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# Parents' Accounts: Factors Considered When Deciding How Far To Involve Their Son/Daughter With Learning Disabilities In Choice-Making

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# Parents' accounts: factors considered when deciding how far to involve their son/daughter with learning disabilities in choice-making


## Abstract

There is limited literature on the processes of choice-making in families of young people with learning disabilities. This paper examines the factors considered by parents of young people with learning disabilities when deciding their own and their child's role in a range of significant choices (health, social care and education) about their child's life. The paper reports data collected from a sub-sample of 14 parents recruited from 11 families participating in a longitudinal (2007-2010) qualitative study based in England. The parents all had children with learning disabilities and participated throughout the study. Data were collected over three semi-structured interviews. Parents' accounts demonstrated a continuum of parental involvement ranging from young people being unaware a choice was taking place to young people being fully involved in choice-making. Parents did not always adopt the same approach to choice-making; different approaches to their own and their son/daughter's level of involvement emerged when parents discussed different choices. Five choice-making factors are presented. These factors were used by parents to guide their own and their child's level of involvement. Although young people's level of understanding was considered, it was not always the most important factor. Other factors were important and, at times, could be considered more important by parents. The other factors were: parents' views on the nature of the choice,

protecting their child, parents' personal attitudes/beliefs and confidence in practitioner knowledge. Insights from these factors highlight some important practice issues when practitioners work with families of young people with learning disabilities making significant life-choices.

**Keywords**

Parents, young people with learning disabilities, choice-making, choice-making involvement, choice-making factors.

**Highlights**

- Parents do not always adopt the same choice-making role.
- Different types of choices lead parents to adopt different choice-making roles.
- Five factors are identified as guiding parent's role during family choice-making.
- Level of young people's understanding is considered but not always prioritised.
- Practitioner awareness of these factors can assist more sensitive family working.

## 1. Introduction

Encouraging service users, including people with learning disabilities and their families, to make choices and take greater control of their lives is a key English health and social care policy and practice objective (Department of Health (DH) 2006; HM Government, 2007; DH, 2009). For people with learning disabilities, there are many well-rehearsed debates surrounding the importance of choice, for example, from the early ideas of normalization theory (Wolfensberger, 1972) to broader social and psychological self-determination theories (such as, Willink et al., 2009). Increasing disabled people's choice and control is also an important part of the social model of disability (see for example Abberley, 1987; Oliver, 1996; Barnes & Mercer, 2010) and is advocated by disabled people themselves. This has been recognised in English policy by such strategies as Valuing People (DH, 2001; DH, 2009) and the movement towards person centred planning (HM Government, 2007). Choice and choice-making opportunities are also important for young people with learning disabilities approaching adulthood as choice-making is viewed in wider society as part of the transition to adulthood (DH, 2008a).

However, there is a limited literature on the processes of choice-making in families of young people with learning disabilities. The aim of this paper is to explore the choice-making considerations that parents of young people with learning disabilities take into account regarding their own and the role of their child when faced with significant choices regarding their son/daughter's life. The paper demonstrates that parents do not always adopt the same choice-making

role; different types of choices lead parents to adopt different choice-making roles. Increasing practitioner awareness of these factors can help to facilitate more sensitive and flexible working with families of young people during choice-making.

## 2. Choice-making and people with learning disabilities

Historically, it was believed that people with learning disabilities could not make choices, nor would it be wise to allow them to do so since their lack of understanding and vulnerability could lead them to make 'wrong' or 'risky' decisions (Jenkinson, 1993; Kearney & McKnight, 1997; Ware, 2004; Smyth & Bell, 2006; Guess et al., 2008).

In recent years, this assumption has been challenged by people with learning disabilities themselves and is supported internationally by the findings of research (for example, Lancioni et al., 1996; Canella et al., 2005). It has demonstrated that people with learning disabilities (even severe) can make choices, but that this ability is moderated by the type of choice being made and the support available to them. Authors have also moved away from a simplistic notion of involvement. Involvement in choice-making is now regarded as operating on a continuum (Lancioni et al., 1996; Cannella et al., 2005; Smyth & Bell, 2006). Furthermore, in England, legally people with learning disabilities understanding and 'capacity' should be presumed until otherwise established (England and Wales, Mental Capacity Act, 2005).

An important distinction needs to be made between ‘expressing a preference’ and ‘making a choice’. Preferences are presented as expressing a subjective like/dislike of a particular thing which the individual already has some prior experience (for example, preferred foods, activities, people). In contrast, choice-making is a process in which options or alternatives are identified, weighed up and a selection made (Kearney & McKnight, 1997; Ware, 2004; Smyth & Bell, 2006). Choice-making is therefore a cognitively more complex and demanding activity. At the same time, choices vary from simple to complex according to the demand made on an individual’s cognitive processing skills and abilities. For example, making choices about the future requires the ability to anticipate events and weigh-up potential consequences (Ware, 2004).

International research on the barriers to choice-making by people with learning disabilities has typically focused on barriers in service settings, such as organisational structures and staff practices, beliefs and attitudes (Jenkinson, 1993; Harris, 2003; Cannella et al., 2005). Similarly, research with young people with learning disabilities has also focused on formal contexts (schools, community living), for example, the literature on self-determination (Chambers et al., 2010). Much less is known and understood about choice-making within families. For example, in programmes to teach people with learning disabilities choice-making skills, few explore in-depth the important role and attitudes of parents (Henderson, 1994; Chambers et al., 2007, Small et al., 2008).

## 3. Choice-making in families

However, there is a growing general international literature on the different roles family members play in choice- or decision-making; for example, in health or treatment related choices. This has demonstrated the role played by parental attitudes and beliefs, and parenting styles in determining children's involvement in choice-making (Peterson-Badali et al., 2004; Pyke-Grimm et al., 2006; Jackson et al., 2008; Mack et al., 2011; Coyne, 2008; Lease & Dahlbeck, 2009; Commendador, 2010).

The limited research on families of young people with learning disabilities recognises that practitioners can play an important role in family choice-making. This is demonstrated in the recent conversation analysis based research of Pilnick et al. (2011; 2010) documenting the importance of practitioners subjective understandings of young people with learning disabilities and their parents choice-making interactions. How professionals interpret and act on these family interactions can guide service outcomes for both young people and their parents.

