

Listening to children: have we gone too far (or not far enough)?

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Informed consent . . . is more than just a legal obligation, imposed on physicians by society . . . It also has a moral basis fundamental to human relationships: the recognition of individual autonomy, dignity, and the capacity for self-determination. From this moral perspective, informed consent has value in and of itself . . . Patients generally benefit psychologically from their involvement in decisions, and they can make real contributions to the efficacy of treatment through their observations, perceptions and active participation¹.

The starting point for this paper is a reflection on four children I had contact with, in my role as their ward psychologist at Great Ormond Street, several years ago. The first was an eight-year-old girl with cancer, who said that she did not want any more treatment, she would rather be dead. I gave her as much support as I could and she died a month later.

The second was a ten-year-old boy with a moderately severe facial disfigurement, who said that he did not really want to have an operation scheduled for a few weeks' time. Once again I did what I could and encouraged him to discuss it with his parents and then write to the surgeon to explain his feelings. The operation was postponed.

The third was a twelve-year-old boy with leukaemia who also said that he did not want treatment. In his case I pulled out all the stops to persuade him to change his mind, which he did.

The fourth was a fifteen-year-old boy who I held down while he had blood taken against his will.

Why did I vary in my responses to these children? In trying to come to some answers, I have looked at three areas—the idea of children's rights; the law; and the question of when parental decisions should give way to those of children.

THE RIGHTS OF THE CHILD

It is sometimes said that children's rights are a phenomenon of the late twentieth century, but ideas on the subject are not that new. In 1669 a 'lively boy' presented a petition 'on behalf of the children of this nation', protesting 'that intolerable grievance our youth lie under, in the accustomed severities of the school discipline of this nation'².

In 1923 Eglantyne Jebb, the founder of the Save the Children movement, wrote, 'I believe we should claim certain rights for children and labour for their universal recognition'. Nevertheless, the document most frequently cited in this context is the UN Convention on the Rights of the Child (1989), the adoption of which has been described as representing 'a watershed of immense significance'². And the most often quoted clause is:

States parties shall assure to the child, who is capable of forming his or her own views, the right to express those views freely in all matters affecting the child, the views of the child being given due weight in accordance with the age and maturity of the child.

Let us unpack this a little. The crucial element of this statement is that children's views should be heard, should be given 'due weight'. A theme that runs through much of the writing on children's consent is the critical distinction between children being heard and their having autonomy. The UN Convention is a long way from saying that children should be autonomous.

To reinforce this: another frequently quoted notion is the 'ladder of participation' put forward originally by Sherry Arnstein and adapted for children by Hart³. The ladder is designed to illustrate levels at which children can take part in decision making. At the bottom is 'manipulation'—for example, when children are given placards to carry at political rallies without having any idea what they mean. (A friend of mine claims that the first words he taught his elder son were, 'forward with the proletariat'.) The rungs of the ladder go up, via 'tokenism', 'consulted and informed', to the top, which is 'child-initiated, shared decisions with adults'. Again, we have a sharing of views, not autonomy.

A further reinforcement comes from an example of what children themselves think about this. The UN have produced a version of the Convention rewritten by a nine-year-old. Article 12 is rendered: 'Whenever adults make a decision that will affect you in any way, you have the right to give your opinion, and the adults have to take that seriously'.

On one aspect I have found no help from the published work—the notion that rights imply duties as well. I think I can see how one can expect children to have duties of courtesy and consideration to others along with rights.

But perhaps the lawyers see things differently.

THE LAW

The legal position is simple, complex and contradictory. The 1969 Children Act sees the child's welfare as paramount in any question concerning the upbringing of a child or the administration of a child's property. Courts have to have regard in particular to 'The ascertainable wishes and feelings of the child concerned, considered in the light of his age and understanding'. The critical questions, then, are: When does a child become competent enough for his or her wishes and feelings to be paramount? How do we judge understanding?

In the United States there is variation on medical consent from State to State. Many allow certain minors to consent to treatment without their parents' permission, the criterion being not so much the age of the child as the treatment concerned—that to do with contraception, alcohol or drug dependence and abortion for example. In the UK, the Family Law Reform Act of 1969 set sixteen years as the age below which legally responsible parents had to give consent to any medical interventions. Use of age as a sole criterion is clearly a nonsense. As Alderson⁵ has pointed out, 'An arbitrary age of consent raises the anomaly of the magic birthday. How can someone be an incompetent infant one day, but a mature adult the next?'

