

Children as partners in their diabetes care

**An exploratory research study
September - December 2003**

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Abstract

Can young children understand and also take an active part in managing their diabetes care? In-depth interviews were conducted with 24 children who have type 1 diabetes, and 29 parents, to elicit their views on these questions. The children were aged 3-12 years; they attend diabetes clinics in an inner London teaching hospital, and two large district general hospitals, one in inner London, the other in a commuter town. Two paediatricians and two specialist diabetes nurses were also interviewed.

The children and parents reported:

- their high levels of knowledge and skill;
- high levels of satisfaction with the care from the specialist diabetes staff;
- criticism that non-diabetes-specialist health practitioners often severely lacked knowledge about diabetes and were unable to provide adequate and safe care for the children;
- the importance of direct experience of diabetes as a source of knowledge and skills,

and therefore:

- the need for practitioners to recognise and learn from the wealth of knowledge amongst children and their parents to help practitioners to provide the best possible care and support, working as partners with children and parents.

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1. Introduction

Readers of this report

This report is for everyone who would like to see more effective diabetes care, with lower rates of later complications, and better quality of life for people with diabetes. Most people with diabetes are adults, and many points in this report apply to adults too, as well as to children. This report is also relevant to young and older people with other long term conditions that affect their daily life.

New areas of diabetes research

With the rising incidence of diabetes in younger children, questions about how they can be informed and involved in their care are raised more often. Yet very little research has been conducted with children about their knowledge and experiences of diabetes, an exception is Clark 2003). Research about behaviours and attitudes is conducted mainly with adolescents and adults, and tends to emphasise their difficulties and morbidity (Mortensen 1997; Brandt 1998; Amer 1999; Grey 2000; Anderson *et al.* 2002; Povey and Hallas 2003). So this report explores four fairly new areas in diabetes research:

- the views of children aged from 3 years onwards;
- positive ways in which children can share in managing their care;
- social problems that arise in everyday life, rather than personal problems within the children themselves or their families;
- methods of listening to children's accounts, rather than using questionnaires, or tests, or only adults' replies.

The main sections of the report

We begin by reviewing the social, medical and research backgrounds and the questions these raise for this project. We list our aims, introduce the families, and explain our methods. The main section reports how our findings reply to the questions in the introduction. We end by reviewing the key questions and answers, and the practical recommendations that arise from these.

2. The medical, social and research backgrounds and the questions they raise for this project

The growing incidence and costs of diabetes

Around 1.3 million people in the UK are currently diagnosed as having diabetes and about 15% of them have type I diabetes. The incidence of type I or childhood diabetes is rising, particularly in the early years (Shield and Baum 1998; Greene 1999; NSF 2001). Half of all people with long-standing diabetes have serious complications and besides the high personal costs, the economic costs of diabetes for the NHS are very high (BDA 1996). However, large clinical trials have demonstrated that good control of blood glucose concentration can reduce the development of serious complications (Assal *et al.* 1985; Muhlhauser and Berger 1995; DH/MRC 2002).

Policy makers and practitioners urgently want people with diabetes to acquire more knowledge and skills, and to take on much more responsibility for their own care, because the NHS does not have enough staff or resources to provide all the essential care (NSF 2001; DH/MRC 2002). Also, the care is much more effective when people understand how to manage it themselves.

Questions for this project

At what age can young children begin to take an informed share in managing their diabetes, and perhaps start to form life-long healthy habits?
Is it worth informing them, and encouraging them to be active partners in their care?
Or is it unwise and unkind to expect this of children aged from 3 or 4 years?

Medical and social challenges of living with diabetes

Type 1, or insulin dependent diabetes mellitus (IDDM), is a treatable but incurable condition, which requires daily blood tests and injections of insulin. A healthy balanced diet low in sugar and regular hospital appointments are all part of the diabetes regimen. Children with diabetes have to work the daily regime into their lives, and to deal with having painful injections and blood tests. They constantly have to be alert to avoid 'hypos' (hypoglycaemia - very low blood sugar levels which can cause faintness, unconsciousness or even coma) and 'hypers' (hyperglycaemia - high sugar levels which increase the risk of later complications). They also somehow have to find ways of combining life with diabetes and 'normal' everyday life with their friends and peers who don't have such restrictions.

When can children begin to accept and cooperate with their treatment?
When can they understand about insulin injections and diet and sugar levels?
How do they manage to live the complicated double life of being a child with diabetes and also a 'normal' child like their friends and peers?

What is already known about type 1 diabetes care?

The Diabetes and Complications Trial (DCCT 1993), perhaps the largest piece of research involving children with diabetes to date, was conducted in 18 countries from 1983 to 1993 by the US National Institute of Diabetes and Digestive and Kidney Diseases. The results of this randomised controlled trial of intensive insulin therapy showed that maintaining good control of blood glucose levels could reduce the risk of eye disease by 76%, kidney disease by 50% and nerve disease by 60%. However the trial also showed 'that freedom from complications is a shared responsibility between patient and professional ... when there is a discrepancy between the goals of patients and professionals, those [goals] of the patient and their parents are more likely to reflect the outcome of the treatment.'

When do children begin to have personal goals?
When do adults begin to need to take account of children's goals, if the diabetes care is to work well?
Or is it dangerous to listen to young children and negotiate with them, and better to control them firmly?

Management of type 1 diabetes means life-long daily treatment preformed mainly by the person with diabetes or their parents or carers. They live for years with the 'horror of daily injections', which often turn into an undignified tussle. Many parents are tempted from time to time to 'forget about' their child's insulin' (Fox 1995). Understandably, children and young people find the regimen restrictive (Williams 2003), and such feelings were reported in a study of 27 7-18-year-olds attending a diabetes clinic. Injections and blood glucose testing were perceived as annoying or a 'hassle', and diet was associated with feelings of being restricted or missing out on 'nice' food (Fox 1995). Simply telling children that they must endure these indignities without understanding, partnership or information is unlikely to encourage their willing cooperation with the routines. There are many reports of surveys, trials, over-views and longitudinal studies about the processes and outcomes of children's health care

and life-styles, but very little is known, as reviewers note, about children's own views (Brunton *et al.* 2003; Eiser and Morse 2001) – or their understanding, values and motives.

Can younger children understand not only how to manage their diabetes, but also how this can positively help them in the short and long term?
Can they understand about health care goals and values as well as routines?
And if they can understand, does this help to reduce conflicts about their care?

Education and diabetes control

Research has shown that educating adults to self-manage their condition increases their engagement with their care. They learn on intensive education courses how to calculate and adjust their insulin dose to match the food they choose to eat and the energy they expect to expend, The Dose Adjustment for Normal Eating (DAFNE 2004) Trial in the UK showed a positive impact on blood glucose levels and care practices, and significant improvement in people's reported quality of life (Heller *et al.* 2002). For some people, it seems that the education course required for DAFNE self-management could be key to practising good health care. They have time to learn and talk in depth with practitioners, skilful educators, and other people with diabetes. As one DAFNE participant said, 'It's given me the real reason for doing blood tests' (DAFNE 2004).

The significance of this statement is apparent when contrasted with reports of young people's negative feelings about doing blood tests (Povey and Hallas 2003). 'I used to think that I was just going to come [to the clinic] to get told off about my blood sugars – it really used to put me off' (young man aged 16). 'Sometimes in my mind I'm a bit anxious, but I don't tell anyone. I'm scared of my blood samples. When they take my blood samples and everything ... whether it's going to be bad or good. [If it's bad I feel] a bit ashamed ... a bit worried about how I'm going to improve it' (boy aged 9). Their emphasis is not placed on doing the blood tests to benefit themselves and for their own well being, but with an aim to get a good appraisal from the doctor. The worry that ensues, understandably, can have the impact of 'putting them off' engaging with health practitioners.

However, there are negative pressures on health care staff that can deter them from sharing knowledge with patients. There is increasing anxiety about managing risk and preventing litigation either for under-informing/treating people or for enforcing unwanted interventions (Kennedy 2001). Caught between these twin pressures, practitioners are not encouraged to increase life-threatening risks for patients, as self-management of insulin doses might do, without clear protocols and medico-legal protections. Centuries-old traditions of the expert doctor and nurse managing the helpless ignorant patient have to change, if the aims of the National Service Frameworks for Diabetes (NSF 2001) and for Children (NSF 2004), that patients will be informed and active in their care, are to be achieved. Education for competence (knowledge, skills and attitudes) needs to be complemented by education for capability (the abilities to adapt and generate new knowledge and skills) that supports learners' own goals, and avoids rigid prescriptive goals (Fraser and Greenhalgh 2001).

The original DAFNE research in Germany (Assal 1985) was piloted with children but has not yet been formally tested or used with them. One DAFNE researcher commented, 'I think it's crying out for a trail of adolescent patients – after all, kids are the ones who are going to decide whether or not we reduce complications' (DAFNE 2003). This is especially vital since sub-optimal glycaemic control during adolescence

appears to have a lasting effect, even when better control is achieved later (Cooper 2002).

Can children understand and share in using fairly complicated methods of controlling their diabetes?
Would these methods be associated with better diabetes management and quality of life?

How willing are practitioners to hand responsibilities to their patients?

The success of the DAFNE trial in reducing blood glucose levels, whilst not increasing the incidence of hypoglycaemia, demonstrates that adults with diabetes can be capable and responsible. Yet the DAFNE website also notes, 'There is sometimes resistance to giving this amount of responsibility to patients. There's been a sense that this sort of treatment is just too hard for patients to take over for themselves' (DAFNE 2004). There is also a sense that some practitioners underestimate and find it hard to trust their patients. The National Service Framework for Diabetes (NSF 2001) urges practitioners to 'empower' their patients. Yet research reports tend to show more examples of patients' problems, failings and needs, than of 'empowered' people managing their diabetes well.

Practitioners are likely to lack trust in child patients even more than in adults, especially if they assume that children are too young to understand and share in managing their diabetes care. However, only children with diabetes and their parents really know why they do, or do not, carry out practitioners' advice, what works well, what problems they face, and how they try to solve these. And only when we start from children's experiences and perceptions can effective partnerships and support develop that involve children and their parents more actively in their care.

Why have there been so few reports from research and practice about successful and more equal partnerships between practitioners and people with diabetes, and about what works well?

What are the serious problems that deter doctors and nurses from offering people more choice and control over managing their diabetes (such as practitioners' fear of risk, blame or litigation)?

How can negative attitudes and routines particularly restrict children's involvement in their care?

Positive patterns from the start and the socio-economic context

Amer (1999) advises that nurses coordinating the care of newly diagnosed children must recognize the significance the diagnosis has for the child. They should identify those factors that place the child at risk for poor adaptation, and help children to adapt, calling on psychological or social support resources, when needed, as early as possible. Research has found that positive support from others does help the family to adapt. Amer's review cited key factors that include: family cohesion and adaptability; positive coping strategies; and social support. Children who are diagnosed when younger tend to adapt better than those who are older at the time of diagnosis (Amer 1999). Research about the relationship between diabetes-related parental behaviours (conflict around and involvement in treatment tasks), regular blood glucose monitoring (BGM), and glycaemic control also showed the importance of support from others. The study found that greater family conflict about the diabetes care is significantly related to poorer glycaemic control (Anderson *et al.* 2002).

However, this type of research may simply find, unsurprisingly, that families who generally cope well, resolve conflicts, and have supportive networks, cope well with diabetes. Whereas families who already have difficulties and feel unsupported find diabetes harder to cope with. British children with diabetes tend to fare worse than children in other European countries (Mortensen *et al.* 1997), and although the UK is the fourth richest country in the world, it has exceptionally high levels of childhood poverty, economic inequality and 'social exclusion' (Hills *et al.* 2002). Recently, 49% of children in inner London were living in poverty (Hood 2002).

It has been known for a decade that childhood ill health increases in the wealthier countries when inequality and relative poverty levels increase (Wilkinson 1994). This suggests that besides research about individual medical and psychological needs and support, research about the socio-economic context is also needed in order to understand childhood diabetes and ways of managing it.

As most diabetes care is performed in the home, it is vital to investigate families' methods for coping at home, and the kinds of support that they welcome. Diabetes practitioners and researchers hold a great deal of practical and research knowledge and years of experience – much valuable and vital information. However, only the young people with diabetes, their parents and carers have the daily experience of living with diabetes, and the expertise for managing and coping with it.

How can research learn from children's and parents' views about how to help them to adapt to the diagnosis, and to set up and sustain positive patterns of daily care at home?

How can research about childhood poverty and 'social exclusion' inform ways of understanding and managing diabetes?

Advocates for children

The Royal College of Paediatrics and Child Health mission statement (RCPCH 2004) 'champions the rights of children.' The College lists the duties of a paediatrician, including that they should:

- 'pay due regard to the domestic, sociological, environmental and genetics dimensions of the health of children';
- understand their 'holistic and life-long health';
- 'be aware of current medical and political affairs affecting the lives and health of children';
- 'serve as advocates for the health needs of children locally, nationally and internationally';
- 'see themselves as ambassadors for children';
- place 'the child's best interests at the centre of all clinical considerations.'

What political dimensions does the RCPCH mission statement bring to paediatric care?

How could this specifically benefit children with diabetes?

Gaps in research

It is widely acknowledged that there is a dearth of research on younger children's views about their diabetes and that such evidence is critical. 'Improvements in patient care will stem from physicians' awareness of patients' perceptions and from developments in insulin therapy' (Fox 1995), and from research about patients' views (Amer 1999; Brandt 1998; Grey 2000), to fill in gaps in research knowledge about young children's views in particular (DH/MRC 2002). 'The competence of even young

children to make judgments about their condition and assume responsibility for self-management may have been underestimated by health care professionals and is an area for research' (DH/MRC 2002: 29). In 1999, a review of 187 reports of research published since 1980 on children's adaptation to diabetes stated: 'The priority research areas should include eliciting information directly from the children who are coping with IDDM' (Amer 1999). Amer adds that 'the role of coping and stress-processing needs to be studied further, especially from the child's perspective' and in particular their perspective within the 'social-ecological environment of the family' (page 632). Brandt's review (1998) highlights the need to 'draw out the families' knowledge and experience differently [from factual reports] and thus supplement an empirical approach' with interpretive ones too that attend to children's perceptions as well as their observed or reported behaviour. Several reviews also stress that particular groups of children seem to have been consistently excluded from research (Brandt 1998; Grey 2000). 'Minimal attention has been devoted to populations of color, the underserved, various socioeconomic classes, or the developmental periods of early childhood and late adolescence.'

Greene (1999) highlights the need to elicit the views of children from a very young age, and to examine the roles of other family members and other carers. As she states, 'There is little in the literature that describes people with diabetes in the pre-school group separately from the management of older children. Attention to the well being of the child at this age is difficult and time consuming. A satisfactory outcome of a healthy and normally developed child and a family confident in their abilities in the management of the diabetes is a result of close co-operation, support and effective communication between the families and their health carers and advisers (Greene 1999).

Why has there been so little research about young children's views and experiences? Which kinds of research methods are most effective in encouraging them to give detailed accurate views?

3. The aims of this exploratory study

- To elicit the views of children with diabetes aged 3-12 years about their condition.
- To explore the ways in which young children can and do share in their medical and health care.
- To provide information on children's views about coping and living with diabetes, and their ways of sharing their health care in partnerships with concerned adults.
- To involve as highly varied a purposive sample as possible, in terms of the ethnicity, socio-economic background, and age of the children, and their experience of diabetes.
- To take account of additional difficulties that children and parents may encounter at home or school or in their community, whilst also reporting on the issues that are common to many children with diabetes.
- To collate and report the experiences of these children and their families in order to inform children with diabetes, their parents and carers, health care professionals, and policy makers and researchers concerned with diabetes.
- To learn from and help to promote positive ways of supporting and involving younger children in their diabetes care.

4. The children, parents and practitioners, access, and the interview settings

The first two groups in the project

Our original aim was to interview a purposive sample (a small sample but a deliberately very widely varied one) of ten children aged 3-5 years and ten children aged 10-12 years. We hoped to involve very young children because they are least heard. The two age groups involve transitions: the younger group moving into early years centres and to infant school; the older group transferring from primary to secondary school. These moves may make children and parents more aware of aspects of care they have been taking for granted, so that they can talk about them more explicitly, and may compare different contexts.

In order to cover as highly varied a sample as possible in this small study, the research was conducted in a disadvantaged and very ethnically diverse area in southeast London, and in a relatively advantaged commuting area in southeast England. London has the most diverse population and, as mentioned, the highest proportion of disadvantaged young people in the country (Hood 2002), who are likely to encounter a range of extra difficulties in managing diabetes.

The children and their parents were contacted through the paediatric diabetes clinics they attended during September and October 2003. We used the practitioners' knowledge about the families' experience of diabetes, their ethnicity, and socio-economic background such as housing area and parents' employment.

An 'opt in' method of selection was used which respected confidentiality of the children and their parents. The consultant paediatricians and diabetes nurse specialists provided descriptive lists of potential participants without names. We then selected 12 children from each hospital (six in each age group). This allowed for 2 families to choose not to opt in (although if all 24 did 'opt in' we had planned to interview them all).

In South East London only four children between the ages of 3 and 5 years attended the clinic, so we also included two young 6-year-olds. There were more children in the upper age range, and enough children within each age group from the Surrey clinic. We used the practitioners' knowledge of the families, and invited families from a variety of backgrounds to take part in the study.

The clinic staff sent information leaflets (Appendix 1), invitation letters and reply slips with prepaid reply envelopes and our contact details. We initially had five responses in each clinic. In London, however, we sent reminder letters and further invitations, from which we received three more responses from families wishing to participate in the research.

The opt-in method respects confidentiality, and it is easier for people to decide not to take part without feeling any pressure. However, there are lower response rates, advantaged people are most likely to respond, and it is much harder to ensure a diverse sample. Children and adults who might like to join the study if they had the chance to know more about it are missed out.

Most families were white British, one was white South African, one was from Sierra-Leone, and one was mixed-race. Parents' occupations included a range of both blue-collar and white-collar occupations, they were mainly middle-class.

Families were interviewed at their home except two families preferred to combine the interview with their regular visit to the diabetes clinic, and one mother and daughter were interviewed at the mother's office. Some children and parents were interviewed separately, but four families preferred to be interviewed together, including the two youngest children, although it was made clear that discussion would first focus on the children and then their parents. In five of the families, the child or the parents left the room during the other person's session. One boy needed to eat his meal when the interviewer arrived, so she talked first with his mother, and he later joined in the discussion with them. In the other two interviews, the children and parents stayed together as they had nowhere else to go to. There were no apparent differences in the type of discussion whether families were interviewed separately or together. Nine children chose to use our drawing materials and to provide a picture and a few younger ones used the play materials.

The third group in the project

Within limited time and funding, the researcher at City University was able to spend two afternoons in a diabetes clinic in an East London hospital with many local British-Asian families. Partly because of time constraints she used slightly different methods.

- A convenience instead of a purposive sample, of 9 children.
- An 'opt-out' method – families were invited to take part and had little time to reflect.
- Children aged 6-11 instead aged 3-6 and 10-12 years.
- Four children were interviewed in pairs, by their choice. They were very keen to talk with other children with diabetes.
- At the second session, a colleague attended in order to explain the project and invite children in the waiting room to take part, while the interviews were being conducted.

The self-described nationality/ethnicity in the East London hospital were 1 Pakistani, 1 Asian, 2 Somali, 2 White British, 1 English, 1 White English and 1 Danish.

As with the first two groups, the children's sessions lasted from 10-60 minutes depending on their preferences or when they were called to see the nurse or doctor. One child set out the play mobil model of a clinic and two did drawings. Where children were happy with this, sessions were tape-recorded, only Jo refused. Parents were present and/or took part in interviews in all but one, a joint session with Maria and Rezwana.

At each clinic with the third group, three children refused to take part, none of whom appeared to be noticeably younger than those who agreed; one 13 year old wanted join in, but was above our age limit; two children wanted to take part but their parents said no. We discuss the merits of the slightly different methods in section 7.

Table 1 The interviewees: children, parents and practitioners

Age	Research name	Age when diagnosed	Parents present/interviewed
	<i>The boys</i>		
11	Alex	5	Mother and Father
6	DJ	15 months	Mother and Father
11	David	8	Mother and Father
11	George	9	Mother
6	Guy Fawkes	6	Mother
4	Jake	15 months	Mother
10	James	7	Mother and Father
11	Jimbo	16 months	Mother
12	John	10	Father
11	Johnny	4	Mother and Father
9	Mr Football	8	Mother
7	Simba	4	Mother
10	Umar	4	Mother
10	William	7	Mother
	<i>The girls</i>		
12	Edwina	10	Mother
11	Holly	2	Mother
6	Jessie	15 months	Mother
7	Jo	3	Mother
3	Maisy	16 months	Mother
7	Maria	3	Mother
7	Moogum	5	Father
11	Nicola*	4	Mother
11	Rezwana	6	Mother
5	Emma*	15 months	
	<i>The practitioners</i>		
	Consultant paediatric endocrinologist		
	Consultant paediatrician		
	Diabetes nurse specialist		
	Children's diabetes nurse specialist		

* *Pilot interviews*

The 57 interviewees were 24 children, 29 parents and 4 diabetes specialists. The children chose their own research names to protect their anonymity.

5. The methods of collecting and analysing the data

5.1 Data collection

Literature review

The literature review involved identifying relevant research reports and reviews, and gaps in the research to date, as well as key issues and questions to examine in this project. We refer to the literature mainly in Section 2 'Backgrounds' and Section 6 'Findings.'

The interviews

We conducted in-depth, semi-structured, tape-recorded interviews with the interviewees - the children, their parents, and also four practitioners. As mentioned, the researchers suggested to families that they would prefer to conduct interviews separately, speaking first with the child and then with the parents. This was in order to suggest that the children and their views were of paramount interest to the project, not merely as an aside to their parents' views. However, it was important to us that the families felt comfortable, and so children and their parents could choose if they preferred to do joint interviews.

Original interview schedules (appendix 2) were developed and piloted with two girls aged 5 and 11 years and one mother. We made some adjustments in the light of their comments, but the pilot interviews were so similar to the revised schedules that we have included them in the analysis. Children and also parents were assured that they would remain anonymous, that they could refuse to answer any questions they did not feel happy about, and that they could end the interview at any point.

We asked open questions such as, 'Do you remember when you first began to have diabetes? What was it like and what happened?' We aimed to follow the children's narratives, priorities, and order of events, and to fill in any missing details from the schedules later. Greenhalgh (1999) found that narrative methods are valuable not only in researching the views of people with diabetes, but also in devising effective methods of promoting their informed involvement in their care. We responded to cues from children when they seemed to want to pause or to end the session, or were more interested in some topics than others. For this reason, we did not cover every schedule topic with every child. In this qualitative study we wanted to hear rich accounts, rather than brief replies to every heading. The interviews began with children's everyday lives, how they enjoy their free time, their likes and dislikes, moving on to relationships and social life, then diagnosis and first experiences of diabetes, going to the clinic, sharing in daily health-care and their overall view of diabetes.

