make it into adulthood and sorry, you're off the end and if he dies well, it doesn't look too bad, because we're all expecting that anyway.'*



*'It's good - being in a relationship - it's somebody to talk to.'*

## 7. Conclusions

### What are the most significant findings in this study?

Although around half the families recalled having been involved in some planning for transition for school and from children's to adult services, there was **an alarming absence of examples of formal transition planning** as required by the various statutory instruments and policy guidelines in the past twenty years.

While many young men had good things to say about their time at school, college and university, there were **many examples of systemic failures** to meet their needs in relation to physical access, access to a full curriculum and, most commonly, to participation in activities outside of school, particularly work experience, field trips and social outings. Many of these exclusions seem to be in breach of the Disability Discrimination Act (as well as other Human Rights legislation).

Families and young people felt that **they did not have enough specific information about choices** post-school and post-college.

**Only one young man had had experience of paid work.** Others who had looked for work had faced insurmountable obstacles.

About 30 percent of young men were at home during the day and not doing any kind of education, training or work. Most of them felt that being at home was not stimulating enough and their parents agreed. These young men had **very limited social opportunities or friends beyond their immediate family.** It seemed entirely possible to us, given the lack of real options post school/college that many of the younger men we interviewed who were still in education, would, in the end, also end up at home.

All but three of the 40 families interviewed characterised their **overall experience of service provision as problematic.** Families described having to constantly prove their needs and getting them met was often a protracted and acrimonious process.

Despite policies recommending the use of key workers or co-ordinators for families with disabled children, we found **very few examples of professionals taking on this 'keyworker' role.** Most parents said that it was up to them to sort things out.

**Family care officers and neuromuscular care advisors were the most positively regarded professionals overall.** This seemed to be because of the overview role that they had. This post, to some extent, straddled the social and health care divide and was seen as a reliable source of information and support. However, the service was only partially available in the South West, not available in the West Midlands (over the duration of this study), and in the North East, not always recognised as a source of support for non-health related issues.

Across the three regions there were fairly **wide variations in service pathways to health care and health care professionals.** Perhaps of most concern was the absence of adult neuromuscular specialists in the South West. Within each of the three regions there was praise from families about some individual medical professionals and in the North East, the majority of families who attended the Muscle Centre said that they valued the expertise and continuity of relationships and service provision which was available there.

There were very wide **variations within and between regions in the nature and level of support available to families in terms of care packages** provided. The way in which young people's needs were met seemed to owe more to how tenacious and resourceful parents could be in fighting for support, and to their finding particularly helpful professionals – and less to the actual level of their son's needs. Some families resisted outside care altogether. Most parents were still doing a lot of physical care and support; this hampered their son's capacity to develop 'normal' young adult relationships with their parents. None of the young people who were eligible for a direct payment in their own right had one.

**The ways in which families talked about living with and being affected by Duchenne was highly individual.** The main theme was that young men said that they preferred not to think about it very much because they said it was too hard to stay positive if they did. They did not want it to be ignored. Parents were not always sure what their sons did, or did not know, about having Duchenne. They were not always sure what they should tell their sons, given relatively recent increases in life expectancy and developments in medical interventions.

Both young men and their parents said that they **tended to 'live for the day'**, in large part because the future was so uncertain. There was a strong desire to 'get on' with the ordinary business of family life although achieving this was often hampered by a lack of support from services; some of these services were perceived as finding it hard to relate to the young men as more than the sum of a person with Duchenne.

The young men with Duchenne, their siblings and parents demonstrated **huge resilience in the face of some extraordinary challenges**. Relationships within families were often extremely close, mutually supportive and characterised by warmth, humour, and an overwhelming desire to 'lead a good life' despite the obstacles that they faced.

### **How can the health and well-being of young men living with DMD, and that of their carers be maximised, particularly at the transition to adulthood?**

What did the young men and their parents identify as being helpful at the transition to adulthood? Relationships which were long standing, had continuity and were reliable stood out as being the most positive. They were highly valued as they **made a difference**.

We highlight 'making a difference' because it seemed to us that many of the 'trappings' of statutory transition procedures and processes did not make any difference to families. What helped were relationships with professionals who knew the family and the young person well and who seemed to care about what happened. The role or background of this person did not seem to be the deciding factor. Some families had a particularly helpful physiotherapist, whilst for other families it

could be their social worker, or a family care officer. The characteristics of professionals and services that were most positively regarded also included: trust, being approachable, being contactable, reliable at getting back to people and returning calls, knowledgeable about Duchenne, being flexible, and making an effort to engage with and relate to the young person with Duchenne in their own right.