Gillick

The Gillick case is usually cited at this point as having changed notions of age as a critical variable, for 'a Gillick competent child', even one well under the age of sixteen, may give valid consent without parental permission, providing he or she is of sufficient age, maturity and understanding. In Lord Scarman's words:

... as a matter of law the parental right to determine whether or not their minor child below the age of 16 will have medical treatment terminates if and when the child achieves a sufficient understanding and intelligence to understand fully what is proposed⁶.

So the law is simple: if you are Gillick competent you may give consent to treatment. But the definition of competent is far from simple. Legally this is a matter for the medical profession to decide. In Scotland, 'The validity of a child's consent turns on personal capacity as judged by the opinion of a qualified medical practitioner attending him' [Age of Legal Capacity (Scotland) Act 1991, Section 2(4)]. But what is meant by 'qualified' in this context? And on what criteria does the medical practitioner decide?

As a psychologist I might be expected here to advocate the use of an intelligence test. I do not, because such instruments were not designed for this purpose. And many adults would fail to register an IQ that might be seen as reasonable for a cut-off point. Alderson and Montgomery⁷

turn the picture on its head and argue that we should presume that the child is competent and it is up to the adults concerned to show otherwise.

I said earlier that the law is simple, complex and contradictory. It is simple in that it comes up with the notion of a competent child. It is complex in that such a child is not easy to define. The contradiction comes in the fact that, while in theory the 1989 Children Act allows a child of sufficient understanding to refuse to submit to medical examination or treatment, in practice this is not the case. As Reder and Fitzpatrick⁸ conclude, 'The current, somewhat confusing picture is that Gillick competent children may give consent to assessment or treatment but can have their refusal overruled by parents or those in loco parentis.' The cases often cited in this context are the overturning of a fifteen-year-old girl's refusal to accept psychiatric medication, a sixteen-year-old's refusal to accept treatment for anorexia nervosa and the refusal of a girl on an interim care order to submit to a psychiatric examination⁸. There is some sense in this. If it were not so, children all over the country could legally refuse all sorts of practices, from going to the dentist to having their toenails cut. But it sits a little oddly with the care that has gone into ensuring consent.

The Royal College of Paediatrics and Child Health pronounced on this issue in 1997, concluding that there should be a presumption of competence unless a child is obviously incompetent:

It should be the duty of the professionals to assess the individual child's competency for decision making. Good practice goes beyond observing minimum legal standards and takes account of higher ethical standards of respect for children's views as well as concern for their welfare.

The report goes on to make distinctions between (1) informing children, (2) listening to them, (3) taking account of their views so that they can influence decisions, and (4) respecting the competent child as the main decider about proposed health care interventions.

The very important point is made that these four levels require different degrees of competence. Very young children, not thought to be competent to make more than what for an adult is the most trivial decision, can still be informed about their illness and the treatment. It seems that children can often understand far more than we think they can, if the information is given in a sensitive way. But to say that children should be informed is misleadingly simple. The complexity of the matter can be summed up in the two questions, what do we tell them about, and when?

If a child is to have surgery, do we explain all at once about the condition which requires an operation, about the blood test, about the pre-med, about the anaesthetic, about

the recovery room? Or do we take it bit by bit? We are surely talking about a process, not a one-off event. And what if the child says OK to the operation but no to any needles?

Some other suggestions have been made. Pearce¹⁰, Alderson and Montgomery⁷ and King and Cross¹ have all put forward variations and I have borrowed these plus the Royal College's document to come up with the approach below.

CHECKING ON COMPETENCE

Take a history

What is the family pattern of decision making? (If the family expectation is that children do not make major decisions, and if the child expresses comfort with this, then should we try to go against a family pattern?)

What decisions does the child make as a matter of routine at home and school?

What experience of this or other illnesses has the child had? (Children with a mass of experience of hospitals and treatments may be in a better position to make judgments than inexperienced adults.)

Understanding of the procedure in question

One needs to know:

- How well the child understands the disorder
- How well the child understands the reasons for the treatment
- How well the child understands what will be involved
- How well the child understands the possible risks and benefits
- Appreciation of the consequences of treatment.

Does the child understand issues in terms of time, especially the near and far future?

Some questions for the professionals

- How much time has been spent on explanations and discussions?
- Was all this a one-off event and, if so, was that really enough?
- Was the child given an opportunity to be alone with a professional?

Some of the questions put at the beginning of this paper have been addressed. A discussion on the best interests of the child may now help.