We began with the topic of children's 'ordinary' everyday lives, in order to give a social and not a medical-patient-centred emphasis. The social approach looks at how diabetes fits into children's many other concerns, instead of assuming that diabetes dominates over all other aspects. It may not do so. The interviews also included some activities, for example, using toy hospital figures to act out the experience of going to the clinic with younger children, or drawing a picture, if they wished, about things or feelings or activities to do with diabetes.

There was not time to complete the full schedule including the games-scenario with any one child, since there was too much to cover in one session. In the third group, several children were called to see the doctor or nurse. One child, Maria, played with the play mobil model clinic, but she was called away before there was time to discuss

how she had set it out. Two children did drawings. Moogum's was of her "diabetes stuff", and Jo's was of "the worst things about diabetes" – this included chocolate and doughnuts, because she cannot eat them when she wants, as well as her injecting equipment.

Observations

We observed several clinic sessions. One was in a paediatric community setting with a very well stocked and popular play area. Another was in an adult-centred hospital clinic hospital, in a newly opened Private Funding Initiative (PFI) wing. The staff had to work hard to find an area for the children to wait, and had raised funds themselves to buy toys and activities. The third outpatient clinic was held in a pleasant new community health centre, though there appeared to be no provision for children in the waiting area. The first clinic's play area was so much enjoyed by the children that some of them insisted on going back to play there after seeing the doctor instead of leaving straight away. The play was likely to relax them, besides encouraging them to attend the clinic. Since 1959, it has been official policy that children should have separate areas from adults (Platt 1959). It therefore seems unfortunate that the two newly designed and built clinics had no properly planned provision for children. The visits conveyed a vivid sense of the different ethos of the clinics (Hammersley and Atkinson 1992), and of the generally friendly, personal relations between the families and staff. Informal discussion with the practitioners also provided much useful background information.

The interviews in the families' homes helped the researchers to understand the social and family context of the interview accounts. Even the visit to the mother's office, for example, was highly informative. It was during a half term week, when Edwina had very much hoped to join a school trip. She was excluded because, she and her mother considered, the teachers did not want to be responsible for a girl with diabetes – although the teachers did not admit this and kept her on a waiting list that turned out to be too full. Edwina was clearly sad to miss the trip and to spend the days instead at her mother's office, though she was dignified and uncomplaining during the interview. This was just one, though a vivid significant example, of many ways in which she felt rejected and excluded at school. The settings for the interviews gave valuable extra information that reinforced the families' accounts.

Participative research methods and underlying theories

So far, there has been little research about younger children's views on diabetes, partly because traditional researchers have tended not to expect children to give valid, interesting or relevant views. Statistical research relies on standardised replies drawn from detailed questionnaires, but young children may find these boring or partly irrelevant. Researchers may then assume that children are not yet able to take part in research, instead of seeing that the problem might lie in the research methods and not necessarily in the children. Traditional researchers tend to:

- observe children with methods based on an animal model of research,
- examine them in laboratory conditions isolated from their everyday context,
- give them artificial tests and hypothetical questions,
- test them against norms,
- design questionnaires about the children for adults to answer,
- use adult-centred units of analysis such as the family,
- search for causes for children's behaviour,
- propose a scientific universal model of child development.

In contrast, participative studies tend to:

- observe and also, crucially, talk with children as people,
- use flexible approaches that children share in deciding instead of pre-planned formal methods, such as using toys, games, drawing materials, cameras and maps,
- meet children in their everyday contexts and relationships where they have expert knowledge,
- avoid tests and assessments and adult-assumed norms,
- try to see children's perspectives and how they organise and make sense of their lives as rational agents, instead of relying wholly on their parents' or teachers' views,
- see the child as the unit of analysis, such as finding out how resources or decisions are often very unequally shared out within the family or the school,
- search for children's motives and explanations and contextual reasons for their behaviour.

The advantages of participative research are that it can obtain rich detailed accounts from children, and greater understanding of their diverse thoughts and values that influence their behaviour (Christensen and James 2000). This is vital if we are to understand their questions and problems and successes, in order to find positive ways to help children and parents to manage diabetes. Another advantage is that the methods can show, for example, when younger children begin to be able to take part in research and discuss their diabetes competently. The methods and processes of the research can therefore be as important as the data, in showing when competence begins, and how health care policies may need to change to take account of younger children's abilities. However, it is very time-consuming to collect, record, transcribe and analyse the detailed data from participative studies. The studies are usually small-scale, and therefore raise concerns about how reliable the findings can be.

The advantages of traditional methods are that they can produce very large-scale and statistically reliable evidence relatively quickly and economically. However, the impersonal standardised approaches do not always encourage children to participate as fully as they might, and tend therefore to overlook and under-estimate children's competence. Unfortunately, when these reports are highly respected for their statistical reliability, they are most likely to influence policy and practice, and readers are less likely to question the validity and accuracy of the original data. One way to combine the advantages and reduce the disadvantages of both methods is to combine them, by using in-depth participative methods with a sub-sample of people who take part in larger surveys.

As Judy Dunn noted, in-depth qualitative research with children 'in conversation' finds them to be far more capable than surveys and experiments can show (Dunn 1995). Participative research shows that children can be:

1. *Informed* - about their chronic condition and treatment, with unique and essential knowledge about its impact on their daily life, that adults need to know about if they are to give informed care;
2. *Active contributors* - sharers in their health care from birth, such as when breast feeding works best if the baby sets the timing and pace;
3. *Rational and wise* - willing and able:
 - to cope with complex and distressing information,
 - to weigh risks and *future* long-term interests,

- to have reasons, if they do not carry out prescribed treatments, such as trying to reconcile their sometimes conflicting clinical and social interests, and these reasons need to be addressed, not ignored or overridden, if problems are to be resolved,
- to influence decisions and matters that affect them in thoughtful ways they can explain.

4. *Altruistic* – able to consider other people’s needs as well as their own (and not being trapped wholly into an egotistical present as commonly alleged).
(See, for example: Mayall B 1994a, 1994b, 1996; Alderson P 1993, 2000; Hutchby and Moran Ellis 1998; Phillips 2000).

An example of policy which takes account of the recent childhood research are the reports by the BMA (2001) and the RCPCH (2000). These advise adults to start from a presumption of competence in school age children, instead of from a presumption of incompetence. It is easier to prove incompetence (such as to show that someone cannot understand) than competence. Children with diabetes aged from 2 years have to be able to understand enough of the nature, purpose and benefits of their treatment to help them to cooperate instead of being overwhelmed by fear and anger.

5.2 Data analysis

Qualitative data analysis involved reading and re-reading the observation notes and interview transcripts. We used constant comparative analysis to identify and explore the major themes in our questions and in the themes raised by the interviewees (Glaser and Strauss 1967; Mays and Pope 2000). Partly using the edit-find facility in MS Word, references were sorted into individual word files covering each of the main topics and themes. The files were later linked together into longer reports, and data were further analysed while we added commentaries and interpretations to draft reports. Microsoft-excel was used to record some quantitative data regarding the attributes of the children and parents involved, and to identify which themes were covered by each interview. This helped to indicate how generally the themes were of concern to all the families.

Reliable, generalisable or transferable and valid data

This project is too small and non-representative to be able to provide reliable evidence to support specific generalisations. Instead, we aim to question and perhaps falsify widely held generalisations, rather than to make new ones. Large samples are needed to demonstrate that all 4-year-olds have certain skills. Yet very few 4-year-olds need be involved to show that at least some of them can understand why insulin injections are needed, and that they do not all have to wait until they are 7 or 10 years old. The children we interviewed may be unusually intelligent, though this was not mentioned and most of them seemed to be ‘ordinary’ children, whose responses may be taken as fairly typical and not exceptional.

However, we do not assert generalisations about what everyone in a certain age-group can know, or do, or exactly how they should be treated. Instead we suggest ways of moving beyond misleading prejudices and stereotypes about children’s deficits. Then it is easier to work out with each child how far, and at what age, they begin to have reasonable information and support, and are willing and able to understand and share in managing their diabetes. Here, the relevant knowledge and skills are not firm generalisations. Instead, they are flexible and partly transferable evidence. If parents report that their 4 year old can understand and do blood tests and injections, this raises questions about how many other 4 year olds are able and willing to do so.

Validity in this qualitative study is therefore not concerned with producing replicable findings that enable people to predict exact responses in all children who have diabetes. Instead, validity is more concerned with:

- the interviewees' rich details when describing their lives;
- the researchers' accuracy in reporting and interpreting those accounts;
- how differences between accounts are interpreted;
- how closely other people's understanding of the data fit this report;
- the coherence of our framework for understanding children's abilities (Geertz 1993; Harding and Gantley 1998; Mays and Pope 2000; Alderson 2001).

Our framework for understanding why many young children are in advance of *child development age-stage theory* involves: using participative research methods that tend to show how ordinary children are 'precocious'; and using the *childhood studies* approach that looks for potential competence rather than deficits in young children's social, intellectual and moral experiences (for reviews of the childhood studies research literature see Alderson 2000, Mayall 2002).

6. The findings

The first section, 6a details the children's competence, their responsibility, skill, knowledge and maturity, and 6b further illustrates the value of their direct personal experience for gaining knowledge and skills and the need therefore for greater recognition of both children and parents as capable and expert partners in managing the health care. Section 6c discusses the interviewees' accounts about the care they have received from specialist and non-specialist healthcare professionals and others such as school and nursery staff. Having established the value of input from children and parents to managing diabetes, the analysis then draws on the major themes that appeared to be most pertinent to the families: 6d, children 'just want to get on with their lives', so they need devices and routines that help them to do this, 6e, children with diabetes are 'normal and not different to anybody', 6f, the need to share expertise, information and support among parents and children and 6g, information at the time of diagnosis and later.

The interviews began with talking about fun activities, such as Maria saying that during the holidays she liked doing homework about animals, Nicola saying she would like to swim with dolphins, and Rezwana said, 'Going out in town with friends, like to the zoo.' However, this report concentrates on the later talking about diabetes, though we do not want to imply that diabetes was necessarily the topic of greatest interest or importance to the children.

6a. Recognising children's levels of responsibility, skill, knowledge and maturity

The children displayed commendable levels of competence. Children's accounts of what they did and were able to do, along with parents' descriptions of their child's capabilities, were revealing. Indeed one diabetes nurse specialist conceded that she was sure that the children she saw were capable of more than people gave them credit for. The levels of competence obviously varied, but every child seemed to have some exemplary skills, among being able to:

- take their own blood tests;
- inject insulin;
- understand the need to restrict their diet;

understand their need for insulin injections;
interpret their bodily sensations;
explain the meaning of diabetes to other people;
refuse sweet foods or limit the amount they eat;
assess food values;
choose appropriate food to suit their glycaemia and insulin levels and energy needs;
cope with being different from their friends;
cope with the clinics.

Blood tests and injections

The high level of skill amongst these children is perhaps best exemplified by the ability of some of the younger ones. For example, Nicola at 4 years and DJ at 6 years took on the role of doing their own blood tests and injections.

Int: Do you do your own blood tests?
DJ: Yeah.
Int: And you do those sometimes or often, everyday?
DJ: Every day.
Int: And when do you do those?
DJ: In the morning and near dinnertime.
Int: Do your own injections?
DJ: Yeah.
Int: Do you do those everyday yourself? Because you said your mother does them sometimes as well?
DJ: Everyday, because I've got a pen and I've got another one which hurts me. And I only do the pen.

Some children don't do injections until they are older, some are still finding it difficult at age 11 or 12, so for Nicola and DJ this is a real achievement. Holly at 11 years could do injections, such as when she enjoyed one of her favourite things, sleep-overs at friends' homes, but she preferred her mother to give the morning injection. Her mother said, 'She needs 50 and it is a lot to push in and her hands are smaller than mine.' Jo aged 7 wanted to learn how to do injections in her leg so that she could join her friend when they stayed the night together, and she missed not being allowed to do this. Her mother offered to go to do help her in the morning, but the friend's mother did not like that plan, and Jo's home was too small to have friends to stay.

Rewana's mother does the injections except at weekends, when Rezwana does them so that she can get up early and watch cartoons. She prefers her mother to do them now, though she did them all herself last year. Like several children she developed bumps in the sites she could reach easily. The skin becomes desensitised and so the needle hurts less. The doctors then ask parents to take on doing the injections in harder to reach sites. Rezwana and Maria both prefer their mothers to do injections. Like some other younger children who had not yet started to do their own injections, Maria thought she would be 15 or 18 before she began. Children often assume that they will have to be almost grown up to take on certain new responsibilities, but then find a year or two later that they can manage them (Alderson 1993).

From 4 years of age, when Nicola was sent to stay away from her family with relatives, she would explain and show them what she had to do. These children demonstrate that even very young children should not automatically be discounted from being able to be a major partner in sophisticated parts of their care.

During his short interview, Umar and his mother agreed that 'he likes mum to do all the work' of managing the diabetes, whereas several children seemed to find using the needles themselves was less painful than when adults did this for them.

George: I prefer to do it [blood test], cos I know, cos she [mum] just does 'duusssh!' [jabbing action].

Mother: That's what you're meant to do!

Like Simba, Moogum did her own blood tests and was pleased when a low result meant she could have sweet food. Holly's mother recommended saving up sweet treats for these times, such as a piece of fudge or a particular ice cream. Not only could the children feel rewarded, and enjoy the treat, they could also join in talk at school about these tastes.

Adjusting insulin doses

A few older children showed an even greater level of skill as they were able to judge how much insulin it is appropriate to take in particular situations. We do not have examples of younger children talking about this, although this may be because they are not taught or encouraged to adjust their dose, rather than they are unable to do so. Maisy's parents gave her extra insulin if she was high after lunch, and Jessie's family adjusted her insulin dose after she went to see friends or to a party, but in both instances the parents made the decision. Yet young children could be reliable about restricting the number of 'treats' that they ate, such as Emma aged 5 years, deciding how many sweet things to eat at a party. When aged only 4 years, on one occasion, while they were away from adult supervision, although her friend ate lots of chocolates Emma said that she did not join in this secret treat, and her low blood sugar levels confirmed her words.

Here is David aged 11 talking about when he is at a party.

Int: Do you like parties and birthdays? What do you do about deciding what to eat there?

David: Well it would depend on whether it was before I had had my insulin or after. Do you mean before or after?

Int: So you consider that when you're at a party?

David: If it was after I would tend to have two or three [a small amount of treats], if it was before I would have some and then I would give myself a couple of extra units.

Int: And you would decide that for yourself?

David: Yes.

On one occasion, David demonstrates his awareness that his blood sugar levels are affected both by what he eats and how much insulin is in his body. If he is eating before he does his injection, he will be able to increase the amount of insulin to counterbalance the extra sugar he has taken. As well as having this complex knowledge, David also displays a very responsible approach to having treats, and how he can skilfully and independently manage his condition.

Jimbo (age 11) was also highly independent and skilled at managing his blood sugar levels. Here his mother describes how he voluntarily chooses to give himself an extra injection to combat high sugar levels, and that he has the knowledge to calculate just how much insulin is needed.

Jimbo's mother: Well the other night, so for instance, he phoned me up, so when he comes in at night he always phones me up and we work out, well if you're this or if you're that, what do you need to eat or not eat. So the other night I had a message on my answer phone, 'This is Jimbo, I've come in and I'm 20, [high] so I need some rapid [release insulin], but I don't know, so I'm working out to give myself two, but I'm not sure whether you would have wanted me to have three, but whatever, you aren't here to answer the phone so I am making the decision to give myself two.' So when I came home I said, 'Well done.' And I mean Jimbo is always checking himself all the time. In fact we use more strips in a couple of months than I think most people use in a year, but that is Jimbo all the time, you know wanting to check what he needs.

Jimbo's mother's account also shows his awareness of the risks of getting the dose wrong. His sugar levels are at a point that he needs to decide whether to give himself two or three units, and he errs on the side of caution and is confident enough to give a rational explanation to his mother for this decision. Jimbo's musings on how much to give himself are very important. If he overdoes it, he will be in danger of having a 'hypo' potentially leading to unconsciousness or coma, but if people with diabetes are constantly too cautious about how much insulin to administer, they are at risk of ketoacidosis in the short term (too many ketones in blood stream that lead to headache, drowsiness and deep breathing) and other major complications in the long term such as cardio-vascular, retinal and kidney problems.

What is really striking here is Jimbo's willingness to engage with his condition and his confidence to tackle situations that arise. His high level of self-monitoring demonstrates a keenness to manage his condition rather than delegate this responsibility. His skills and ability to do this may indeed be the reason for his high level of engagement with his condition.

One further example of an advanced level of competence and skill comes from Johnny. Johnny is a boarder at his school and therefore has had to be extremely independent in caring for and managing his diabetes. Although this position is perhaps enforced in his case, it exemplifies just how independent some children as young as 11 can be. Johnny has a pump that slowly releases insulin and thus works rather like the pancreas in people without diabetes.

Int: And you're on a pump aren't you?
Johnny: Yeah.
Int: So what does that involve, what kind of things do you have to do then?
Johnny: Well every three days I have to change my cannula. Sometimes I forget to do it, so I do the next day, but it doesn't really matter. I have to remember to take my boluses [mealtime dose of insulin to cover the extra carbohydrates taken in at that time].
Int: So you do those yourself?
Johnny: Yeah I do those all myself, I just press a button and it goes in.
Int: And is that at a preset level?
Johnny: I've got to calculate it and put it in.
Int: And how do you calculate it?
Johnny: Well I just have this book, which has the carbohydrate content of some foods, and I've memorised it now, and I know what to put it in.

Int: So you make a judgement on what you're going to eat and how much you're going to give yourself?
Johnny: Yeah.

It's not clear how long Johnny has had such a high level of competence. He has been on a pump for around a year, and has managed to memorise the book of carbohydrate levels. His mother explained how ingrained this is at mealtimes, for Johnny and his friends. Johnny had just been on a school tour abroad.

Int: Do you see any difficulties with Johnny and his friends because of diabetes? If so, how?
Mother: On the tour they were absolutely fascinated and they were saying 'Oh Johnny what are you going to bolus? I think that's one point five.' And then someone else would say 'No that's two.'

Here the fact that friends of Johnny's, who do not have diabetes, understand about decisions regarding his bolus injection demonstrates how able children are to understand and act on concepts of the relationship between carbohydrate levels and insulin.

Choosing food

Like many of the young children, DJ can recognise the kinds of food he should eat. For children with diabetes, food is not the benign substance that it is for most children. Eating the correct types of food is essential to maintain balanced blood-sugar levels throughout the day, everyday.

Int: What kind of things you have to eat if you are diabetic?
DJ: Dry things, [plain] biscuits and stuff
Int: And what things are not good to eat?
DJ: Chocolate and sweets

Here DJ correctly identified first slow release starchy carbohydrate for evenly balanced blood sugar levels, and secondly the quick release sugary carbohydrate types of food that give dangerous peaks and troughs in blood sugar levels.

George explained that his 'control' over his diabetes involved eating a little every two hours with daily blood tests, as an important way of preventing the need for insulin injections so far.

George: Well I have to take my blood often, to find out, so the doctor knows, like I'm keeping control. If it's like too high, that means I've eaten too much sugar. If it's too low, you eat something, carbohydrate, like bread...

Moogum seemed from her replies not to understand about her diet. She said, yes, she was treated differently from her sisters by her parents.

Moogum: Like, like, they don't, when I want a biscuit or something, they say 'No.'
INT: Do you know why they say that?
Moogum: No.

However, as we will show later, her responses suggest that she was more informed, though at first she said she was not willing to talk about this: 'I would like to um [pause] not tell anybody in my life.'

Some children were very aware about carbohydrate levels in foods. Nicola was complimented on her fit appearance and she replied spontaneously, "That's 'cos I've got diabetes. I have a healthy diet." However, 'normal' looking children with diabetes like Nicola still have to cope constantly with challenges about whether they are 'normal.' An example of how they had to combine their knowledge about carbohydrates, unusual for younger children, with being seen as 'normal' was shown when Nicola, then aged 9 years, was checking and discussing the carbohydrates listed on drink cartons in a shop. Most of the drinks would quickly induce a severe hyper and so she was applying crucial knowledge. A woman standing near by said, 'Worried about slimming already?' in a critical tone, looking at Nicola's slim figure, as if implying that her parents were abusively trying to induce anorexia nervosa. This is one of countless examples of occasions when children and parents have to decide whether to explain the disability, or laugh off the comment, or ignore it.

Mr Football was interviewed with Guy Fawkes, and when Guy mentions vinegar and soya, Mr Football shows how informed he is; Guy again shows how he learns from his bodily senses.

Mr Football: [Things like vinegar] don't do anything, you're allowed vinegar... it's soya, made out of soya beans, its got no sugar really, its got a bit of sugar, but it tastes quite sweet but it's got less than normal milk, so it's better and it's quite sweet isn't it? It's a bit sweet.

Guy: It tastes like some juice! I tried to taste it sugar-free, no added sugar.

Mr Football aged 9 and his mother talked in detail about energy information on food packets. Jo aged 7 would choose each morning with her mother what kind of snack to take to school. It seems that the experiential knowledge about types of food gradually became classified into knowledge about carbohydrate content, as well as fast or slow release energy and appropriate times to eat different foods.

Understanding and explaining diabetes

Children's understanding of their condition seemed to be much broader than the 'need to know' type of information that allowed them to function on a daily basis, such as knowing what type of food to eat, or how to calculate insulin doses. Several children also showed an ability to stand back and describe this complex condition in a way that was comprehensible to others. At 4 years, Nicola said, 'Insulin is the key that turns sugar into energy.' Having lacked energy, and become very ill during the six months before her diabetes was diagnosed, she vividly understood these words.

David: It's an illness and an organ in your body isn't working, and it's stopped producing this liquid, and you need this liquid to turn sugar into energy, and this liquid is insulin, and so you have to have injections of it. And you can't have so much sugar in your food.

David's description was the most comprehensive explanation offered in this study, and he has succinctly described diabetes in a detailed but comprehensible way. Many parents talked about how they wish that they could have had a simple explanation at the time of diagnosis, when they felt bombarded with different types of information. Indeed, several parents noted that information aimed at the children's level was the most helpful in the early days after diagnosis. David noted that his description was based on what his mother had told him, but that he had simplified it for his friends. However, it is likely that many adults would welcome such a simple description.

