

The expectations of parents of disabled children

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Following the diagnosis of a child's disability, parents have to develop new expectations concerning the child, their role as parents and the support services that are designed to meet their needs. Research shows, however, that these needs frequently remain unmet. In this article, Fran Russell, who writes as a parent of a son with a learning disability and as a professional with experience of practice in early years support services, explores parents' perspectives from a different direction. She argues that an investigation into parents' expectations could lead to a greater understanding of how parents of disabled children respond to their new-found situation. Fran Russell's own research, undertaken as part of her Education Doctorate programme at Leeds University, reveals that little is currently known about parents' expectations and indicates a pressing need for parents to be better informed, at an early stage in their experience of parenthood, in order to interact more effectively with professionals at a range of levels.

Introduction

'From that moment my life diverged from the way of the lists. It was as if I had been following some roughly mapped route and suddenly the car swerved wildly and I began to plough through terrain I had never dared venture into. When a baby is diagnosed with cerebral palsy, it is unclear where in this foreign land she will fall. Low expectations of children with cerebral palsy – as with all children with disabilities – inevitably encourage such children to underachieve. My daughter might do all sorts of things – and she might not. There would be no certainties. When I tried to construct a Life List it dissolved into daily tasks. I could no longer imagine what lay ahead.'

(Birkett, 2000, p.190).

At the time of diagnosis of their child's disability parents, like this one, can find their expectations of becoming a parent shattered. What they envisage will happen to themselves and their child in the future can be difficult to imagine until they start to develop some understanding of their new situation and to build new expectations. What parents *need* in order to support them during this process and in caring for their child has been investigated and

services designed and delivered to endeavour to provide for these identified needs with the outcomes evaluated (see, for example, Beresford, Sloper, Baldwin & Newman, 1996). Yet there is little evidence of research about what parents of disabled children themselves *expect* from such services and whether their expectations are realised.

In this article I will argue that, while it is important to investigate and provide for what parents of disabled children need, it can also be useful to support them to explore, articulate and review what they expect. Generating and reviewing expectations is an essential process in developing a person's understanding of any new situation. It is a process that can support parents' understanding of their child and the implications of their disability and can enhance the relationships that develop with professionals involved in their child's education and care.

The needs of parents of disabled children

The concept of need was formalised in education as a result of the Warnock Report (DES, 1978) which recommended the identification of pupils who had special educational needs (SEN). Alongside their children, parents are also perceived as having particular needs – the need for information, advice, support and practical help and the need to be involved at every stage in the identification and assessment of their child's SEN (DfES, 2001). Addressing the needs of these parents is approached through a combination of informal social support networks, including friends and family, voluntary organisations and statutory Parent Partnership Services (Wolfendale, 2002). The aim of support services is to work in partnership with parents so they can play an active role in their child's education. Yet, despite this support, for many parents their needs continue to remain unmet and are less likely to be met than those of their child (Beresford, 1995).

Many have regarded this 'needs'-based approach towards pupils with SEN and their parents as an individual deficit approach that identifies and therefore segregates pupils and, as a consequence, their parents (Rieser, 2001). The process of identification, rather than helping to meet the child's needs, can create needs for parents. Socially they are identified as different from the main population of parents, through the identification of their child's disability, and are therefore perceived to require help to fulfil their role as a parent. Emotionally many will need support to adjust to their new-found situation and the continued care of their child. Intellectually they need to learn and understand a new body of knowledge relating to their child's diagnosis and the systems designed to support them.

Parents therefore can experience stress arising from, for example, their child's care needs, their own emotional needs and negative reactions by others to their child. Further anxiety can be caused when seeking and trying to understand information, accessing a large number of services and working with a variety of workers who are not co-ordinated. While many families learn to adapt and develop their own ways of coping, they continue to remain vulnerable (Beresford, 1994). Rather than becoming proactive partners with people involved with their child's care and education, parents can become dependent, passive and experience a lack of control or have to deal with conflict in order to have their needs met.

The processes of identification and assessment of children's needs can therefore exacerbate parents' feelings of isolation, uncertainty and loss of confidence in themselves by creating needs that are not met and so lowering their self-esteem and endangering their well-being.

Parents' expectations

All parents develop expectations about their child's education based on their own experience and information provided by the school concerned, the media and informal networks of parents. Legislation has helped focus attention on what a parent has the right to expect (DES, 1980; 1986). This includes the right of all parents to, for example, be involved in the choice of the school their child would attend, have an annual report on their child's progress and have parental representation on the school's governing body.

