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Disabled children’s rights in everyday life: Problematising notions of competency and promoting self-empowerment

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Introduction

Children’s rights in Scotland are covered by a number of Acts, Rules, Regulations and Guidance which include: the Children (Scotland) Act (1995), the Adoption (Scotland) Act 1978, Children’s Hearings1 (Scotland) Rules 1996, the Age of Legal Capacity (Scotland) Act 1991, educational guidelines, Rules and Acts relating to the Court of Session and the Sheriff Court, regulations relating to adoption, fostering, residential childcare and child protection, recent amendments brought about by the Children (Scotland) Act 1995 and the recently enacted Standards in Scotland’s Schools etc. (Scotland) Act 2000. Despite this protective web2 (which we will refer to as guidance and legislation) there is still much uncertainty surrounding how children’s rights are upheld in practice. Whilst the guidance and legislation (post the UN Convention on the Rights of The Child) stresses the importance of taking the child’s views into account, it also contains caveats that can be used to limit a child’s ability to have his or her voice heard and taken account of during a variety of proceedings and in different settings (Marshall 1997; Tisdall 1997).

We find that very often in Scotland the wording of guidance and legislation...
includes provisos such as: ‘taking into account age and maturity’, 3 ‘when in the child’s best interest’, ‘wherever possible’, or ‘where costs are not prohibitive’. This means that many institutions have ‘get out clauses’ when it comes to including children. For example, schools were given exemption from the Children (Scotland) Act 1995 requirement that those providing services from children should take account of their views (Children in Scotland 1999) and the Standards in Scottish Schools etc (Scotland) Act 2000 states that schools only have to say whether they consulted children about their development plans, there being no requirement that they should consult children. Despite the inclusion in the Act of a requirement that children’s views should be taken into account when considering ‘significant decisions’, schools are under no legal obligation to consult children on everyday matters (see Tisdall et al. forthcoming). As well as this ‘special’ status afforded to schools, the Scottish guidance and legislation (like that in England) (Bell 1993) allow children’s opinions to be overlooked on the grounds of ‘safety’ (when inclusion in decision making processes could harm the child) or ‘competency’ (when the child is not thought capable of understanding the process). 4

These provisos are not special to Scotland. There are, as Lee (1999) points out, ambiguities to be found in articles of the UN Convention on the Rights of the Child and subsequent national legislation. He suggests that these ambiguities centre around the way that legislation defers the question of children’s competency to represent themselves. In this paper we attempt to address the gap that Lee has highlighted. We employ ethnographic data from an ESRC funded project, ‘Life as a Disabled Child’, to discuss how adults actually judge competency in everyday settings. 5 By examining how disabled children’s views are already taken into account by various adults we are able to illustrate the variety of ways in which disabled children are judged competent. By comparing these everyday processes to writing on

3 In terms of competency and maturity, The Children (Scotland) Act, drawing on Article 12 of the UN Convention on the Rights of the Child, states that attention must be given to a child’s views subject to the child’s age and maturity. In Scottish Law, a child of 12 years of age or more is usually deemed of sufficient age and maturity to form a view. Younger children’s views will be taken into account where they exhibit ‘sufficient understanding’ (Marshall 1997). However, the Act itself is unclear over how competency is assessed or who assesses it.

4 Marshall (1997) indicates that in a Children’s Hearing when an issue of ‘safety’ arises a parent, judge, or ‘safeguarder may decide what action is in the best interests of the child. However, Marshall (1997) also points out that young people have suggested that those withholding information should also consider the effects on the child of the child uncovering sensitive information by accident.

5 In the interest of confidentiality we do not provide any further information regarding the schools we attended. The study involved participant observation in school and home settings and informal interviews with children and adults. Readers interested in our research methods should see Davis et al. (2000) and Davis (1998), Davis (2000).
children’s rights we are able to contribute to discussions concerning such issues as: who should decide competency, where and how should competency be assessed, over what time span should a judgement be made and what criteria should be employed. Following this discussion we highlight a number of cases of good practice in relation to competency and self-empowerment amongst disabled children. These cases enable us to demonstrate that disabled children, whatever their impairment, can be competent participants in everyday decision making processes when they are provided with opportunities to interact with other children on an equitable basis, their participation is properly planned and not reliant on short term adult assessments of competency, and when they are able to work with reflexive adults. By this we mean adults who understand that disabled children, like other children and adults, are flexible social beings whose behavioural patterns, communication abilities, level of involvement and level of interest will vary over the duration of an activity.