Simple descriptions also came from younger children like DJ and Jessie. The next passage from the interview with Jessie is when she was playing with Playmobil figures. The interviewer (KS) had a child figure who was coming to the clinic for the first time and Jessie played the doctor and the nurse. This passage shows her ability to describe the essential components of carrying out diabetes care for others in a very accomplished way and also her confidence in her own, and other children's, ability to be an active and responsible partner in their care.

Int: This is my little girl. She's just got diabetes and we don't know what to do. Can you tell us what we need to do?

Jessie: When she's feeling a bit funny you need to give her loads of sweets. She needs to eat up all the time, and when she's feeling low you must always give her some sweets, and when she's feeling high you must always, always not give her sweets, you must give her a sandwich or something.

Int: And how would I know if she's high or low?

Jessie: She'll tell you, I'm sure.

Int: Is there anything else I need to do to look after myself?

Jessie: Yes, you need to do your blood sugar and your leg, but I think your mummy will have to do the leg, and yourself to do your finger. Here's your finger prick, and here's your pen.

Int: OK and what do I do with the finger prick?

Jessie: There's a little pricker inside, and you have to push the end, and there's a little button and you have to twist it, and then you have to press it and it makes a hole in you, and then you have to squeeze out blood, and then put it on the special tab, and put it into the machine, and then you have to see how high or low you are so you can have some treats or not. So that's how you do it.

Jessie's comments show that she has complex and informed understanding of what to do when blood sugars are high or low, and also a confidence that children are active and informed partners in their care. For example, 'You need to do your blood sugar and your leg, but I think your mummy will have to do the leg, and yourself to do your finger.' Such descriptions and demonstrations of knowledge would perhaps be very reassuring to newly diagnosed children and their parents, demonstrating just how competent and knowledgeable children can be.

Mr Football said he would advise a boy of his age, newly diagnosed: 'Try to accept it as quickly as possible. [pause]... After a while it does get better because after a while you just get used to having injections, and after a while they don't hurt as much.'

Causes of type I diabetes are more abstract, and largely unknown, and so perhaps harder (for anyone) to grasp than the practical care routines. It may be that they are not explained directly to younger children, or not in ways that they understand or remember. Moogum has three older relatives with diabetes who may not know that the difference between the causes of type I and type II, which is far more related to life style such as inactivity and obesity, and so they are very different. Or else she may be mentioning a guilt that young children frequently feel unless they are directly reassured that they are not at fault.

Int: Do you know what causes diabetes?

Moogum: Yes, like eating sweets so much. If you eat so much sweets then you get diabetes.

Interpreting bodily sensations

The children had to listen to and learn from their bodies from an early age, like Holly whose experience is described later. Most of them had felt very ill, either when they were diagnosed or later if they had severe hypos or else ketones in their urine. It is therefore not surprising that were thoughtful about interpreting their sensations. Simba was asked why insulin is important.

Simba: Cos you're diabetic. If you don't take it, I can die.
Int: Really?
Simba: And if I have a hypo I can die. [phrase unclear]
Int: And what's a hypo?
Simba: Cos when I don't eat all my food, I go to bed. And in middle of the night I start feeling shaky. I always look at the wall, like that [demonstrates] and stay like that.
Int: And what do you do then?
Simba: I say, 'Help!'
Mother: Do you really?
Simba: Yeah. [His mother laughs] Cos I thought I was getting sucked down a hole. [My mother gives me] Hypo stop, sort of jelly thing and she gives me chocolate and last time she gave me mini roll –

When asked, 'What happens when you get low blood sugar, what do you feel like?,' Guy Fawkes and Mr Football replied:

Guy: Happy! [mother laughs in background]
Mr Football:: I feel very faint and I do feel very very hungry and I can't see but my lips normally go white.
Int: Why do you feel happy when you have low blood sugar.
Guy: I can eat things sometimes!
He goes on to talk about sweet things.

Maisy's mother recounted how her daughter could be very astute at recognising and interpreting bodily sensations. Although Maisy is only 3-years-old she is able to recognise her needs and make her mother aware of them also.

Maisy's mother: In the day, she can be really low but you wouldn't know, but at night obviously I think she feels it more, when she's er ...
Int: What does she do then?
Maisy's mother She's just shouting, she just shouts for me.
Int: And you sort of diagnose it from what she's doing, rather than, does she ever come and tell you?
Maisy's mother No, because she's in a cot she just shouts, she shouts, and says she's hungry. So I say, 'Um, we'll see about that.'
Int: And so what would you do then if she says that?
Maisy's mother Test her blood, bring her a sugary drink, and bring her in here and munch on a couple of packets of crisps, we used to be all really good, and cereal, we used to eat really good food, but if she's going to eat it at that time of night. But she does go funny, kind of like a blue pale colour.
Int: And you know you said sometimes she'll say she's hungry and she's low, and sometimes she's not?
Maisy's mother It's fairly even, especially at night, sometimes she says she's hungry just because she knows I've got something in my bag. But then

sometimes I think she says she's hungry but her blood sugar is quite good, but it could be dropping quite quickly. So she's obviously thinking 'I'm starting to go funny, get something in me now.'

Maisy was quite uninterested in talking to us about her condition, as she was only age 3 her vocabulary was somewhat limited, however, when asked by her mother to show me how she felt when her blood-sugar levels were low and she was 'wobbly' she demonstrated by holding her hands up and shaking. Thus Maisy could understand that there were times when she would feel different and, more importantly as the passage above shows, that she can recognise that she needs to communicate this with some urgency to obtain the sugar she needs. This suggests that it may often not be young children's lack of understanding that is the main problem, but lack of sensitive and effective research methods to discover their levels of understanding and thoughtful management of their diabetes, that misleads adults into underestimating young children's competence.

The mothers of two other children, including one of the very youngest children Jake, aged 4, also discussed how their children were able to interpret their bodily sensations with regards to feeling hypo and the urgency with which this needed communicating. Indeed, Jake's mother recognised a change in Jake's behaviour after an incident when he was left with low sugars for a very long period as his family spent hours at hospital waiting for assistance from accident and emergency staff.

Jake's Mother: Actually when he's low it can be a problem because he can get really aggressive, which he didn't used to, but since that hospital experience, it's very strange.

William's mother recognised that her son could also be quite forceful when he had low blood-sugars

We had experience on the sports field about two weeks ago, and he'd not taken glucose tablets, and he said, 'Mummy I'm low,' and I said, 'Yeah I know, I can see.' And he said, 'Mummy I'm low now!' Then I know, and he is that sort of direct, that I've got to act quickly.

Mr Football remembered having a severe hypo six months after he was diagnosed.

Mr Football: Well during the night I just screamed, I don't remember it but my mum's told me I just like screamed and my mum come in and like thinking I'd had a nightmare and I was all floppy on one side and I couldn't talk – I remember actually being in there, right, saying, I wanted to have my injection, cos I knew that was like my routine, but like I had had a drip in my arm so I didn't need it. But I couldn't think of any words I was saying, erm 'I've gotta have my thing-y', I was getting very very frustrated that I couldn't remember

He also remembers the next few days in hospital, and several attempts to get a drip into his hand.

Mr Football: I was sort of conscious by then but I just wanted to do something [drawing] that I couldn't do like cos I wasn't, I was bedridden for a day or so –

Mother: He could think ok, but he couldn't get his body to do/

Mr Football: /Anything/ -

Mother: /He couldn't tell what his name was, he didn't know where he was or who he was and he was trying to tell us that he had pain in his stomach and he kept coming out, he was saying, 'My football hurts'/

Mr Football: /Cos I really really like football – like the basics were there, cos I was/

Mother: /Everything he cares about was there but it was all coming out jumbled wasn't it [laughs]-

Mr Football: Yeah-

Mother: It was so scary and he still finds it quite upsetting sometimes to talk about it and I think in the back of his mind and our minds, could that happen again...[The doctors] thought he'd had a stroke because he was all floppy down one side and he couldn't speak and his voice was slurred. I mean we thought it as well, although we didn't voice it, but it was a scary time, that was 2 years ago. Once you've been through the worst case scenario you sort of deal with anything [laughing].

These kinds of very unpleasant experiences, at the time of diagnosis and later on, may help children to stick to a more careful routine, knowing that it helps them to keep well. It illustrates the serious knowledge they have to live with, that they can so easily become extremely ill. It also illustrates their generosity in talking to us when, as they say, they find this so upsetting.

Mr Football indicated the persistence and courage that could be needed before he could do routines such as blood tests so well, and also showed how he knew about his body's reactions.

Mr Football: It was hurting when my mum was doing it and I had to do it a lot of times before actually the blood come out... It doesn't hurt anymore really. Every couple of months or weeks it'll just hurt, but that's normally when my blood sugar levels are low...I really prefer doing it myself cos if someone else is doing it, it seems to hurt more.

Guy Fawkes [also present agreed]: If my mum done it, it hurts, if my dad done it, it still hurts, if I do them, it don't hurt.

Coping with the clinics: talking

We have mentioned the drive for patient 'empowerment' (NSF 2001) so that 'the patient must be at the centre of everything which the NHS does' and the service is 'imbued with the idea of partnership between the health care professional and the patient' (Kennedy 2001:435, 438). Part of this effort is to encourage children to talk more directly in the clinics with the doctor and nurse, and to get them to 'take responsibility' for their diabetes. We asked the children if they preferred to talk to the practitioners or would rather that their parents did this. Mr Football said, 'I don't mind really', who the doctor talks to. His mother mentioned a weekend about diabetes that they had attended.

Mother: And they [course leaders] keep stressing that it's *their* diabetes [the child's] not yours [the parents'], which as a parent is very difficult to grasp –

Mr F: Basically they would take care whether they was talking to me or whether they was talking to my mum cos I had to have the jab in my arm, I have to have like once a year.

Mr Football seems to be making the point that the talking and decisions about diabetes in the clinic are very different from the practical aspects, jabs, drips, insulin levels, the very complicated diet and other life style decisions, which children know about and

generally manage, control and accept, but which are not much discussed in the clinic. Having to cope with all the pain and the daily complications constantly reminds children that they are at the sharp end. So talking in the clinic may neither indicate how much the child knows and does, nor necessarily encourage children to take more conscious responsibility.

Int: Does the doctor talk to you or does he talk to your mum?

Simba: Me.

Int: Which do you prefer?

Simba: Talk to my mum. Cos he talks so, he talks but he can't stop talking.

Mother: Doesn't he treat you like a grown up though, doesn't he? He treats you like a grown up.

Simba: He treats me like a thirteen year old girl –

Jo preferred the clinic nurse to talk to her mother not to her. Her mother also says that after the staff have explained to her, when she repeats it to Jo, 'I tell it in Jo's way.' Jo described the doctor as having a loud voice 'and he tells us off' sometimes.

Maria: Sometimes she [the nurse] talks to me and sometimes she talks to my mum.

Int: Which do you prefer?

Maria: My mum.

Int: Why's that?

Maria: Because I haven't got no questions to say.

Int: But your mum does?

Maria: Yes.

We support the policies to respect and involve children, and this project is intended to inform such practice. Practitioners who care for children with chronic conditions and who get to know them well over the years often lead the way in this friendly respect and involvement, and in listening to and learning from children, as was clearly shown in our interviews and observations of the clinics.

However, children vary and change, and genuine ways to involve them start from the child's own terms, rather than enforcing a standard method. Whereas some children are keen to take a leading part in discussions, others prefer to use their parents as mediators, interpreters, negotiators or defenders (see also Alderson 1993). Sometimes, when parents speak for the child this can help to equalise the power sharing between the child and adults, such as by protecting the child from direct attention, possible criticism or blame about, say, high blood sugar levels. Parents can field awkward questions, proffer excuses, sort out misunderstandings, and generally relieve pressures on the child. Yet parents may also add to the pressures, such as by interrupting and silencing children who want to speak, by giving information that the child wants to keep private, and by blaming and criticising the child more than the clinic staff would want to do.

We can only speculate on possible reasons why some of the children in this study preferred to keep quiet. We did not ask them directly because we did not want to probe on topics, like this one, that they said they preferred not to talk about. We were grateful to them for agreeing to talk to us at all, and we were conscious that any reservations they might have in the clinic they might also have in talking with us. Yet we suggest reservations that some children might have.

It is unusual for children to be the centre of attention in a triad with two adults, a parent and a professional, except at school and often this is to discuss a problem. To expect the child to speak quite freely breaks very strong conventions that children should mainly keep a respectful silence at such times. They may have to invent a new role and etiquette that they have not observed from other children. The expectation that they should talk also draws even more attention to the child who is identified with the problem being discussed. Other possible reasons why some children prefer to keep quiet may be: feeling shy, timid or embarrassed; difficulty in finding the right words and manner, such as speaking loudly enough to be heard clearly; being expected just before seeing the doctor to be quiet and compliant such as when giving blood and urine samples so this will be a sudden switch of roles; boredom and not wishing to talk about diabetes yet again but to 'get on with life' (see later); feeling fatalistic, that they have to accept many things they do not like and would not choose, so it is pointless to discuss them; sometimes frustration that the adults will not really listen, or that nothing can be done about the main problem – having diabetes; scepticism that the adults may be forcing the child to talk in order to add to the misleading pretence that the agenda is child-centred and children are being 'empowered' and consulted. If children do talk they could risk feeling more vulnerable and exposed, so that keeping silent can enable the child to keep some control and security.

Mr Football, for example, seems to be more concerned about practical matters, such as jabs, than being informed (he has said he already knows), or giving information, or sharing in decisions. His reference to the annual extra blood test that very much upset many of the children, including older ones, suggests this resignation. The children seemed to accept coming to the clinic and to enjoy parts of it, such as the playroom in one centre, but the interviewer noted that despite one boy's confidence and saying he 'doesn't mind' coming to the clinic, he cried loudly when he had his annual blood test, as other children did and she thought it was traumatic for them.

The local anaesthetic cream may not have been used properly, such as not waiting long enough after application for the cream to take effect. Some adults argue that the waiting adds to the fear or disrupts the clinic timing. In that case, children can put on the cream before they come to the clinic. If they are feeling very upset about the test, to expect them to talk, when they are unwilling, could add insult to injury.

Coping with the clinics: using their own equipment

Besides tending to leave the adults to talk about the adult agenda, a second way of coping in one clinic was that the children brought in their own blood test machines, preferring these to the nurses using the clinic machine. An advantage for us was that they could explain their routines using their own equipment.

Simba usually does his own blood tests and insulin injections (aged 7) and he explained the procedures in detail. He was surprised that the interviewer, who was using a doctor's room, was not a doctor, and knew little about diabetes. When his mother tried to help him to explain he said to her, 'Don't think I'm shy!' He altered the dial on his 'pricker' to 2 before the nurse used it to collect his blood, so that the needle would not go in so deeply. To explain how he dialled up his syringe he took his equipment out of his bag and demonstrated skilfully. Other children also dialled to control the depth the pricker would penetrate their skin, Moogum used 4.

The experiences of these children seem to contrast with experiences at another clinic where several children mentioned that they feared the regular blood tests done at the clinic as this wasn't taken in the usual fashion, from their finger, it was taken from their ear.

Int: What do you think about going to the clinic? Nice things, not nice things?

Jessie: I feel a little bit scared.

Int: Why is that scary?

Jessie: They prick your ear and take some blood.

The interviewer (KS) met Jessie again at her appointment at the clinic where Jessie was to receive a reward from her mother for her bravery in enduring the ear-prick. It's unclear why the clinic chose to use the ear to take blood, but it is clear that although aged just 6 years, Jessie felt very confident and easy about using her own finger pricker herself.

Summary on children's knowledge and responsibility

Some children are, therefore, able to grasp and deal with complex issues. The children cited here might be exceptional, although as mentioned we did not select exceptional children. However, they can show us that children as a group should not altogether be discounted from being competent and independent managers of their condition. Johnny and David are likely to be able to manage the DAFNE programme (DAFNE 2004; Heller *et al.* 2002) if it were offered to them.

Although children may be capable of performing such tasks, traditional views of children cast them as untrustworthy, irresponsible and lacking in maturity (Mayall 2002). Yet in this study, we also found evidence of children displaying a very mature attitude towards their condition, for example Alex who has had the additional complication of needle phobia.

Int: Do you think you have been told enough? Was it given in a good way for you/for kids?

Alex: Yeah I thought it was. Because even though I was seven they know I've got to live with it, and they know what's going to happen, so they know they're going to get used to it, and just gives them courage as to what's going to happen.

Int: Any worries? (About the future)

Alex: No not really, if I'm good in what I'm doing.

Both Alex and his father attributed Alex's mature nature directly to his having to cope with diabetes.

Int: Though no one would wish their child to have diabetes, are there any positive things that have come out of your child having diabetes?

Alex: My attitude has got better.

Father: I think he's responsible beyond his years. I think he's had to be. His teacher even said, 'If you give him a job he'll do it, and within a certain time.' So I think it's affected his attitude, he's mature beyond his years.

Other parents were astounded at how mature their children could be about their condition. This was further highlighted by the fact that some children were seen as being mature about their diabetes – but in other respects 'a regular kid' such as James.

James's mother: I mean James, for 10 years old, it's quite scary sometimes, how mature he can be. It feels sometimes like it can be

forced on him. But you know for a 7 ½ year old to overcome that at that age [when first diagnosed].

DJ's Mother: I sometimes forget that he is only 6. He's very responsible, he's very grown up too. Diabetes-wise he's very grown up.

Several children showed how they took on high levels of responsibility in managing their care. The most striking case of this was perhaps Johnny, the boarder who was almost entirely responsible for his care at age 11. David had to do an injection during every school day. As we have mentioned, some children as young as 4 to 6 years were clearly responsible for major parts of their care, such as doing injections at home and outside of the home if they went to visit or stay with friends or relatives. DJ had a watch to remind him when to get the snack he needed to maintain even blood sugars and prevent hypoglycaemia. As DJ's mother notes, she feels able to rely on DJ to be responsible for his condition, but does not necessarily trust the other adults whose care he would be in, if he stayed away from home.

Although he doesn't go and stay with friends and things like that, I know I could [let him], it's not because I don't trust him, I would trust him to be able to tell them, 'I need my snack.' And because he's got his watch it goes off at every snack time, they would know, but I wouldn't trust them [the adults].

These examples suggest that young children's competence in general may be under-estimated, and that when they are exposed to exceptional risks, such as having diabetes, they have the opportunity to demonstrate unexpected competencies.

6b. The importance of direct experience of diabetes for gaining knowledge and skills.

The above descriptions of children's skills, knowledge and maturity demonstrate that at least some of them are able to be active, reliable partners in their diabetes care. Obviously there are other partners such as their parents, school staff, the specialist diabetes care team and GPs. However, this next section demonstrates the key nature of experiential knowledge about diabetes in managing the condition. By revealing how essential this knowledge is, it is possible to argue that the children's role, as a partner in their care, should be acknowledged more fully by others. The weight of their role in the partnerships should reflect their level of skills and knowledge, and also their willingness to be responsible, by respecting and encouraging them but not forcing them.

The interview schedule had no explicit questions about experience. Yet examples were highlighted in all the interviews of how helpful direct experience and sharing of experience can be. Two people talked about how experiencing the condition for themselves allowed them to realise that they could manage it. Their own experience of the diabetes regime was an important element in their acceptance of it as the next two excerpts show.

Int: Do you remember when you first knew you had diabetes?

Alex: I was about five. Yeah it was really tough on me because I felt like something bad is going to happen to me, but as I gradually got on it was alright.

Maisy's mother: You know because I thought it was all going to be these big syringes that you push in, and you put in bottles, and stuff you know I thought it was going to be all that. I think the injection pen doesn't look too bad I can do it. I know it sounds awful, I mean I think I could put a needle in anyone else but myself.

Alex and Maisy's mother were the two people we met with the most severe needle-phobia. So the examples illustrate how experience can be really helpful to people who are coming to terms with their fears.

Education for self-management of diabetes has been defined as 'the process of providing the person with the knowledge and skills needed to perform self care, manage crises and make lifestyle changes to successfully manage the disease' (Clement 1995). This involves bridging the gap between knowledge, and wanting and knowing how to adapt and apply it in practice on countless different occasions. Most British hospitals do not provide formal diabetes care education and most patients do not regularly receive it (Audit Commission 2000). Routine recommendations by staff in the clinics (Donnan *et al.* 2002) and didactic education programmes appear to have little effect on people's behaviour. Experiential programmes that attend to practical skills, to changing behaviour, discussing risks, and taking account of people's cultural beliefs and values are found to be more effective (DAFNE 2004; MRC/DH 2002:29). Our interviewees tended to agree on the value of learning from experience, such as stressing the helpfulness for families with newly diagnosed children of hearing about others' experiential knowledge. Three parents in particular said that this was the kind of information they needed but did not get.

DJ's Mother: And quite a lot of the information you get doesn't sort of tell you, this might happen, or this might happen, or you know, it's all how to control it, and how to deal with it but not in ...It would be nice to hear someone who's dealing with it everyday saying, 'Oh well yeah, this has happened today and ...' You know those sort of things.

Johnny's Mother: Well I went to the one [support meeting] in the summer holidays, and it was all old people and Johnny. So there isn't a network of support. I have to say it's something we would welcome. Just to talk about things like trying out different cannula sets and that sort of thing. We've got no one to share the worries. I would love to discuss with somebody about travelling across time zones. And I did at the hospital with [diabetes nurse] and all the people, and they all had different advice, because there's clearly no hard and fast way of doing it, but I would have loved to have chatted with a mother who's done it with her own child.

James's mother: [The dietician] gave me the basic info, but to do that first shop, but I think shopping is one of the worst things for the family with other children anyway, if I could have taken someone else along with me that would have been wonderful. Another mother, not necessarily a trained dietician or anything, but another mother to do the first shop, here's your list, let's see what we can get.

Others who did receive information from those with direct experience said it was the most helpful kind of information, for both the child and the parents. William's mother told the story of meeting with friends who had a child with diabetes.

William had a friend called Robert who came over soon after [William was diagnosed], with his parents, and Robert did a [blood] test, to make it 'Hey William this is fine.' And it was, it was fantastic. And I learned a lot. It was a huge help, because the mother gave me things, just tips 'Spaghetti will make them high, never give them spaghetti or pasta at night. Don't ask me why because it's supposed to be one of those high carb low glycaemic index, but it doesn't work.' But things like about Sorbitol, Sorbitol taken in any quantity will give them a runny tummy, but long-term will affect their eyesight, it was just something she'd found out.

Others found that the best information they received in the hospital was from one of the nurses whose husband had diabetes. She said, 'Look I know about this because I do it at home.' David's father described this as the 'most helpful thing' because it was 'someone who knew about it, lived with it.'

