

Choice and change: how disabled young people with degenerative conditions and their parents make choices about care and services

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Disabled young people with degenerative conditions and their parents face many service-related decisions. Previous research has typically focused on professionals' work with these families during decision-making situations. This study shifted the focus to look at the realities of choice-making processes *within* families, exploring the respective roles and experiences of young people and their parents.



Key findings

Choice-making roles within families

- The process of making significant choices was shared between young people and parents, something which was welcomed by both parties. The young person's level of understanding influenced the extent to which parents were actively involved in choice-making. However, this was not the only – or always the most important – factor governing a young person's role in making significant choices.
- A number of other factors influenced the extent to which young people wanted to assume full responsibility for making a choice including: their age, the nature and perceived importance of the choice, and the contribution they thought parents could make to the choice-making process.
- Most parents undertook 'work' (in some cases, considerable) to support choice-making with or on behalf of the young person, such as identifying and scrutinising options and, post-choice, ensuring the choice was implemented and sustained.

Experience and challenges in choice-making

- The way in which young people and parents viewed, or 'framed', a choice varied between families facing similar decisions.

- Choice-making could cause high levels of stress/worry for parents and young people, especially when carried out against a background of limited information about viable options and/or high levels of risk for the fragile health of the young person. Positive outcomes of choices could take time to develop.
- A choice which achieved a desired outcome could at the same time have negative consequences, for the young person and/or their parents. These were 'traded off' against positive outcomes.

Support for choice-making

- Families wanted to be primarily responsible for making choices about the young person's life. Professional support was valued (if patchy in practice), particularly for providing or accessing information and helping to ensure smooth implementation of choices.
- Peers with similar health conditions were identified by young people as a unique and valuable source of information.

Background

Extending choice to users of publicly-funded services is central to current policies. New opportunities for exercising choice have been introduced in both health and social care. However, little is known about choice-making processes within families where a disabled young person has a degenerative condition. Previous research has focused on how professionals work with these families and has drawn attention to difficulties in securing choices, especially at the key life stage of transition to early adulthood, owing to factors such as the fragility and deteriorating nature of the young person's health, their often complex needs, and limited service options. This study investigated the realities for these families of making choices about services and support over a two and a half year period.

An overview of the analyses

Analysis of interviews with young people and parents focussed on five distinct topics, see Table 1. It also shows the source of data for each topic.

Table 1: Analytical topic and sub-samples

Topic	Data source
Young people's accounts of making service-related choices with parents and peers	Interviews with all the young people (n=27)
Young people's experiences of making significant medical choices	Interviews with all young people who talked about this topic (n=10)
Involving young people with learning disabilities in service-related choices: factors considered by parents	Interviews with all parents whose child had learning disabilities (n=14)
Making choices about moving on from full-time education: the roles and experiences of parents	Interviews with all parents who talked about this topic (n=23)
Factors and processes supporting satisfaction with service-related choices made: evidence from parents' accounts	Interviews with all parents who reported satisfaction with a service-related choice/s (n=23)

Findings

Young people's perspectives on making service-related choices with parents and peers

A key aim of the study was to explore young people's perspectives on their role and involvement in making significant choices about their lives. Young people differed in terms of their preferred role in choice-making, with this also varying according to the nature of the choice. Some young

¹ For brevity we will use the term 'young people' throughout this publication to refer to disabled young people with a degenerative condition

people, particularly those without learning disabilities, either described making choices as a process they shared with parents or reported that they had largely taken control of choice-making. The young people with learning disabilities were more likely to report sharing choice-making with their parents, or handing over responsibility for making choices to their parents.

Shared choice-making was generally viewed as a positive experience by the young people. A range of factors guided how much involvement they wanted or expected from their parents:

- Chronological age: as they grew older many young people took more of a leading role in choice-making. However, involving others, especially parents, was still important.
- The nature of the choice: the young people did not always want to assume responsibility for taking the final decision. Young people were most likely to revert to sharing choice-making with parents when the choice related to an issue or situation which was perceived to carry high risks (in terms of health) and/or had significant implications in terms of their future lives.
- Parents as information providers: Parents could be more actively involved when they were seen as holding relevant or valuable knowledge and/or experience :

"I mean, I do listen to mum a fair bit, I mean it's my decision in the end but I do listen to mum a lot ... 'cos she's very clever, I don't know, it's just, well she's my mum and she knows best ... " (Young man, 14 years)

Peers who had faced a similar choice were sometimes involved early in the choice-making process during the information-gathering phase. They were viewed as a unique source of information, based on personal experience, and also as role models.

Making choices about medical interventions: young people's experiences

A sub-sample of young people reflected on a choice they had made about a significant medical intervention (for example, spinal rods, gastrostomy).