By discussing children’s rights within the context of everyday social interaction, this paper contrasts with much of the literature which deals with children’s rights in the UK. This, in the main, tends to focus on specific issues such as procedures in children’s panels, the use of child witnesses or children’s participation in particular legal scenarios and such distinctive and sometimes quite rare events as divorce, adoption, offending and kidnapping overseas.

Our analysis is located within the somewhat more mundane everyday life experiences of children within educational and residential institutions. By investigating children’s rights in this context we are able to conclude that, although legislation and guidance is important, it will only afford disabled children protection when combined with more local innovation. This should encourage adults and children to understand their interdependencies, act in more equitable ways, and, practise better forms of dialogue and communication.

**Judging competency: How, who and where?**

Most of the guidance and legislation in Scotland that cover the rights of disabled children and their right to have their voice heard and opinions taken into account are also covered by a proviso that the children should exhibit competency. In our experience competency is denied to many disabled children in different day-to-day settings by a variety of adults. In many of the research settings we found little evidence that children were perceived
as active social agents capable of making choices. As one care worker told us:

They find it very difficult to make up their own minds. We have to tell them what they want to do, help them decide.

We soon came to learn that very often children were denied agency not because they were incapable of making choices, but simply because their ability to make choices went unrecognised. In the following extract, the same care worker is talking to Sam:

Sam carries on with tidying up, he knows where everything is and where it goes but keeps on asking me to do things for him. I refuse and he carries on and finishes the task. The helper comes in and sees what Sam is doing and says to me:

Helper: “He’s quite a good man, needs to be directed but he can do it. Aren’t you Sam? Sam are you going to do relaxation after Tea?”
Sam: “I hate relaxation” (clearly and emphatically). Helper: “Sam if you don’t come up with something you’ll have to do it.”

The care worker infringes the rights of Sam by not listening to his views. Impairment is used to justify this denial of rights. In this case, it is because Sam has a learning difficulty and, consequently, is not perceived as being competent. Previously, we have argued that disabled children are not seen as competent because they are seen as different, ‘not like us’ (Davis and Watson, in press a). This difference arises because the children are judged against supposedly objective criteria. For example, the children are seen as not being able to achieve set attainment targets and levels, they are seen as being unable to communicate and interact with their peer group and others and they are seen as being unsafe, a danger to both themselves and those who work with them. We have further argued that these criteria, far from being objective, are subjective and are often imposed unreflexively (Davis et al. 2000).

As Lee (1999) points out, the deferral of decisions of competency brought about by various legislation means that certain children (in his case child witnesses) are put under a lot of pressure to prove their competency. We would argue that many of the disabled children we met were persistently put under the same type of pressure and that perhaps this occurred because they were subjected to adult surveillance on a more routine basis. However, we would not want to mark disabled children as completely different from other children because we are also aware that childhood in the UK is often considered to be a vulnerable time (Jenks 1996) and therefore, that it is likely that all children’s competency is constantly under review by adults.
Very often the persistent review of disabled children’s competency leads to disagreement between children, their parents and different professionals. For example, in the following extract Joe’s mother talks about the conflicting perspectives of Joe’s condition:

If the teachers have got this perceived idea that the child is thick, they pass that onto the child and therefore the child picks that up and they actually tell themselves that they are thick. Now Joe especially, we had that with Joe. When he first went to see the neurologist, and the neurologist asked him a few questions, his answer to the neurologist was, ‘Oh, I cannae dae that, I’m thick.’ The neurologist looked at me as if to say ‘Have you been telling him he is thick?’ Then she said to him, ‘Who told you that, Joe?’ And he turned round and says to her ‘[My teacher] told me I’m thick.’ And you know what it took? Years to get him to break that. Years. We were constantly at home telling him, ‘Yes, you can do it son, just take your time, you’ll manage’. And he was going intae class the next day, and she was saying, ‘You’re thick, totally stupid’. So therefore, whatever we were doing at home, was being broken the next day at the school.

