

## **Children's competence to consent to medical treatment**

Priscilla Alderson, Katy Sutcliffe and Katherine Curtis

Elements of informed and voluntary consent and their relevance to children are reviewed with examples from research with children aged 3 to 12 years who have insulin dependent diabetes.

### **Meanings of consent**

This paper reviews elements of consent that may be used as criteria to assess the competence of the person asked to give or withhold consent. The criteria are illustrated with selected examples from research with children who have insulin dependent (juvenile or type I) diabetes.<sup>1</sup> The purpose of this paper is to consider whether children can fulfill agreed criteria of competent decision-making, set by the *Declaration of Helsinki* and the *Nuremberg Code*<sup>2</sup> for medical research, but also relevant to medical treatment: *informed consent* based on understanding the nature and purpose of the intervention, the likely effects and any alternatives; sufficient *comprehension* to be able to make and signify an understanding and enlightened decision; *voluntary consent* as free power of choice, with the *autonomy* that includes the courage and resolve to stick to the decision whatever the outcome; *legal capacity* to give consent. The paper concludes by discussing the relevance of children's competence and consent to twenty-first century health care and ethics.

Consent is usually considered in relation to surgery or medical research, although Anglo-American law expects consent to be elicited before any touching of the patient. One study found that some children in hospital were most upset by having their nametag fastened round their wrist.<sup>3</sup> Such minor routines for practitioners may be major issues for patients, and one aspect of respect for consent is practitioners' sensitivity to patients' varying views and values. Type I diabetes involves numerous daily decisions by children about whether to resist or comply with their prescribed diet, injections and blood tests. Our research examined how these "minor" decisions relate to informed and voluntary consent.

An earlier study of 120 children aged 8-15 years having, on average, their fourth elective operation showed that the adults caring for them respected the informed decisions about major surgery made by some children aged from 7 years.<sup>4</sup> Instead of age or ability, the research found that experience is the salient factor in the children's intellectual and moral competence. A craniofacial surgeon considers that "most" children can actively participate in major surgery decision-making at about 8 years.<sup>5</sup> Diabetes, however, involves decisions that are both harder and easier than decisions about surgery. Although often complex, surgery decisions can usually be specific, fairly clearly explained, and the fear, pain and disruption of surgery are time-limited even if the effects are not. In contrast, the diagnosis and prescriptions for type I diabetes expect the person to make a

continuing, life-long commitment, a practical consent associated with profound, existential, partly non-specific and unknown changes in personal identity and daily life.

## **Developmental versus social research**

These children's decisions about diet are made in a social context and at the intersections between simple mundane choices and starkly life-threatening risks, everyday versus complex endocrinological knowledge, and their peers' versus their health practitioners' conceptions of the good life. Daily management of diabetes mellitus (Latin for honey) illuminates exceptionally clearly children's intellectual, moral and social competencies, because it is about controlling sugar, a key currency and symbol of childhood. In many cultures, confectionery is used to signify affection and popularity, inclusion or exclusion, to mark passing time (birthday cakes), celebrate festivals (Easter eggs and other sweets), reward, bribe, barter or (by withdrawal) threaten and punish children. Against this dominant sugar economy, children with diabetes have to avoid sugar, and to cope skillfully with being different from their friends without losing friendship and respect.

Philosophy, however abstract and analytical it is, can only be as sound as the social evidence and theories on which it relies. Bioethics is still dominated by outdated Piagetian child development age-stage theories of children's ignorance, inexperience, and inability to make truly informed autonomous decisions,<sup>6</sup> as if the mind and conscience grow as slowly as the body. The recent Hastings Center review on consent, for instance, excluded examples of people aged under-18 years.<sup>7</sup> If children are pre-rational and pre-moral, like animals or machines, their views can hardly be informed or trust-worthy, and their responses would be either mindless compliance or irrational resistance. Locke and Kant denied that children and women could attain the rationality and independence necessary for autonomy.<sup>8</sup>

Traditional developmental psychological research uses methods that are liable to intimidate children and it thereby can underestimate their actual abilities and appear to confirm developmental theories.<sup>9</sup> The methods that can be off-putting include standardized questionnaires with representative (healthy) groups, testing of hypotheses, use of "laboratory conditions", "objective" observations and assessments of children's responses without considering their own reasoning and explanations.