The next excerpt demonstrates that it is perhaps gaining the knowledge from personal experience that is the crucial factor in each of these exchanges, rather than necessarily speaking with someone. For example, Jake's mother valued a book written by a mother of a toddler with diabetes as the most helpful piece of information she had found, in some apparently quite extensive searching.

Jake's mother: There were a couple of books on the Internet that were fantastic.

Int: In what way were they different to the other information you received?

Mother: There was one book written by... a mother, they were different in that they weren't very clinical like the other books, this was just written by a mother whose daughter was diagnosed with diabetes, and it was just going through about her feelings, about how she felt.

Some parents gave examples of key instances where experiential knowledge has been vital in getting good support for their children. For example, David's parents had originally chosen a small church school, believing that it would be more supportive for their child. However, the small school was very unsupportive, not allowing him to have essential snacks and telling him to sit on his own when he felt he was going hypo. The parents felt compelled to move their son to the larger local school. David's experience has improved greatly. He is much more supported and his parents feel that it is because the school currently has experience of looking after several other children with diabetes that they are able to 'manage them like clockwork.'

Besides the practical experience of living with and managing diabetes, the child's bodily experiences, appearance, sensations and behaviours also give vital signals to inform everyday management. Holly, for example, developed diabetes when she was 2 years old and was very informative

Holly's mother: By the time she was 3 she knew when a hypo was coming on. She'd say, 'Mummy, my mouth feels funny, my eyes feel funny.'

Several families also described how some experiential knowledge could be a key factor in getting a diagnosis, especially in the face of a lack of knowledge in some GPs (see next section).

6c. Specialist and non-specialist diabetes practitioners' knowledge, skills and attitudes

Specialists

Whereas adults with diabetes are cared for mainly by primary health staff, most children attend hospital clinics. The specialist diabetes staff that children and parents came into contact with received the highest praise. The knowledge and experience of these staff was well respected by children and parents alike.

Int: And what about Maisy's consultant and the nurse specialist, how do you find them?

Maisy's mother: Yeah they're fine. I can say to them 'I don't think that's a good idea.'

Int: So you think he does listen to you.

Maisy's mother: Well I've seen him right from the beginning. He was the main man, and I think 'Well he knows.'

Parents and children also appreciated the kind manner and respect they received from the specialist staff at the clinic. Johnny's parents particularly praised his team, comparing it to the less happy experiences of Johnny's father, Dave.

Johnny's mother: I think, I mean Dave has had lots of illness in his time, but [Johnny's] diabetes team are very friendly, they always have talked to Johnny, [names both consultants] in particular, they always talk to Johnny, 'How have you been feeling?' It's fantastic, it's so nice, even when he was little and fairly monosyllabic, they talked to him. So I think the care has always been great, and no-one has ever panicked even when he's been quite ill, and Johnny's never known he's been quite ill, because no one has ever raised their hand up in horror and said, 'Look this is terrible.'

The families especially appreciated the practitioners being available most of the time, knowing that there many other calls on their time and that for most of the specialist practitioners in this study, caring for children with diabetes was only one of their responsibilities. The children and parents usually indicated that they liked as well as respected their diabetes doctor and nurse. Many children in modern Britain know only a few adults, outside the family and school, who are genuinely interested in them, talk with them regularly, know them for years, and care about them and their interests. So their relationships with the practitioners can potentially be one gain for children with diabetes.

During their interviews, the four practitioners also expressed affection and great interest in the children and parents, and stressed the importance of respecting and not judging the families, however different their life styles might be from practitioners' own personal preferences.

Non-specialists

Having established in section 6b how helpful experiential knowledge can be, the interviews also highlight how dangerous a lack of such experienced knowledge and observation can also be. Although only 24 families were interviewed, most of the

parents' and some of the children's accounts of support and care included at least one incident about generalist staff – GPs, nurses, A&E (accident and emergency) and general paediatric ward staff, and other adults such as school staff, lack knowledge and insight. The accounts often describe seriously inept care of these children by non-specialists. Consistent criticisms about their in-patient care by people with diabetes are reported (Audit Commission 2000). It is interesting that young children too are aware of and worried by low standards.

For nearly all the children in this study, diagnosis was delayed until they were ill or very ill. Holly's mother soon suspected diabetes: 'She was drinking and wetting all the time, so thirsty, she'd drink anything.' But the GP said that children aged only 2 years did not get diabetes. Four months later, Holly had become thin and wasted looking, she kept falling asleep, and had no energy. Her mother took a urine sample to the surgery and asked a nurse to test it. Holly was admitted to hospital that evening. Some children needed life-saving intensive care by the time the condition was diagnosed.

There seem to be three main problem areas in the initial stages of children's diabetes.

1. GPs who may lack understanding, do not diagnose diabetes, and may even refuse to believe that young children can develop it.
2. Hospital staff such as A & E staff and ward nurses who lack sufficient knowledge to support families
3. Non-specialist staff who do not recognise the emotional needs of a child who has just received a diagnosis.

1. GP's lack of knowledge about diabetes

All but one of the seven children, who were under three when they first became ill, found serious difficulties in getting a diagnosis. Seven families reported difficulties in getting a diagnosis from their GP. Some parents were even laughed at when they suggested to medical staff that their child's illness might be diabetes. Johnny was diagnosed when he was 4 years old.

Johnny's mother: Well it's the usual thing, the usual story, of them getting tired and losing weight, and being very sleepy, and drinking lots, and as Johnny was explaining to you, he got taken to the doctor, and we actually asked for a sugar test, and the doctor laughed, and said it was a urine infection 'bring him back in 10 days, get him to drink lots', and you know by five or six days later he was really quite ill, and the second one knew straight away.

Nicola also became very ill when she was aged 4, during the 6 months after her mother asked the GP if Nicola had diabetes and before the diagnosis was made. Like Emma, Nicola was rushed into intensive care. Only one family registered a formal complaint, although other families mentioned that they had wanted to, but that pressures at the time prevented them from pursuing it. The registering of the complaint in Johnny's case resulted in his GP's practice having to recall several children who had been sent away for ten days with the same diagnosis he had originally been given.

This next passage about Johnny's diagnosis further highlights how vital GPs' knowledge can be when it is based on direct experience of living with diabetes that alerts them to make the diagnosis.

Int: And you said that when you went to see that locum doctor initially you'd asked to have a blood test done? So did you have some prior knowledge about diabetes?

Mother: A friend staying with us whose wife is a GP and he's also a diabetic, and she said say to the doctor.

Int: So you've had one doctor diagnose it and then another doctor saying 'no.' So you went back and they diagnosed it ...?

Mother: Didn't even have to say, 'We came last week,' or anything, he knew straight away.

One family's request for a blood test was also based on experience, as they judged their son's symptoms to be similar to their diabetic cat's.

The lack of knowledge about childhood diabetes amongst some GPs without prior experience is further highlighted by John's diagnosis. Fortunately, this doctor, though believing it unlikely that a child would have diabetes, was not so reluctant to do a test.

John father: It came about two years ago, we were in America, he was drinking lots of water, pretty clear signs, and becoming more irritable, and we initially put it down to the change in his environment, his eating habits, but general concern as the holiday went on really. So when we came back we took him to the GP. The GP's view was that it wasn't diabetes, and in her time she as a GP hadn't seen any children with diabetes, but to do a blood tests just to see. So we did a blood test and she said 'My God, you know it's 25, 30, plus, plus, plus.' So you know, it was diabetes.

However, some medical staff refuse to believe information direct from their colleagues that young children and babies can have diabetes, as Jessie's story shows.

Jessie's mother: But you know it wasn't until the third GP, the first one they gave her antibiotics, the second said, 'Carry on taking the antibiotics', it wasn't until the third one, these were all emergency doctors through, and the third one said, 'Go straight to hospital and have a blood test.' And we went from there straight to the hospital. The third one said, 'She needs a blood test.' I mean he was open to the fact that it could be diabetes, that's when we knew really, and then when we got to hospital and within an hour she was in intensive care. And, yeah, it was scary; it was very, very scary, because we weren't really prepared for that at all. And the consultant at the hospital where we were staying on holiday, phoned the head GP at our local practice to say, you know, 'One of your patients has become diabetic, she's in hospital', and he just refused to believe that a 15 month old baby could possibly be diabetic, he just refused to believe it. And the consultant at the hospital that Jessie was in said he couldn't believe how rude he had been. He said, you know, he was really shocked at how he had spoken to him. He said you know, 'I am a senior consultant at the Royal General Hospital, and take it from me that this little girl is diabetic.'

2. Non-specialist hospital staff lack sufficient knowledge to support families

Parents described how besides GPs, A&E staff and ward nurses often had insufficient knowledge or skills to support families in times of crisis, such as the point of diagnosis.

John's father: He was admitted for three days, we had nurses asking him whether he'd had his injection or not, how many units of insulin he had had. So [his mother] stayed with him at night and I would spend the day with him, you know. But there was a real sense that we weren't in

safe hands; it felt very unsafe. And partly because of that we were tumbled into this kind of chaos really, you know into a situation where ... I mean to be honest we'd spent a few days reading up on diabetes and various other things, and I felt, without being arrogant, that I knew more than some of the staff on the ward about what was happening. So you know, it was not good.

This lack of knowledge of non-specialist staff seemed to put even more pressure on anxious parents and newly diagnosed children, rather than providing even simple support, as James's mother's account shows.

The only thing I'd say about the medical staff, I do get the impression that diabetes wasn't their strong point, I mean obviously they can't be a hundred percent on everything, but you would think, 'Haven't you got a book that you can actually quickly look up when you get that case?' because they must happen time and time again. The nurses on the ward didn't have enough knowledge of diabetes, more so the younger ones, it's to be expected, they can't be. The thing that shook me and scared me a little bit, was that the diabetes nurse had been to see me in the morning, and she had an injection pen with her and she showed me, and the two nurses didn't know how to use it, and I actually loaded it, dialled up and stuff, and I thought, 'I hope I'm getting it right.' That was the day he was diagnosed. I'd seen the specialist nurse in the morning and I had to do it that evening after being shown once. But I would have thought things like the pens, I would have thought there would be someone showing me how to do it, to reaffirm what I'd learnt in the morning.

Some parents felt that practitioners, such as nurses, did not recognise that their knowledge about diabetes would be very limited immediately after diagnosis. Others found, when they were more experienced and returned to hospital for emergency help for their child, that this was not always adequate. Johnny and his parents felt they were bombarded with contradictory information by different rounds of staff on one hospital ward.

Johnny's mother: [One hospital] was interesting, because they didn't have a diabetic registrar on duty while we were there, and they sent a day locum, and we were told, 'Did we understand what brittle diabetes was?' 'No.' 'Well Johnny's a brittle diabetic.' And they sent someone to teach us all about brittle diabetes, and we had this for 12 hours until the shift changed, and then someone else came on and said, 'He's not a brittle diabetic. Forget everything you've been told.'

Indeed other parents, such as Jake's mother, have begun to feel, when they became more expert, that they can't rely on the non-specialist hospital staff for support at all because of their experiences.

Because that to me, that was my safe haven, that hospital there, you know that's it, if I had any problems we could just go to the hospital and it would all be OK, and it wasn't, it wasn't OK. And I thought, what do we do? If that is the place where we go, when we're at the end of our tether? And now, I mean Jake's had problems like the last week, he's had a bout again, and I thought, 'Well I'm not going to bother, I've got glucose syrup in there, and I'll wait until he's asleep, and I'll get a syringe', and you know I'll get through it like that.

Jake's mother's reaction wasn't uncommon but it was the result of a particularly harrowing experience for their family in A&E.

Recently, Jake was ill and refusing to eat or drink, he had a throat infection, and he didn't want to swallow fluids. So we coped with it as much as we could at home, for about four or five days, it's like force feeding him anything we could get our hands on, glucose syrup, anything. And eventually it just got beyond, we couldn't cope any more, and his blood was like 2.6 or something, and we couldn't get it up, so we took him to hospital. We waited five hours to be seen. Five hours. And eventually he passed out. And he's never been to the stage where he's passed out. We were seen by the registrar, but I was waiting to put, I wanted him to go on a drip, he needed to go on a drip, and we kept complaining, and they kept us waiting for five hours. And that's another thing I regret not complaining about [in addition to problems at the time of diagnosis], because it's done now. And so what happened then, this is unbelievable. Our turn to be seen came so I took him through, by this time he was unconscious, and the nurse said something about taking him to resus, and as soon as I heard that I was like, 'Oh I've seen this on Casualty.' And I thought he doesn't need resuscitating, you know it's not what he needs. So total lack of understanding. I was hysterical, my husband is trying to calm me down, but then he was getting annoyed because of the whole situation. And I just said, 'Just get some glucose of some description.' Because I thought, you know, I could have coped better at home myself; I thought I was going to get the help from the hospital. So in the end, my husband, when they started wheeling off to resus, he thought, 'I've had enough' and tried to drag him off the bed, he said, 'We can cope better at home.' He pulled him off the bed and started to take him out the unit, and then funnily enough his blood came up slightly, so we took him back, managed to get some glucose syrup down him, of course then he's right as rain, you know not for long. Five hours!

It is hard for families to cope with sub-standard services and although several parents mentioned the desire to make official complaints, in the stressful period after diagnosis, where attention is focused on their child, few parents have the extra energy needed to do this in order to help to raise standards.

3. Non-specialist staff and their lack of understanding of the emotional needs of children and parents

Several of the families described a lack of understanding about the emotional as well as the medical needs of their newly diagnosed child. John's father highlights a severe lack of understanding.

There were children there a little older than John who'd been brought in in a crisis, he was on a ward where, we were just getting used to this diagnosis, and there were people, [aged] 16, 17 who were obviously in quite a lot of distress, and it was one big ward, and John could see all this and obviously he was absorbing this environment and wondering whether this was him in three or four years time. So that kind of, that whole process was, I thought, awful. I thought it was, I mean the GP, I've got a lot of respect for my GP, we've been with her for years and she's great, but she didn't really understand the process of what happens to young adults or children when they're diagnosed with diabetes, she didn't understand that process. The way it was told to him was awful. I mean he

was traumatised for three or four days at least. You know he literally had gone under the table and was crying. Well we'd been told that he wasn't going to be admitted, we'd planned the weekend around him going in to give some blood tests and blah, blah, blah. And we were immediately told that he would be admitted, so there was no time for dialogue. There was no time for any education; there was no time to engage in a narrative with any of the clinicians there really.

John illustrates how serious the effects can be of such an introduction to a lifetime of essential medical support.

John: I hate hospitals. I hate them. I just really don't like hospitals. Ever since I went I just hate hospitals.

Int: Ever since you were diagnosed?

John: Yeah, I hate hospitals, I don't know why.

Several children mentioned memories of loneliness and fear. Guy Fawkes, diagnosed just after his sixth birthday, remembers being frightened at being in a room on his own in hospital, on a drip. 'There was nobody. No one to talk to. There was no little boys...I was almost dead.' Jo remembers being diagnosed when she was 4, and her mother changing the sick bowl for her before she went into a coma.

Simba seemed to sense a distinct lack of sympathy from one ward nurse.

Simba: They were not nice. I didn't like them.

Int: Why not?

Simba: They were too rude. Yes, this lady says, I am not giving you custard and cakes!

Int: Is that what you wanted?

Simba: She said it in a funny way.

Int: Is that what you had asked for?

Simba: No I asked for something on toast.

Edwina was also upset suddenly to find herself among very sick children, and found this a very negative introduction to the condition she was told she would have for life. Edwina was in a six bed room, and she had to be quiet for the sake of the sick children. Her mother noted that:

Sometimes it seems unfair on the ones that are not so ill because they are all mixed up in the same place. And the ones who are not so ill who could quite easily move about get restricted because obviously the ones who are very ill need more attention.

How were John and Edwina to know that they too would not become as sick as the other children they saw, who did not have diabetes?

The apparent indifference of some hospital staff can increase the distress, as John's father showed. He described John crying and hiding under a table, and added:

He didn't want to come out, it was awful. And at one point the nurse said 'I prefer children in comas really, they're much easier to deal with.' She said most children come in in comas and they're much easier to deal with. And they had no understanding then, of the complex nature of such

a diagnosis, of someone with a ten year old or any age. So we kind of, it was a really, really traumatic awful experience.

Aside from the lack of compassion of some non-specialist hospital staff, children and parents mentioned other unnecessarily distressing factors. When the children are admitted to hospital they will be introduced to needles, and they will be becoming aware that this will be a feature of everyday of their life. However, many children described how they were put through unnecessary pain during their introduction to needles which made them very anxious about their future.

Int: And can you remember the first time you did a blood test? Did somebody else do that for you?

John: Yeah, they just pricked it, they didn't have one of those things with a needle that pricks it [the hospitals use disposable finger prickers which aren't pens, and have much larger needles in], and I thought, 'Oh God I'll have to do this for the rest of my life.' The pen prickers aren't too bad.

Indeed many children found their first experience of finger pricks alarming, and remembered this in particular, despite having done it thousands of times since.

David: And the minute I sat down because I was so tired, and so I sat down and this lady came round and had this pricker and jabbed it at my finger, and it really hurt.

Others described how they underwent very painful procedures unnecessarily.

Int: What happened [when you were first diagnosed? Did you visit or stay in hospital? What happened to you there?

Edwina: They put the thing [needle for line] in my hand but they didn't do anything [with it].

Having a butterfly needle put in is one of the most painful things that children described that they experienced. In one clinic children were observed undergoing their annual review, which involved taking blood from a vein. The pain of this would be similar to the butterfly and some children wailed with pain. For Edwina this was the beginning of needles forever, but this introduction was far worse than the needles she has to have daily. During the interview an overall picture built up of Edwina being very bored and miserable in hospital for a week, feeling helpless and unable to ask or protest, and wondering if every day for rest of her life with diabetes would be as unpleasant. The beginning need not be so oppressive and frightening.

David described how pain is part of the emotional impact of first learning that you have diabetes.

Int: And can you remember what you felt then?

David: Quite worried, and I was crying.

Int: And why were you crying?

David: Because it hurt so much, and I had know idea what was wrong with me, and what they were doing.

Moogum gradually became more willing to talk during her interview, such as describing vividly events when she was diagnosed.

Moogum: I went, I was sat on a chair with my daddy and then, they called out some people for lunch and then I had lots of blood tests, every time when I had one, and another person comes to me and saying, 'Can I have your blood test?' And then all of my fingers had dots on them. And then, and then um, I sat on a bed like this [indicates the couch in the doctor's room] and then my dad sent me some food. And then my mum came and brought me some dinner and then when, and then we went home and then, and my arm was all folded.

Int: Folded in? [pause]

Moogum: Stuff.

Int: Wrapped in? [pause]. Cloths and things?

Moogum: Yeah. And then I felt very scared because – and then, the needle was coming in.

Int: About needles going in?

Moogum: Yeah. And everybody said that I'm brave.

Int: Did they? And how did you feel at the time.

Moogum: I felt happy.

Int: You felt happy about that. Did you stay overnight in the hospital?

Moogum: Yeah.

Int: Yeah, what was that like?

Moogum: That was scary.

Int: What was scary about it?

Moogum: Because it was dark and there's, I had nobody to play with and then I found a little toy on the floor.

Int: Did you? Was there any other children there?

Moogum: [shakes head]

Int: Was your mum and dad there with you?

Moogum: [nods] My sister was at home in bed and she was crying because she thought I was dead.

Mr Football vividly remembers his fears about some aspects of being diagnosed aged just 7 years.

Mr Football: Well, I was diagnosed with diabetes two weeks after my birthday and I remember on my birthday...I had...had some sweets, chocolate cake, like most people would do on their birthday, and I was sick, was a lot, and I started to moan, cos my blood sugar levels must have been really really high and I remember...having to stay home from school and...my mum phoned the doctors, and my mum had closed the door cos she didn't want me to hear that she thought I might be diabetic, I heard, then I was scared, cos I didn't know what it, what diabetes was then. And we went to the doctors and they said, 'You're diabetic', and as quick as that. But after I'd done my blood I was sick a lot while I was in there. And that's all I can remember...

Mother: His blood [sugar] went so sky high that he's lost consciousness...It was scary wasn't it?

Optimal care at the time of diagnosis

It would seem that these children, who are now very adept at dealing with diabetes and with needles, would have a lot of expertise to share with staff. They could inform staff about better ways of introducing children to needles, and of being more aware of the momentous occasion this will be for young people coming to terms with having diabetes. Urgently needed changes might then be made, such as using finer more child-friendly needles as suggested by John.

One of the Paediatric Diabetes Consultants described how even if a child was well enough to be treated at home, the under-staffed service could not provide the necessary support at home for the first days. The only specialist doctor and nurse both worked part time on children's diabetes. Therefore most newly diagnosed children were admitted to hospital regardless of their need for inpatient care, for the first days. In another hospital, the consultant felt that parents and children both preferred to have the support of staying in hospital in those early days.

It is not possible to know, from our small sample, whether the families' experiences of the wards were typical or unusual. Would most families, looking back later, vote to have stayed in the ward or at home during the first days? Possibly, children who were very ill and needed intensive care when first diagnosed, a high proportion in this small sample, might have found it easier to adapt to the strict diabetes regime, realising that it keeps them from feeling so ill. When children who feel fairly well are suddenly told they are ill and have to follow the strict regime, they are likely to find this far harder to accept.

When people have bad experiences, such as at the diagnosis of diabetes, they are liable to have dreadful haunting memories of that time, and may need to express anger and grief and blame (Seale 1998). Criticising the doctor or nurse can be a case of shooting the messenger who gives unwanted news. Even so, our interviewees raise serious general issues about sometimes avoidable problems which certainly warrant further investigation.

Here is a summary of key problems that children and parents found during the admission to hospital of children who were well enough to stay at home during the first week after diagnosis.. Fifteen families found some difficulties in children's wards among the following::

- lack of experience and knowledge among non-specialist ward staff who provided almost all the care;
- sometimes lack of sympathy and understanding by staff for families during this severe crisis;
- some children liked the food, but Edwina, for example, did not and since a major problem with diabetes is learning to manage with a highly restricted diet, this can give an even worse introduction to the new lifestyle;
- seeing other very ill children and not being clearly told that they did not have diabetes;
- having to be very quiet and bored because of the sick children's needs;
- enduring unnecessary pain from larger needles and inexperienced staff, and again wondering if every future day of their life will be as bad;
- having to submit to routines, including teaching programmes, which involve procedures that are not all necessary to the child, such as junior doctors inserting butterfly needles for training or 'just in case they might be needed' but then not using them;
- feeling extremely helpless and powerless, as hospital patients tend to feel, controlled in many daily details, such as meal and rest times, television viewing, access to friends and, not unreasonably, dreading that 'being a diabetic' means losing much control over your life and identity and choices;
- finding that their requests and protests are not heard, or not having the energy to make formal protests, as some parents also reported;

- taking on the 'sick role' of being a helpless, inadequate, dependent person, whereas specialist staff want to encourage children and parents to feel as confident and competent as possible.