Research involving families of young people with learning disabilities has also identified that parents can facilitate or impede their son/daughter's involvement in choice-making (Grigal et al., 2003; Almack et al., 2009). However, less is understood about the specific roles parents may assume when there are choices to be made for/about their son or daughter, and the processes by which

they decide about the role the young person will play in the choice-making process (Rueda et al., 2005, Bianco et al., 2009, Murphy et al., 2011).

Two generic USA based studies offer models of the roles parents may assume and how, in consequence, this influences their child's involvement in choice-making (Snethen et al., 2006; Lindstrom et al., 2007). Snethen et al.'s (2006) on decision-making around chronically ill children's participation in clinical trials identified four roles parents assumed as this choice was being made: 'exclusionary', 'informative', 'collaborative' and 'delegated' roles. 'Exclusionary parents' aimed to protect their child and this frequently resulted in their son/daughter not being involved in the choice being considered. 'Informative parents' aimed to help their child understand and participate in choice-making but wanted to make the final decision. 'Collaborative parents' sought to support and empower their child's choice-making and 'delegatory parents' largely handed over choice-making responsibility to their child.

Lindstrom et al.'s (2007) study looked at parents' attitudes to their child's (all of whom had 'special educational needs') involvement in choosing their post-school destination. They present a continuum of parental involvement based on three roles: 'protectors', 'advocates' and 'removed'. These are broadly similar to the roles identified by Snethen et al., with Lindstrom et al.'s 'advocating' parents straddling Snethen et al.'s 'informative' and 'collaborative' roles.

To begin addressing gaps in the literature, this paper reports a study which, in part looked at parental perspectives on their and their child's role in choice-making when there were significant choices to be made regarding their son/daughter's life. All the young people in this sample had learning disabilities. Separate papers report the young people's perspectives (Mitchell, forthcoming; Mitchell, 2011, Mitchell, 2010).

## 4. Method

### *4.1. Study design*

The findings reported here are drawn from an English longitudinal qualitative based study (the 'Choice and Change' project) of the choices made by three groups of disabled people (adults, older people and young people with life-limiting conditions and their parents) regarding their health, education and social care over a 30 month period. Data were collected during three semi-structured interviews conducted between 2007 and 2010. Ethical approval was received from an English National Health Service medical research ethics committee.

### *4.2 Selection and recruitment*

The sample of young people and their parents were recruited from two English children's hospices. Hospices were chosen as an efficient route to recruit young people with degenerative conditions, as they provide support for a wide range of degenerative conditions and assist young people and their families at different stages of degeneration, from initial diagnosis to end of life care. The young people in this study were at different stages of their illness trajectory; however,

the research did not involve young people in the end stages of life. Before seeking to recruit young people to the study, the researcher consulted hospice staff about each young person's stage of degeneration.

Hospice managers distributed project information to families with young people aged 13-21 years. Families contacted the researcher if they were interested in participating. Thirty-three families were recruited to the study. Recruitment proved challenging, reasons for non-response were not collected but hospice staff indicated that young people's deteriorating health had affected recruitment.

This paper focuses on findings from a sub-sample of 14 parents representing 11 families. This sub-sample met two criteria: i) their child had learning disabilities; ii) they had participated in all three-interview rounds. Participation in all three interviews was important as it provided data on different choices and opportunities for reflection. Table 1 documents key characteristics of this sub-sample and the choices parents chose to discuss during the interviews.

Insert Table 1 about here

Mothers participated (two were lone parents) from all 11 families. In three families both mothers and fathers chose to participate. As documented in Table 1, the young people had a range of life-limiting conditions and learning disabilities. Parents' own judgements of their son/daughter's learning disabilities were used (in four cases 'moderate' and in seven cases 'severe').

### *4.3 The interviews*

A core topic-guide, modified for each group participating in the project, was used. At each interview round choice-making processes associated with new, ongoing and completed choices were explored. Core topics such as, sources of information, the role of other people (both practitioners and family members) and outcomes of decisions (anticipated and known/experienced) were discussed. In each round participants chose which choices they wanted to discuss based on personal priorities. The choices discussed frequently arose from a decision point in their child's life, such as leaving school or whether to have a medical intervention. During second and third interviews parents were asked to reflect back on decisions they had already made. For some decisions, it was possible to obtain a longitudinal perspective as participants chose to describe a choice across different interview rounds. For other decisions, participants chose to describe a choice they had already made. The benefits of repeat interviews were developing a relationship with parents over a number of meetings which facilitated increasingly rich data.

Semi-structured interviews were chosen as this provided flexibility to tailor each interview to the specific choices parents chose to discuss whilst also ensuring that key project themes were addressed consistently across the sample (Ritchie & Lewis, 2003).

Written consent was gained at each interview. The interviews (lasting between 60-180 minutes) were conducted in parents' homes. Three sets of parents chose to be interviewed jointly. All but one parent consented to their interviews being audio recorded. Written notes were taken for this parent. Recognising that the study could raise potentially sensitive issues, the project identified an individual in each hospice to provide information and/or counselling if requested by parents.

### *4.4 Data analysis*

The interviews were fully transcribed and then thematically analysed drawing on the Framework Approach (Ritchie & Lewis, 2003). Framework analysis was chosen as it provides a flexible system of analysis through which data can be systematically summarised (whilst also allowing easy return to the verbatim text), it also facilitates comparisons over time and between different groups (important within a longitudinal study such as Choice and Change involving different groups of participants, as noted above).

Analysis involved four stages: first, data 'immersion' (reading transcripts) and the development of a coding frame representing both *a priori* and emergent themes and topics (such as parental roles, young people's roles, information). Second, verbatim (and written notes from one parent) text was coded (using MAXqda software). Third, coded data were summarised and displayed in a set of thematic charts. Finally, the charts were scrutinised in order to identify themes, patterns in the data and draw comparisons. Data from the three

interview rounds were entered on the same charts alongside the data source (i.e. interview round number). Organising the data in this way allowed the biographical flow (Thomson, 2007) of participants' accounts to remain intact over time. To aid methodological rigour, a sample of transcripts was double-coded by a colleague. The two researchers then met, discussed their coding and amended the coding frame and its use in light of these discussions. In addition, the whole project research team met regularly to discuss their analysis and data summary, sharing ideas and experiences with one another.