Here, a picture is drawn of a teacher who has not only made up her mind that Joe lacks competency but intends to reinforce that perspective on a daily basis. She also fails to explore and develop new techniques that might enable him to achieve his full potential. As a consequence of Joe’s consultation with the neurologist he was diagnosed with ‘severe dyslexia’ and eventually he received different educational provision. Through these interventions, he was given back competency, his behaviour was understood and, whilst he was still seen as different, he was no longer seen as incapable of agency.

Competency, therefore takes on a temporal role, it is situated and fluid. Though the teacher has a fixed view of Joe as ‘thick’, Joe and other people interpret his behaviour differently. There are multiple competing versions of the real Joe which different adults employ when deciding how to interact with him. Here, Joe and his mother’s sense of injustice relates to the fact that they feel the teacher has been unwilling to question her perception of Joe. Children often told us that they felt some adults had a distorted view of them and their capabilities and that this could create tension between them and their teachers, as in this example with Jane, who was also diagnosed as dyslexic:

When a wis in primary school there was this girl picked on mì and shì stole ma shoes and chuckèd them away in the woods an a told the head

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7 See Corker and Davis (2001) for an example of how competing versions of the real in one setting such as the school are related to information known about a child in other settings such as the home.
teacher and she niver believed mi, like she thought a done it ma sell and she told ma mum ad made it up.

Whether a child’s version of their experiences was respected owed much to whether the listening adult could set aside the label attributed to the child (their willingness to look beyond the child’s impairment), the extent to which the cultural atmosphere of the setting allowed the child’s problems to be addressed (the willingness and ability on the part of adults to believe the child and act on what the child said) and the existence of relevant organisation structures (the ability of the adults to implement, for example, anti-bullying policies within the setting).

Very often adults’ assumptions stem from a lack of dialogue which occurs because an adult refuses to adapt their first impressions of a child or because they fail to enter into dialogue with the child to investigate if their assumptions hold any water. In the following example, George, a boy with severe multiple impairments, is denied competency because the teacher fails to ask a few simple questions:

In ‘symbol class’ the children are doing a story about Simon and the symbols. They have to interpret symbols and say what they mean. In this example they are asked to say ‘Simon likes to go out with his dad.’

Teacher: (To John as an aside but in front of the class) George’s got a brother called Simon, so we’re not too sure if this isn’t confusing.

At the end of the class, John, having earlier been told by the teacher that she thinks that George has little cognitive ability, very little capacity for memory and that he responds ‘parrot-fashion’ to questions, investigates for himself:

John: ‘George whose dads is this? Is it yours?’
George: Dad.
John: ‘A knows it’s a dad but whose dad is it?’
George: Simon’s.
John: ‘Was it your friend’s dad?’
George: ‘Yes.

The teacher here fails to consult with George, to check out if he understands what the symbols mean. Based on her pre-conceptions of George’s ability, she assumes incompetence and attempts to pass this assumption onto John. However, John investigates for himself and finds that George is fully aware of who is being talked about, indeed so much so that a few days later John
checked with George again and found that he still remembered that it was his friend’s father that they had been talking about. Here, George not only establishes his own competency but he also scotches the myths surrounding his capacity to remember things. He does so because he and John are able to develop a dialogue, something the teacher does not do. That is, they are able (as Lee 1999 recommends) locally to resolve the ambiguities surrounding George’s competency through face to face discussion. This requires negotiations between adult and child which are dependent on the context and the attitudes and patterns of behaviour of the adults present (Davis 1998; Roche 1999; Davis et al. 2000). It also requires a shift in the power relations between adults and children, underpinned by reflexive practice. This shift requires the adult to assume responsibility when communication breaks down by posing the question ‘what did I do wrong?’. It is less important who judges competency,8 than whether that person is able to acknowledge that their personal and professional perspectives may cloud that decision.9