These kinds of experiences can convey far more powerful messages of helplessness than words alone can either convey or easily counteract. Dedicated diabetes practitioners want to reassure children and parents that they can be 'in control of their lives and choices' and that life can be as full and 'normal' and rewarding for people with diabetes as for other people. But after diagnosis, a few days in a children's ward can seriously undermine these messages.

Experienced families who had to return to A&E or the children's wards when the child had a hypo or was ill had similar criticisms. The problem then shifts from initially shocked and inexperienced families feeling let down by non-specialist staff, to experienced families feeling that their vital expertise is ignored by general hospital staff, sometimes dangerously so, as in the earlier example by Jake's mother.

Parents knew that children's wards regularly care for children with diabetes. One person suggested that the staff could have an information book because worryingly low levels of knowledge among non-specialist practitioners, such as GPs and ward staff, risk dangerously poor levels of care that potentially affect many children and not only exceptional cases. DJ's symptoms were so advanced at the point of diagnosis that he wasn't expected to survive. Yet cases like his could be avoided if experience was shared more between specialist and non-specialist staff. During their interviews, specialists described their work with colleagues but also explained how limited their time was.

We have quoted children's and parents' accounts to emphasise that their experiences are not only valid and important, they also have the potential to be a valuable resource. The children and parents also spoke more generally about how they wish to lead their lives. Given the importance and relevance of their views, the next section sets out the issues that appear to be most pertinent to children and their parents.

6d. Children 'just want to get on with their lives', so they need devices and routines that help them to do this

The children's and parent's accounts of their experiences indicated that children just wanted to get on with their lives. There were many examples of how children, often very deftly, dealt with their diabetes care in order to be able to carry on with what they enjoyed doing, for example playing out with the friends. Sometimes, having snacks, doing injections, doing blood tests could impede their enjoyment as it meant they had to break away from what others were doing. Children stressed that the problem for them was more about the inconvenience and interruption to their daily life, even more than feeling anxious that the diabetes care made them stand out as different.

This was a very strong theme in the interviews with children. All the children, except Johnny who was on a pump and two of the youngest children (age 3 and 4), complained about having to stop what they were doing, and enjoying, in order to do their injections or blood tests. One doctor also recognised this as a commonly held view of children. The strength and uniformity of their feelings are further highlighted firstly by the fact that we asked no questions specifically about inconvenience; the children raised this problem themselves. Secondly, several of the children said that the

most annoying thing about doing injections was not, as one might expect, the pain, rather it was the nuisance. Edwina and James illustrate this theme.

Int: Are there any not so good things, the worst thing, about having diabetes?
Edwina: Injections.
Int: Is it that they hurt?
Edwina: Doesn't hurt. Sometimes I can't be bothered.
Int: The nuisance?
Edwina: Yes, I could be in the middle of something fun, and my mother goes, 'It's time to do that thing'. Gets on my nerves.

Indeed James indicated that the more time that is taken up by diabetes care, the more annoying it is for children.

Int: You mentioned about doing injections before, what don't you like about doing it?
James: Because it's boring.
Int: And your blood tests, is that the same?
James: That's worse because you have to do it four times a day instead of twice.

They make the point that although adults often dismiss the value of children's time, to children their time is precious. Besides being a drag, having to break away from activities can adversely affect social life.

When asked if there were any good aspects to having diabetes, George said, 'It gets me out some lessons in school.' Simba combined good with bad aspects.

Simba: Oh yeah, it's good, not good.
Int: So it sometimes good and sometimes not good? What's the good bit?
Simba: It's *just bad!* (with emphasis)
Int: It's just bad?
Simba: Cos I love chocolate. I love sweets, but I can't have it. That's what's wrong, *bad*. My sister says she stopped [eating sweets] but she didn't. So when she was in the photo she had rotten teeth going [shows across mouth] like that – and she had all black teeth and yellow.
Mother: So it's better to be you, isn't it?
Simba: It's better for me not to – because I can die like that, innit?
Mother: Mmmmmm
Int: And you have good teeth.
Mother: Yeah exactly!
Simba: Like these! (showing teeth)

Moogum also saw mixed good with bad aspects. Her sisters' teasing seemed to be the worst thing, but:

Moogum: I like, I like, I like um [pause] I like, I like about the diabetes cos I like diabetes, because every time, when I get the biscuit, my sisters always say "ohhhhhhh"!

Int: So are you saying that sometimes they get sweets but you don't get them, but other times you get biscuits and they don't get them?
Moogum: Yeah.

Other children saw the risks of disease or changes in life style as their worst things.

Mr Football: I think the worst thing is that basically anything could happen, like your pancreas could do anything, like I had a coma and that's the worst case scenario. So anything can really happen.
Guy Fawkes: It's a sad thing to change everything [in your life].

For several people the worst thing is 'Needles!' For Jo it is also feeling sad when her sister has doughnuts. She drew a picture of the worst things about having diabetes – insulin syringe, needles, blood test machine and the kinds of food she liked to eat but could not, a doughnut and a chocolate bar.

David: Well at my school they have these four people consoles at school, and sometimes people don't share them, and if I've got one and I have to go off and do my injection then I can't get a go afterwards.

As this disruption was one of the key and most common themes in the children's accounts, it would seem important to factor this in when practitioners prescribe the daily regimes. If children feel that they can fit these activities easily in to their lives, then they are less likely to resent doing them, and may be more likely to cooperate with their treatment regime in both their immediate and long term future. Uncoordinated care could disrupt children's lives. A boy who had to have an injection and snack at school found that the school staff interpreted the doctor's prescribed routines in ways that stopped him from enjoying playtime with his friends when he had to go over to a remote part of the school for his care. Resentments are well documented in research with adolescents, but we found that younger children are also very concerned about sustaining friendships, disrupted time, and not being seen as too different from their friends.

Because of the 'drag' of doing injections, Edwina sometimes couldn't 'be bothered.' She was having hypos at school and being taken to hospital by ambulance, until her mother started to supervise her morning injection more closely, to make sure it was done.

Many practitioners and parents are aware that flexibility may benefit the children's feelings about doing injections and blood tests. It is not easy to find the balance between over- and under-supervising them, especially while children keep growing and changing. It is also hard to avoid being too rigid or too flexible, balancing between letting children go at their own pace or trying to hurry them up if they are slow. They may need to be faster to avoid being late for other events, such as getting to school. They may also need to speed up because more and more time is being spent on the injections while the children and parents become still more bored, worried, and perhaps angry, about the routines.

The literature on adolescents records how daily management problems can increase with age, and our research suggests that resentment about inconvenience can be building up from at least as young as 6 years of age, in the case of DJ. It may be beneficial to explore the beginnings of resentment and resistance through further

research with younger children rather than focus on the ages when young people become more openly non-compliant.

Product developers and practitioners need to understand the great importance of devices and routines for children that are both quick and easy to use, since it is known that fewer injections and blood tests per day may lead to reduced control and more later complications (DCCT 1993). However, control of diabetes is not achieved in a social vacuum and the pertinence of inconvenience and disruption to young children attests to the need for practitioners and product developers to acknowledge and respect that. Ways to resolve children's difficulties with the regimes need to be found that avoid restrictions on their social life whenever possible.

It was quite striking that one of the few children who did not voice such concerns was Johnny who used a pump. Indeed his mother had initial concerns that it might cause him to feel more different. He, however, had no such concerns and was perhaps the best adjusted to his condition of all the interviewees. Childhood asthma questionnaires found that British children aged 11-12 (though not adolescents), expressed less concern about being different than Australian children expressed (French and Christie 1996). Further research to find out the benefits of being on a pump in relation to children's concerns would be useful.

The asthma research also found that Australian children were noted to be more independent and informed than British children, suggesting strong links between knowledge, confidence and skill in managing chronic conditions. Assessors of quality of life warn against confusing causal factors with consequences or effects (Eiser and Morse 2001). We cannot say whether Johnny's generally happy successful lifestyle was a cause or an effect of good diabetes control. He spent much time on music and sports. The social context appeared to be important. For example, after Johnny developed diabetes, his small school adapted the snack arrangements so that everyone fitted in with Johnny's routine. In contrast, Edwina said she felt bored, excluded, picked on and punished at school for having diabetes. This may be linked with her feeling possibly not very well, because of poorer glycaemic control. Alternatively, the less strict control of the diabetes may follow feelings of sadness and perhaps lower self-esteem linked to her experiences at school.

We suggest that instead of attempting to trace causes and effects, it may be more useful to look for associations between physical and social quality of life, as well as the families' socio-economic background. If there are clear associations between all these, efforts to improve, for example, glycaemic control alone while ignoring unhappiness at school, may fail. The diabetes nurses described their strenuous efforts to inform individual school staff and to change attitudes. They work against a culture of discrimination against disability in some schools, reinforced by league tables and schools competing against one another, so that students who take up more staff time (cost more) and who may fail are unwelcome in competitive and under-resourced schools. Around 40 per cent of young people leave school with no qualifications and many have a deep sense of failure (Gillborn and Youdell 2000). How does this affect those with diabetes? If they feel they are failing at school does that help them to feel successful in managing their diabetes? Young people from ethnic minorities are disproportionately affected both by diabetes and school failure. Many teachers feel overworked, stressed and lacking in time to help children with unusual needs, and core teacher training still ignores children's and disabled people's rights (UN 2003). So just as children's success or distress in coping with diabetes is more than a personal individual matter, and reflects and interacts with their social surrounding, teachers'

responses to children with diabetes are partly shaped by political and economic contexts. Matters will not wholly improve until these change.

The importance of this theme of personal inconvenience is even more poignant when contrasted against another strong theme that was instigated by parents about how much hard work diabetes care entails. Children indicated that it was a very real and constant annoyance to have to fit their diabetes regime into their lives, yet their terminology was often much milder than their parents'.

There were many descriptions of ways in which children and parents had to buckle down and get on with things. There were also many descriptions of children almost shrugging off difficult things and seeming to take them more in their stride than their parents did.

George, for example, does not yet have insulin injections. He talked about the prospect in a matter of fact, realistic way that children often used, especially if their parents were present, as if they wanted to reassure their parents. On attending the clinic:

George: Well it's not a big deal really.
Mother: He gets a bit nervous, because they're not sure when they're going to put him on insulin, it's always a – they might do, they might not and he gets a bit worried the night before. Just in case they say, today, that yeah they're going to do it. So he gets a bit panicked about it –
George: I'm alright about it now.
Int: Yeah? [pause]. What makes you alright about it?
George: Because I've thought about it and well I've realised there's nothing to be worried about cos I'm going to have to get used to it anyway at some time in my life, so, it doesn't really matter.

Some parents overwhelmingly talked about getting over their initial fear of performing injections. They often remarked that after the initial shock wore off they felt they 'just had to get on with it.'

Int: You say it was because you didn't want to hurt him?
DJ's Mother: Because I knew I couldn't have done it right, straight off, I was just too shocked. So [his father] did it for a couple of days, it took me a couple of days before I could.
Int: And how did you [father] feel about doing the first ones and everything?
DJ's Father: I didn't like it all but it was the fact that they was basically saying, 'If you don't get around this and like deal with it then he's going to be spending his time in hospital.' So it was a case of, 'Well it's got to be done so get me head around it and deal with it.' And that was what I was basically trying to tell [his mother], 'Get our heads around it and we can get home.'

Children often talked more generally about 'just getting on with it' and showed that they could be accepting, and wished to play things down.

Int: Can you think of any times when people haven't treated you very well and been a bit thoughtless?
William: ... I can't really think of any.

Mother: Only the one time when Daniel bought chocolates for him and his father.
William: Oh yeah I went to see West Ham and I just felt left out.
Mother: What about at school when you don't get puddings?
William: Well I'm getting used to it now because it's happening quite a bit, but I don't mind it so much because it happens quite a lot, I'm getting used to it.

The next example exemplifies both the worries and the hard work that can be associated with diabetes care, but David still advises 'just to get on with your life.'

David: Well it's quite worrying because you might have a hypo, so I worry about that. But it's quite difficult to remember your injections, and if you forget them you might die. My father told me about a kid who forgot her injections for a week and she died, so try to remember. Try just to get on with your life.

By his picture David wrote: "DON'T LET AN INSULIN PEN PLUS NEEDLE CHANGE YOUR LIFE. YOU'RE JUST THE SAME AS YOU WERE BEFORE."
(see title page).

It may be said that the children did not feel able to talk openly about their problems, that they were putting on a polished performance of acceptance for the researcher, either because they didn't want to appear weak, or because they did not trust her as an adult to confide in, as DJ's mother commented.

DJ's mother: I mean if I actually mention something to him now he most probably, 'Oh yeah, yeah, I remember now,' sort of thing.
Int: Can you think of an example?
Mother: I think most probably deep down inside he does feel really different, from things that he has actually said to me, like when he's in the garden and playing and stuff, and he's got to come up for his snack, and he hates it, and he's got to stop doing what he's doing, and it's a hassle.

Alex who had needle-phobia showed this ambivalence, first admitting some difficulties and later brushing them off.

Int: And can you describe a bit about those feelings, you say you were feeling a bit low?
Alex: Well sometimes it's hard to live with it because you feel you're down in the depths, and you feel like you want to get back up, and they [friends with diabetes] just help you with your feelings and they just bring you back up.

And later:

Int: Any worries in general about diabetes?
Alex: No not really. If I'm good in what I'm doing.

These may be an important coping mechanism that the children are using very successfully to offset any upset they have. DJ's mother discussed this further.

DJ's mother: I don't think it sort of worries him too much, because when you ask him, I mean when you was asking him some of those questions I was expecting him to come out with quite a bit, but I just don't think he

really thinks about it too much. At the time, when you're so young, things sort of matter at the time when it's happening, but once it's gone and done with, it's forgotten about.

Comments from David and others, and the caption to his drawing above, also suggest that it is a coping mechanism, a conscious effort to be 'normal' to 'just get on with things' and not let diabetes get you down. Just how keen the children are to do this is demonstrated by John's comments, when he was asked what advice he would give to a newly diagnosed boy similar to his age.

John: I'd say, 'Ask someone who's really got diabetes.' I don't think I act like a, I don't think I'm a good person to ask about diabetes, because I'm more of a novice at diabetes. I just know the basics, I know what to do at what times, I know it works out OK.

Int: From your experience though?

John: I don't know, I'd say, 'Go and ask someone else.' Because also I, it's too serious and deep for me and I'm just having fun, not like saying 'Oh diabetes ...'

Alex in particular put on a polished 'grown-up' performance to show his competence.

Int: Do you ever go and stay with your grandparents or aunties?

Alex: Yeah that's fun.

Int: What do you do with them?

Alex: I just like sitting down talking with them as well. And I do my homework because there's peace and quiet there.

Int: And what happens then with your diabetes care?

Alex: I keep it casual, and I do my needle when I need to do it, and if I feel low or high I will do my blood, just in case I need some sugar or sweet, so I test my blood.

Int: So you do your own injections there?

Mum: But his nan draws them up.

Alex: No I do do it.

It seemed important to Alex to demonstrate his competence, rather than talk about any problems. Similarly William spoke as a conciliatory, accepting and mature person rather in contrast to his mother's view. With DJ and Jake also, it tended to be mothers that would bring up negative issues that their sons hadn't touched on. This seemed to happen less during the girls' interviews. We have too few interviews to generalise from, however Williams (2002) found that for the boys with diabetes or asthma that she interviewed, their mothers were more likely to be protective and active in managing the boys care than they were for the girls.

Alex hardly talked about his needle phobia, until prompted later in the interview, after his mother had mentioned it, and Alex used a non-emotional tone.

Alex's mother: And I don't know, with his father working, I used to have to give Alex the needle and hold him down. And the people opposite said they were about to call the social services because he screamed so bad, because they thought he was being beaten.

Father: It was old Les, and he said, 'If it wasn't for the fact that I knew you, I would have called social services. It got to the point, you've got a certain window, but this was going on for hours and hours.'

Int: And how did you overcome that?

Mother: [mouths the words so Alex can't hear] We haven't.
 Father: He's a hundred times better than he was.
 Mother: Oh yeah he didn't inject himself up until just over a year ago.
 Int: And he's eleven now, so that's still quite an accomplishment.
 Mother: Well that's because he wanted to go away with his school. And that was it really, so that was, he'd had ten years of us doing it to, 'You've got to do it if you want to go.' And so he did it.
 Int: And he seems quite keen now to take that on?
 Mother: (Shakes her head)

As other research has found, children are often stoic in front of their parents, sometimes to protect their parents (Bluebond Langner; Alderson 1993). Parents can help interviewers by reminding and encouraging children to talk more fully about problems, as in the interview with William and his mother noted earlier about puddings.

It may also be that these things seem much worse from an outsider's point of view than from the view of the individuals themselves, which comes back to the importance of experience, such as when many children and parents find that actually performing injections is not as bad as they had expected.

Int: And how was that (doing the first injection)?
 Maisy's mother: I remember thinking, 'Oh no I just don't think I can do this.' But you sort of, you feel like a silly girl, you know, 'Silly girl, it's got to be done.' And you know it's got to be done, so I did it.

Children often seem more accepting than their parents.

James's mother: But when it's your child you'd do anything, beforehand if somebody said, 'Could you give your son an injection?' I'd say, 'No way, I'd pass out, I couldn't give my son an injection.' But when it comes down to it, if it's your own child and their health, you do it, you just get on and do it. You've got no choice. I think mentally you said, 'I'd like to say no, but I haven't got the choice. I'll do it because I've got to.' But he did it the next morning, straight away, no, after you were ill, is that right?
 James: Yeah it was after I was ill.
 Mother: So the nurse gave you two and then you did it?
 Int: So you took it in your stride but your mother had more trouble?
 James: Yeah.

6e. Children with diabetes are 'normal' and 'not different to anybody'

Although it was clear that, for these children, the main difficulty with having diabetes was having to fit the regime into their everyday lives, it was also evident that they had some concerns about being seen as different from others. We asked, 'Do you feel that you are different from your friends?' At first some children did not link the questions to diabetes, as if they were more conscious of other differences.

Int: Do you ever have to explain things to others? If so, what sort of things do you say?

Alex: It's just a thing, it just makes you sort of different from them, it doesn't actually mean that I'm actually different from them, I'm just a person going on with everyday life, but I have to take injections and stuff like that.

The caption to David's drawing quoted earlier makes the same point. Alex has already been quoted talking about help from his friends who have diabetes when he felt down, and here he repeats the most cheering comments.

Int: What kind of things did they say to you then?

Alex: 'Don't worry, you know you've just got to live with it. It's just a feeling you've got; it doesn't make you different from other people.'

When asked what advice they would give to newly diagnosed children, the young interviewees tended to give reassuring and practical advice about how to avoid being seen as different to others, or perceiving themselves as different.

James: Well it's OK if you know how to deal with it.

Int: Anything else, any other kind of tips or anything?

James: Just do what you want to do, don't give up on your clubs because you can still do them.

However, Moogum, interviewed 3 days after her 7th birthday, had developed diabetes when she was 5, and prefers to keep quiet about it. She seems to feel sad about being different.

Int: How do you explain it to them [other children]?

Moogum: I don't even talk to them.

Int: You don't talk to them about that?

Moogum: My sisters are always telling someone. I don't like it.

Int: Why? Would you prefer them not to say it?

Moogum: Because if they tell anyone, I'm scared if they tease or something like that.

Int: So you prefer that people don't know about it?

Moogum: Yeah.

Int: Has anyone ever teased you about the diabetes or have you ever felt sad because of the way people treat you about the diabetes?

Moogum: [quietly] Nobody knows.

Int: Nobody knows about it? What about how your parents look after you? Do you think they look after you differently from how they look after your brothers and sisters?

Moogum: Yes.

Int: How's that?

Moogum: Everyone when they have a sweet, when I do not be diabetic I used to have everything. And now, when I'm at home, my sisters say [high, chanting tone], 'You've got diabetes, you've got diabetes', and then I feel sad and I go up to my room and get in my bed and do nothing.

Rezwana said she did not answer her friends' questions: 'Because if I explain to them then they're going to ask me more questions.'

Mr Football, a few days after his 9th birthday, spoke about feeling different from his friends:

Mr Football: Sometimes, but that's only when I'm feeling quite annoyed and stuff like that, I feel that I'm different. But not very often. So when I'm quite annoyed...Well normally, like sometimes, like cos my mum's got diabetes as well, but she's only got type 2, and sometimes I get annoyed that my mum's bloods normally like 5 and mine's normally 16 and 17 and stuff like that. And my mum's is normally 6 or 7. So I get annoyed about that.

Mother: It doesn't seem fair does it?

Mr Football: No, it doesn't seem fair.

He also feels left out if there is a birthday in his class and everyone has a goody bag except him. And he's not sure why, 'Not really, I just feel all like, not the same.' Emma when aged 4 years accepted having a different diet from her friends at nursery. She knew she was allowed to have a small piece of cake at birthday parties but the staff sometimes forgot. Emma did not protest but she would tell her mother later, who would then remind the staff. This problem of being unjustly unnecessarily excluded by the staff was resolved a year later when Emma and her mother agreed that Emma could decide how many treats she could eat at birthday parties depending on her blood sugar level.

The feeling of being different was partly about not being able to share fully in friends' activities but also involved emotions. Moogum did not appear to understand or answer the question about 'being different' directly, but she went on to talk about feeling sad, isolated, different and excluded at times. Mr Football said he doesn't know what to do about it or who to talk to. He felt the teachers didn't really care or listen to him and that made him angry, such as when he needed a snack.

Mr Football: Yeah, but she [head teacher] doesn't, she's thoughtless anyway, she doesn't really care about much apart from if the school, if everything about the school, if like someone getting hurt, it's like if the school's alright, it don't matter.

His mother showed how parents can be very helpful in interviews by quietly mentioning useful points that encourage the child to explain.

Mother: He was quite upset about the competition weren't you?

Mr Football: Yeah, we had a cake competition and I'm not allowed to eat cakes, but I joined in and I won and she gave me a chocolate goody bag, which really upset me because, and it's like jelly babies and stuff like that, I'm not allowed jelly babies *ever*, sometimes I'm allowed chocolate, but it just really, really made me feel really upset.

Int: What did you do?

Mr Football: Well my mum gave it back and I did get another prize but it wasn't about that, it was like she could have at least have thought about me and gave me something before then and not like caring and giving a diabetic a goody bag's an insult.