## 5. Results

At the outset, it is important to note that the findings reported here are parents' perceptions (or rationalisations) of past and present events. They may differ from those of their son or daughter.

As noted above, the views of young people are reported in separate papers (Mitchell, forthcoming, Mitchell, 2011; Mitchell, 2010). These papers report that the young people in this study described very little conflict or differences of opinion between themselves and their parents. This was apparent for young people with learning disabilities and also amongst the wider study sample of young people which included those without learning disabilities. Only a very small number of young people reported there had been differences of opinion with their parents, and all related to treatment/ health care decisions. Furthermore, after further discussion with their parents, these young people felt that an amicable decision had been reached. Indeed, the young people in this

sample frequently emphasised ‘being of a like mind’ to their parents This absence of conflict contradicts many commonly held general stereotypes of young people, choice-making and parents (Trujillo, 2000) and more specifically, between young people with learning disabilities and their parents (Pilnick et al., 2011). This is clearly an area which requires further research.

Parents’ accounts in this paper revealed a continuum of both parents and young people’s involvement in choice-making ranging from young people being unaware that a choice was taking place to young people taking full responsibility for the final decision. Different patterns and approaches emerged when parents described different choices. Five factors appeared to be influencing this (see Figure 1). These factors have been separated for analytical clarity but were frequently interrelated.

Insert Figure 1 about here

### *5.1 The priority given to the young person’s level of understanding*

Some parents (both of young people with severe and moderate learning disabilities) regarded their son/daughter’s level of understanding as an extremely important factor influencing how much they involved their child in choice-making processes. For these parents chronological age was largely irrelevant: they typically discussed their son/daughter as a ‘baby’ or a ‘child’:

> … but I think it’s this business of him being an adult and he’s really a child in an adult world.

(P2/Mother, Interview Round 1)

Other parents (again both of young people with moderate and severe learning disabilities), whilst recognising their son/daughter's learning disabilities, felt that this should not automatically exclude them from participating in choice-making. Instead, a number of additional factors were taken into account when deciding on their child's level of involvement and/or their own role. These included:

- their views on the nature of the choice
- their desire to protect their child
- personal beliefs and attitudes, especially around life-stage and transition to adulthood
- confidence in practitioners' knowledge and understanding.

## *5.2 Parents views on the nature of the choice*

### *5.2.1 Level of complexity*

The complexity of the choice being made was frequently identified as influencing the level of their son/daughters involvement in a decision. Choice complexity was defined along two parameters: cognitive demands (relative to their child's learning disabilities), and the 'significance' of the decision.

Cognitive demands concerned the number of potential options and/or the amount information which needs to be processed and understood in order to make a choice. The extent of their own child's learning disabilities thus directly informed parents' perceptions of the complexity of a choice. Hence, for one

child, a complex choice could be choosing an outfit to wear whereas, for another it could be deciding what to do after leaving school. Parents managed what were perceived as overly complex choices by limiting the number of options presented to their son/daughter and/or simplified the information they passed on to them.

> We've found our role is like having to put a big ring-fence around him, give him the information and say [to practitioners, here in education] 'don't confuse him any further, let him choose.'
>
> (P4/Father, Interview Round 1)

This 'filtering' of options and/or information was frequently premised on the belief that they (as parents) knew the most 'appropriate' or the 'best' choice options to present to their child. Importantly, it allowed parents to involve their child in making choices: something which all parents aspired to, even if limited to the more 'everyday' choices as this exert highlights:

> Clothes wise, perfume wise we give her choices … I'll give her a couple of choices and if she doesn't come up with anything I'll say, 'right, it is this or that, which one now.'
>
> (P9/Mother, Interview Round 3)

Complexity was also spoken about in terms of its 'significance', and this meant the potential consequences or impact of a decision on future well-being. The importance of their child being able to comprehend consequences and, more importantly, being able to understand possible future outcomes was noted by

parents of young people with different levels of learning disabilities (both moderate and severe). When parents felt their child did not have the cognitive ability to comprehend the 'significance' of a choice, the level of the young people's involvement in the choice-making process was reduced. In this excerpt a parent describes why, once her son had chosen college as his general post-school destination, she then assumed responsibility for choosing the actual college:

> … if it's a buzzing atmosphere [in a potential college] he's 'in there', you know. But he can't look beyond that and say, 'Well, you know, hang on, there's no way I'll be able to stand that for three years'.
>
> (P7/Mother, Interview Round 1)

This mother also described wider ramifications of this decision for other family members, especially her own caring role, which she did not believe her son could grasp.

### *5.2.2 Perceptions of risk and danger*

The perceived level of risk or uncertainty was another characteristic affecting parents' decisions regarding their child's involvement in choice-making. Medical treatment choices (such as spinal surgery) were typically those perceived as the most 'risky' choices which families faced. Where there was minimal or lower risk, many parents felt able to adopt a 'delegatory' approach in which the young person assumed greater choice-making responsibility. This difference is demonstrated in the case example presented later (see Figure 2).

### *5.2.3 Experience opportunities*

The possibility of being able to actually experience the different options constituting a choice facilitated increased levels of involvement for young people. Educational and leisure choices were examples of areas where experience opportunities appeared to support young people's involvement in choice-making.

> When he visited [local college] his face lit up … once he'd seen [local college] that was it, his mind was made up.
>
> (P4/Father, Interview Round 1)

In contrast, parents felt it was difficult to involve their son/daughter in medical choices such as surgery. This was because possible future consequences could not be directly experienced prior to choice-making (see Figure Number Two).

## ***5.3 Parents desire to protect their son/daughter***

Parents described adopting a protecting role which resulted in a limited level of choice-making involvement for their son/daughter. Irrespective of their child's learning disabilities, some parents described their son/daughter as emotionally vulnerable and hence sought to protect him/her from the stress and anxiety which can be associated with choice-making. This was demonstrated in a range of choices but most clearly in significant health or treatment choices (such as surgery) where parents felt it was 'kinder' not to involve, or to involve young

people as little as possible. Parents often explained this in terms of their son/daughter's fear of medical procedures arising from past experience (see Figure 2, choice 2).