Within this context adults may fail to attribute agency to children if they are unable or unwilling to take into account the effect of power relations between themselves and the children they work with. Implicit in the lack of dialogue between George and his teacher is a power relationship. The teacher, by deciding not to ask George more questions, disempowers him at the same time as privileging her own knowledge. Davis (1998, 2000) argues that those who work with children and disabled people should not revere them for their simplicity and assume that their cultural norms are somewhat lesser to their own. He suggests that those working with disabled children have much to gain from adopting flexible roles that enable them to reposition themselves as ‘learner’. However, opportunities for learning tend to be obstructed where the enquirer (such as the teacher above) does not question his or her own assumptions and assumes ignorance in others, whilst failing to consider whether they themselves are ignorant. Those who are to assess competency in others should first be reflexive about their own prejudices. Moreover, they should

8 There is much opportunity for professionals, parents and children to be set against each other in relation to both judgements of competency and decisions concerning a child’s welfare. Though for example the Age of Legal Capacity (Scotland) Act 1991 affirms the medical professionals’ right to judge competency this could be challenged in the court and a judge may overturn a decision by evoking another part of the guidance or legislation. (See Bell (1993) for a discussion of this occurrence in England in relation to the Gillick case, James and James (1999) for a discussion of the problems of the court being the final arbitrator and Morrow and Richards (1996) and Alderson (1995) for further discussion of the Gillick case and the ethics of including children in decision making processes.)

9 However, we also believe that a child, parent, other relative, friend, and various professionals should all play a part in the process of judging competency. Indeed this would not be too innovative an idea within the context of law because, at present in Scotland, all of these people can represent a child in a children’s hearing (Marshall 1997).
question the appropriateness of the criteria by which they judge competency.

Marshall (1997) equates competency with the ability of a child to state a preference but she is aware that other professionals, such as educational psychologists, may have different perspectives from her. There has been much recent criticisms of developmental psychology and ‘medical model’ tendencies to judge disabled children by ablest test criteria (Shakespeare and Watson 1998; Priestley 1998). At the centre of this criticism is the belief that it is wrong to pathologise disabled children because they do not achieve specific age related targets. Further, the testing of children is centred around Anglo-centric notions of normality which do not account for culture and context (Woodhead 1998; Woodhead and Faulkner 2000; Alderson 2000). As Alderson states when discussing measures of ‘normality’ in comparison to measures of average height expectancy:

Abilities are similarly measured for ‘normality’ without taking much account of how much children’s abilities vary depending on how and where they are tested, how much help with the task or previous experience they have, and many other factors. Thus, ability is turned into a static thing, instead of being seen as widely varying responses depending on the context and relationships concerned. (2000: 55)

It would appear that many who measure for ‘normality’ forget that children are flexible social actors (James and Prout 1995) and that they behave differently depending on the social context and who is present. Cockburn (1998) tells us that: ‘Incompetence is not something natural or innate but is socially produced . . .’ (p. 109) ‘It is necessary to replace binary characterizations of people such as immature/developed; mobile/disabled; competent/incapable; included/excluded, and adopt less dichotomized ways of identifying people’ (p. 111). These authors are arguing against fixed notions of competency in childhood and they are supported by some psychologists who are critical of practices within their own paradigm.

Woodhead and Faulkner (2000) point out that researchers within the developmental paradigm have, by contemporary standards, been neglectful of the ‘rights, feelings and potential of young participants as social actors’ (p. 13). They point out, citing Donaldson (1978) in relation to the work of Piaget, that when the context of a test is changed children are observed to demonstrate more ‘sophisticated’ reasoning than Piaget had claimed and (drawing on Vygotsky) that laboratory studies of children often ignore the social construction of knowledge and the impact of the presence of the psychologist and other children on the child being assessed. As such, these works bring into question whether there can be such a thing as an objective test
of competency and warn us not to privilege one academic paradigm over others.