In contrast, the fairly rare examples of qualitative social research with children who have chronic illness or disability reveal far higher levels of knowledge and competence relating to their condition.<sup>10</sup> These studies use: observations and interactions with children in the context of their everyday lives; examining topics in which the children are expert; semi-structured narrative interviews; use of toys, drawings and other non-verbal media; avoidance of normative tests and judgments; efforts to establish friendly rapport with children, and to understand their perspectives and reasoning.<sup>11</sup> The newer social research is also informed

by cogent critiques of child development theory,<sup>12</sup> and investigates how children's competencies are recognized or denied, encouraged or inhibited.

Taking these social research approaches, the "children as partners in their diabetes care" project<sup>1</sup> investigated children's views about their diabetes, their share in managing their care, and their everyday likes and dislikes, achievements and problems. We observed diabetes clinics in three English hospitals, two in inner city, multi-ethnic, disadvantaged areas, and one in a commuter town. With their consent, we held semi-structured tape-recorded interviews with 24 children aged 3-12 years and 29 of their parents (usually with their child), 2 pediatricians and 2 diabetes nurses. The mean age at interview was 8.7 years, and at diagnosis was 6.0 years (see table 1). Fifteen of the families in a purposive (deliberately diverse) sample were contacted by post with information leaflets and requests to opt into the research, and they were interviewed at home. Nine families in a convenience sample were contacted and interviewed in a diabetes clinic. Some children drew pictures. The children chose their research names to protect their anonymity.

Open questions were asked to encourage detailed narrative responses, for example, 'What was the best day during your last holidays?' The interview transcripts were systematically read and re-read, and analysed for themes raised by the interviewees,<sup>13</sup> such as their views on normality, and for their direct and indirect replies throughout the session to the main research question: 'When do children begin to be able and willing to take an active part in managing their diabetes care?' The replies are analyzed in this paper to examine whether some of the children could meet the criteria for informed and voluntary consent. (Notation: ... denotes words omitted. Numbers in brackets denote the child's age in years).

### **Informed consent – understanding the intervention's nature, purpose, methods, means and duration**

The main purpose of insulin treatment, at least twice daily, for type I diabetes is to prevent too high (hyper) or too low (hypo) blood sugar levels (glycaemia) when the pancreas no longer secretes insulin. Too high a dose could induce a hypo, a coma and in rare cases death. Too low an insulin dose and consistently high glycaemia result in feeling unwell with very serious longer-term morbidity (amputation, blindness, renal problems) and early mortality, problems suffered by one third to one half of British adults who have diabetes.<sup>14</sup>

David (11): 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.

The children's embodied knowledge of hypers and hypos enables them to understand the "nature and purpose" of their treatment. They talked of being faint

and hungry, turning white or blue with hypos. Simba (7) 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.  
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...  
Int: And what do you do then?  
Simba: I say, "Help!" ... Yeah...cos I thought I was getting sucked down a hole. [Mum gives me] Hypo stop, sort of jelly thing ...

While her mother described hypos, Maisie (3) showed the researcher how hypos make her feel "wobbly", by shaking her arms. Having been ill with hypes, exhausted, white and thin for months before the diagnosis, Nicola (when aged 4) intensely understood her explanation, that insulin is the "key that turns sugar into energy". Some children were so ill when they were diagnosed, they required intensive care. At times, some lost consciousness with hypos and were rushed to hospital and they vividly recalled these occasions. Their formal endocrinology may have been rudimentary, but they knew their treatment was life-sustaining.

All the children also understood the "methods and means" of daily treatment because they shared in performing these.

Interviewer (showing a doll): 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 (6): ...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.

Some younger children performed their blood tests and injections, such as Nicola (from 4) and DJ (6), whereas some older ones preferred to rely on their mother. Children also explained how they measured their blood sugar levels, and gradually learned to assess their carbohydrate intake, adapt their diet, and meet their changing needs (see reference 1 for details).