The young people engaged in a complex process of trade-offs, considering both the costs/risks and benefits to their health of accepting a medical intervention, alongside broader social and emotional quality of life factors such as the importance of 'normality' and preserving non-medicalised aspects of their life. Choosing when to accept an intervention often involved balancing these needs or aspirations with medical necessity, sometimes even life-preservation.

For many, making a choice about a major medical intervention was a 'scary' process, especially when it was viewed as irreversible. When making such decisions, the young people typically wanted to talk through their options with their parents. They also valued information which was tailored to their particular needs and situation, and included information about the wider impact of an intervention beyond their physical health:

"the palliative care people were more helpful than the actual doctors ... because the doctors just explain things on medical terms, whereas, the people who know you [palliative care team] have got like an insight into your life, can maybe talk about how it'd be for you personally, 'cos it would be different for everybody even though the treatment would be the same." (Young woman, 22 years)

Peers who had faced a similar choice were seen as a particularly valuable source of information:

"Some of my friends have got the exact same condition as what I've got. So I just talk to them about it [having a gastrostomy]. It makes me feel better 'cos they understand what I'm going through." (Young man, 17 years)

Involving young people with learning disabilities in service-related choices: factors considered by parents

Choice-making can be a cognitively demanding process. Parents of young people with learning disabilities, whilst encouraging their son/daughter to express preferences and have control over their day to day lives, sometimes had to make a judgement about how their child could participate in making more significant or complex choices. In these situations parents described a continuum of involvement in choice-making by their child. This ranged from the young person being unaware that a choice was being made to the young person fully participating in the choice-making process. The level of involvement in choice-making that parents felt their son/daughter could assume was influenced by a number of factors (see Figure 1).

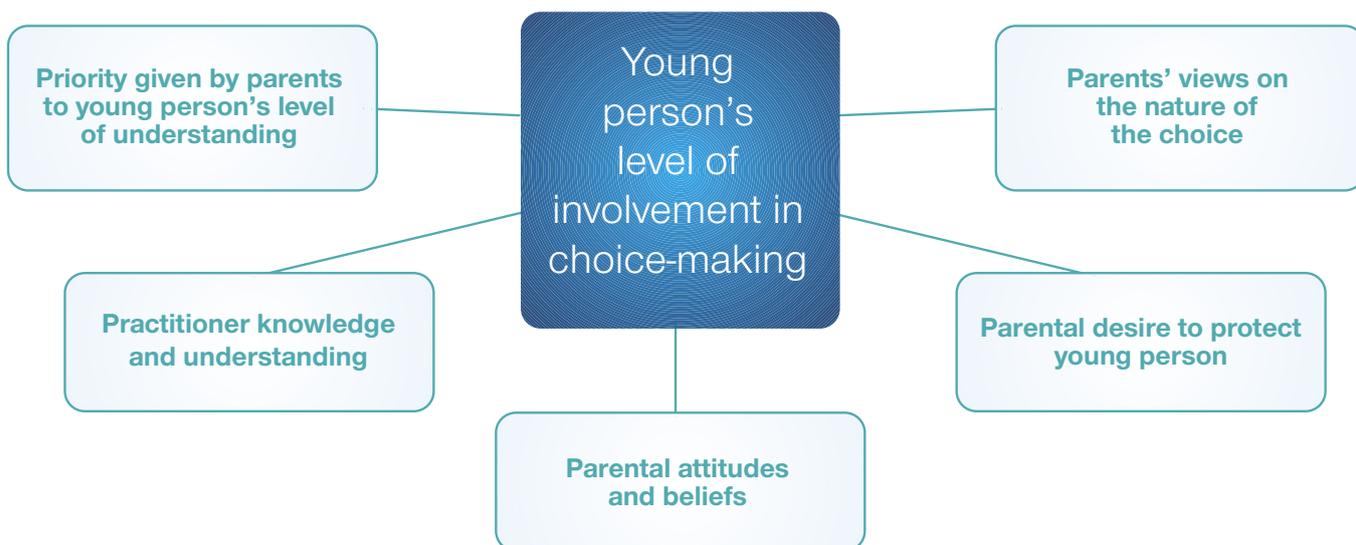
Importantly, the young people's level of understanding was not the only, or the most significant, consideration in the level of involvement parents assigned to their son/daughter.

Other factors included:

- parents' perceptions of a particular choice; for example, the perceived risk it may bring to their child's health
- the level of complexity in the choice, especially the young person's ability to weigh up potential future outcomes
- parents' own personal attitudes and beliefs, particularly the value they placed on their child becoming more independent as they grew older
- parents' perceptions of how well staff knew and understood their child influenced whether they felt it was appropriate to take a more passive approach in choice-making thus allowing their son/daughter to assume, with support, a more active role.