Elsewhere we have argued that crucial to the process of developing avenues of communication is the amount of time an adult spends getting to know a child (Davis et al. 2000). On our project many hours of participant observation were carried out (at home and in school) with the various children who participated in the project. By visiting the children over a number of months, and seeing them with different people in different settings, we learned a lot about the variability of their lives. As such, we would caution against the use of short term, one visit, tickbox, assessments of competency. A person visiting a disabled child for a few moments on a specific day might gain a completely different impression of the child’s abilities than if they had visited at another time. Not least as Davis et al. (2000) point out, because automatic co-operation with strangers might not be a behavioural pattern that the disabled child (or anyone other child, Trisiliotis et al. 1995) wishes to comply with. Many disabled children are aware that adults pathologise them on the basis of apparently objective biological, educational, social or cultural criteria (as Tommy will point out below). Hence, as a result of this it should not be assumed that disabled children’s non-compliance, silence, or resistance is a sign of incompetence.

We not only found that children’s behaviour varied, but we also found that not all the adults who work with children in institutional settings exhibit the same behavioural patterns. Often members of staff highlighted differences between themselves and their colleagues. For example, one teacher described to us what she called the ‘She doesn’t like Ribena syndrome’:

Children come here aged four to five and on their first day here are offered the choice between Ribena and orange juice. The child chooses orange and its assumed forever more that they don’t like Ribena and they are never again given the choice.

This anecdote serves to illustrate that value systems develop over time, and that staff have long term knowledge of the children, which, if used unreflexively, inhibits the ascription of competence. This also serves to warn us that although those who have worked longest with disabled children may be best placed to judge competency, this will only be of benefit to the child, if the adult does not resort to stereotyping.

Relationships between staff and children were built up over many days, months and in some cases years and we found that competence was often denied to those children who an adult, for whatever reason, did not like. George, for example was seen as a particularly troublesome child, people commented on how difficult he was to toilet, to lift in and out of his chair and
to feed. Some staff developed fixed, unyielding notions about the children based on either their own past relationship with that child or from knowledge inherited from colleagues. As well as competence being ascribed on past and present knowledge of the child, it was also based on adult perceptions of what a child might achieve in the future:

We know that they are not going to get jobs after they leave here, so why does it matter if they can’t tell blue from red. OK its good they know but I think it’s more important they have fun when they are here. (care worker)

Although this comment might be interpreted as philanthropic, it is, in effect a denial of the right to education. Again, this statement relates to the notion that these children will not achieve universal developmental targets, and, consequently, are incompetent. We are particularly concerned that children who are already judged as lacking because they have failed to meet developmental targets in their past and present childhood, are denied competency because adults perceive them to be incapable of achieving specific outcomes in their futures. Our concern relates to the potential that this judgement becomes a self-fulfilling prophecy.

As above, the process through which these judgements occur is related to the context where adult-child interaction takes place. For example, elsewhere we have discussed how streaming within schools affects the way adults and children attribute status to each other’s beliefs and actions (Davis and Watson in press a). We also found that competency in a residential setting was judged more on social ability than academic ability. As a care worker told us:

It’s more their physical capabilities we’re looking at rather than their academic ability. It’s more their social awareness and interpersonal skills.

All these data point to a social construction of competency and maturity across sites, across people and across belief systems. This suggests that if disabled children are to be afforded rights in various settings, rather than searching for a universally accepted criteria by which to assess competency, it may be better simply to assume that all children of what ever age and maturity are capable of contributing to discussions concerning their lives, and place the emphasis on developing techniques and avenues of communication which make this possible.

10 Within this context it should not be automatically assumed that the ‘best’ techniques for listening to children are to be found in the new sociology of childhood. As argued elsewhere (Davis 1998; Davis et al. 2000) these techniques are only as good as the reflexivity of the person who employs them and they may be alien to many children due to cultural or biological factors.
This will be a difficult task, as it will require the transformation of child-adult relations (Roche 1997). However, it will not necessarily be an impossible task because children are already a central component of social relations (Cockburn 1998) and, as we shall demonstrate below, examples of good practice already exist which can be utilised to encourage more equitable relations between adults and children.