As before, parents acted as information filterers but also appeared to adopt more of a gate-keeping role, filtering not only how much information their son/daughter received but also from whom. For example, one young person's parents explained that they had not included their son in heart scan discussions with doctors or passed on information prior to the scan in order to protect him from unnecessary or undue concern:

> I have been in touch with the cardiologist and we've [Mother and cardiologist together] agreed that he's [cardiologist] going to see him [son] and they will do an ultrasound on his heart.
> (P7/Mother, Interview Round 2)

This 'protecting' meant that in some choices, young people were not only excluded from the choice-making process but were also unaware that a choice existed or was being made.

### *5.4 Parents' attitudes and beliefs*

All parents expressed an ongoing sense of responsibility to be involved in the choices their son/daughter was making. However, the degree and form this responsibility took differed. Parents who primarily used their child's level of understanding to inform how and when they involved their child in choice-

making reported a strong sense of parental responsibility and expected this to continue.

> I just feel that's something that I really have to, you know, it's my responsibility to make sure he's happy wherever he spends his days. (P8/Mother, Interview Round 2)

For these parents, their child's chronological age was viewed as largely irrelevant.

Other parents recognised and valued their son/daughter developing choice-making skills. Parents described supporting the acquisition of these skills by, for example (as noted above), simplifying choices and, where possible, providing direct experience of choice options. Parents also acted as information providers, seeking out information and/or interpreting complex information into a more understandable format for their child. Information filtering was here used in a facilitative rather than protective manner.

### *5.4.1 Life-stage and transition to adulthood*

Impending adulthood influenced some parents' decisions about their son/daughter's level of participation in choice-making. This was not necessarily linked to the reported level of their son/daughter's learning disabilities. Thus, parents of young people with both moderate and severe learning disabilities described assuming or anticipating a reduced role in choice-making as their child moved towards/into adulthood. Relinquishing some parental responsibility,

although not always easy, was viewed positively as part of their son/daughter growing up and becoming more independent.

> For me it's, it's about realising that [daughter's] choice now, cos she's 21. She's, you know old enough to make her own decisions and it's about letting her have that. It was quite difficult at the time, cos when you've got a child that's as disabled as [daughter] is, your automatic reaction is to just take over.
>
> (P6/Mother, Interview Round 2)

Responding to changing external circumstances, especially young people moving out of the family home also influenced the role parents played in decisions about or for their son/daughter. Parents of young people moving to residential college/supported accommodation reflected on how they had re-assed their role, often taking a more advisory role in their son/daughter's choice-making once other people, especially paid support workers, had become more involved and trusted. One mother, for example, explained, realising that she was no longer the only person who 'knew' her son; his college support workers views were now also important when choices were to be made.

### *5.5 Confidence in practitioners' knowledge and understanding*

Some parents (especially those whose son/daughter had communication impairments) expressed concern that young people's communication of their wishes and/or needs were not always understood or valued by other people.

> **Interviewer**: [So are you saying that they [practitioners] just assume cos she's deaf and blind that she can't make choices?
>
> **Mother**: Yes, absolutely … yes, she has learning difficulties because she can't access information.
>
> (P9, Interview Round 2)

Whilst possibly retreating from an earlier level of involvement in choice-making, these parents identified their role as acting as an advocate for their child.

In particular, as noted above, parents whose son/daughter had moved to residential college/supported accommodation described themselves acting as advocates. This role was also reduced as parents felt care staff and other practitioners became more skilled and knowing of their child's communication preferences.

## 6. Case example

A case example is now presented to illustrate the factors and processes described above. Three choices (spanning education and health) that one young person's parents' discussed are presented. The case example documents how these three choices were approached and interpreted very

differently by the young person's parents, which in turn, led to different levels of involvement for their son in the choice-making process.

Insert Figure 2 about here

## 7. Discussion

Interviews with a convenience sample of parents reveal a continuum of involvement in choice-making for young people with learning disabilities. At one end, young people unaware a choice was being taken and, at the other end, young people fully involved in choice-making, some even making the final decision. It was also clear from parents' accounts that the level of involvement of these young people in choice-making was 'choice specific'.

In the introduction two models of family choice-making were presented (Snethen et al., 2006; Lindstrom et al., 2007). Although this study explored a variety of choices over a range of decisional areas (health, social care, education, leisure) and, particularly, focused on families with a child with learning disabilities, the concepts put forward by Snethen et al. (2006) and Lindstrom et al. (2007) proved useful. In particular, Snethen et al.'s typology of parents' roles in family choice-making presented as exclusionary, informative, working collaboratively with the child or delegatory. All these roles were observed in this study.

The analysis presented here, however, extends this earlier work because it was possible to examine the roles parents assumed across different types of choice-making situations. Thus, it has been possible to identify the range of factors which affect the roles parents choose to assume with respect to a particular decision and the level of involvement they assign their son/daughter. These factors provide a helpful interpretative lens into the processes by which young people with learning disabilities may, or may not, be involved by their parents in making choices that affect their lives.

An important finding from this study was that the young people's level of understanding, although considered by parents, was not the only or always the most important factor which influenced the role parents assigned their child in a specific decision-situation. There was not a simple division between parents of young people with moderate learning disabilities and those of young people with severe learning disabilities. Whilst some parents did feel their son/daughter's level of understanding largely precluded them from choice-making, others felt that level of understanding should not automatically exclude their child (see also Murphy et al., 2011). Other factors were identified as having a role to play including the complexity of a choice (a factor also identified by Ware, 2004); the perceived risks; and the opportunity to experience options. The importance of people with learning disabilities accessing experiential information is similarly recognised in past literature (Cannella et al., 2005; Guess et al., 2008).

Parents' views about their child's emotional vulnerability, and the extent to which being involved in making a choice may threaten emotional well-being could also be an important factor. The notion of parents' primary motivation being one of protecting the young people was also identified by Linstrom et al. (2007) and Snethen et al. (2006).

The influence of existing patterns of family interaction and parenting styles on the roles individual family members assume in choice-making situations has been identified (for example, Lease & Dahlbeck, 2009; Commendador, 2010) including, families of young people with learning disabilities (Murphy et al., 2011). Our data particularly identified the influence parental beliefs and expectations, around adulthood and independence, had on their and their son/daughter's role in choice-making situations.