THE BEST INTERESTS OF THE CHILD

The best interests of the child are central to the Children Act and to the UN Convention, to be applied in all actions

concerning children. Indeed, the precursor to the UN Convention, the Declaration of the Rights of the Child of the League of Nations, adopted in 1924, recognized that 'mankind owes to the child the best that it has to give.'

But once again we are back with problems of definition: as Alston and Gilmour-Walsh¹¹ have pointed out, 'One issue that the drafters of the Convention did not discuss is how a determination as to what is in the child's best interests is to be made.' There have been plenty of questions raised as to what this phrase actually means.

The choice of criteria is inherently value laden; all too often there is no consensus about what values should inform this choice . . . Even if predictions (as to the consequences of policy alternatives) were possible, what set of values should a judge use to determine a child's best interests . . .¹².

One of the most telling comments comes from a judge in Canada, Justice Rosalie Silberman Abella, concluding, 'what is best for the child is often only best understood twenty years after childhood'¹³.

FOUR CASES

To return to my four children.

Amy

Amy was eight years old, bright, alert, a bit bossy. She had been through the familiar pattern of cancer treatment—remission, relapse, remission again and a second relapse. It was clear that conventional treatment had no more to offer but there was a new drug that might prolong her life for a year or so, or might not. It might have very unpleasant side effects, or it might not. All this was explained to Amy and her parents. The family relationships and the doctor-patient trust in this case were excellent. 'No thanks,' she said, 'I'd rather be dead than go through all that again.' After several meetings and further discussions she went home and died peacefully.

Many people will immediately ask, can an eight-year-old really understand about death? Current thinking on this topic is that the concept of death has many components and develops gradually. One does not go to bed one night without the concept and wake up next morning with it. Current thinking also is that many children of five to six years of age have a good grasp of the fundamentals of death, although their concepts of an afterlife are sometimes idiosyncratic¹⁴.

Tommy

Tommy was the boy with a facial disfigurement. I was seeing him because of his depression. His parents wanted him to have an operation because they thought that this would help his mood; and, because he would soon be transferring to a secondary school, they wanted him to look

better before meeting a new group of children. But it soon became apparent that his depression was much more to do with family factors than with his face. He opened up to me that no one listened to him: 'When my parents got divorced they didn't talk to me about it, dad just went. When my mum moved to a new house she never asked me whether I wanted to go, she just bought it. When I went to a new school I just had to go, no one asked me if I wanted to change. And now they say I've got to have an operation.' One session with the surgeon and the operation was postponed.

Robert

The third was a much more tricky one. Robert was a quiet, studious twelve-year-old with leukaemia. The chances of long-term remission with conventional treatment were good. He trusted the medical staff, and his parents were united in supporting him and the medical team. But they were a family of Jehovah's Witnesses and Robert made it very clear that he did not want to have any blood products introduced into his body, not even his own blood. The ward staff were upset at the thought of going against his wishes, to the extent that some said they would refuse. His parents told us that if we were to give him a transfusion they would simply walk off the ward and let us get on with it. That did not reassure the staff who were so concerned about Robert's mental state.

It was a long story. The outcome of meetings with the parents was that we wanted to treat and in the last analysis we would. But Robert's feelings were not to be ignored. During my sessions with him I ascertained that his interpretation was that God is merciful and understanding, that what counts is what one does one's best to do. So I put it to him that if God really thought that Robert had done his very best to avoid blood products, then God would be understanding and would not punish him. Robert agreed to this and I drew up a typed page which was inserted into the medical notes to the effect that he, Robert, did not wish to have any blood products introduced into his body. He signed it and I countersigned it. I explained that this did not mean we would not give him a transfusion, only that we had formally registered his disagreement. What I did here, of course, was to help him formally to refuse consent, although there was no pretence involved.

He subsequently did have a transfusion, putting out his arm and saying, 'OK get on with it'. This case was subsequently discussed with representatives of the Witnesses who were happy with the solution we reached.

Matthew

The fourth patient, Matthew, a very large fifteen-year-old, had come in for an operation and required a blood test. He

and I had known each other for almost all of his life and he made no bones about telling me that, as he had got older, he had come to be more and more fearful of needles. He wanted the operation but saw the needle as a hurdle. I had just written on the treatment of needle phobia so I was very ready to try various techniques with him. He cooperated well during the preparation but when the time came for the blood to be taken he freaked out and refused, verbally and physically, struggling with the doctor. I helped by holding him down. Once all was over we dusted ourselves down and he said consolingly, 'That's better. Next time I have to have a needle you hold me down, forget all that psychological rubbish.'

CONCLUSIONS

Four principles have emerged.