“Duration” can refer to the pace and timing of treatment. Through daily cycles, the children came to understand, plan and manage their constantly recurring needs for snacks, meals and insulin. “Duration” also refers to the lifelong nature of the condition. At any age it can be hard to prepare for 10 or 30, years ahead, so that this is not simply a limitation of childhood. The children indicated some understanding of permanence, in their practical acceptance in adapting of their lives to cope with diabetes. Some spoke of always having diabetes. John diagnosed when aged 10 said during his first blood test “they just pricked it...and I thought, ‘Oh God I’ll have to do this for the rest of my life’.” The children did not talk or behave as if they *expected* an end and a cure, however much they may have longed for that.

### **Informed consent - anticipated benefits, potential hazards, inconveniences and discomfort**

However benign and well intentioned the caring adults, children suffer unless they can sense and trust in the adults’ benevolence. Human beings are meaning makers and even premature babies learn to anticipate when they will have a heel prick or a caress.<sup>15</sup> It is logical for young children to believe that the treatment (needles, withheld sweets, pain and frustration) is worse than the disease, and therefore unless they are very clearly informed and reassured, children risk experiencing a form of the “torture”, which consent is designed to prevent. In its extreme form, torture involves “breaking down a person’s sense of identity” through inducing an utter sense of helplessness, unpredictability and confusion.<sup>16</sup> Children need to have some faith that the benefits of treatment outweigh the hazards, inconveniences and pain, and at first this could be very hard. “It hurt so much and I had no idea what was wrong with me and what they were doing,” David (11, diagnosed aged 8). As already mentioned, children who were extremely ill before diagnosis were better able to understand cost-benefit equations that justified their life-saving treatment. Moogum, diagnosed when she was aged 5 years, said, “My sister was at home in bed and she was crying because she thought I was dead.” Guy, diagnosed just after his sixth birthday, remembered being frightened alone in a hospital room and on a drip. “There was nobody, no one to talk to, there was no little boys...I was almost dead.” One mother and Alex (11) who both had severe needle phobia experienced fear and horror, although Alex remembered, “I was about 5. Yeah it was really tough on me...but I gradually got on alright,” with explanations, support and, at 10 years, wanting to become independent enough to go on a school journey. Children tended to say “inconveniences”, their irritation and boredom with disruptive treatment routines were worse than pain, “it’s a drag” (and see below).

## **Informed consent - effects on health or person, alternatives**

Consent is often assumed to concern an active practitioner's intervention on to an individual passive patient. However, the management of chronic conditions involves numerous interventions, medically advised but often performed by the patient, from taking medication or exercise to dieting. To follow the diabetes medical regimen conscientiously demands persistence, ingenuity and will power, which depend on the person deeply understanding the wanted and unwanted effects of the condition and treatment on their "health or person".

The interviews began with the children talking about what they liked and enjoyed. They had varied interests, diabetes was not necessarily a topic of great interest or importance to them, and they repeatedly said, "I just want to get on with my life," and have a "normal" time with friends.<sup>17</sup> The children aimed to fit in diabetes care around their daily activities, and a main reported problem was when adults obstructed this aim: teachers who singled out children as different, or made them miss playtime to stay in to have the snack, or refused to allow them to join school trips, and a friend's mother who would not allow one girl to join in sleepovers at her house. One boy left an unfriendly school and was happy at his new school, another (small) school rearranged snack times so that everyone fitted in with Johnny's needs. For the children, "alternatives" included ways to make the diabetes care quicker, easier, less obtrusive and painful - or the reverse. For example, several children said that they found using needles themselves less painful than when adults injected them.

The children were asked what they would tell a newly diagnosed child of their age about diabetes, and they tended to emphasize support, reassurance, and concern for the child's feelings. Mr Football (9) '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.' David (11) illustrated the complicated balancing of information and values, aspirations and sense of identity as a "normal" person with unusual needs when making proportionate decisions. He had heard of "a kid who forgot her injections for a week and she died," and he emphasized that he would tell a newly diagnosed boy "it's quite difficult to remember your injections, and if you forget them you might die [but also] Try just to get on with your life." David drew a picture of a cheerful looking boy next to a huge pen, with the caption in capitals, "DON'T LET AN INSULIN PEN PLUS NEEDLE CHANGE YOUR LIFE. YOU'RE JUST THE SAME AS YOU WERE BEFORE."