Supporting children to speak for themselves: Competency and self empowerment

So far we have dealt with negative experiences concerning issues of competency and disabled children and our concerns surrounding the way in which competency might be established. It is important to note that the negative cases we have used above are not the end of the story and we have encountered a few examples of good practice in school and residential settings. In this section we document examples where disabled children were assumed to be competent and illustrate how this assumption enabled them to empower themselves in relation to making choices about issues concerning their lives. In so doing, our aim will be to highlight the need not only to afford disabled children rights in various settings, but to set up structures and ways of working with disabled children which enable them to confront disabling practices themselves.

We illustrate three different approaches to self-empowerment. In each case, processes of empowerment are instigated by adults and involve children participating in different ways. There are two key elements in all these examples. The first is that the adults question their own interpretation of the child’s behaviour; the second is that they offer the child the opportunity to state their own views.

First, is the example of Wilbur, a child diagnosed with Asperger’s Syndrome who was under threat of exclusion from his mainstream school. This example is, initially, completely controlled by adults. Wilbur’s behaviour had started to deteriorate and, in one term, he had seven letters of referral from various teachers all complaining about his behaviour. However, one teacher submitted three letters that described how his behaviour had improved and also pointed out that he was being bullied by other boys in the class and how other children were leading him astray and using him. The school set up a monitoring system and observed him for a term (twice a week) and came to the conclusion that his behaviour was a result of his reaction to other children. They decided not to recommend he move to a special school. This sort of example enabled us to realise that sometimes listening is actually seeing,
giving competency is as much about observing the children as it is about listening to them (see also Corker and Davis 1999).

In our interviews with Wilbur he told us how much he liked the school and felt that it responded to his needs. In the following extract the difference between his experience and that of Jane, above is made clear.

John: You were saying you get bullied?
Wilbur: Well if they hit, hit me, and stuff like that then they just run away. They know that, they know that, know that an adult’s coming. They run away.
John: So is there a structure in the school – like a way of?
Wilbur: Well they pick it up quickly here – They just excluded straight away.
John: Right. So it’s quite strict. Well that’s my word. But do you think that’s an appropriate response?
Wilbur: Yeah. ‘Cause I was getting bullied and he was just taken up to the office, and he got excluded straight away cause this school, they’re dead against bullying.

This, however, takes time. Wilbur was observed for twenty hours and some staff were also prepared to accept his behavioural difference and not to pathologise his behaviour as essential and innate. They did not automatically assume that his behaviour was caused by his impairment. As such, their approach was more progressive than that of most of the adults in other schools we visited.

In contrast to this example where adults took an active role in assessing Wilbur’s competence, in the next example we describe how Tommy, a boy with a mobility impairment, tried to overcome the prejudice and discrimination that he was experiencing in his new school. Here, Tommy and various adults work together in an attempt to highlight Tommy’s competency to his peer group.

Tommy lived outside the usual catchment area of this school, but went there because of its accessibility; consequently, at first, he did not know any of the other pupils. Since arriving at his new school, Tommy had felt unable to make any friends, he felt excluded by all his peer group and was not enjoying himself. His solution to the problem, which was negotiated with both his teacher and his mother, was to talk to his class about who he was and what it meant to him to be a disabled child. The other pupils asked him questions about himself and, throughout the discussion with his classmates, he kept on reiterating how he didn’t feel any different from them. For example, one boy asked him ‘What can’t you do?’ he replied:
I’m actually the same as anybody else . . . most people think that disabled people sit in their homes crying because we wish we were like them. But I don’t do that. It doesn’t affect me. It doesn’t affect my personality. I think, what you see is me. I don’t want to be any different.

Most of the children wanted to know what he couldn’t do; could he get up stairs, could he draw, do PE, and so on. Some of the questions made us, as researchers, uncomfortable. They could be described as prurient, as invasive. Tommy talked about how he didn’t like being stared at, yet what was happening here was the equivalent. We questioned the ethics behind this enterprise. However, if we accept that Tommy is a competent agent capable of making up his own mind and putting his own point of view across, then do we have to accept the validity of his choice? As Tommy said at the end of his talk

I’ve really enjoyed being able to talk. Do you think you’ve learned anything?