The first is that we should listen to children. I like the children's version: 'Whenever adults make a decision that will affect you in any way, you have the right to give your opinion, and the adults have to take that seriously.' But, as I have made clear, this does not always mean doing what they want.

The second is that consent, and the refusal to give consent, should be a process, not a one-off event. Only through discussion can one really listen to children, and only over time can one ensure that they listen to us and that

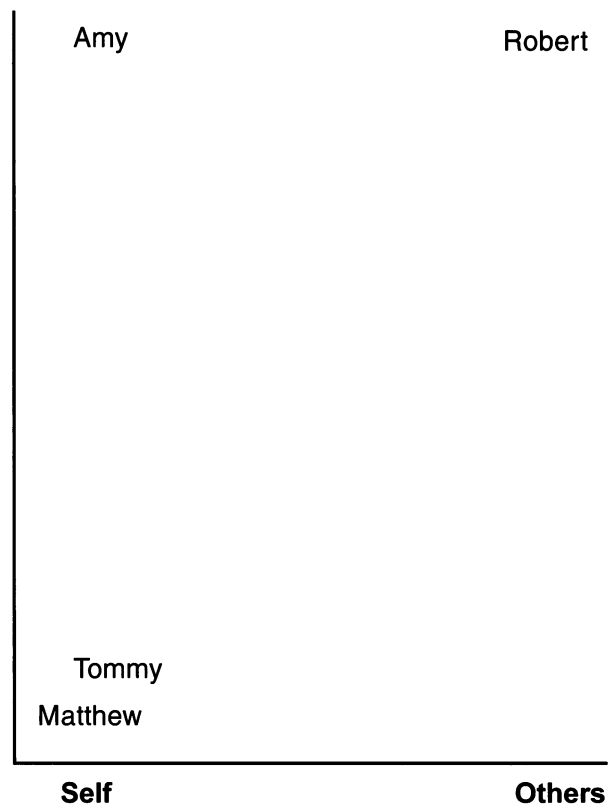


Figure 1 Placing autonomy

the message of mutual respect is imparted. During this process one can come to some conclusions on the degree to which a child is competent.

The third is that there is a developmental aspect to a child's autonomy. In one dimension the extent of autonomy develops; it is self-evident that whereas a six-day-old can decide nothing, a six-year-old can and should decide quite a lot. In another dimension the weight of decisions grows. One would not expect a four-year-old to come to conclusions on matters as serious as those weighed by a fourteen-year-old (although these matters may, to the four-year-old, be of enormous importance). So we can have one dimension of decision making which I have called heavy *versus* light. To spell this out: a light decision is what colour one's pillow case should be; a heavy one is whether to withhold treatment for a life-threatening condition.

The fourth was to ask how much influence the decision would have on other people, and among other people I include the adult that the child will become.

These two last points can be expressed along two axes, which I have labelled self *versus* others and heavy *versus* light (Figure 1).

The decision that Tommy, the boy with the facial disfigurement, should not have an operation had little effect on anyone but himself. But what about the older Tommy, the adult who might have looked back and wished that he had the operation? Not really a factor, since there was always a chance that he could have it when he was older, as was made quite clear by the surgeon. So he can be plotted near the centre of both axes.

Amy was a different matter. Her place on the model is not quite the same as Tommy's because the decision was of considerable weight. But while her death would undoubtedly have widespread ripples, we were talking only about prolonging life by a year or so; there was not to be a grown up Amy. (I do not wish to appear to minimize another couple of years: thirteen-year-old Garvan, knowing he was dying, said to me one day, 'Wouldn't it be wonderful to live to be sixteen.')

In her case the ripples of her death would have come anyway and what we gained by listening to her was the sense that we were respecting her wishes. Also, in years to come her parents might be able to look back on the decision with a sense of having helped her achieve something.

And Robert? Had his original wishes been heeded the impact on his family and others would have been enormous

and the impact on the future Robert would have been devastating: he would not have existed. It was this that led the ward team to behave as we did. He is placed on the extreme of both axes.

And what of Matthew? There really was no dilemma here. He and I both knew that he wanted the procedure to be done; all I had to do was help him over a hump. He, too, came in the middle of the model.

So, in conclusion, I suggest that we can forget ages as a determinant in this process. Instead we should ask ourselves who will be affected by the decision, and to what extent? The wider and the deeper the ripples the more careful we should be about children's autonomy. In my model, the further towards the top right hand corner one plots a child, the more wary we should be of granting autonomy; we must always listen to children, but at times they must listen to us.

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