Parents' role as advocates for their child in choice-making situations matches onto that identified by both Lindstrom et al. (2007) and Snethen's et al. (2006). Linked to this was the finding that parents perceptions of the adequacy of practitioners' knowledge and understanding of (or lack of) their son/daughter's needs and wishes. This concurs with findings from other research which has identified parental concerns regarding staff knowledge and skills regarding communication (for example, Harris, 2003; Jenkinson et al., 1992).

## 8. Practice implications

English policy (DH, 2008b; DH, 2009) advocates the importance of practitioner sensitivity to parents/carers' needs and this study reiterates this. Practitioners working with families of young people with learning disabilities during choice-making need to be sensitive and responsive to family dynamics, patterns of family interaction, and parents' (and young people's) views about the role(s) they wish to adopt.

An important role played by parents in supporting their son/daughter's participation in making significant life choices was that of information provider: both to the young person and to practitioners. Reviews of English policy (Bercow, 2008) have noted practitioners' lack of knowledge and skills, especially listening to and communicating with children and young people with learning disabilities. As noted above, this was also a concern for parents in this study. Parents, especially those of young people with communication impairments, felt they could play an important role for practitioners in providing information about how their son/daughter communicated their wishes and feelings.

Parents can also be an invaluable resource for practitioners, especially during the transition years when young people move to new services and/or situations (DH, 2008a). However, it is recognised that practitioners face a difficult task at this time, balancing parents and young people's wishes which may not always coincide. Practitioners also need to balance this with their own 'duty of care' (Sloper et al., forthcoming) and broader safeguarding policies. As Murphy et al.

(2011) highlight, working out ‘the right way’ for each family is important. Practices must be flexible enough to support the different roles different families adopt during choice-making and, as this study has demonstrated, practitioner sensitivity must also extend to how each family approaches different choices.

Parents’ perceptions of their child’s ability to be involved in the types of choices covered by this study could, at times, appear quite limiting, especially when parents felt that they should make the final decision. However, it is important to place final decisions in the context of choice-making as a whole because the experience of involvement can, as Edwards & Elwyn (2006) note, be just or in some cases even more important than who makes the final decision. Although not specifically related to people with learning disabilities, Entwistle & Watt (2006) demonstrate the importance of participants’ subjective views and experiences of their own involvement. Hence, traditional ideas of participation (i.e. viewing and judging whether a person has been involved in choice-making or not, solely by their level of active involvement, especially, in the final decision) may not accurately reflect parents’ own subjective interpretations of their participation and their son/daughter’s participation.

Despite this, it must be recognised that whilst the researcher did not seek to make any judgements about parents and the level of involvement they gave their son/daughter. In situations where practitioners believe parents are not allowing their child to take the most appropriate level of participation, practitioners need to identify an approach to deal with this. Practitioners may

need training and guidance in how to address this with parents, whilst remaining supportive and sensitive to individual family dynamics. The factors outlined in this paper can help practitioners understand more clearly the ideas and priorities of parents of young people with learning disabilities as they face different types of choices with their son/daughter and the complex considerations underpinning these choice-making processes.

## 9. Study limitations

This was a small scale in-depth English study. The paper focuses on the views of parents of young people with learning disabilities who have life-limiting conditions. As with any qualitative research, the purpose was to explore and describe a range of views and experiences. However, the small and specific nature of the sample means care needs to be taken when drawing wider conclusions and implications.

The specific characteristics of this sample of parents - having a child with learning disabilities and a life-limiting condition - must be acknowledged,. Amongst parents there was general ongoing recognition that their child's life was limited and so quality of life was important. However, how far parents referred to the life-limiting nature of their son/daughter's condition during the interviews varied. This was demonstrated between parents of young people with learning disabilities in this sub-sample and, parents of young people without learning disabilities in the project's wider sample (33 families). Amongst the latter group of parents, Maddison and Beresford (2012) found that the life-

limiting nature of their child's condition was given some specific consideration in relation to the role the young people took during choice-making. In contrast, amongst this sub-sample of parents of young people with learning disabilities, this was not as apparent. Parents' accounts did not specifically discuss in detail the life-limiting nature of their child's condition with regard to how far they chose to involve their son/daughter in choice-making. However, this may have been associated with the type of choices these particular groups of parents chose to discuss and/or were influenced by the young people's degenerative stage rather than different groups of parents adopting different approaches to their child's life-limiting condition.

As noted above, the paper reports parents' presentations of their and their son/daughter's choice-making and the roles they adopted. These are parents' subjective rationalisations of events, in many cases retrospective recollections. As past literature (Kirchler et al., 2001) has shown, reporting what actually happened and what is presented to others can differ, especially over time. Similarly, although parents interviewed jointly gave a unified account, their ideas at the time of choice-making may have varied, as couples' relationship roles can differ.

Past literature (not specifically people with learning disabilities) has highlighted different opinions between parents and children in health-related decisions (Varma et al., 2008, Brody et al., 2009). In this study, parents did not report any direct conflict with their son/daughter over the choice they wanted and finally

selected. There were also no direct examples of parents saying they wanted their son/daughter to do one thing and young people doing another. This may have occurred for a number of reasons, such as the choices parents chose to discuss and young people's level of understanding. Parents and young people who had experienced differing opinions or conflict may have chosen not to participate in the research. It is also acknowledged that many of the young people were not in a position to make their choice 'happen' without parental involvement, for example, parents liaising with practitioners (see Maddison & Beresford, 2012). Despite this, the study's in-depth qualitative insights provide important additions to our understanding of choice-making in families, especially families of young people with learning disabilities, and highlight some practice issues which have wider resonance.

## 10. Future Research

Recognising the limitations of the study and its essentially exploratory nature, there are a number of issues and areas which would be interesting to explore in future research, for example, extending the study to a larger sample of young people with learning disabilities and their parents. It would also be interesting to examine the role of different parenting styles, exploring if different styles do influence young people's involvement and if so, how. The absence of conflict has also been noted, research that particularly examines young people and parent conflict during choice-making would provide an informative point of contrast. In addition, acknowledging the role that practitioners can play in choice-making (see Pilnick et al., 2010 and 2011) it would be interesting to

explore how practitioners work with young people with learning disabilities and their parents as they make different types of choices, in particular, considering if the factors discussed in this paper are similarly used and/or viewed as important by practitioners.