Studies that have explored parents' expectations of teachers and of the school indicate that parents expect quality of teaching, their child's academic progress and happiness, homework, fair discipline and information (West, David, Noden, Edge & Davies, 1996; Crozier, 1999; Foot, Howe, Cheyne, Terras & Rattrey, 2000; Tartar & Horenczyk, 2000). Parents of children with SEN may develop similar expectations but additional legislation associated with pupils with SEN has set out what they have the right to expect in relation to the initial assessment and ongoing review of their child's educational needs (DfES, 2001). They will also develop expectations related to their child's individual needs and development and of the services and support they receive but the only studies found concerning expectations of parents of disabled children (Au & Pumfrey, 1993; Bennet, Lee & Lueke, 1998; Woolman, Garwick, Kohrman & Blum, 2001) have not provided any conclusive information.

In none of the studies referred to above was the notion of expectations explored, yet their origins, the ability of a person to articulate them and their effect on behaviour and beliefs are very complex. A closer examination of these can inform us more about how parents can develop a greater understanding of their child and the implications of their disability as well as how relationships develop between them and those involved in their child's education. This is an area I am currently focusing on in my doctoral research. In a study entitled *Starting School: the expectations of*

parents of disabled children (Russell, in preparation) I have followed the experiences of 17 parents of disabled children during the period that their child moved into full-time education. During three separate semi-structured interviews with each family I asked parents about the content, basis, development over time and outcome of their expectations. Some of the experiences and expectations the parents talked about are referred to in this article. Pseudonyms have been used to ensure anonymity.

Expectations and parents of pupils with SEN

'The concept of "expectancy" forms the basis for virtually all behaviour. Expectancies can be defined as beliefs about a future state of affairs. As such, expectancies represent the mechanism through which past experiences and knowledge are used to predict the future.'

(Olsen, Roese & Zanna, 1996, p.211)

Expectations are therefore subjective predictions about the future. They originate from and affect a person's beliefs, knowledge and experience and can affect a person's behaviour during the social interaction they have with others (Tajfel & Fraser, 1978). Expectations based on a firm underlying structure are associated with a high degree of certainty whereas expectations that originate from subjective knowledge are less likely to be realised (Torr, 1988). The value of working through a process of setting and reviewing expectations is that an individual will learn because those that are not fulfilled are reviewed and possibly modified in the light of a person's new experiences. This will occur against a background of the values held by an individual and members of the society in which they live (Olsen et al., 1996).

Expectations originate from and have an impact on an individual's interaction across their social environment. For example, cultural values will influence the beliefs on which expectations are based and, through the development and review of expectations, a person gains a greater understanding of their personal experiences. It is therefore useful to examine the origins and effects of parents' expectations using the ecological model proposed by Bronfenbrenner (1977) in his study of human development. This is a study of how a person develops their understanding through interaction with their social environment at different levels. Bronfenbrenner identifies four levels, which are:

- **the microsystem**, or the relationship an individual has with their immediate physical and social environment;
- **the mesosystem**, incorporating the interrelationships between the most significant settings in which an individual is involved at a particular time;
- **the exosystem**, including other specific formal and informal social structures that impinge on and so influence events;
- **the macrosystem**, encompassing the prevailing ideology and the institutional culture that informs the other systems, including the economic, social, legal, educational and political systems that determine the beliefs and values of a society.

Each of these levels can be used to examine the concept of expectations more closely with particular reference to parents of disabled children. A summary is provided in Figure 1.

In the following sections, I go on to explore interactions at these levels in more detail using examples drawn from my own research.

Figure 1: The relationship between Bronfenbrenner's ecological model of interaction and the experiences and expectations of parents of disabled children

Level of interaction	For a parent of a disabled child this concerns their experiences of:	Expectations developed that are associated with:
Microsystem	<ul style="list-style-type: none"> their child caring for a child who has additional support needs 	<ul style="list-style-type: none"> their child's development their own role as a parent the role of significant other people in their child's life
Mesosystem	<ul style="list-style-type: none"> services received to support their child's and their own needs 	<ul style="list-style-type: none"> the role of people delivering services interaction with people delivering services
Exosystem	<ul style="list-style-type: none"> national and local systems and structures designed to meet the needs of children with SEN the working practices of people involved in implementing these systems and delivering services and their attitudes towards disability, pupils with SEN and their parents 	<ul style="list-style-type: none"> how systems and services will meet their child's and their own needs
Macrosystem	<ul style="list-style-type: none"> the social environment and cultural values 	<ul style="list-style-type: none"> the social values bestowed upon them and their child

The microsystem

The parent of a disabled child has personal experience of their child and their parental role in caring for a child with additional support needs. They also have direct communication with others, including their child's doctors, teachers and therapists, who should provide factual information about the child's condition and services available but will also convey social information and values. As a result of such experiences parents will begin to develop expectations about their child, about their role as a parent and about the role of significant other people in their lives at that time from their own personal experience. Rhiana, for example, has cerebral palsy and her mother talked about the relationship she developed with the play therapist who gave her advice

about caring for Rhiana. Her initial expectation of Rhiana's future development was that it would be slow. She said:

'I would like her to be able to do more for herself. Like – she can play with toys but to be able to pick things up ... just little things really I'm expecting. I'm not expecting great things to happen because I know it is not going to.'