What young men and their parents said would be most helpful, particularly at transition was:

**Information about options post school/college** was desperately sought by many families; this was not general information, but specific information about real, local options. As well as being affordable, these would meet essential requirements including transport to get to and fro, good quality support, in an accessible building with accessible toilets. Most importantly, this would be something in which the young person was interested, with others of similar ages and where there were chances to make and meet friends.

**Information about the changes to services and entitlements** at the transition from childrens' to adults' services. It seemed to us that the surprise or shock of losing key people or access to services was at least as bad as losing the services. If families are treated as partners with the professionals, and prepared for the differences that do exist between childrens' and adults' services, they may feel less anxious.

**Easy access to high-quality health care and services.** Services like physiotherapy and hydrotherapy help physical well-being. This may sound like a 'given' but in fact as we have seen in one region, families were being directed towards their GPs as their main health contact once their sons reached adulthood.

**Keeping the emphasis on everyday 'normal' life.** Young people did not have much to say about the structure of services, or the processes of transition and of course this is no surprise. Their dominant concerns were friendships, their social life, their overall health, their families, and whatever they were doing day to day. Duchenne rarely went away and families had developed all kinds of coping styles and mechanisms to deal with this, but they did not like it when other people treated the young

person with Duchenne, and his family, as if there was nothing else in their lives except Duchenne.

**Opportunities to talk about DMD.** It was important for the young men to know that when they did want to talk about their concerns or questions, that they would be able to do this – with parents primarily, but sometimes also friends, other family members, or trusted people outside the home. A small number of young had experienced the value of talking to a psychologist and being part of a group of peers where there was frank discussion about living with Duchenne. Clearly one size does not fit all and some young people might not want to talk to anyone outside the family, but it seems important for opportunities to be presented to young men and their families which they can then decide to take up, or not.

### What about government policy?

Government policy in England is expressed in the National Service Framework (NSF) for Long Term Neurological Conditions (Department of Health, 2005). This was published in 2005 and aims to improve the lives of people with long term neurological conditions such as DMD by:

- giving people choice, through services planned and delivered around their individual needs
- supporting people to live independently and play their full part in society
- coordinating partnership working between health and social services and other local agencies.

The NSF calls for **person centred services**, sensitive to changes at transition, which promote independence and autonomy, and which offer, or signpost, a range of health (including psychological/emotional health) and social care services. It is based on a set of 'quality requirements' (QRs) which are expected to be implemented locally over a ten year period ending in 2015.

The NSF has a potentially important contribution to make. It is directed at commissioners and providers of services. Thus, **it reiterates importance of transition planning and of care-coordinators and encourages commissioning of multidisciplinary teams** with social care as well as health care. It reminds professionals that giving people information is an active process.

**The NSF also promotes the use of flexible services** and the use of direct payments and individual budgets. But, as we have seen, there is some way to go to make these systems work effectively. It encourages appropriate equipment to be provided to maintain health and improve quality of life. However, there is no ring fenced funding; this is the responsibility of local commissioners and it seems that many families will continue to have to 'fight'.

Finally, the NSF points out that recent policy and legislation, such as the Carers and Disabled Children Act 2000, is intended to support family carers in their own right<sup>2</sup>. However, it recognises that services for family carers of people with long term neuromuscular conditions should be improved. Commissioners can give funding to family support groups. However, as we have seen, policy and good intentions are not enough.

### It's relationships that matter

As discussed above, good relationships between our group of young men with long-term conditions and their families and professionals make an enormous difference. Relationships between services and young men and families can be both a source of support and stress. Good relationships are characterised by the features mentioned above: reliability, trust, longevity and so on. It is difficult to account for why some families had better relationships with services than others and equally difficult to work out why some families were actively involved with services whilst others were less so, and of these, some were more, or less happy about their low levels of interaction.

Some families were more able to exploit networks of support beyond services and draw on friends, neighbours, colleagues or friends. It seemed to us that some of these families felt more in control of events. Whilst some families did seem able to solve their own problems and bypass services to a degree, some families were better equipped to do this than others. In too many cases, parents appeared to have been worn down by years of effort; sometimes they seemed to have entered a state of passivity: they had hoped that something, a visit or a service, would happen, but were not really surprised when it did not, and so they did not 'chase it up.'

2. [www.Direct.gov.uk/Carers](http://www.Direct.gov.uk/Carers)

From the perspective of young men and their parents, the best relationships, just as in 'ordinary life', were those where they **liked** the professional and felt it was reciprocated, or even, as one parent put it, 'someone who's on our side.'