Here Mr Football shows how hard and unfair experiences lead children to see clearly the medical model of disability. This assumes that his diabetes is the main problem and is a nuisance, for example, to the head teacher, who simply wants the school to run smoothly. The reference to 'someone getting hurt' could be to the current high anxiety in schools about risks and accidents. But it could also imply that the head found his diabetes, and his 'being hurt' in the sense of being different and not being perfectly fit, as inconvenient to her, when she came in and talked about his snack in

front of the whole class but without seeming to 'care.' Mr Football can also see how thoughtless teachers can very much increase his problems.

In the social model of disability, the main problem is seen to lie not in the impairment such as diabetes, but in the barriers and problems that an 'uncaring society' creates (Oliver 1996). For example, one school disrupts a child's playtime with rules about where to eat a snack, another school changes the routines so that the child can fit in with everyone else.

One response to unfair differences, described by Moogum, is to be sad. Another is to be angry and protest as Mr Football describes, seemingly encouraged by his mother. They explain how they both dislike having to keep explaining matters, such as about diet, when he wants to be the same as other boys, and when people don't seem to understand, or are merely curious

Confident children tended to cover over differences and the questions of 'being normal.'

Int: If you go to football, or you're going round to your friend's house and they have food, or...don't have food, do you ever feel different from [your friends] in any way, around that kind of thing?

George: Not really.

Mother: He doesn't really like to say –

George: I don't really eat a lot of food. I'm not a big eater, - when I want to eat, I eat the lot. But when I don't, I don't pick –

Mother: He doesn't like to say, do you? I'm a bit like that. You don't like to mention it cos you think you're the only one. [George's mother also has diabetes.]

George added that he kept trying to explain to friends at school, but it was boring to keep repeating the points and they weren't interested, so he doesn't bother.

Simba did not seem to see diabetes as the main difference between himself and his friends.

Int: And do you more or less feel the same as your friends or do you sometimes feel different?.

Simba: I sometimes feel different because they swear...

Int: Do you feel that your mum looks after you in a different way from how she looks after your older and younger sisters?

Simba: [adamantly] She looks after me *better!* She says she loves me *better* than them.

We aimed to conduct social interviews about the child as a person, rather than medical ones that perceive the child mainly as a patient. Simba responded to this by talking about the toy animals and his baby sister's christening, and by wearing Halloween teeth, though the interviewer asked him to put these on a teddy so that she could understand him better.

Simba's mother marked clear differences between him and other children in the school. She had a meeting with all the teachers, and a photograph of Simba and a notice about diabetes, saying he should go to the front of the queue, was displayed in the school dining hall. George's wish not to draw attention to his diabetes shows the

importance of helping children in very different ways, depending on their preferences. Simba seemed quite happy about the picture, as he needed to do less explaining to adults, which was 'boring.' The countless 'boring' repetitions in daily advice and routines were conveyed by Simba (with his Halloween teeth back in his mouth).

Mother: Why don't you touch sweets?

Simba: (Impatiently) Cos they're *sugar-y* innit!

Again Simba showed that he, more than his mother, either saw the social emphasis in the interview, and/or was more interested in talking about social aspects of his life, when he mentioned being bullied.

Mother: But that's not because you're a diabetic is it?

Simba: Yeah, but she's talking about friends.

Mother: Oh I see.

Int: Yeah, I did ask you about your friends. And you said your friends don't really care so much about if you try to explain the diabetes.

Simba: No, *three* of my friends, they let me in the queue at lunchtime because I have to [get my food quickly] and some people say, no you can't, and people like girls say, 'He has to go in the front man, he's diabetic! Are you stupid or something?'

Some children seemed defiantly positive, aiming to show the world, and other young people with diabetes, that they are able to avoid diabetes limiting their life. But the way these messages are given suggests they feel that having diabetes means they have to protect their liberties to a certain extent. They want to show people that it doesn't make them different. This was also shown when we asked children if they felt more or less the same as their friends. The overwhelming message from the children was 'Yes', and it was often said with a sense of resentment that we should ask such a question. We got the feeling from many children that they wanted to protect and promote their sameness, their normalness. The strongest presentation of this view came from John's advice to a newly diagnosed boy of about his age quoted earlier. John's words that diabetes 'is too serious and deep for me' seem to differ from others who suggest they can identify as being someone with diabetes and still be seen as normal. Like others, John is defiantly positive, but distances himself from a diabetic identity. In his statement below he acknowledges that talking with other people with diabetes is useful, but again stresses that his friendship with another boy with diabetes centres on other distinctive traits and interests the boys share than diabetes.

Int: But you happened to get on with this guy anyway, so did you discuss having diabetes with him?

John: Yeah I did, a bit. But just basically I said to him, well we just agreed that you know, we just want to be normal and we don't want to like make a big deal of it. And both of our parents are always like, 'Oh go to this meeting, there's loads of other diabetic kids,' and we both agreed, 'What's the point? you know, because we're fairly normal.'

John seems to think that being identified primarily as someone with diabetes will stop him from being seen as the 'fairly normal' person he is.

In all it seemed that these children were suggesting that it is important for them to be regarded as normal, but they feel that this may be under threat because of their diabetes.

A few boys did extra blood tests everyday but seemed to fit these quickly and efficiently into their busy lives, and to feel expert and in control. They choose to do this. The children with difficulties seemed to be the ones who 'hate doing it', resist, 'dawdle', get into trouble, and need help with finding quicker, easier, more convenient ways and devices that suit them. Several mentioned how pens are easier than syringes. A new blood tester enables people to use other parts of the body than finger tips, and younger children's views about these devices need to be researched.

6f. The need to share expertise, information and support among parents

This section reports views about depression and support groups. Depression was explicitly talked about in four of the interviews – by four adults and by only one child. This example at first seems to differ from many children's views of diabetes, that they want to position themselves as being normal, and that diabetes doesn't need to affect their lives. However, Alex may have had to face his anxieties more than others as he has needle-phobia. However, despite his vivid descriptions of depression, being 'down in the depths', Alex was still one who forcefully said that he was not different, and that he could cope and take a relaxed attitude, and (as quoted above) his friends successfully helped to 'bring him back up.'

Parents, however, were more likely to cite their own depression. The four parents who talked about this explicitly included both of those parents who stated that they tried to take a positive mental attitude towards diabetes. Perhaps their recognition of depression spurred their need to be more positive. Indeed Jessie's mother's comments about the 'very dark time' they trudged through are only voiced in relation to her explicit aim to adopt a more positive attitude now. Therefore it may be useful to families to know that they will go through periods of depression, as John father recommends:

I think I'd say for the parents as well, that you will go through a lot of emotional swings, I mean I think for about six months I was pretty depressed, I felt really miserable, I wanted to take the illness off John and have it myself really. You go through depression, guilt, you know, lots of things really.

Perhaps some literature on this would be useful for parents, warning about the depression that they are likely to go through in order to help them realise a more positive attitude later. Indeed Jake's mother cites the book that she found particularly useful, the first hand experience of a mother caring for a toddler with diabetes, as stating that depression may be common among fathers. Of the four parents who mentioned depression explicitly, two a positive attitude now, a third said she was able to recognise it because she had read about it, and a fourth was made to recognise it because of a comment from a friend. It seems that all these parents had something to trigger their recognition of their depression, whereas others may not have had such a trigger, therefore these may be questions to investigated further: How likely are parents and young children with diabetes likely to suffer from depression? What services are needed for them? Can recognition of depression have a positive impact on their subsequent outlook on living with diabetes.

Support groups

Several parents saw the value of sharing support and their hard-won personal experiences and information in groups, but families tended to be less keen on activity groups for children with diabetes. Some of the children were too young for these. The ambivalence considered earlier, between being 'a normal person' or 'a person living with diabetes', may affect children's and parents' willingness to join a group that emphasises the 'diabetes identity.' Only one child and one parent had attended a group. Others said they were not interested in joining. Yet some mothers spoke enthusiastically about rewarding contact with other mothers.

Jake's mother: I mean I've only ever talked to about two other mothers who have babies, you know other children, and they were so relieved to talk to somebody else, and I felt the same, you know to talk to somebody else. And they tell you all these little tricks of the trade, you know, and it makes your life so much easier. You know it's so nice, because sometimes you want to pull your hair out. At one of these meetings I found out something I'd never known before, that if their sugar is over 17, because if he's got high blood sugar I think, right let's take him out, but if it's over 17 then they shouldn't do sport because it can take it higher. But it's not common knowledge, because at this meeting this woman was saying, 'Oh my daughter's sugar is 20 and I don't know what to do.' And another one said 'Well take her for a run around the block.' So really it's not common knowledge.

Several parents felt that informal opportunities for information sharing were limited but very valuable, like Johnny's mother.

Int: You have a good deal of experience of caring for a child with diabetes. What advice would you give to a parent with a child who had just been diagnosed? In particular about sharing the care with their child?

Mother: Gosh, I don't know, just meeting this lady in the States, and we had so much to talk about, because I've never met anyone, and we've never been introduced to another family.

Int: So what kind of things did you chat about when you met this parent?

Mother: We looked at the pumps, and we looked at each other's charts that we keep from blood testing, how many blood tests, doing five blood tests a day, and how it's done in America is very different, and we looked at the different types of sets we use, and we talked about diet and exercise and how unpredictable it is, the days they're going to be in front of the TV.

Int: And so you found that ...

Mother: Really useful, it was fantastic.

David's and Williams' parents gave similar accounts of how chance opportunities had been very valuable to share information with the parents of their sons' friends who had diabetes. Other parents said they longed for such opportunities but had not yet found them. One parent discussed how the waiting room at the hospital did not seem to be conducive to these types of discussions, having only struck up a conversation once with another parent in six years of attending the clinic. No other parents suggested that this was an opportunity either. At both the clinics the specialist nurses and doctors had made attempts to put families in contact with each other, but no families stated that they had taken this up.

6g. Information: at the time of diagnosis and later

For parents and children, there can be few worse experiences than to learn that the child has a serious, incurable condition that will change every day of the rest of the child's life. Added to this, families are likely to feel bewildered and confused by the news and the new skills they have to learn. They may be frightened and angry if the diagnosis was delayed while the child became ill, sometimes very ill. The time of diagnosis poses hard questions for health care staff.

- * How can they give enough and not too much information in the first days?
- * How can they respond to different families' diverse needs and reactions?
- * What kinds of support do certain children find helpful or unhelpful?

People's memories of a severe shock tend to be startlingly clear, and also vividly affected by seemingly small details. For example, a doctor may give clear useful positive information, but a mother may mainly recall with distress how he glanced at his watch as if in a hurry. Some practitioners comment that the mother was really distressed by the diagnosis and transferred this to the doctor's manner, so that doctors cannot ever get it right and will always be blamed. Other practitioners say, 'We may not be able to get it right, but we can get it better by learning from these kinds of details.' So we report families' responses here in the hope that these will inform some practitioners, and confirm for others that certain people, at least, appreciate their high standards. We cannot generalise from this small sample, and again emphasise that children's and parents' views differ.

Children and parents tended to say they felt disappointed with the information that they were given at the time of diagnosis about the problems of living with diabetes, and about possible solutions.

Some children and parents could recall, when asked, certain things about the information given at the time of diagnosis. Yet in general there was no clear recollection of being formally given this information either initially or later on, although some parents said that they were informed as and when they needed to be, during the diabetes clinic visits. Some of the children were too young at the time of diagnosis to be able to recall whether they received information, and some of them, including older ones, felt that it was something that they just innately knew, such as DJ and Jessie.

Int: Who tells you things about diabetes?

DJ: Don't know.

Int: And when people have told you was it in a way that was good for you, good for kids?

DJ: Good for kids.

Int: Was that something that you read or something that people told you?

DJ: Just know myself.

Int: So how did you learn about diabetes then, because you obviously have a good knowledge now?

John: I just do know.

Like many adult interviewees, George clearly remembered the *incidents* in hospital when he was diagnosed 2 years earlier, but not the *detailed information*. Like others he also found it hard to be certain when he learnt new knowledge, as his mother had diabetes he already knew quite a lot. Families learn so much through daily experience

and trial and error that the reference at the end about 'picking up' information is highly relevant to their learning methods.

George: I had to have glucose tolerance.
Int: What's that, you'll have to explain to me.
George: It's where you have a tube put in your vein, just where your arm bends, knee, elbow. And you have to have a tube put in there and then you have blood tests every hour is it, half hour?
Mother: I think it's every hour.
George: And then in the middle you have a glass of lemonade and then half an hour after that you have your blood tested and then they find out from that really.
Mother: It tells you how quick your body gets rid of the sugar. You weren't allowed to eat, was ya, that night before, from about nine or ten o'clock the night before –
George: From eight o'clock until it had finished –
Mother: You went in hospital at eight didn't we? And we got out quite late in the afternoon.
George: In some ways it was good cos you play on games and stuff like that...But after I had it done, I felt very weak, I couldn't walk that much –
Mother: Bit ill weren't ya?
George: I looked very pale and I had to eat something.
Int: And what did people tell you about diabetes at the time, can you remember?
George: I'm trying to remember [pause] I can't remember.
Mother: Not a lot really. But we already knew didn't we...
George: I wouldn't say lots but –
Mother: You knew the basics didn't you? [because she has diabetes]
George: And some of the advanced bits.
Mother: But he's picked it up quite a lot since, inn't ya? ...
Int: I was wondering if maybe your mum did most of the explaining rather than the doctors?
George: Yeah. I would say that, cos she did explain a lot to me. Cos we used to sit down sometimes and she used to tell me about it and if she gets low blood sugar I have to do certain things [he explains] to make it go up and –

Other children could remember specific pieces of information that they were given.

David: At first I couldn't understand most of it really, all of your life you'll have to do injections and blood tests, that was all they told me at the first day.

Int: What did people tell you, then or later, about: -
William's mother: William hadn't received any further information or education really since that time of the initial education in South Africa.
Int: What diabetes is?
William: I think I learnt that more lately, I think I remember that they did sort of explain what it is.
Int: Can you remember that time William – can you remember anything of it?
William: Sort of, not very much. I just remember they like took a plate and they divided it up into different foods, they showed me a that it was a fist size of meat and then two fist sizes of pasta or rice, and then one of vegetables.

But some children felt that they were bombarded with too much information in those early stages and that, at such a distressing time, it was difficult for them to take it in.

John: Oh yeah they did but I wasn't really listening. My mother and father were listening more. It was too much to take in then.

Int: Do you think you have been told enough? Was the way it was given a good way for you/for kids?

David: I don't know, I could understand it but how you are then it's difficult to take it in.

Most parents said they felt too saturated with information at first.

Maisy's mother: But you think, OK I've got my books. I mean you could fill a suitcase with all this information, and as I say I was so tired, I felt totally swamped.

Jake's mother: Yeah what it was, all of a sudden, I think they gave us a day, and then all of a sudden we had the diabetic nurse coming in, then we had the dietician coming in, and we just thought, God you know it was bombardment, one after the other. God you know it's too much to take in. I mean I know a bit about diet, and stuff like that, it's almost common sense, it's just too much everything, you know. A certain amount of grams of carbohydrate and this and that, and it's just too much to take in, but you haven't got any choice but to take it in. We were given leaflets and things like that, but you get bombarded with leaflets. I got bombarded with leaflets, and you tend to read a few, and then I just sent for a few books off the Internet.

Furthermore, several parents stated that they had found books aimed at children, with very simple explanations of diabetes and caring for diabetes, the most helpful in the early days, as other information was too complex for them at that time when they were trying to come to terms with bad news.

Int: Can you remember when you first had diabetes, what people told you about what causes diabetes?

Mr Football: I probably wouldn't have known if anybody did tell me anything.

Mother: They did but at the time –

Mr Football: I don't remember anything –

Mother: I think you're so shocked you don't really take an awful lot in – you know now don't you?

Mr Football: Yeah I know now what like causes diabetes, but I don't remember anybody telling me anything.

Int: Do you remember people telling you stuff [to Guy Fawkes]?

Guy Fawkes: When I was [word unclear] I was almost dead.

Int: Right, so you weren't really in the mood to be –

Mr F's mother: They tell you so much information so all you can get your head round at the time is that you're [son's] got to have injections all the time.

Beyond that you don't really want to know at that stage what's caused it. You're just so shocked.

Mr Football: Wasn't they saying earlier that they don't think my pancreas is working at all?

Mother: Yeah, now.

Mr Football: My pancreas isn't working at all –
Mother: They told us at the time that his pancreas stops working and they said they'll come and – at the moment once it's newly diagnosed, it is still working a bit. But it's dying basically. And they've just told us today that his pancreas is now gone –
Mr Football: It isn't working at all –
Mother: It's beyond resurrection [laughing], slowly the information starts to sink in, but at the time you're just, your child is just lying on that bed with tubes and then you've got to inject them, and then he's got a medical condition that can't be cured, and that is all your brain will take in. As time goes on and the panic subsides a bit and you really [find] that life goes on and you deal with it, but at the beginning you don't take all that information on board.

With the gradual absorbing of information that changes daily life, it may be harder to remember exactly when each item was learned and this may be why some children reply to the question, 'What were you told when you first had diabetes?' that they sort of always knew about it.

Guy Fawkes: [pause] I knew it already!
Int: You knew it already? How did you learn it?
Guy: I thinked!
Int: What about the people here, do they tell you about it?
Guy: A little bit.
[Mr Football agreed that the nurse informed him but:]
Mr Football: Yeah. But now I sort of know what causes it and stuff like that so now I just come here for how much I've grown and stuff like that.

Mr Football's knowledge also seemed to have been 'picked up' gradually, partly by overhearing and observing.

Mr Football: It runs in our family. My mum has it, my granddad has it, lots of people in our family has it and the injections like cos your pancreas has stopped working in some, or like people that have just been diagnosed it worked a little bit, that's basically your insulin, that's your pancreas really, and people that have type 2 diabetes, their pancreas does work a bit, it will stay like that for a while but in the end they will have to have injections as well, but the tablets that they have to take just give them, just give the pancreas a boost to produce more insulin.
Mother: He takes it all in, doesn't he! [laughing].

Maria: I was born diabetes...And I was one years old, I didn't used to have it, when I was two, I never, when I was four I did, when I was five I did, when I was six I did and still I have it.
Int: Will you always have it now?
Maria: Yeah.

Maria's account is accurate in meaning that type I diabetes is inherent, although hers did not develop until she was 4. She shows that young children can understand quite complex matters, such as their life history, and therefore shows the importance of informing them at times and in terms that suit them.

From very early in life children are meaning makers. An experiment with 6 month old babies involved showing them 'effects' before showing them the 'causes'. The babies' eyes opened wider in surprise at this illogical sequence (Siegal 1991). If experiences

such as regular blood tests, injections, hospital visits and a restricted diet are not explained to children in terms of helpful treatments, they will make up their own explanations. These are likely to involve guilt and fear of punishment (Miller 1980; Melzak 1992) and will not help children to be informed and willing partners in their health care. It is therefore vital that medical and other practitioners supporting these children understand and respect the issues that are important to them, listen to them, and make sure that they are valued as partners in their care. This includes helping parents to explain as much as possible to the children, with the use of child friendly materials.

Continuing information

William's mother could compare services in South Africa, where he was diagnosed, and in England. She felt strongly that the system of family education in South Africa was far superior to the 'hit and miss drip-feeding' and leaflets provided in Britain.

William's mother: And then as I said, that morning [of the diagnosis] my doctor, my GP arranged for the, she was the paediatric specialist and she had a team set up, and they were fantastic. The education that we received there I haven't had anything like that here in the UK. I mean I went to support groups...When I've been to the support groups here, parents know nothing! Absolutely nothing! I came here and I knew about the glycaemic index, I knew how to control his diet. Parents had no idea. We spent that week with the paediatric diabetic doctors, an hour a day, just learning about why, what happens...And the next week we spent an hour a day with a dietician. Parents here aren't given enough education, and you're treated, you know, you're a non-medical person and that's it, and you're put into a box and you're not entitled to think about it, somebody will tell you what to do. Here you're prescribed your insulin dose and taught to eat to match your insulin dose, whereas I was taught to regulate the insulin and fit it around his diet.

Other parents criticised the information they received.

Int: The information they gave you what did you think of it?
DJ's mother: It was, but it's like anything, even to this day I think, unless you actually, I mean I think most of the diabetes stuff that you get, or you can get hold of, generally, doesn't just be for children, it's generally for both or just adults. It doesn't just necessarily. I mean DJ belongs to Diabetes UK...they've got a children's club... There's the magazine that I get to read, it's OK for me, it's OK, but it's generally more for adults than it is for kids. I don't think they do enough information just for kids, or that I've been able to get hold of.

Int: Do you mean information about kids for you? Or do you mean information that's for kids?

Mother: Both, both. I mean [diabetes nurse has] given us a lot of information and stuff, you know on diabetes and that, and there is some stuff that we get for children...but I don't think there is enough. I think most of the information we had just basically told us that it wouldn't affect your life...it's not sort of in your face telling you the hard graft of it basically, because it is [hard].

Int: Do you think they explained enough to you so you could explain to her that it really is worth having the injections?

Edwina's mother: Mmm, well it's just them saying her pancreas isn't producing enough insulin.

Edwina: I'm tired of hearing that. I think it's quite stupid and tiring.

The information that seemed to be most appreciated was information that was based on direct experience.

David's father: The most help I think on the whole, was a nurse who was on that weekend, who'd got a husband who was diabetic, and she basically said, 'Look I know about this because I do it at home.' That was the most helpful thing, someone who was knew about it, lived with it.

In particular, information was valued that was based on direct experience that dealt with emotional issues, as Jake's Mother mentioned earlier.

Information received at consultations was also appreciated.

Johnny's father: We were kind of drip-fed weren't we?

Mother: Yes it was appointments really, we've never been given anything to read, which has always surprised me actually now, because I didn't know about DKA (diabetic ketoacidosis) which he had. And perhaps OK, perhaps I should go out and buy books; I look up a lot of stuff on the net. So yes, as [my husband] says, drip-feeding really, just lots of appointments, and all particular to Johnny and his health care, what he is eating, how active he is, when he's inactive, changes of lifestyle, changes in the school day. But not really, 'Look out for this, or this could happen', if you see what I mean. Which I suppose is sensible, I can see why they don't say, 'Oh don't do this or this might happen, don't do this or this might happen.'

John's father: I have kind of regular chats, I mean I come along with John to the surgeries and the discussions there with the various kind of clinicians, and I'm always kind of aware that [diabetes nurse] is on the end of the telephone if we have concerns, and usually I kind of ring her when we're going away just to kind of tell her what's happening, where we're going, what we're doing. So she knows about that. So to be perfectly frank there's nothing I particularly feel, there might be big gaps in my knowledge, I don't know, but there's nothing I feel I particularly need to know.