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**Table 1 Sample of families and choices discussed by parents**

| Identity | Parent interviewed | Young person | | | Choice(s) |
|---|---|---|---|---|---|
| | | Gender | Age** | Disability*** | |
| P1 | Mother* | Female | 17 | Complex medical needs (CMN), moderate learning disabilities (MIDs) | Which further education (FE) college |
| P2 | Mother | Male | 21 | CMN, MIDs | Where son lives (away from parental home)<br>Which post-school daytime activity |
| P3 | Mother and Father | Male | 14 | Duchenne Muscular Dystrophy (DMD), MIDs | Which secondary school (leaving middle school)<br>Whether to have spinal rod surgery<br>Degree of physiotherapy undertaken |
| P4 | Mother and Father | Male | 17 | Rare neurological condition (RNC), MIDs | Which FE college<br>Where son lives (away from parental home) |
| P5 | Mother | Male | 18 | DMD, severe learning disabilities (SIDs) | Which specialist bath meets son's needs<br>Whether to accept a gastrostomy<br>Which post-school daytime activity |
| P6 | Mother** | Female | 19 | CMN, SIDs | Which post-school residential unit<br>Which post-school daytime activities<br>Whether to accept a flu injection |
| P7 | Mother | Male | 18 | RNC, SIDs | Which FE college<br>Whether to have investigative heart scans |
| P8 | Mother** | Male | 22 | CMN, SIDs | Which post-school daytime activity |

| Identity | Parent interviewed | Young person | | | Choice(s) |
|---|---|---|---|---|---|
| | | Gender | Age** | Disability*** | |
| P9 | Mother | Female | 14 | Deaf, blind, SIDs | Which leisure based clubs and activities |
| P10 | Mother and Father | Male | 19 | CMN, SIDs | Which post-school daytime activity<br>Whether to accept a gastrostomy |
| P11 | Mother | Female | 15 | Genetic condition, SIDs | Whether to move to self-directed support (personal budget)<br>Whether to start using respite/short break services |

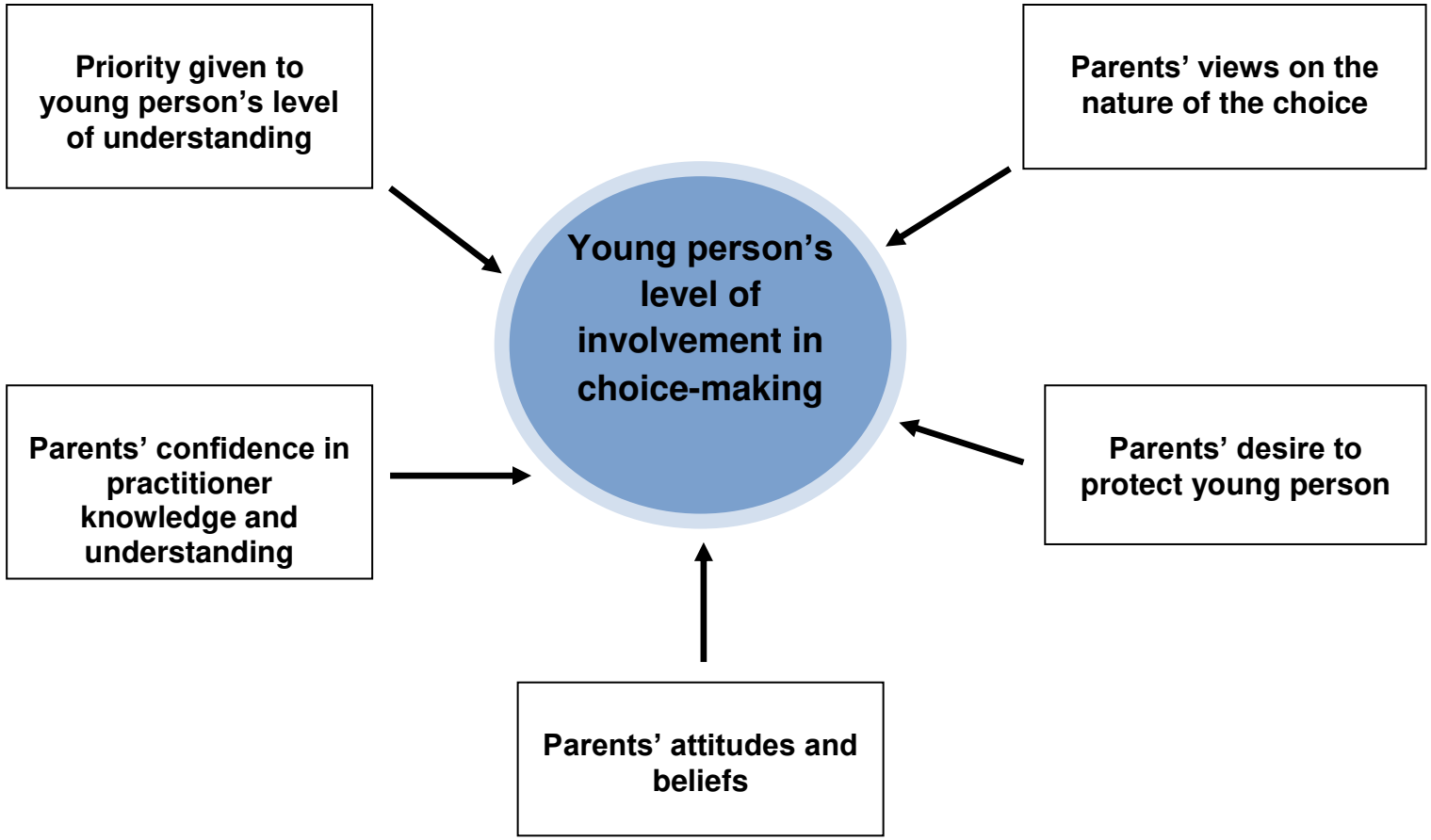
* Ethnicity – one family was British-Pakistani