To which the whole class replied ‘Yes’. In a later interview Tommy was asked if he felt that his talk had had any long-term effect. He replied ‘People are more relaxed with me. Beginning to chat and so on, on things and they will listen but only to a short thing’. Following the talk he had gone out with a number of his classmates to the cinema and for day trips into the city centre. In that respect, it had been a success. However, it had also been a strain on him and he later commented about how he didn’t want to spend his whole life ‘battering down walls’.

This example is important because it illustrates that in the everyday flux of disabled children’s lives the way that guidance and legislation deal with issues of competency are unimportant in comparison to assessment by peer group. We would also suggest that this is the case for non-disabled children. Thus, though the guidance and legislation which underpin children’s rights are important because they set precedents and act as stimulants for change, they do not in themselves enable children to have rights. What enables children to exercise rights is acceptance by other children and adults. Children’s rights are intertwined with relationships and anything, which enables the establishment and maintenance of empowering relationships, will also act to support the rights of children.

This finding is supported by the data in our final example which, when compared to our early example of George, demonstrates that children, whatever their impairment, when given the right circumstances, are capable of agency and competency. Here, we present some edited field notes from a weekly committee set up by children and young people in a residential setting. The children range in age from 13 to 17 and include children with
learning difficulties and other impairments. It is a large data extract, but is included to show the extent to which the children and young people are able to come to their own decisions. A care worker (Bill) facilitated the group. The children themselves had set up their own ground rules for the group to ensure that all the members were heard. They took it in turns to chair the meeting and in this meeting Suzie, a girl with learning difficulties, was chairing:

Suzie’s leading it and Gary says “I want to do something next Tuesday.” Joe says, “But I’m away on that day.” And they say, “Yeah, it’ll be quite nice to go out to a café.” But Joe wants to go, so Bill, rather than intervening, gets the two boys to negotiate and to decide on what day they want to go. The meeting is held up again because they suddenly realise that Cindy isn’t there. So they all wait for Cindy to turn up. And Suzie says, “Now Cindy’s here, we’ll start the meeting.” Which seems very confident and is kind of breaking down my original view of her. She’s very capable of doing this, taking on this role. It’s just that she has a different way of behaving. Jerome prints out in handwriting what’s been said in the meeting and Lucy types it out in Braille. The first thing Suzie talks about is African Café and Joe says, “When is it on?” And Suzie doesn’t answer the question but says, “They’ve got a Braille news there.” Lucy says, “The problem is what kind of food do they have?” And Joanne says, “Here’s the menu.” Gary reads it out “There’s ostrich on the menu”. Cindy says, “Ooh that’s terrible. I’m not going.” Bill intervenes and says, “It could be quite good to go on Tuesday the 20th, but some of you are away.” Suzie asks “What about tonight? Cindy, Kerry, Lucy and me are going out tonight for a walk. Maybe we could go to the restaurant as well and try it out and tell you about it.” Kerry says “Oh, we can just get a bus round.” [Discussions continue and they talk about going to the cinema at a later date] Lucy says “Wait a minute. That means that, that Cindy’ll be on her own here for half an hour.” Cindy interrupts and says, “That’s ok I’m used to that.”

Another child, Fanny says that there’s a musical called the Sound of Boogie Nights and she really wants to go. The children pick up on this and immediately say it would be a good idea. But again they had to enter into the negotiation of what day to go and that was quite interesting. Once they’d worked out a day Gary said, “Who’s going to get the tickets?” Bill said, “Would you like to do it?” Gary, “Yeah I’ll do it. We’ll walk up there one evening this week and I’ll do that.” The adults only rarely organise something, once they decide to do something the children have to go and get the tickets.
In this example, Bill has allowed the children to make up their own minds, and they were able to negotiate their way through some fairly complex issues and ensure that the voices of all the members of the group were attended to. These data clearly show that, in the right circumstances and if given the opportunity, these children are capable and competent.