Within families, different choices led parents to adopt different approaches to their child's, and by implication their own, involvement in making individual choices. However, all parents, irrespective of the age of their child, felt it was important for practitioners to listen to them as parents and to continue respecting their views on the most appropriate level of involvement in choice-making for their son/daughter.

Figure 1: Factors considered by parents when involving their son or daughter with learning disabilities in service-related choices



Making choices about moving on from full-time education: the roles and experiences of parents

Little is known about choice-making processes within families when a disabled young person is moving on from full-time education. Twenty-three of the parents talked about choice-making at this key stage of their child's life. 'Destinations' varied and included: supported living; higher and further education organisations (residential or day); day centres and other daytime activities.

A minority of parents 'framed' the decision in terms of finding something local to occupy the young person during the day. However most drew on notions of 'normality', talking about their son/daughter's right as a young adult to move on in life, to make their own choices and achieve maximum independence within the challenges set by their physical impairments and (where relevant) learning difficulties:

"Your wish is always that your kids would have as normal a life as all other kids do...it's about recognising well, OK, it can't be as normal as that but ... there has to be some choices that are hers ... if you don't have that choice ... you're not a person, you're just a thing." (Mother of young person aged 19)

Parents differed in their level of involvement in these choices. A few were relatively passive, viewing either the young person or a professional as having lead responsibility. Most, however, played an active role. The level of their involvement, or the degree to which they assumed responsibility, was influenced primarily by the young person's perceived ability to make the choice.

Parents' 'work' in the choice-making process could be considerable. It included identifying and gathering information about options and scrutinising these through personal visits to potential settings, something which was thought crucial for assessing their suitability. Once a decision had been made, most parents' 'work' continued in the form of securing funding, checking practical and care arrangements, 'easing in' the young person to a new setting, and maintaining ongoing contact with the service provider. Such 'work' for parents could not only be heavy, but also a struggle in the context of meeting the needs of the whole family:

"A lot goes on behind the scenes, it's like a fabulous film but nobody knows what goes on to make it ... and it's a lot of work, a lot of stress and, in-between all that, people are trying to live normal lives aren't they, you know, do the supermarket shopping and take the kids to the dentist ... all the mundane things you do as a parent ... I do a lot of juggling, I keep a lot of balls in the air." (Mother of young person aged 16)

The fragile nature of the young person's health condition was a constant presence in parents' minds throughout the choice-making process. It influenced their expectations for their child, the criteria they used to select the post-school destination, the 'work' they did to realise a choice, and the intensity of their emotional experience.

Factors and processes supporting satisfaction with service-related choices: evidence from parents' accounts

The parents participating in this study included both those who were satisfied with the outcomes of service-related choices they had made for or with their son/daughter, and those who had been disappointed. The accounts of parents who had made choices which proved both durable and satisfactory were analysed in order to understand the factors and processes which foster and support parental satisfaction (see Figure 2).

The foundations for parental satisfaction with a choice were laid at the outset through 'framing' the choice in terms of a main desired outcome for their son or daughter (for example, developing independence, or improving physical health). This 'framing' of the decision steered families through the initial phases of the choice-making process when options were being investigated and then weighed up. Post-choice satisfaction was founded on parents feeling confident that the best choice had been made from the options available.

Evidence over time of the main desired outcome being achieved naturally contributed to parents' satisfaction with the choice made and, crucially, enabled parents to 'trade off' any negative consequences. These included the sometimes substantial personal costs to parents (in terms of time, practical or financial resources) required to ensure the choice was a success, and/or the negative emotions which choice-making and the consequences of choices could arouse, including sadness, guilt and anxiety.

It was clear that achieving a sense of satisfaction with a choice could take time. However this was not simply the time needed for positive outcomes for the young person to develop. The passage of time also allowed parents to develop trust in new service providers and adapt to new roles or situations. For some parents there were also 'knock-on' benefits, such as returning to paid work.

Figure 2: Factors and processes supporting satisfaction with service-related choices



Implications for professionals

This study provided the opportunity to explore a wide range of issues associated with making service-related choices by young disabled people with degenerative conditions and their families. This section sets out three key implications arising from the findings.

Supporting the choice-making process

Making choices about services is a process involving mental, practical and emotional 'work' sometimes stretching over many months, even years. Whilst families may wish to assume responsibility for making a choice, they do want support during the choice-making process. The accounts of young people and parents suggest that practice could be improved, especially in terms of:

- meeting families' information needs as they seek to identify viable options
- providing appropriate support or services to ensure parents are not shouldering responsibility for ensuring the desired outcomes of a choice are achieved
- acknowledging the emotional demands a daunting, choice-making process with uncertain outcomes can place on families.