## **Comprehension – weighing information to make an understanding and enlightened decision**

The children showed that they understood from around 4 years, the general principle of managing glycaemia levels and something of the complicated

weighing of detailed information. From the start their parents explained carbohydrates values of different foods and helped them to choose appropriate meals, packed lunches and snacks. Parties and other treats could be stressful times, when the children had to watch other people enjoying more sweet food than they could have. Ruby's mother described how, when aged 4, Ruby did not protest at the time, if the nursery staff forgot that she was allowed one piece of cake on birthdays, but later asked her mother to remind the staff for next time. When she was 5 years, Ruby was trusted to do a blood test and work out at parties how many sweet things she could eat. When she was 4 years she had not joined in with a friend who found and ate almost a whole box of chocolates while no adults were near, as Ruby's subsequent low blood test result showed.

Children learned to plan their carbohydrate intake based on their glycaemic level, insulin dose, planned activities and whether the insulin and the food were fast or slow release. In Britain most families are expected to try to fit the diet to the prescribed insulin dose in this way. A few parents and children used the more complicated but also more liberating method of adapting the insulin dose to suit the chosen diet. In countries where practitioners promote this latter more informed and autonomous approach, people achieve better glycaemic control,<sup>18</sup> and some of the older children showed that they could do this. David (11) described how he would increase his insulin dose at a party to be able to have extra treats. "If it was after [my insulin dose] 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. Jimbo's (11) mother described his answer-phone message he left for her, which said, "I'm 20 [high] so I need some rapid [release insulin] but I don't know..." adding that he was not sure if his mother would advise a dose of 2 or 3 "so I'm giving myself 2". The high risk of an overdose illustrates the mutual informed trust parents and children have to develop because parents cannot always be present.

Weighing information and burdens versus benefits before reaching an informed decision involves complicated immediate and long-term considerations. Despite the adults' caring support, diabetes decisions can be more difficult for children than for adults. Children's moral agency may not be recognized, their complicated consent may be underestimated as compliance, their sometimes reasoned "refusal" may be dismissed as foolish resistance, such as if they occasionally decide that it is more important to join in their friends' activities for their social health, than to comply strictly to the regimen for their physiological health. Adults frequently make such life style choices. While children may be blamed for poor glycaemic control, their costly success may be attributed to the caring adults. It is even harder to balance short and long term interests, today's sweets against health in 20 years time, when adults are understandably loathe to tell children about the very serious morbidity and mortality risks of diabetes, but then blame children for being irresponsible. When type 2 diabetes, which follows unhealthy life-style, is mistakenly confused with type 1 diabetes, which often develops in slim, fit, active children, children may wrongly be blamed for their ill health by people who know little about diabetes, and this can further undermine respect for and trust in the children and their decisions.

Adults can make any decision for themselves, but an “enlightened” decision made for or by children has demonstrably to serve the child’s welfare or best interests. Most of the interviewees showed how even young children could be informed, responsible and reliable. An exception was Edwina (12) who sometimes collapsed at school and had to be taken to hospital. She was unhappy at school and she illustrates how school children’s ability to make difficult choices to promote their health appears to be less age-related than support-related in how far the child feels that the responsible adults are working with and not against her, in her best interests. Edwina drew a face, one side smiling, the other side crying, with the caption “diabetes can be good, bad, happy and sad. It can be painful and not painful” suggesting ambiguity and difficulty for herself and those around her to adjust to her fairly new identity, she was diagnosed two years earlier. Enlightened decisions link to maturity, wisdom and discretion,<sup>19</sup> and parents’ comments on their children’s maturity are given later.

### **Signifying a decision**

Children can clearly express consent or refusal in their body language as well as by speaking or writing and by actively taking or resisting the medication or other prescription. Even the youngest children signified their informed commitment to the diabetes regimen many times a day. If Maisie (3) feels hypo at night “she shouts and shouts”, said her mother, and Holly’s mother commented, “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’.”

### **Autonomy, courage and resolve**

Besides the intellectual competence needed for informed consent, voluntary consent involves moral maturity and autonomy, emotions as well as reason, journeying from fear and rejection of proposed treatment, through doubt and uncertain weighing of the information, towards hope, trust and confidence in the treatment.<sup>20</sup> The endless regimen could be very hard and painful with the “hated” routines. Alex (11) used to scream so much about injections that the neighbors talked about it. He spoke of being “down in the depths” sometimes, and believed that prior explanations were vital for children, so “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.” Alex echoed a legal ruling from 1767 before the era of anesthesia, which acknowledged the surgical patient’s arduous emotional labor: “It is reasonable that a patient should be told about what is about to be done to him, that he may take courage and put himself into such a situation as to enable him to undergo the operation.”<sup>21</sup> Resolution was needed at first to accept the diagnosis and new personal identity and life style, and some children constantly had to summon up resolve, as such by the 4 year old who

hovered the needle over her skin for some while before taking courage to insert it.