The way ahead

Through these data excerpts we have shown how, in many cases, despite the existence of legislation such as the Children (Scotland) Act, disabled children are often denied competency and their opinions are often ignored. We are not in a position to state if this is unique to disabled children or is simply a reflection of how all children are treated (our instincts would suggest the latter). However, what it does show is that despite the laying down of a procedural base for the bureaucratisation of children’s rights, in the mundane, day-to-day lifeworld of disabled children, these rights are often denied. The Children (Scotland) Act creates legislation and sets up a discourse which suggests that children’s rights must be taken into account, but it appears to act more as an appeal to progressive change rather than an effective mechanism to achieve such change. It provides a discourse behind which people can claim that they are doing something but does not allocate an effective voice to disabled children. This situation is compounded by the fact that much of the legislation surrounding children’s rights is set within guidelines and not laws and, therefore, does not afford disabled children, or non-disabled children, strong protection (Tisdall 2000, personal correspondence).

The solution may, at first glance appear to be a widening and tightening of legislation, so as to ensure that the rights of disabled children are met. Yet as Mason (2000) has argued, legislation is often ignored. It frequently only sets minimum ethical standards and does not provide protection, except in extreme cases. Further legislation may only serve to increase the distance between disabled children and non-disabled adults, or it may do more harm than good (James and James 1999).

We would argue for a multi-layered approach to disabled children’s rights, which as well as a strengthening of present guidance and legislation would require local authorities to invest in a number of training programmes for all staff. These programmes should include: equality training, a greater emphasis on reflexivity and an encouragement to question everyday practices. As Lee (1998) points out, central to this process would be the identification of ambiguities at the local level and face to face negotiation between the children and adults present. We would look for more sophisticated local ways to uphold the rights of children. Indeed, in the cases highlighted above, good practice
occurred in different settings (school classrooms and residential units), with children with different impairments and with staff from different professional backgrounds (teachers, teaching assistants, care assistants, social workers). The legislation and guidance which encourages adults to include children were different in each location, yet the children and adults present did not allow those factors to deflect themselves from trying to create a more equitable environment through observation and dialogue. In a Durkheimian (1964) sense we are arguing that because rules are interpreted at the local level, the opportunity arises for good practitioners to emerge who are able to interpret the rules in ways that benefit the children. This is in keeping with those who argue that good practitioners are often adept at adapting rules in particular contexts (Jordan 1994).

The examples of good practice illustrated above required the adults working in each location to be proactive. Their aim, particularly in the case of Wilbur, was to prevent relations deteriorating to the point where the law might be invoked. We would suggest that it is crucial that disabled children should not have to seek judgments in the courts against education authorities because their rights are not recognised. Going to court is often painful and, because of the lack of disability awareness in legal settings, is an extremely risky processes. There is considerable debate as to whether legislation ever provides disabled children with protection of their rights. Corker and Davis (2001) have argued that there is little mention of the rights of disabled children in the various books about children and the law; the dominant discourse in law views disabled children in terms of dependency, vulnerability and protection and that law in itself is very often individualising and dehumanising. They also illustrate, as we have, that despite some cases of good practice, local interpretations of the law and policy result in ‘wide spread abuses of the human and civil rights of disabled children and the silencing of their voices, rendering them invisible under the law’.

Hence, as well as legislation and guidance, what is required is that those who work in institutions are encouraged to communicate and negotiate more effectively with children. We are not only arguing for structural change at national and local levels, we also believe that children themselves can be central to the processes of change. Our hope is that examples such as the ones above, where children are entrusted to create their own self-empowerment, can become an everyday occurrence. We are, however, not trying to promote the concept of an autonomous child (Cockburn 1998). In contrast to this construct (and in keeping with Cockburn 1998), we believe that the examples we have employed above demonstrate the need for co-operation between adult and child. However, this process requires trust to develop between adults and children and this is not helped by discourses which assume children are
sources of trouble (Roche 1999), or which judge children against normative standards and future potentials. It will require a rethinking of the language of rights and citizenship. As Roche writes:

We need to think through the terms on which participation is being offered, to be aware of the context in which children are being 'invited in' and the risk of responsibility for making a decision being thrust upon children in circumstances not of their choosing. The languages of participation and empowerment are cosy but we need to be more critical of the circumstances of inclusion and the kinds of adult support (e.g. advocacy and representations) that children might need. (1999: 489)

References

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