It would seem that parents tend to be more satisfied with receiving the wisdom and experience of specialist practitioners as they develop their own knowledge over the years. Yet the anxious and critical initial period around diagnosis is a problem. As parents' and children's accounts attest, experience is the critical factor in gaining knowledge. Therefore, providing the right kind and amount of information before they have gained much experience is likely to be difficult. However several parents clearly indicate that the current information giving system at the time of diagnosis is deficient. Children and parents tended to feel swamped with too-much complex information, and would have preferred simpler and experience based information.

Edwina expressed some of the ambiguity in the children's feelings about diabetes.

8. Conclusions and recommendations

The concluding section summarises the main findings of the study on children as partners in their diabetes care, then reviews some of the limitations of this research, and replies to questions raised in the introduction. We list areas for further research, and close with some practical recommendations.

Children as partners in their diabetes care: what is partnership?

The children's and parents' accounts of living with diabetes illustrate clearly the importance of recognising that young children strongly influence their daily care. Even children aged 1 to 2 years have final control over deciding, for example, whether, what and when they will eat. They may be able to eat only so slowly that it is hard to divide the day, as advised, into spaces between snacks and meals.

Parents cannot watch children all the time, and so they have to be able to trust children to care for themselves, such as saying 'no' if a friend wants them to share a box of chocolates and there are no adults nearby. Some of the children were able to do this by 4 years, when a few also did their own blood tests and injections.

We do not give these examples to say that all 4 year old children can, or should, or would want to be so responsible. However, the interview accounts showed how informed and capable even young children can be, as well as the importance of learning from children and working with them from the start as much as possible to plan and provide their care.

The 'championing' of children's rights' (RCPCH 2004) is now advocated in health care policies, and these rights, enshrined in the UN Convention on the Rights of the Child (UN 1989), are often analysed into three groups:

- provision rights (such as to health care, education, an adequate standard of living);
- protection rights (such as from abuse, neglect, discrimination and risks);
- and participation rights (to form and express views, to take as full a part as possible in family and community life - disabled children's rights are especially noted – with the rights of all children to respect for their 'worth and dignity').

The children emphasised their participation rights in terms of 'being normal' and 'just getting on with my life'; they showed how they participated in managing their health care. Yet almost all the twentieth century literature and research on children has concentrated on protecting and providing for children, regarding them as developing and not yet full persons or participators-partners (James and Prout 1997; Alderson 2000; Mayall 2002). However:

There is increasing belief that self-management is central to effective care of chronic disease. This requires a shift in the balance of the partnership between health care professionals and patients towards greater patient autonomy and self-sufficiency (DH/MRC 2002:8).

Such policies to 'empower' patients may refer to adults, but do not specifically exclude children, and certain guidance mentions children, for example: Partnerships between children and adults, with children 'at the heart of' policy deliberations are advocated (NSF 2004). Partnerships can, however, be very unbalanced, with one person having far greater control than the other. In such cases, 'partnership' is simply be a new word for traditional unequal relationships. Real partnerships involve some equality and

mutual trust and respect, which involve three fairly new ways of thinking about children:

- seeing that young children are people too, not simply human-becomings who will one day develop into full human beings;
- checking when adult-child relationships are inevitably unequal (for example, economically and politically) and when relationships are avoidably and even unhelpfully unequal (such as if adults insist on keeping control, mistrust children, and try to force compliance when children are ready to be responsible);
- promoting and respecting children's and adults' informed and willing cooperation, when they listen to one another, sort out misunderstandings, and negotiate new ways forward on terms they can both accept.

Research reports about adolescents with diabetes who skip doing their injections or have an unhealthy diet and risky life style would seem to undermine the previous points, and evoke the response, 'Maybe a few exceptional young children understand and can be trusted, but most cannot do this and it would worry them too much and put their health and life at risk to try to trust them.'

We suggest that 'ordinary' young children can be competent when they are treated and helped as if they are competent. Whereas children of all ages who are treated as if they are incompetent are in a double bind: either they accept the label and carry on being incompetent, or they resist the label but are then seen as rebellious and therefore incompetent. More equal partnerships between children and adults cannot widely occur until there are great changes in underlying beliefs about incompetent children who must necessarily be controlled by adults. These beliefs dominate public opinion, the mass media, and many services and policies for children.

Health promotion, such as helping families to improve their diabetes care, is often discussed in terms of changing people's knowledge, attitudes and behaviours. If children are to be respected more equally, children and adults often have to change their knowledge and attitudes that children are inevitably ignorant, inexperienced and dependent, before their everyday behaviours and relationships can change.

Partnership and research with children

Many obstacles to forging partnerships with children could be overcome with better evidence from research. Parents, health professionals, and others need good quality evidence to reassure them that partnership with children will not produce adverse effects in the long term, and to guide them about how to manage partnership (Povey and Hallas 2003; see also Dixon Woods *et al.* 1999).

The competence of even young children to make judgements about their conditions and assume responsibility for self-management may have been under-estimated by health care professionals and is an area for research (DH/MRC 2002).

In section 5.1 we reviewed theories and methods in traditional research that have tended to exclude and underestimate children. Besides more research with younger children, further research that uses respectful and inclusive theories and methods is needed (O'Kane 2000; Alderson and Morrow 2004), as we have aimed to do in this

study. Toys, pictures and games encourage some children to talk (Clark 2003; O’Kane 2000), as Jessie showed earlier. Several children chose to do drawings. Narrative methods can not only obtain richer accounts from children and more realistic reports of their lives and abilities, but these participative methods also complement and expand the findings about children’s competence, and demonstrate useful methods to use in working and caring partnerships with children who have diabetes.

We noted how children tend to show more knowledge in their narratives than in answer to direct questions. This suggests that direct questioning by practitioners in the clinics (unless the children know them well and feel relaxed and used to this format), besides research questionnaires, are likely to produce limited insight into children’s understanding. As mentioned earlier, Moogum, for example, fully answered questions, such as about her friends by listing lots of names, but said she ‘did not know’ in answer to direct questions about her diabetes. Later, her conversation about her everyday life and routines revealed that she did understand reasons for the routines. This has been found in other interviews with children (Alderson 1993; Alderson and Goodey 1998) where in longer narratives children gave vivid, detailed accounts in response to general open questions.

Main findings of the study

These are some of the main points drawn from the interviews:

- parents and children learn most about diabetes through personal experience, including children’s own bodily sensations;
- young children can understand a great deal about daily diabetes care;
- children have their own preferences and goals, such as wanting to ‘get on with their lives’ and to have fun with their friends;
- from the start, they need clear positive explanations about the daily routines, and why these are helpful, because otherwise the diabetes care can seem cruel and pointless to children;
- it is important that the routines fit as smoothly as possible into the child’s everyday life and goals;
- some children become adept at sharing in managing their care, whereas others find this hard, and may resist and have to be forced to comply;
- children and adults can then get into virtuous cycles of growing trust and confidence, or vicious cycles of growing resistance and frustration;
- far more needs to be known about how these patterns begin in early and mid childhood;
- it seems to be important to involve children as much as they are willing and able, without treating them as more or as less responsible than they can and want to be, though we cannot be certain about this until more research is done about partnerships with young children;
- traditional age-stage theories of child development are not helpful when they underestimate and mistrust young children’s competencies;
- policies about involving young children need to be based on up to date research with young children and parents.

Limitations of this study

This exploratory research is one of very few studies about children’s and parents’ views on being partners in managing diabetes care, and about the views of younger children who have diabetes. Initially, we have involved only a small sample. Therefore, we cannot say how widely agreed these families’ varying responses might be among children with diabetes and their parents generally, despite the strongly expressed

views on certain themes, certain similarities between their experiences, values and questions, and confirmation from some referenced larger studies.

Our policy with two of the three groups, to adopt an opt-in approach for ethical reasons, further reduces the generalisability of the findings. We invited families from a range of ethnic and socio-economic backgrounds to take part in the research, but the opt-in replies were mainly from white middle-class families. They may be in a privileged position and able to cope more confidently with managing diabetes. They may also have fewer additional difficulties, and for these reasons be more willing to talk to researchers. The study in the clinic at Newham involved a far more ethnically varied and possibly representative group, but less time for interviews. Future research could combine initial contact in the clinics followed, with consent, by home visits. It is encouraging that three children and two parents refused invitations in the clinic to join the project, suggesting that families did not feel under pressure to agree, although the atmosphere and routines in the clinics may possibly put children and parents rather on guard, and they may find it easier to relax and talk freely at home.

Replies to the research questions raised in the introduction

We have partly answered the research questions, from section 2, throughout the report, and in the summary of main findings above. Here, we give summaries and additional replies.

*At what age can young children begin to take an informed share in managing their diabetes, and perhaps start to form life-long healthy habits?
Is it worth informing them, and encouraging them to be active partners in their care?
Or is it unwise and unkind to expect this of children aged from 3 or 4 years?*

Research findings show that experience rather than age appears to influence children's understanding and their share in their daily care to a great extent, and that they benefit when they are informed, and encouraged to be involved as soon as they are able. This involves recognising their growing knowledge. A 3 year old who has diabetes may know far more than a 53 year old who has not. Young children learn the meaning of hypers and hypos, and the effects of types of food, through their bodily experiences as, for example, Holly's mother described. Medical information about the causes and processes of diabetes can help, but it is different from practical knowledge about personal daily care. A few of the children seemed to be exceptionally highly informed, although even very well informed parents can have difficulty in trying to control their child's glycaemia. Earlier research has reported that although this is 'impossible with children', they are mainly all told to do it and feel bad about failing (Eiser 1990), so that it is important not to blame children.

Many people find that they go on learning by trial and error. John realistically said that instead of explaining to a boy his age, he would say, 'I don't know, I'd say go and ask someone else.' Because also I, it's too serious and deep for me and I'm just having fun, not like saying 'Oh diabetes ...'

Psychologists propose a developmental view of chronic illness, such as seeing adolescents who are upset, as being upset because they are adolescents not necessarily because they have the illness (Eiser 1990). And yet this transfers blame from the person's disease to their age and still sites the problem within the person, in a medical model. Instead, the social model also looks at the context and surrounding social difficulties. So again, linking age to levels of understanding is not necessarily realistic or helpful. Children may misunderstand, for example, because matters have not been explained clearly, rather than because they are too young.

*When can children begin to accept and cooperate with their treatment?
When can they understand about insulin injections, diets, and sugar levels?
How do they manage to live the complicated double life of being a child with diabetes
and also a 'normal' child like their friends and peers?*

Similar replies also apply to these as to the previous questions. We do not yet know enough about the earliest ages when children begin to understand and cooperate with their care, and to find neat ways to live the 'double life' of having diabetes and being 'normal'. This is partly because too few young children and their parents have been asked. Sensitive imaginative research methods are needed. For example, parents and children may initially say '7 or 8 years' when certain competence developed, but then during discussion start to remember earlier examples. Also, because adults often do not expect younger children to be competent, they may not notice the competence, or they may discourage it, for fear that it is unfair to expect children to become responsible too soon. So complicated narratives, beliefs and values have to be unravelled when starting to find answers to these questions.

*When do children begin to have personal goals?
When do adults begin to need to take account of children's goals, if the diabetes care
is to work well?*

Babies express strong preferences that can seem trivial but are also vitally important to their health and welfare, such as their views about food, or about their mother leaving them. They also have lifelong strong desires to relate and interact with people, to enjoy, to learn and explore. So perhaps personal goals continue from the first weeks and months, rather than appearing some years later. The older children's goals – to sustain friendships, have fun, not be interrupted when they were absorbed in interesting activities, and to avoid pain if possible – are firmly held by very young children too.

Links between having diabetes, a sense of personal identity, making moral choices and having personal goals are shown in the following review of two kinds of medical ethics.

* Medico-legal consumer ethics concentrates on explaining clinical procedures, and the risks, costs and hoped-for benefits to people, so that they can make informed choices and adhere to medical instructions.

* Alternatively, Socratic ethics asks: 'What is the good life? How can I attain it? What kind of person do I want to be? And what kind of community do I want to be a member of?' (Frank 2004).

Some children in this study showed that they are thinking about these Socratic questions from an early age. Am I the same as my friends, or am I different if I cannot share sweets with them? How am I different? Does it matter? Will they still accept and include me as someone who is 'normal' like them? The answers that children find to these moral questions are likely to influence how they manage their diabetes. This study has only begun to explore younger children's sense of how diabetes affects their moral identity, who they are, who they want to be, and what having diabetes means to them.

A second way in which children thought about personal goals is shown by the social or the medical models of diabetes. The consumer ethics just mentioned tends to fit the medical model of disability, by concentrating on medical problems and solutions, and by treating people as fairly passive, needy health service users. In contrast, Socratic

ethics more nearly fits the social model of disability, when the disabled person is an active citizen who engages in three challenging activities that:

- 1) Identify the problems of disability with disabling social structures and routines, instead of within the impaired person;
- 2) Move beyond medical solutions to include personal and social solutions too, in order to be able to live the 'good life';
- 3) Work to change disabling social structures in order to be able to live in 'good communities'.

Children such as Edwina and David who had serious problems at school learned how other people, who saw diabetes in the medical model, could disable and trap them in ways explained by the social model. John, Johnny, Jimbo and others, who rejected the medical model and asserted their 'normality', seemed almost to gain confidence and abilities through coping so well with their diabetes as part of their fulfilling lives in positive communities.

Young children can share in taking these three steps. For example, Emma was described earlier as missing out on treats at birthday parties when the nursery staff forgot that she was allowed them, until she arranged with her mother that she herself could choose what to eat.

- 1) Emma and her mother identified the social problem of very high sugar diets especially at celebrations, and the staff being forgetful.
- 2a) They transferred choice, control and responsibility from the staff to Emma, thus moving beyond the medical model of risk and strict compliance, towards flexible choices that take account of Emma's social life and values too, her views of the 'good life' as a 5 year old with her friends.
- 2b) Emma was a main agent in this move and her parents negotiated with her, learning from her as a trustworthy competent person about how much control she was able and willing to have over her life with diabetes.
- 3a) This involves changing social structures and assumptions, such as when the staff accept that Emma can be responsible, or when Nicola's young friends explained to their mothers what food to provide when she visited them. In this newer pattern, adults learn from young children, and 'able' people learn from 'disabled' people who have the greater knowledge.
- 3b) Another example is when Johnny's small school altered the arrangements for snacks so that everyone could be treated in the same way with him.
- 3c) Mr Football and his mother took these steps when they gave back the 'goody bag' prize and said that he should have an appropriate prize, identifying the problem with the teachers' lack of thought, and working to change their disabling assumptions.

The medical model tends to see people with diabetes as inevitably disabled, deficient, and marked out as different. The social model enables them to be more like their peers, more included, and respected.

Is it dangerous to listen to young children and negotiate with them, and better to control them firmly?

This question refers to types of parenting and partnerships. Our small sample suggests that children are more likely to want to cooperate when adults show respect and interest in even the youngest children's time and values and their 'goals', such as 'just getting on with their lives'. Together, children and adults are then better able to negotiate ways to combine physical, social and emotional health and welfare. The

children and parents indicated that adults encourage children's trust and cooperation when they show that they are trying to fit the diabetes routines into the children's lives, even with very young children, such as negotiating with them what treats they can have.

This report emphasises young children's competence. We do not want to imply that because children are able to do injections they are also willing to do them. Some younger and older children wanted their mothers to do them partly or wholly. Some who had become independent wanted time off, such as if they were doing tests at school or for other reasons they might not want to explain (Williams 2002). We would like to emphasise that young children's competence can be understood as a reason to trust and respect them and to share decision making with them, including decisions about how much they share responsibility for their daily care.

Parenting has traditionally been classified into three models: authoritarian, permissive and, the recommended model, authoritative (Baumrind 1978). When the models were proposed in the 1960s, they would have also been widely supported as appropriate husband-wife models. However, all these unequal 40 year old models do not fit satisfactory adult friendships or partnerships today. And are parent-child relations so very different? Do they have to be so much less equal than adult-adult relations?

Parents are advised to 'set boundaries'. It is however less often said, firstly that all human relationships involve setting boundaries between what is valued or tolerated between two people of any age, and what is not. And secondly, there are problems when parents set arbitrary sometimes selfish and even cruel boundaries, but justify this as their right or their duty. Parents do and should hold most of the power and responsibility. Yet a fourth model of 'the negotiating parent' may be more rewarding. It may also more accurately describe many parent-child relationships today. Health practitioners who aim to work as respectful partners with children (NSF 2004) face problems if parents want to be authoritarian or even too authoritative, when children with diabetes are also authorities on this subject and have unique and essential knowledge that adults have to listen to and learn from if they can give adequate care.

So the new moves in paediatrics depend on acknowledging and working with new moves in modern parenting, that update older psychological models. There are growing tensions between relaxed permissive parenting, versus powerful and almost paranoid pressures on parents and carers, such as from the tabloid press, to avoid all risks to children. These tensions stretch the gaps between emotional and practical parenting, between freedoms and choices for children (such as with pocket money, fashion, food, television, computers) and tight restrictions (on their own time or space or freedom to roam). The extra challenges raised for families by childhood diabetes offer valuable ways to explore, in future research, contemporary types of parenting that respect children's rights (Lansdown 1995a, 1995b) and the effectiveness of these types in encouraging children's informed diabetes self-care.

Can younger children understand not only how to manage their diabetes, but also how this can positively help them in the short and long term?

Can they understand about health care goals and values as well as routines?

And if they can understand, does this help to reduce conflicts about their care?

Again, our study provides further questions rather than firm answers. Only a very few examples of competent young children are needed to demonstrate that at least some 3 or 4 year olds can have quite a mature understanding and sense of responsibility.

We do not know how exceptional they are, or whether many or most children would be as mature if they were treated as mature people.

Children are unlikely to understand long term goals fully, such as to reduce their morbidity and mortality risks in adult life, because adults are loathe to explain these frightening risks to them. It can therefore be hard for children to understand the need to keep down their sugar intake, if this does not seem to them to have present ill effects. It seems that adults tend to rely on vague warnings and children's trust and goodwill, although several children spoke of 'death' and they may know more about the risks than the adults realise, as other research has found (Bluebond-Langner 1978; Lansdown 1987; Judd 1989). Edwina's mother warned her about future problems but Edwina said that she found the threats unhelpful and boring. Research about smoking and AIDS demonstrates that threats have little effect on helping people to live more healthy lives. So maybe confidence and satisfaction about living a healthy life now and for the future is incentive enough for many children. We cannot be certain.

The question about whether young children who have greater understanding about diabetes have less conflict with their parents also needs further research. It may be that those who understand more have parents who prefer explanation and reasoned discussion to conflict, and this need unravelling. There are also questions about how far models that work well with some families will work for others, how to take account of cultural and socio-economic differences for example, and how far it is reasonable to expect families to change major aspects of their lifestyle in order to try to adopt more positive ways to cope with the diabetes.

Can children understand and share in using fairly complicated methods of controlling their diabetes?

Would these methods be associated with better diabetes management and quality of life?

These questions refer to programmes such as DAFNE (2004). Some of the children and parents in this study use aspects of the DAFNE programme and seem likely to be interested in learning more about it. Perhaps many or most of them would choose to do so, if it was offered to them routinely. Again this is a question for research.

Why have there been so few reports from research and practice about successful and more equal partnerships between practitioners and people with diabetes, and about what works well?

Why has there been so little research about young children's views and experiences?

Which kinds of research methods are most effective in encouraging them to give detailed accurate views?

In section 5.1, we contrasted traditional and more recent research methods. Traditional methods have tended to assume that patients' knowledge and skill are inferior to those of practitioners, rather than different but complementary. Psychological research, in the medical model of searching for problems, needs and deficits in order to provide help for them, has also tended to report negative views of patients' abilities. Until recently, social science research too has tended to see patients as users of services rather than partners in their care. Stacey (1988) gave one of the first accounts of how women are the primary health carers at home. Mayall (1994b, 1996) showed how children care for their own health, and Alderson (1990, 1993) reported parents' and children's rather unequal negotiations with doctors. The rise of self-help patient organisations, firm consumer voices, and political concerns to involve patients as partners in order to cut costs and improve standards of care are all helping

to promote greater equality between practitioners and patients. Yet it will take time for the more equal approaches that are beginning to influence research theories and methods to be widely used and respected, and published in the journals.

Psychologists have researched children for over a century, but far more recently have begun to explore children's own perspectives. Sociologists still frequently ignore children as if they are natural pre-social beings and as if only adults count. A great deal of work needs to be done to develop effective research methods, and an accepted body of research evidence, on young children's views and abilities, to counteract the currently still dominant methods and assumptions that underestimate young children – as well as some patient groups.

How can research learn from children's and parents' views about how to help them to adapt to the diagnosis, and to set up and sustain positive patterns of daily care at home?

Replies given to the previous set of questions apply to this question too. The research methods will need to be participative, involving parents and children as far as possible as equal partners.

What are the serious problems that deter doctors and nurses from offering people more choice and control over managing their diabetes?

How can negative attitudes and routines particularly restrict children's involvement in their care?

There will have to be many accompanying political-structural changes if NHS staff are to adopt new knowledge, attitudes and behaviours and to hand more control and choice over to families. For example, as mentioned earlier, growing anxiety about managing risk and preventing litigation could deter many staff from wanting to encourage parents and children to set their own insulin doses, unless they have very clear protocols and medico-legal protections. Given the greater worry in the mass media and public opinion about risks to children, there are more barriers that prevent the involvement of child patients. When new programmes of care are introduced, it would be helpful to include research with practitioners, parents and children on the barriers, facilitators and problem-solving methods that they meet with through the process of making changes.

How can research about childhood poverty and 'social exclusion' inform ways of understanding and managing diabetes?

The social context for each family is vitally important and we would like to have reported more about this. For some children, there was a striking association between good glycaemic control and reports of being generally happy and successful in their school, friendships and hobbies. In contrast, one child with poor glycaemic control described feeling bored, sad, excluded and 'picked on' at school. Quality of life assessors avoid confusing causal factors with consequences or effects (Eiser and Morse 2000). It may be impossible to identify whether feeling unhealthy because of poor control leads on to psychological, social and educational problems. Whether diabetes control mainly affects or is affected by other key aspects of a child's daily life might not be the relevant question. Matters may only improve, and problems be addressed adequately, when several integrated issues are tackled together, personal, medical, social and educational (Hood 2002). Again, this is an area for further research.

What political dimensions does the RCPCH mission statement bring to paediatric care?

How could this specifically benefit children with diabetes?

Although the paediatricians' remit is limited - they cannot reform schools very easily - their Mission Statement (RCPCH 2004) claims that they act as children's advocates and promote their rights. The paediatrician who described how, when children will not do their injections for themselves but are also frustrated that they cannot go to stay with friends, he uses this opportunity to help them to learn to be more independent and to enjoy more freedoms, thereby promotes their participation rights. We plan to write a report about this project illustrating how promoting their rights can benefit children with diabetes.