While acknowledging that no one would wish to have diabetes, we asked if anything positive could ever come from having it. Alex replied, "My attitude has got better," and his father said, "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'...he's mature beyond his years." James's mother said he is "a regular kid", but "for 10 years old, it's quite scary sometimes, how mature he can be [and] for a 7½ year old to overcome that at that age..." (when diagnosed). DJ's mother commented: "I sometimes forget that he is only 6. He's very responsible... Diabetes-wise he's very grown up... I would trust him... but I wouldn't trust them" - adult friends who might look after DJ but forget to supervise his diabetes care, which DJ would remember.

The courage to consent includes willingness to take responsibility for risky decisions without blaming others, despite subsequent problems. It has been argued that even if children are able to give consent it is unwise and unkind potentially to burden them with this kind of guilt and blame. Pediatricians used to argue similarly that it was unfair to ask parents to consent to major risky decisions for the same reason.<sup>21</sup> Their health care is inevitably so much in the hands of children with diabetes, and they feel blame and guilt if, for example, they have too many hyps. In our small sample, the children who achieved the best control were those who were most informed and trusted to plan their care, and although the pattern of cause and effect here is not definite, the association is clear between adults' trust and children's confidence and responsibility.

### **Voluntary consent, free power of choice, without force, fraud, deceit, duress, overreaching or other ulterior form of constraint or coercion**

The idealized notion of freely given consent has been criticized on several counts. It was originally conceived for "non-therapeutic" medical research<sup>22</sup> not for beneficial medical treatment. No one is omnipotent or omniscient, indeed without numerous influences and partial constraints we would not have a range of options to choose from, or the values and experiences that inform our choices. Patients are inevitably constrained by their illness, their mortal needs, their limited knowledge of medical complexities, and the present limits of medical skill and knowledge (no great advances have been made in diabetes care since insulin treatment began around 80 years ago). The survival of patients of any age sometimes depends on their being encouraged or cajoled into complying with treatment, when respect for their autonomy mingles with protective care. Yet although there may be a grey middle ground where persuasion verges into deceit, threats or pressure, there are clear differences between duress and reasonably "free power of choice" when avoidable pressures are withheld.

Some authors have concentrated so much on the pressures that practitioners should refrain from exerting, that they propose: because of the "many confusing associations surrounding the term 'voluntariness' [it should be replaced by the

term] non-control that does not have the history and connotation that burdens [sic] the terms 'freedom', voluntariness' and 'independence'."23 This view seems to attribute all agency to the practitioners and none to the patients, whereas "free power of choice" is control – by the patient who ultimately makes the decision. Children have traditionally been assumed to lack the Kantian autonomy and will necessary for voluntary decision-making. However, this diabetes study and other research with children24 demonstrate that at least some young children can make and keep to informed, wise and brave decisions. Their decisions are "voluntary" in the sense that they are continually being made and remade, with many occasions for choice. Adults cannot always be in control, and undue adult compulsion risks evoking resistance.

### **Legal capacity to give consent.**

The final element of competent valid decisions is the legal status of the decision maker. In Britain, doctors have no age bar, and can accept legally valid consent from children who, in the doctor's clinical judgment, are able to make informed and wise decisions in their best interests.<sup>19 25</sup> The "age of consent" varies widely between countries, illustrating how an age or *status* based criterion for competence is contested. Competence may also be assessed on *outcome* and whether the assessor agrees with the decision or, more fairly, competence is assessed by *process* and whether the methods of making the decision seem justifiable. Although United States law does not accept minors' consent, the concepts of "assent" and of "mature minors" enable doctors to respect the agreement or refusal of certain minors.<sup>26</sup>