However, by a later interview, she had reconsidered, saying:

'She will definitely make progress but I don't know if it will be as slow as I thought.'

Goodnow and Collins (1990) suggest that parents' ideas will not automatically change as a result of presenting new information. Parents' response to lack of agreement with professional opinion about their child is that they change their expectations, ignore the information or change their reference group. Parents of disabled children could react in a similar way as a result of their expectations not being confirmed. So by offering parents opportunities and support to reflect on events, their understanding can be enhanced. Their subsequent expectations can then be based on different dimensions and from a variety of perspectives to enable more complex expectations to be generated with a greater possibility of the parent's adjustment to their new role over time. This can be very challenging for some parents because they may choose to ignore relevant information or search for that which confirms their original beliefs rather than considering alternative options. A number of people working with families in the period following diagnosis advocate counselling for some parents following their child's diagnosis as it can provide opportunities to support parents to reflect on and develop the expectations they have for their child and themselves as new information is gathered.

Certainly in my experience of talking to parents in my research study they valued the opportunity they were given to talk about their expectations which changed and developed over time in the light of new information and experiences.

The mesosystem

Parents of disabled children will automatically generate unconscious expectations of people delivering services designed to meet the needs of disabled children and their families. They will often only become aware of such expectations if they are not confirmed. Some parents interviewed talked of having to fight for what their child needs because they have not been able to secure resources that they had expected. For example, Sharon's mother had great difficulty securing her a special school placement that was contrary to professional advice. She had expected the professionals involved would support her during the time of the assessment but instead she said that she felt excluded from the decisions that were being made.

Expectations become more conscious when an event requires thought and preparation. For example, expectations can have a planning function for parents and professionals. Each party can form different expectations, which, if articulated, communicated and discussed, would enable trust to develop between them as clear goals and responsibilities are negotiated. Alternatively, where trust in a relationship breaks down, parents expect fewer positive outcomes so lower their expectations (Lake & Billingsley, 2000). Problematic relationships between parents and professionals that result in conflict and distrust can lead to anxiety and depression, which is an issue for some parents caring for a disabled child. Robert's mother, for example, described her feelings when channels of communication with the LEA broke down so what she had planned for Robert did not happen. She said:

'It is the frustration I had at certain points and the distrust that I felt and the sort of mindset I was in where I was quite stressed out and ... well, I was on the verge of being ill again, I think. In the end, when it all works out, you are sort of quite relieved but also sort of feel let down really.'

After Robert had been in school a year she explained how communication with the school had developed so she could discuss her concerns. She explained how she came to trust the people involved.

Expectations help a person make behavioural choices because people behave differently during interaction according to their expectations of the other person. When parents of disabled children interact with, for example, their child's teacher, there is a danger that relationships can develop that are based on a stereotypical view of the parent and teacher rather than knowledge and experience of the individuals concerned. The behaviour of those involved will affect the social interaction that occurs and can lead to negative assumptions and expectations being confirmed. If, however, interaction between parents and professionals is based on honesty, openness and trust, both parties can be explicit about what they expect of each other. Dale (1996) proposes that professionals working with parents of disabled children should encourage them to discuss their ideas and expectations in order to play a more active role in the relationship that develops between them. She proposes a model of partnership that is based on negotiation that can provide an opportunity for parents to think through new situations and future events in order to reconsider expectations and plan accordingly.

In this way parents can generate more complex expectations that take account of different perspectives and dimensions which are more likely to aid their adjustment to and understanding of any new situation. Fay's parents, for example, were unhappy when the provision of a qualified support worker written into her Statement did not materialise. The person appointed had few skills and no support to develop them further. Fay's mother had attended a course organised by the local parent partnership

service so knew what she had the right to expect and requested an early review. During their discussions with the headteacher, Fay's parents thought that she was defensive and did not listen to their views so the situation was not resolved until a new headteacher was appointed. In contrast, the parents said the new headteacher listened to their concerns, then discussed and agreed what was possible. As a result a programme was implemented that involved regular meetings between the school staff, the headteacher, Fay's mother and the learning support assistant so everybody could agree learning goals for Fay and how to achieve them. Through this process Fay's parents gained a better understanding of what they could expect from the school. Her mother's comment to me was:

'I found it unbelievable that one person could make such a difference.'

For this to happen it is essential that reciprocal channels of communication be established between parents of disabled children and practitioners in order to provide clear information and communicate the expectations they have of each other and of the child. Regular contact would enable this to happen and give parents the opportunity for greater involvement. It can also help to avoid the complaints of some teachers that parents' expectations are too high, which can lead to conflict (Morris & Ellison, 2000). It would, however, be useful for parents and professionals to have access to training or support to develop effective communication and negotiation skills.