It is important that the support and advice provided by professionals draws on their cumulative experience of working with other families who have achieved successful outcomes over time.

Young people and their involvement in making choices

The evidence from this study is that chronological age is an unreliable indicator (even among young people without learning disabilities) of the extent to which young people want to assume full responsibility for making a choice. Within health care, competency to consent (in the absence of learning disabilities) is sixteen years. In social care, the transfer from children's to adult services takes place around eighteen years and the practice and ethos of the two services is radically different, shifting from a family-centred approach to supporting a young person's independence.

Whilst statutory services may suddenly change in the way they work with families, it is not necessarily the case that similar changes have happened, or are desired, within families. Some of the young people in this study were making highly significant choices (for example, treatment decisions, or moving away from home, despite very fragile health). They wanted to share the 'burden' of that choice-making with their parents, and also were aware that their parents may well have a role to play in supporting them once a choice had been made.

Practitioners have a difficult path to travel here. Some young people may want to be more independent in the choices they make about their

lives than their parents allow. Others may want their parents to share or assume responsibility for decisions: something which, to the practitioner, may or may not appear to be appropriate. **What is important is that practice and procedures are sufficiently flexible to be able to support these differences in the roles assumed in the choice-making process, both between different families and, within a single family, between different decisions.** In addition, where necessary, practitioners need to work sensitively with families to discern and support, at an individual level and for a particular choice, the role or level of involvement of a young person.

The value of “experiential information”

‘Experiential information’ was regarded by families as a unique and highly valued element of the information they used to make a choice. For young people with learning disabilities, it can be key to being involved in choice-making. ‘Experiential information’ included visiting options under consideration (for example post-school setting) and, for young people, the accounts of others who had made similar choices. Parents were much less likely to have had an opportunity to access information and advice from other parents who had faced similar situations, but expressed a desire to do so.

Despite its value, ‘experiential information’ was not comprehensively or routinely provided by or through professionals. Clearly supporting access to this sort of information can be resource-intensive and so the potential for providing some kinds of ‘experiential information’ virtually (for example, web-based social networks, real-time or user controlled audio-visual information) is something that may be fruitful to explore further.

Methods

Two children’s hospices in Northern England and the Family Fund² assisted with recruitment. The sample consisted of 27 disabled young people with degenerative conditions (14 had additional learning disabilities) recruited from 24 families, and 44 parents (from 33 families) of disabled young people with degenerative conditions.

Participants were interviewed up to three times over a three year period. The interviews explored recent experiences of making choices about services (in the case of parents, choices made with or on behalf of their son/daughter) including: the information and advice sought, the options considered, factors taken into account when making a choice, and the outcomes of these choices over time. The interviews also examined the roles played by others – family, friends and professionals – in the choice-making process.

The depth and range of the interviews with the young people were adapted in response to participants’ cognitive and communication abilities. The interviews with young people with learning disabilities and/or communication impairments were facilitated by a visual, symbols-based system known as Talking Mats[®]. Talking Mats[®] are a series of A3 sized boards specifically created to explore a particular topic or issue. The content of the Talking Mats[®] for this study was informed by the interviews with the verbal young people without cognitive impairments in the sample. Talking Mats[®] are written in simple English text with Boardmaker[®] symbols. Each Talking Mat[®] board presented a question. Also attached to the board were a set of possible answers. The young person indicated their response to the question by detaching from the board the symbol(s) which represented their answer. Their responses are collected together on a separate board. In this study, Talking Mats[®] were used both to facilitate and support verbal interviews with young people with learning disabilities and to conduct non-verbal interviews with young people with significant communication impairments.

Not all the young people and parents participated in all three interview rounds. Just over half of the young people, and two thirds of parents recruited were interviewed on all three occasions. The verbal data were transcribed and then coded and managed using MAXqda. These coded data were charted to identify common and contrasting patterns with analysis focusing on specific questions. Symbols-based data were summarised into tables which aligned with the more complex charts used to summarise the verbal data. For some analyses, the longitudinal nature of the data allowed the researchers to explore entire choice-making processes in ‘real time’ and to obtain participants’ views and perceptions over that period. For other analyses which were not time-dependent, the data from the three interview rounds were collated.

² The Family Fund is a UK charity providing modest grants to families of children and young people with a severe disability or serious illness

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Further details about the study and a range of journal articles about the research can be found at: <http://php.york.ac.uk/inst/spru/research/summs/DHPpanel.php>

A companion summary from the same study is: Baxter, K., Rabiee, P. and Glendinning, C. (2011) Choice and change: disabled adults’ and older people’s experiences of making choices about services and support, *Research Works*, 2011-04, Social Policy Research Unit, University of York, York.



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