It is argued that if children can only make decisions, which are perceived by the treating doctor to be 'in their best interests', this cannot count as consent. Consent entails respect for any decision that the person makes, including ones that others might regard as against the person's interests. This is true of consent to, and refusal of, treatment for competent adults. However, by law, medical decisions for children have to be agreed to be in the child's best interests. Parents' decisions for their children are as much constrained by this law as children's own decisions. Yet this is not taken to invalidate parents' consent, and so there is no clear reason why it should invalidate children's consent. All patients' decisions and consent are partly limited, first to what doctors agree to provide, and second, to realistic feasible options. These can involve, for example, consenting to months of dreaded chemotherapy as the least harmful/most hopeful decision, although it is very different from the first but unrealistic preference for instant health. The reality of the constraint of consideration for the child's best interests is seen when doctors take parents to court, if they believe the parents are deciding against the child's interests. When the courts are asked to authorise the medical decision to give or withhold treatment, they too are subject to the same child's best interests constraint. There are reports in the US, for example, of children being taken into care in order to ensure that they receive Ritalin, which the parents have refused to administer for diagnosed hyperactivity.

It is also often argued that it is a tautology to imply that children who make wise decisions are competent, and if they are competent they make wise decisions. However, this is the tautology underlying medical law on minors' consent.

## **Discussion**

The “children as partners” study illustrates how the experience of chronic illness enables children to develop related understanding, skill and maturity. Children (and adults) with diabetes often have treats and temporarily suspend strict control and indeed healthy living standards generally. Yet the children showed that from around 4 years they understood the principles and recommended standards of controlling diabetes, they could make informed and wise decisions in their own best interests, and tried very hard to keep them, generally working with, not against, the caring adults. Although having understanding and skill, the children at times wanted their parents to make decisions, do their injections, or talk to the doctor for them.

We are cautious about generalizing from this small project, and do not expect healthy young children, or those with acute or emergency conditions, to demonstrate comparable understanding or maturity about managing a serious chronic condition. However, our findings are confirmed by other qualitative research about the decisions of children with long-term illness or disability, and adults' respect for their competence. African, Asian and South American research projects demonstrate highly developed competencies among young children who are forced to live through adversity and fairly independently.<sup>27</sup> These suggest that advantaged, sheltered children in the richer societies have latent capacities that they need not develop or demonstrate, and that child development theories based on research with advantaged children have mistakenly concluded that young children do not, and therefore cannot and, perhaps, should not have such capacities. Diabetes provides a rare example of Western children having to cope with high risk and adversity. Whereas very large surveys are required to support generalizations, for instance, about the average 4 year old's capabilities, only a few examples are needed to show, as our research does, that at least some “ordinary” young children are well enough in advance of child development theories to pose serious challenges to these theories.

Developmental psychology, and bioethics with its priorities of respect and justice need to revise their widely held underestimations of experienced children's capacities, in order to reflect the realities of children's involvement in managing chronic conditions, and the respect that some parents and practitioners accord to them. This revision involves intellectual work and also the harder ethical and emotional task of rethinking deeply held ideologies, such as beliefs that adults are always right and must retain all control, or that even when older children make informed and reasonable decisions, parents should decide for them, in the interests of preventing discord and of sustaining harmony within the “intimate family”.<sup>28</sup> During research interviews, children and parents

repeatedly showed an awareness, which suggests that they would regard the overruling by parents of children's responsible health care decisions as a violation of parental responsibility and of loving family intimacy. The important question of unwise decisions by competent children that may have adverse consequences is beyond the scope of this paper and the examples given by our interviewees, although it has been discussed elsewhere.<sup>4</sup> In concentrating on children's responses, this paper has only indirectly reviewed parents' vital protective and nurturing role of fostering children's competence. The examples do, however, suggest that effective adults' protection includes supporting children in learning as early as possible how they can share in protect themselves from the severe harms of mismanaged diabetes.

This paper has followed the usual approach of assessing whether *children* are competent. Equally important is assessment of the concerned *adults*. Have they given sufficiently clear relevant information, and resolved confusions and misunderstandings? Do they respect the child's reasonable views and decisions, values and reasoning? Are they willing sometimes to revise their views and to learn from the child?