** Lone parent

** Age at first interview

*** Intellectual disability as defined by parents

**Figure 1** **Factors considered during choice-making**

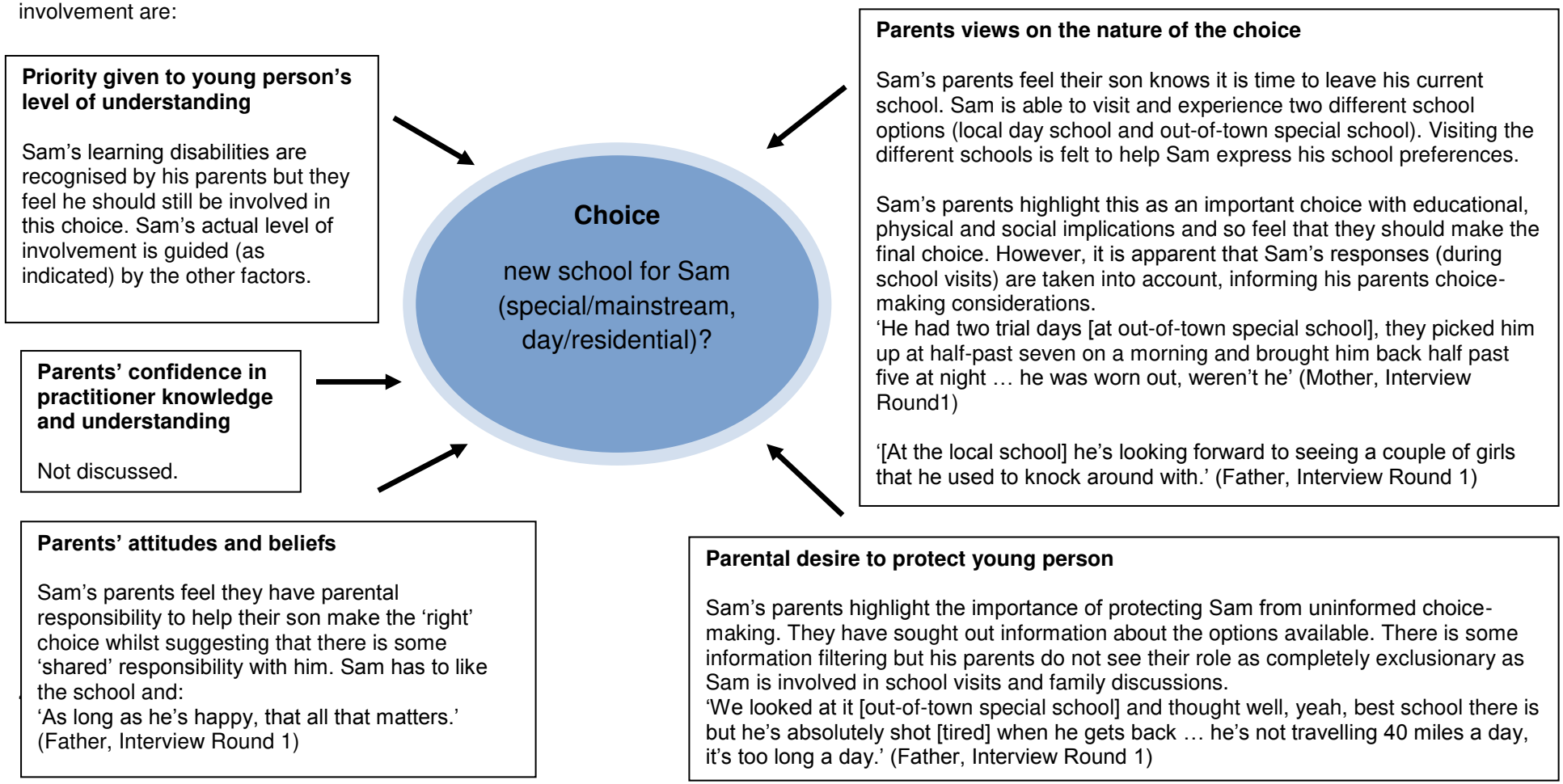


## Figure 2 Case example

Background (P No.3) – Sam is 14 years old (at first interview) and lives with his parents and older sister. He has Duchenne Muscular Dystrophy and is a wheelchair user. He also has moderate learning disabilities and until recently attended his local mainstream school with one-to-one support.