Further research

The responses from our small sample attest to the need for more research with young children, to add to the extensive literature on adolescents with diabetes. Further research is needed:

- To discover more about young children's views, experiences, values and goals;
- To have time to examine in greater detail how the youngest children become informed and involved in their care or become resistant;
- To find ways to help to improve their care from the start;
- To uncover the roots of some of the critical issues for people with diabetes, as they grow older;
- To examine which approaches work well or not;
- To involve children and parents in devising and testing materials, methods and policies for informing and involving families and promoting partnerships between children and adults;
- To see diabetes care in its social contexts;
- To conduct larger studies that more closely combine the different methods used in this study on access, interview settings and timings.
- To involve families from a wider range of backgrounds;
- To see whether the responses from these interviewees are more widely shared.

Recommendations

Although our small study in three hospitals cannot present a general view of current care, we note that our findings tend to be confirmed by much larger studies and overviews involving older people with diabetes, such as their poor in-patient care (DH/MRC 2002: 40, 172), and fear of hypos (DH/MRC 2002: 31, 131).

Making the diagnosis

Primary health care staff need more information about how diabetes can affect very young children, how to be alert to the symptoms, and to diagnose and refer children with diabetes rapidly.

Listening

It is still necessary to remind some health care staff of the decades-old message (MacCarthy and Mac Keith 1965; Burton 1975; Madge and Fassam 1982; Robertson and Robertson 1989) to listen carefully to parents and children, especially when they have the experience of living with a long term condition. Laennec, who invented the stethoscope in 1781, said, 'Listen to the mother and you will hear the diagnosis.'

Funding for children's diabetes services

Government policies to cut waiting lists have drawn funding away from emergency and chronic care such as diabetes services. This is a false economy when sub-standard care can hugely increase future costs. Diabetes care costs 5% of the NHS budget, and 10 % of hospital inpatient resources, largely to treat complications. The costs are projected to increase rapidly (DH/MRC 2002).

Place of early care after diagnosis and specialist staff

An urgent survey is needed of the views of families on the pros and cons of staying in children's wards for some days after diagnosis, if the child is well enough to be at home. Policy makers, managers, and in-service training for paediatric staff, should take note of the resulting practical reports and act on them. In one hospital, the routine was not to admit all children when they were diagnosed, in another, children are admitted because of the lack of specialist diabetes practitioners to provide support in the community. The consultant and nurse were partly funded by adult diabetes services, and the consultant partly by a pharmaceutical company. The costs of inpatient care could be transferred to fund more specialist diabetes nurses, although these funds are likely to come from different budgets. The future Children's Trusts may be able to arrange more consistently planned comprehensive cover.

Non-diabetes-specialist staff in A&E and children's wards

There is an urgent need to collect the views of younger children with diabetes and their parents when they have to return to hospital to use these services, through a survey about good aspects of the care from non-specialist staff, problems, and possible improvements. Too often, experienced expert families are treated as if they are helpless and ignorant by staff who know little about diabetes. The survey findings could be used for staff training and practical handbooks written with the help of parents and children, to enable non-specialist staff to work as partners with experienced families in mutual respect, as specialist diabetes staff tend to do.

Information about managing diabetes

Some families felt 'bombarded with leaflets' at first. Many had difficulty in remembering what they were told at diagnosis and later on. There are reasons for this: stress and anxiety at first; the importance of learning gradually through personal experience; the difficulty many people have in remembering when basic knowledge was first acquired, and when and how it has changed over the years as advice on diabetes management, the child's changing needs, and the families' growing knowledge and flexible adaptations all change. Adults may forget to re-explain to children aged 10 or 12 years, who were mainly informed when they were diagnosed aged 2, 4 or 8 years.

Cautiously inferring from our small sample, and with reference to other research and policy reports, we suggest that attention is paid to designing information that:

- involves parents and children in the design, writing, presentation, production and evaluation;
- forms a coherent series of leaflets/booklets/videos/CDs/DVDs/website programmes, from diagnosis onwards;
- is primarily practical – how to apply the knowledge, how to prevent or solve common problems – such as how to get teachers to accept a child on to the school journey list;
- presents complicated medical knowledge very simply, in leaflet drawings or computer graphics - all tested with children – that bypass literacy and language barriers as far as possible;
- is woven into children's and parents' daily experiences.

Support and information groups

The children and parents tended to hold views on support groups that are shared by people with other kinds of medical conditions, thinking that the groups can be useful but stigmatising. Only a minority ever joins these groups. People tend to anticipate that groups could open up their social opportunities, but maybe to people they would rather not know, or feel identified or 'lumbered' with.

Groups tend to be led by practitioners, or by 'lay' people who identify themselves strongly with the medical condition, as patients, survivors or carers. Yet most people with a medical condition do not identify themselves primarily with their condition, as the children showed when they spoke about being a 'normal' person and getting on with life apart from diabetes. Many people would rather join a drama club or a football team than a 'diabetic group'.

Groups are limited when they emphasise support, implying that members need emotional help, but do little about education and promoting informed independence. An example of how very helpful formal information sessions can be was the South African programme described by William's mother. She thought the uninformative English support group was a poor contrast. Her view is supported by evaluations of the carefully planned DAFNE programme where the group sessions are much appreciated and help to transform people's lives for the better (DAFNE 2004). An experienced mother who read the long DAFNE handbook expressed surprise, great interest in the underlying principles of managing diabetes, and regret that there was never enough time to talk to the diabetes staff about this broad and basic understanding. The key to the success of the South African sessions and of DAFNE appears to be that people learn a great deal, as they listen, talk and apply knowledge together experientially in groups. This helps them to connect information firmly to experience. Knowledge takes on new deeper meanings; it is memorable, shared, practised, valued and so longer lasting.

People may be happier to join information sessions routinely provided for every new family as part of the treatment, rather than 'support' groups for a minority. New forms of self-help groups might be tried – telephone, email, chat rooms, when children and adults can belong and yet not belong, find contacts but remain partly free, share knowledge without having to commit themselves to others in the 'group' until they wish to. We do not write these points as results from our research but as areas for future research with younger children.

Schools, nurseries and other child care centres

Some education and care staff and whole schools practise high standards of care and of including children with diabetes, and show that this can be done. Others choose, or feel forced by unhelpful routines, to make life hard and sad for children with diabetes. Teaching of school staff by diabetes nurses about individual children's needs is valuable but insufficient, since it is unlikely to change systems in schools or offer continuing support. We have stressed knowledge that is gained, adapted and applied through personal experience throughout this report. School staff are better able to carry on learning and improving their support when they relate to the children with diabetes and their parents, as well as to the nurses, as experts who can help and advise the school staff. However, current school policies such as league tables and funding for success deter staff from spending time and resources on children they perceive as carrying extra costs. Fear about litigation leads many teachers to be unhelpful if children need injections, or when they wish to join school trips. The government's new policies to combine health and education services *Every child*

matters 2003 might offer opportunities to improve the care of children with invisible disabilities, such as diabetes and asthma, in schools.

In conclusion:

- Despite the small sample size, the findings suggest that there is a wealth of experience and expertise amongst young children with diabetes and their parents.
- Practitioners and others could learn a great deal from them about their needs and optimal ways to meet these.
- Some participants identified simple and non-costly ways in which services could be improved.
- Children's and parents' expertise could also be used to assist families with newly diagnosed children to learn about the condition, and to reassure them that it is possible to adapt and to live rewarding lives.
- Practical leaflets written with parents and children, telephone help-lines run by them, offers such as to go shopping with the family shortly after diagnosis, could all be valuable activities.

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Appendix 1 Information leaflet for children

Printed as a coloured folded A5 leaflet with small drawings

Living with diabetes

A research project
August - December 2003

This leaflet is for children aged 3-12 years
and their parents

Please will you help us with our research?

This leaflet gives some details about the project.
We have set out the questions you might want to ask, with
our answers, so you can talk about them together before you
decide if you would like to take part.

Please contact us, Katy or Priscilla, if you want more details
and/or if you would like to join the project.

Katy Sutcliffe 0207 612 6644 k.sutcliffe@ioe.ac.uk
Professor Priscilla Alderson 0207 612 6396 p.alderson@ioe.ac.uk
SSRU, Institute of Education,
18 Woburn Square, London, WC1H 0NR

Why is the research being done?

As you know, the way you care for yourself is vital to help you to keep healthy. But, so far, researchers have not asked children much about how they share in their own diabetes care.

We plan to listen to boys and girls, parents/carers, and health staff, and write reports about their views.

The aim is to help families and health care staff know more about the kinds of daily diabetes care that children and parents find work well.

What questions will the project ask?

- * How do girls and boys with diabetes share in their daily health care, such as deciding what to eat and when.
- * When are they old enough to do blood tests?
- * Do you have any problems with diabetes? And, if so, how do you and your parents try to solve these?
- * Do you remember when you first knew you had diabetes? Have there been any changes in your care since then? Would you like to make other changes (if your doctor agreed)?
- * What do you find works well?
- * How would you advise someone who has diabetes?

Who will be in the project?

Ten boys and girls at King's College Hospital and ten boys and girls at Frimley Park Hospital, and their parents. The age groups are 3-6 and 10-12 years. Dr Buchanan has chosen the King's children to be asked to take part. He has not told us your names.

Do I have to take part?

You decide if you want to take part or not.

Even if you say `yes', you can drop out at any time.

And you can tell us if you want to stop, or have a break.

If you don't want to answer some questions, just say `pass'.

You do not have to tell us anything unless you want to. And

you don't have to give us a reason if you say `no' or `stop'.

Whether you help us or not, you will still go on having just the same care at your hospital.

What will happen to me if I take part?

If you agree, one of us will meet you at your home, or at the clinic, to talk to you, and your mother or father. We would

like to tape-record you. You might play some games and talk

with us for between 15 to 60 minutes. We will not look for

right or wrong answers, it is your own views that matter.

Later, we'll ask you to test a question booklet we will be

writing for other children.

Could there be any problems for me if I take part?

We hope you will enjoy talking to us. A few people get upset when talking about their lives, and if they want to stop,

we stop. We can put them in touch with someone to help

them, if they wish. If you have any complaints about the

project, please tell us, or Dr Buchanan.

Will doing the research help me?

We hope you will like helping us. But our main

aim is to write reports that will help very many families in

the future. Maybe you too will find the reports useful.

**Who will know if I am in the research,
or what I have talked about?**

Dr Buchanan will know if you are in the project, but we will not tell him or anyone else what you tell us.

The only time we might have to break this promise is if we think you or someone else might be at risk of being hurt. If so, we will talk to you first about the best thing to do.

We will keep our tapes and notes about you in a safe lockable place, and delete named details about you after the project.

When we write reports about your views, we will change your name, so no one will know you said that.

Will I know about the research results?

We will send you a short report in Spring 2004, and longer reports too, if you want to see them.

The project is funded by a Social Science Research Unit grant.

It was approved by King's Healthcare Research Ethics Committee, project no. - and by Dr Buchanan.

The researchers, Priscilla and Katy, do research and write reports and books about children's and parents' views on health care and education.

If you take part, please keep this leaflet with the copy of your consent form. September 2003, leaflet version 2.

Thank you for reading this leaflet.

Appendix 2 Interview schedule 1.
Children as partners in their diabetes health care
Summary sheet for children’s and parents’ interviews

Actions before interview

- Complete consent form and give participants a copy.
- Request permission to tape the interview.
- Explain confidentiality - no one else will know your name; we will not use your name in any report.
- Explain that they can choose what to say and what not to say – that they can stop the interview at any time if they wish.
- Remind them that there are no right or wrong answers – no one is judging – it’s important to find out what people really feel and how they really deal with things.
- Thanks for taking part.
- Have you any questions about the research?

Mainly after interview

- Fill in section 1
- In sections 2 and 3 tick issues covered and mark ones to be followed up later in more detail and to note changing views and experiences.

Interview method

Concentrate on listening. Use broad open questions to encourage children and parents to use their own style of narrative. Fill in any gaps with prompts – at the time, or towards the end of the interview, or during later contact – for people who may not wish to cover everything in one session. The questions are suggestions only. Children and parents may give long, detailed, mainly spontaneous accounts and only need occasional prompts to guide them gently towards our key topics. Pick up cues from what they say, follow their lead and order of topics.

Records

Interview number _____
 Name of child _____
 Child’s gender _____
 Parent(s)/carer(s) name _____
 Interview name of child _____
 parent(s)/carer(s) Interview name _____
 Child’s DOB _____
 Siblings (b/g - DOB) _____
 Date when diabetes suspected/diagnosed _____
 Contact tel no _____
 Contact address _____
 Date of interview _____
 Length of interview _____
 Where it took place _____
 Parent(s) occupation _____
 Ethnicity/nationality _____
 Any other relatives with diabetes – specify type I or II _____

1 Everyday

[Comment: they may expect us to dive into diabetes so we could say something like, It would be very helpful to me to know a bit about you and you life, and things you like doing, to start with, if that is ok?]

- What did you do today? This week?
- What kind of things did you do in the summer holidays?
- What was your best day of the holidays?
- What would be your perfect holiday day?
- Are you pleased to be back at school/nursery? – or maybe you’d rather have stayed on holiday? [to give a let out]
- Do you like school/nursery?
- What are the best things about school/nursery? And the worst things?

2 Relationships and Social life [*Thank you, and next could I ask you a bit more about things you do with your friends and family?*]

- What do you like doing with your friends?
- Do you feel more or less the same as your friends? [prompt: fit in with them? Like doing the same things?]
- Everyone is partly different, are there any ways that you feel different?
- Do you ever stay for tea/the night at friend's/cousins/grandparents houses? [also allow for parents living apart] What happens then?
- Do you like parties and birthdays? What do you do about deciding what to eat there?
- What do you do when you are with friends or others having sweets/ice creams?
- Do other people, such as friends, or your grandparents or your teachers understand about diabetes? [Make the question broad but short, respond to areas – adding assistants at school when they start talking re school, or friends' parents...]
- Do you ever have to explain things to other adults? If so, what sort of things do you say?
- Do you feel your parents care for you in the same way as for your brothers or sisters? Any differences?

3. Diagnoses and first experiences of diabetes

[The next part is about when you first knew you had diabetes]

- Do you remember when you first knew you had diabetes? [If 'no' move on to later questions]

How did you begin to know?

* What happened? Did you visit or stay in hospital? What happened to you there?

What did people tell you, then or later, about: -

- What causes diabetes?
- What diabetes is?
- Your daily routine of injections and blood tests?
- What kind of things you have to eat if you are diabetic?
- Any other things you have to do about your diabetes?

Do you think they told you enough? Was the way it was given a good way for you/for children? Or do you think they told your mum and/or dad enough?

- Have there been any changes in your care since then?
Would you like to make any (other) changes? (if your doctor agrees)
- Who would you rather was told, them or you? [clarify with them whether we are talking about then, diagnosis time, or now, or both times and difference between them.]

4. The clinic

- What do you think about going to the clinic? Nice things, not nice things?
- And the nurse, your doctor, the dietician?
- And how they help you?
- Have you had to go into hospital much? [How often?]

5. Sharing in your daily health care

- At what age do you think you could/did you begin to understand about: -
 - Your blood sugar getting high and low?
 - Having a balanced diet?
 - Blood tests? [look for different kinds of answers on rationale, science or the practical knowledge or skill of the child]
 - What insulin is and how it helps you?
 - Having a balanced diet and energy counting? [Pilot interviewees asked: does counting energy KIs in food, and calculating your energy (current blood sugar, whether it is supper time, snax before PE, and so on?)]
- Do you: -
 - Do your own blood tests?
 - Do your own injections?

- Choose what to eat and when?
- If so when did you start doing this? If not, when might you be old enough to?
 - Blood tests?
 - Injections?
 - Food?
- How do you/your parents share in your daily health care, e.g. deciding what to eat and when?
- What parts of your healthcare do you like to be involved in?
- Would you change the way you share in your health care? If so, how? Have there been any changes – new routines, aids?
- Do you have any problems with diabetes? And, if so, how do you and your parents try to solve these?

6. Your overall view of diabetes

- Are there any good things about having diabetes?
- Are there any not so good things about having diabetes? [It would be useful also to know the 'worst' thing, if possible, if it is not too pushy or negative to ask at this stage.]
- Thinking about the future what are your aims? Hopes? Worries?
- Do you know what you would like to be doing when you are [ask v young children a year ahead, and older ones 10 years, or when you leave school?]
- If (e.g. a girl aged 10 like you) started having diabetes and asked you what it is like what would you say?
- Is there anything else important about your life or having diabetes that you would like to say?
- While I'm talking with your mum/dad for a bit would you like to draw a picture about diabetes – such as how it affects you, or how you feel about it, or a time when it came up – explaining at a party, maybe refer back to things they've mentioned? Or the best and/or worst things about having diabetes?
- If you think of anything else to say while I'm talking with your mum please will you tell me before I go?

Research Name

- So that nobody knows who you are would you like to make up a name that we can use when we write about you in our work? Do you have a middle name that we could use?

Appendix 2, part 2 Topics/Questions for parents

1...*Diagnoses and first experiences of diabetes*

- What do you remember about the time when the first signs that your child had diabetes started?
- How many days were spent in hospital after diagnosis?
- Have you moved to a different hospital district since diagnosis? And compare hospitals and transfer?
- What did people tell you about:-
 - The cause of diabetes?
 - What having diabetes involves, how it will affect the family?
 - The Daily routine of injections and blood tests?
 - Other Daily things like food, and timing?
 - Any lifestyle changes, or how to fit diabetes care into your lives? Did you have to adapt much?
 - Benefits and allowances? And any other help/support?
- What do you feel about the information given to you?

2. Participation in health care

- At what age do you think your child could/did begin to understand about:-
 - Blood sugar?
 - Balanced diet?

- Blood tests?
- Insulin?
- Balanced diet and energy counting? [see earlier comments on this]
- At what age do you think your child could/did begin to carry out:-
 - Blood test?
 - Injections?
 - Choosing food?
- How do you and your child share their daily health care, such as blood tests, injections, warning of hypos, deciding what to eat and when? [possible prompt] Do you each sometimes rely/depend on one another in different ways?
- What parts of their healthcare do you prefer /would you rather/ do you think you ought to be involved in?
- Would you like to change the way you share in their health care? (if your doctor agreed?) If so, how?
- Does your child's diabetes raise any problems? And, if so, how do you and/or your child try to solve these?
 - What do you think about going to the clinic? Nice things, not nice things?
 - And the nurse, your doctor, the dietician?
 - And how they help you – and respect you as an equal partner in caring you your child?
 - Has your child had to go into hospital much? [How often?]

3. Relationships and Social life

- Do you think you care for X any differently from your other children? If so how? [prompt if necessary, such as detailed daily care? leaving in care of other adults?]
- Do you see any difficulties between X and his/her friends because of diabetes? If so, how?
- What do you do when x is with friends or others having sweets/ice creams?
- What happens when x goes to parties or birthdays?
- Does x ever go to stay overnight with friends/relatives – what happens then?
- Do other adults such as grandparents, aunts, teachers, school assistants all understand about diabetes?

4. Impact of diabetes

- What the biggest problems for you/your child with having diabetes? How do you tackle them?
- Though no one would wish their child to have diabetes are there any positive things that have come out of your child having diabetes?
- Thinking about the future what are your aims? Hopes? Worries for your child with diabetes?

Appendix 2 Part 3 Questions for specialist diabetes practitioners

1. Background/role

- What is your role within the paediatric diabetic service?
- Do you have other roles outside of this?
- What department pays your salary?
- Who else is involved in providing this service?
- How often, and for how long does the diabetic clinic run?
- What does the service aim to provide for people?
- How many people under 16 and over 16 use this paediatric service?
- Are there any changes to the service that you would like to see? (Setting, services provided, time allotted for, staff).

2. Diagnoses and first experiences of diabetes-

- Do patients usually visit or stay in hospital after diagnosis? If not all admitted, reasons why some are admitted? Usual length of stay
- What happens during their stay in hospital?

- Do you provide any information then about: -
 - The cause of diabetes?
 - What having diabetes involves, how it will affect the family?
 - The daily routine of injections and blood tests?
 - Other daily things like food, and timing?
 - Any lifestyle changes, or how to fit diabetes care into daily lives?
 - Benefits and allowances? And any other help/support?
- Who is involved in the provision of information?
- Is any further information provided at later stages?
- Are children updated sometimes as they grow older – any system to make sure this happens?
- Do you provide information to the parent or the child (in the initial stages, later)?

3. The clinic

- What do you aim to provide for a family when they visit you here at the clinic?
- What would an ideal consultation be like?
- Are there any changes you would like to see for the clinic? Are these achievable? If not, why not?
- When a child and their parents visit you how do you decide whom to talk to about various subjects?
- Do you think children and/or parents are able to ask questions they want to? Do any need encouraging? If so how?
- Do children often have to come for stays in hospital? Is the service here linked to that? What do you feel of the service provided on the ward, at A&E?
- Are there any changes you would like to see there? Is there any training for general staff?

4. Sharing in daily health care –

- At what age do you think children can begin to understand about: -
 - Blood sugar getting high and low?
 - Having a balanced diet?
 - What Insulin is and how it helps them?
- At what age do you think children can begin to: -
 - Do their own blood tests?
 - Do their own injections?
 - Choose what to eat and when?
- In what ways do you see children sharing their daily health care with their parents, e.g. deciding what to eat and when?
- What parts of their healthcare do you think children should be involved in? [prompt – at different ages if necessary]
- What do you feel are the biggest problems that children with diabetes face? What do you feel are the biggest problems that parents of children with diabetes face?

5. Relationships and social life –

- Do you see any differences in the way parents care for their diabetic child compared to their other children?
 - Do you see any difficulties for children with their friends because of diabetes? If so, in what way?
 - Do you ever advise what to do when a child is with friends or others having sweets/ice creams?
 - Do you ever advise on what to do if a child ever wishes to go to stay overnight with friends/relatives/on a school trip – what happens then?
 - Do you feel that there is understanding from other services a child might receive, such as in schools?
- Do you think your role involves sometimes encouraging parents to be stricter or less strict? If so, how do you do this?

6. Your overall view of diabetes-

- Are there any good things for a child or their family about having diabetes?
- What do you feel are the worst things about having diabetes for a child?
- What are your aims – re individual patients? Hopes? Worries for the children and families that you see? And aims regarding paediatric diabetes? Main ways forward - Scientific? Clinical? Management and budgets? Prevention? Improving social aspects of management and support?
- What advice would you give to a newly diagnosed child who asked you what it is like? What would be the important things to tell her? What tips would you give her for getting on with things? What would be the most important advice to give to parents?
- Is there anything else that you would like to say?

Appendix 3 Short report for adults

There is a short illustrated report for children, not included here.