For example, the young man who said he could 'have a laugh' with his physiotherapist; the family who said their physiotherapist was almost like a family friend. In the worst scenarios, there were relationships with much less warmth or humanity: carers from an agency which required staff always to wear uniforms, thus inhibiting the young person from going out in public with them; and the carers who came to one young man's home at 9pm every night to, 'put him to bed' so that he did not have an evening social life.

Relationships between parents and those with long-term conditions in this study were complex. There were very strong bonds between parents and their sons, and between young men with Duchenne and other siblings – as well as the ordinary sibling conflicts and arguments. We have described how the close caring relationships could mean a lack of opportunities for parent-child relationships to develop in an 'ordinary fashion'. One of the consequences of this seemed to us to be, at times, an intertwined sense of self and identity between parents and their sons.

Carrying out interviews in which parents and young men elected to talk together, and looking at interview transcripts, it was sometimes difficult to know where parents' views and emotions, and where their sons' views and emotions, began and ended. Sometimes it was hard to know if the young men and their parents had discussed an issue openly and agreed a course of action, or a way of looking at things. Examples included: the decisions to have external carers; undergo certain medical treatments but not others; to fully discuss the nature of Duchenne, or not; and to be involved in support groups, or not.

There are some obvious reasons for this 'meshing' of identities. The experience of 'fighting' to get needs met may well produce a strong family feeling of 'us against them' at times, in addition to the closeness which comes from dependency for physical care and support. The desire for both parties to protect each other from disagreements, expressing certain kinds of emotions or thoughts;

difficulties in thinking about the future, these may all be reasons why some young men with Duchenne are so bound up with their parents.

Unpicking the rights, autonomy, and 'voice' of the young person can be difficult. Professionals could find it challenging, especially as young men grew up, to continue, for example, to be complicit with some parents' views about what young people should or should not know about Duchenne. This is not intended to be critical of parents who clearly face enormous practical and emotional challenges, but to suggest that it should be 'okay' for young people and their parents to have different perspectives – as would ordinarily happen in any family.

We were also struck by the huge shifts parents had had to make to take account of the changes in their son's life expectancy. Parents who did not expect to see their children live much past secondary school had to come to terms with the fact that was not always the case. The adjustment in expectations could be difficult to make and we saw parents and young people struggling with this. Parents did not want to put a lot of pressure on their sons to do or achieve, but they also felt anxious if they did very little. These circumstances seemed extremely challenging to us. There was little evidence that families had the opportunity, or support, to reflect on and discuss these issues openly, also bearing in mind that some members may not have wanted to do this.

### **Finally: what would we like this report to achieve?**

The findings in this report do not make for particularly encouraging reading. As experienced researchers in the field of childhood disability, we were rather shocked at the extent of the difficulties that young men with Duchenne faced. We had previously wondered if families who faced such particularly challenging, life threatening issues might, rightly or wrongly, do better than other families with disabled children.

In fact the opposite almost seems to be true. We were sometimes incredulous that families had such little input from children's social care services, or that knowledge about topics such as direct payments, disability employment advisors, or local policies on transition was apparently so poor. We

certainly do not think that services are staffed by people who want to be particularly difficult or unhelpful. And of course, it is important to restate that some services were providing very good support to families in certain aspects of their lives. So something is going badly wrong. On transition between services specifically, it seems to us that the effort still goes into producing and honing **processes**, with an uncritical assumption that this will inevitably lead to better **outcomes**.

Meantime families and young people are acutely aware of the urgent need for things to improve and to be able to participate in society as much as possible. It cannot be right that some families are fundraising in local pubs to get a good wheelchair, or waiting for several years to get agreement on adaptations to homes or care packages agreed.

Services may not yet have grasped the particular issues faced by young people making a transition to adulthood who do have a shorter life expectancy. ACT's transition pathway for young people with life limiting conditions is a very good model in this respect (ACT, 2007), but we did not find any evidence of its use. Within the bounds of scarce resources and attempts to be equitable

with them, we still wonder if it is not possible to try to offer a 'gold standard' set of services for young people who are likely to have shorter lives. 'Wasting precious time', was how one mother described the bureaucratic delays that her family had faced.

Throughout this report we have been keen to avoid evoking pity for the young men with Duchenne and their families that we talked to. Empathy and a degree of anger at the difficulties that they encounter might be more appropriate. We hope that this report, and the efforts that we will make to disseminate it as widely as possible with the support of our partners, will do something to highlight the voices of young men with Duchenne and their families.

Transition for all young disabled people remains a government priority and a key social policy 'problem'.

The challenge posed by young men with Duchenne, their families, and other groups living with long term conditions, is to ensure that potentially shorter lives are no less valuable and just as fulfilling as any other.



'The same as any other 'dude' I want to be able to hold hands with someone, to love and be loved.'

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