Alice Dreger has vividly shown how parents and doctors do not always understand children's values and best interests, especially when a child has a different anatomy and physiology.<sup>17</sup> The person who is in the body and is the body can have unique insights that may be essential for informed decision making. Woven through daily diabetes decisions is an ethics that Arthur Frank<sup>29</sup> has described as Socratic, and which 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 contrasts this with the narrower defensive ethics (detailed disclosure of risks, costs and hoped-for benefits, to facilitate precisely informed choices and precautions), which is usually debated in the literature.

Rather than assuming that the more serious the disease and treatment, the less young children can or should be involved in making decisions, the reverse view may be more reasonable. Sustainable consent when managing diabetes involves continuous moral, emotional, embodied choices, so that it is vital to involve children as much as possible, helping them to feel reconciled to and willing to 'own' decisions that fit as nearly as possible to the person they would like to be and the life they would prefer to have. With their parents, and when their parents are absent, children have to work out ways to reconcile restrictions on their life style with the diets and choices powerfully promoted by advertising and enjoyed by their friends. They have to find a way to tell their own story that can help them to feel contented rather than frustrated, coerced and unfulfilled. They can bring imagination, courage and humor to answering this Socratic challenge.<sup>10</sup>

It is therefore important not to view consent simply as a one-off *event* involving a test of the child's understanding or ignorance that may find incompetence, by making children feel confused, anxious or alienated. Instead the consent *process* can nurture and enlarge children's understanding, trust and confidence, through the sharing and transferring of insights and responsibilities between adults and children.

**Acknowledgements**

We thank the children and parents, pediatricians and diabetes nurses who helped with the research, also the three research ethics committees for their approval. Priscilla Alderson was very fortunate to attend meetings of the Surgically Shaping Children Group led by Erik Parens at the Hastings Center, funded by the National Endowment for the Humanities, and is grateful to all the members of the group for the valuable discussions.

**Funding:** Social Science Research Unit Childhood Research Fund.

**Table 1:** Purposive sample of children.

<b>Boys</b>		<b>Girls</b>	
Age when interviewed	Age when diagnosed	Age when interviewed	Age when diagnosed
12	10	12	10
11	9	11	6
11	8	11	4
11	5	11	2
11	4	7	5
11	6 months	7	3
10	7	7	3
10	7	6	15 months
10	4	5	15 months
9	8	3	16 months
7	4		
6	6		
6	15 months		
4	15 months		

## References

---

- <sup>1</sup> K. Sutcliffe, P. Alderson and K. Curtis *Children as Partners in their Diabetes Care*, (London: SSRU, Institute of Education, University of London, 2004) (download from [http://eppi.ioe.ac.uk/ssru\\_docs/DiabetesReportFinal.pdf](http://eppi.ioe.ac.uk/ssru_docs/DiabetesReportFinal.pdf)).
- <sup>2</sup> *Declaration of Helsinki* (Fernay Voltaire: World Medical Association, 1964/2000); The *Nuremberg Code* (<http://ohsr.od.nih.gov/guidelines/nuremberg.html>, 1947).
- <sup>3</sup> A. B. Hill, *Biting off the Bracelet*, (Philadelphia: University of Pennsylvania Press, 1979).
- <sup>4</sup> P. Alderson, *Children's Consent to Surgery*, (Buckingham: Open University Press, 1993).
- <sup>5</sup> J. Marsh, "To Cut or Not to Cut?," in *Surgically Shaping Children*, ed. E Parens (New York: Georgetown University Press, 2005).
- <sup>6</sup> A. Buchanan and D. Brock, *Deciding for Others*, (New York: Cambridge University Press, 1989); G. Melton, G. Koocher and M Saks eds, *Children's Competence to Consent*, (New York: Plenum Press, 1983); W. Gaylin and R. Macklin, *Who Speaks for the Child?*, (New York: Plenum Press 1982); L. Kopelman and J. Moskop eds, *Children and Health Care: Moral and Social Issues*, (Dordrecht: Kluwer, 1989).
- <sup>7</sup> J. Sugarman, D. McCrory, D. Powell, A. Kransy, B. Adams, B. Ball and C. Cassell, *Empirical research on informed consent (adults) Hastings Centre Report* (New York: Hastings Center, 1999 29,1: supplement pp s1-42).
- <sup>8</sup> S. Mendus, "Kant: an honest but narrow-minded bourgeois?," in E. Kennedy and S. Mendus eds *Women in Western Political Philosophy*, (Brighton: Harvester, 1987), pp.1-20.
- <sup>9</sup> For example, the still widely cited T. Grisso and L. Vierling "Minors' Consent to Treatment: a Developmental Perspective," *Professional Psychology* 9 (1978):412-27.
- <sup>10</sup> For example, M. Bluebond-Langner *The Private Worlds of Dying Children*. (Princeton NJ: Princeton University Press, 1978); D. Bearison *They Never Want to Tell You*. London: Harvard University Press, 1991); P. Alderson and C. Goodey, *Enabling Education*, (London: Tufnell Press, 1998); C. D. Clark, *In Sickness and In Play*, (New Brunswick NJ: Rutgers University Press, 2003).
- <sup>11</sup> P. Christensen and A. James eds, *Research With Children*, (London: Routledge Falmer, 2000).