The exosystem

Social interactions between parents, teachers and schools cannot be viewed in isolation. Guidelines for meeting the needs of pupils with SEN are imposed nationally through legislation and locally by LEA directives and school management policies. Also influential are the working practices and attitudes of people involved towards disability, the pupils themselves and their parents.

One of the guidelines in the *SEN Code of Practice* (DfES, 2001) is that parents should receive information about the procedures and support available within the LEA and school. However, very few parents have had personal experience of this process before having a disabled child and a recent study by the Rathbone Society (2001) found that many parents of children with SEN in mainstream schools lack the knowledge and information to become fully involved in their child's ongoing assessment.

It can be difficult for parents and teachers alike to understand the complexity of the procedures and the arrangements that have been made locally to follow them. In addition there are frequent changes in policies regarding the education of pupils with SEN of which parents and teachers need to be aware. One parent I interviewed had not expected the whole process of assessment and receiving a Statement to take so long and be as complex. She thought that it was obvious that her son had difficulties. Other

parents told me about inaccurate information they had been given that led them to have certain expectations, which were subsequently not confirmed.

Also of concern to many parents were the negative attitudes of some practitioners towards them and their children that did not comply with the principles of the policies. For example, Kirsty's mother talked about her thoughts after visiting prospective local mainstream schools. She said:

'I found looking around schools really quite a negative experience. I think I had quite a simplistic idea that because the policy in this authority seems to be so much towards integration then the schools would reflect that but I didn't find that they did.'

She went on to comment about her experience of speaking to teachers, saying:

'I think they see it as an extra burden to have a Statemented child in their class. So how it actually works in practice really concerns me.'

The continued development of Parent Partnership Services, outlined in the *SEN Code of Practice* (DfES, 2001), to provide parents with information, advice and support can help them to generate complex expectations, which are based on a firm underlying structure and so have a higher degree of certainty of being confirmed. They can also help develop the philosophy of partnership in all interactions that parents of disabled children have with professionals so that real agreements can be made where each party has an equal contribution. However, although ten of the 17 parents involved in my study knew about the service, only two described support they found useful.

The macrosystem

Tajfel (1978) describes the influence of cultural information and ideology as reciprocal in that the social environment and cultural values mould an individual but an individual can also create and change them. Disabled activists and their organisations have been campaigning for social change. They advocate a move away from the dominant view towards disability, which is based on the 'medical' or 'deficit' model, to a 'social' model of disability, whereby the barriers created by society that prevent people with impairments fully participating are challenged and removed.

For a parent of a disabled child, cultural beliefs concerning disability are critical in all aspects of their lives. They determine the social values bestowed upon them and their child and impact on any interaction concerning educational provision. Parents find themselves interacting at all levels

– the teacher, the school, the LEA, the government – with people who have greater power than themselves over their child's educational provision (Armstrong, 1995). While many of the parents I interviewed were themselves struggling to understand some of these issues and reassess their beliefs, some professionals also have to operate within systems that conflict with their personal values. If people act to raise awareness in society as a whole about the discriminatory practices and attitudes towards disabled people then society may begin to change.

Andrew's mother told me about her experience of having a sister with a complex learning disability. She believed that Andrew's mainstream school placement could help change the attitudes of staff and children towards disability in the future and became very involved in challenging discriminatory practices she encountered at the school. It is, however, difficult for parents to formulate realistic expectations, particularly when, in my experience, many are not aware the issues exist. What is important to them is the educational provision for their individual child.

Conclusion

Expectations are beliefs about what may happen in the future. They originate from an individual's beliefs, personal experience and through the acquisition of social information. They are influenced by social interaction with individuals as well as organisations, legislation and cultural values. As unrealistic expectations can set the scene for disappointment and poor relationships, it is important they are based on a firm structure to increase the probability of them being confirmed.

Lake and Billingsley (2000) suggested that one of the main causes of conflict between school staff and parents was the discrepancy between their views of the child and their needs. This influence was particularly strong where the school staff described the child from a deficit perspective, so perceiving them as problematic, rather than as an individual. An alternative approach, based on the social model of disability, could focus on the child's strengths, their aspirations and opportunities to achieve them. It would involve parents and professionals having ongoing opportunities to share information about what they need and expect which they can discuss so that responsibilities can be negotiated and outcomes considered. As a result, more equal relationships can develop between home and school and parents can gain a greater understanding about the implications of their child's disability. They can, if they choose, challenge the barriers that exclude their disabled children from being fully included in society. For the parents in my study, there would still be no certainties (Birkett, 2000) but perhaps such an approach could help them to have more control over what lies ahead.

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