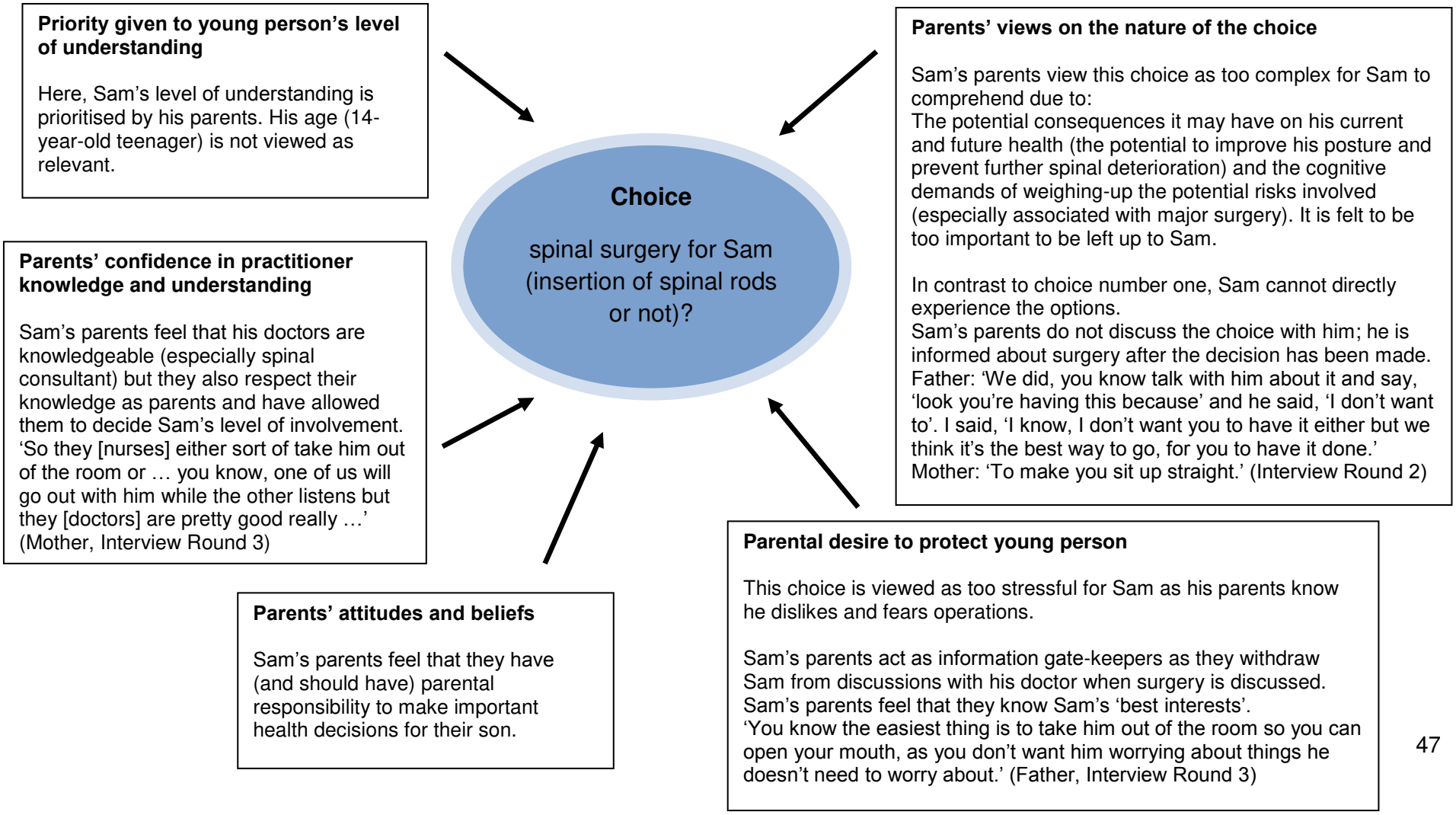
### Choice Number One

Sam's parents discuss choosing a secondary school as Sam prepares to leave the local middle school (leaving age 13-14 years) he attends. Sam and his parents finally choose the local mainstream secondary school. The factors Sam's parents take into account when making the choice about Sam's level of involvement are:



## Choice Number Two

Sam's parents discuss the choice of whether or not to accept major surgery and the insertion of spinal rods. His parents finally choose to accept surgery for Sam. The factors Sam's parents take into account when make the choice with regard to Sam's level of involvement are:



## Choice Number Three

Sam's parents discuss how they now allow Sam to take a more active role in deciding how much physiotherapy he needs each day to help clear his chest.

The factors Sam's parents take into account when making the choice about his level of involvement are:

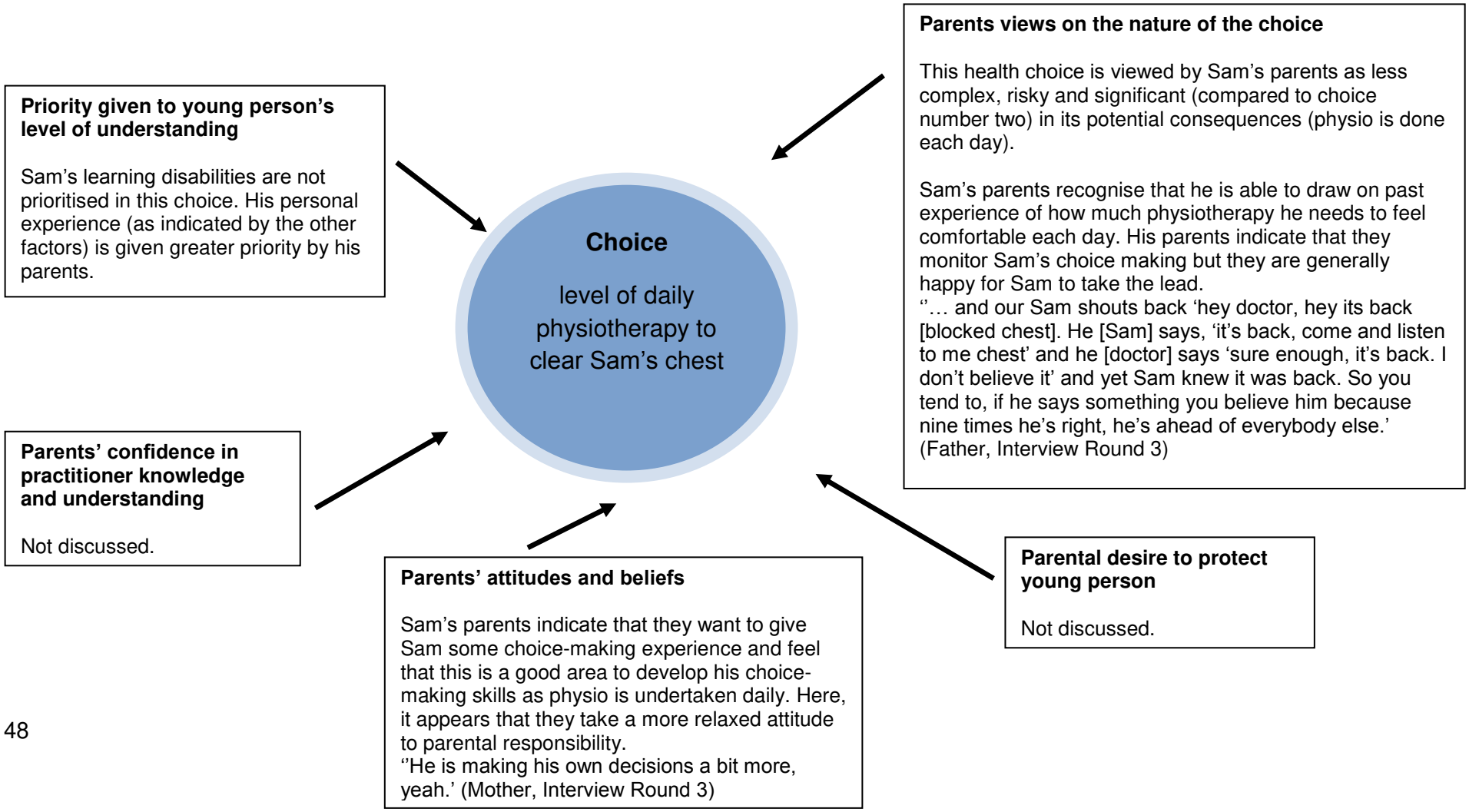


**Figure legends**

Figure 1 Factors considered during choice-making

Figure 2 Case example