- 
- <sup>12</sup> B. Bradley, *Visions of Infancy: a Critical Introduction to Child Psychology*, (Cambridge: Polity Press, 1989); J. Morss, *Growing Critical: Alternatives to Developmental Psychology*, (London: Routledge, 1996); E. Burman, *Deconstructing Developmental Psychology*, (London: Routledge, 1994); M. Donaldson *Children's Minds*, (Glasgow: Fontana, 1978); B. Mayall, *Towards a Sociology for Childhood*, (Buckingham: Open University Press, 2002); A. James and A. Prout *Constructing and Reconstructing Childhood*, (London: Routledge Falmer, 1997).
- <sup>13</sup> A. Strauss and J. Corbin *Basics of Qualitative Research*, (London: Sage, 1998).
- <sup>14</sup> "Diabetes Control and Complications Trial Report", *New England Journal of Medicine*, 329 (1993) 683-698; *National Service Framework for Diabetes Standards*, (London: Department of Health, 2001).
- <sup>15</sup> H. Als, "Reading the premature infant," in *Developmental Interventions in the Neonatal Intensive Care Nursery*, ed. E. Goldson (New York: Oxford University Press, 1999: 18-85).
- <sup>16</sup> S. Melzak "Secrecy, Privacy, Survival, Repressive Regimes and Growing Up," *Bulletin of Ann Freud Centre*, 15 (1992), pp. 205-24 .
- <sup>17</sup> A. Dreger, *One Of Us: Conjoined Twins and The Future of Normal*, (Cambridge MA: Cambridge University Press, 2004) shows the wide extent to which apparently abnormal people insist that they are normal, and see also note 10 above.
- <sup>18</sup> H. Mortensen and P. Hougaard, "Comparison of Metabolic Control in a Cross Sectional Study of 2,873 Children and Adolescents with IDDM from 18 countries," *Diabetes Care*, 20 (1997) 714-720.
- <sup>19</sup> This is clearly described in the English case *Gillick v. Wisbech & W. Norfolk AHA* [1984] 1 All ER.
- <sup>20</sup> P. Alderson, *Choosing for Children: Parents' Consent to Surgery*, (Oxford: Oxford University Press, 1990).
- <sup>21</sup> *Slater v. Baker & Stapleton*, 1767/94 ER 60 (England).
- <sup>22</sup> Nuremberg see ref. 2.
- <sup>23</sup> R. Faden and T. Beauchamp, *A History and Theory of Informed Consent*, (New York: Oxford University Press, 1986) p. 257.
- <sup>24</sup> See refs. 1, 4 and 10 above.
- <sup>25</sup> Age of Legal Capacity (Scotland) Act (1991), section 4 (2).

---

<sup>26</sup> American Association of Pediatrics, "Informed Consent, Parental Permission and Assent in Pediatric Practice" (RE9510), *Pediatrics*, 95 (1995) 314-7; J. Rosato, The ethics of clinical trials. *Journal of Law, Medicine & Ethics*, 28: 362-8.

<sup>27</sup> M. Liebel, *A Will of Their Own: Cross-cultural Perspectives on Working Children*, (London: Zed Books, 2004).

<sup>28</sup> L. F. Ross, *Children, Families, and Health Care Decision-Making*. (Oxford: Clarendon Press, 1998).

<sup>29</sup> A. Frank, "Emily's Scars," in E. Parens ed, *Surgically Shaping Children*, (New York: Georgetown University Press, 2005).