



## **Working with children and families**

### *Children and disability*

#### **RONNIE FLYNN**

Phillipa Russell's role in the Council for Disabled Children has meant that she has paid particular attention to the way in which disability has been treated by the government. She begins by discussing recent changes in the law.

#### **PHILLIPA RUSSEL**

I think there have been, the two most significant changes in policy and practice have related to two pieces of legislation. I have a disabled son myself and I think the thing that has made the biggest difference in his life are the changing legislation policies, practices in education. When Simon was born he was regarded as ineducable which basically meant he was not offered very much except custodial care, well meaning but not interested in his overall development.

I think the other major change has been a real re-focusing in terms of quality of life of disabled children and, and the type of care which is offered to them. When my son was born it was common for children with a learning disability to end up in long stay institutions, in mental handicap hospitals, because it was believed that children with disabilities were better in a health service setting, but of course we know now that those children were deprived of stimulation, they were deprived of affection and even though their physical care may have been all right, it was inconceivable that they would develop normally and grow up happy, well-adjusted children, or well-adjusted adults, I should say. We now know that the quality of care, the personal relationships matter a great deal, and the Children Act 1989, by bringing disabled children firmly within the framework of services, care, rights for all children, has, I think, brought about a real sea change.

#### **RONNIE FLYNN**

There has been a change in the way that disabled people have reacted to their social status.

#### **PHILLIPA RUSSEL**

I think the Disability Rights Movement has had a very important impact on the way that services, disabled people, parents, think about disabled children and disabled people generally. I think disability rights came relatively late on the scene as compared to the rights of people from minority ethnic groups and rights relating to gender and sexual orientation, and of course the rights of women, but the rights of disabled people really emerged as disabled people felt themselves more confident and more empowered to actually say that they were citizens like everybody else, that they could make a contribution to society, and that the real challenge of disability was not the disability, but the barriers which society put in the way of disabled people in achieving a good quality life.

#### **RONNIE FLYNN**

Philippa believes that disabled children should be actively involved in deciding about their lives. She sees inclusion as key to enablement.

#### **PHILLIPPA RUSSEL**

I think one of the big challenges has been for organisations like ours which is a children's organisation, to actually ensure that children start very, very early on recognising that whether they have a disability or not, they have a right to be involved in decision making, they have important views which deserves to be heard, they should be able to plan ahead and think what sort of life they want when they become adults, and they should have the opportunity of meeting other disabled children and disabled adults as role models, so that they understand there is indeed a positive future out there.

However, some disabled children do have real communication problems. Many disabled children have been dis-empowered because nobody's ever asked them to express a view about anything, even about what they would eat for breakfast or what sweater they would put on to go to school. Many disabled people lack the financial support and the transport to actually get to places where their views would be heard. There's ample evidence which shows that families with disabled children are likely to be much worse off than other families, that in effect it costs three times as much to bring up a disabled as a non disabled child. So parents may simply not have the opportunity to get the disabled child out and about so that he and she, he or she feels confident to play a full part in the community.

One group of young people we worked with in a respite care service decided that they would regard themselves as AA inspectors, and actually look at the service as if they were paying customers, and some quite interesting things emerged about what the young people wanted, and what those providing care wanted. But what was important was that they were actually willing to work together to provide a better service. The young people still wanted to use the service, but they actually wanted something that was appropriate to their age, to their interests, and which didn't present them with poorer care than they actually got at home.

### **RONNIE FLYNN**

The Barnardos Family Link project places disabled children with Link Carers who look after them for short-term breaks. Annette and Merenisha have worked for the project for several years and both favour inclusion.

### **ANNETTE**

When I have the children or the child that I've got now, I do as normal things as possible, like we go shopping, we go to the park, I visit family, I make sure that the child fits in with whatever we're doing, and if my son's friends come round, if it's appropriate, that they include that child as well. We do a lot of things out, outside of the house as well in a community, you know. We'll go to arranged social events and we do lots of things out in the community and at home I try to always make sure that he's included in whatever we do.

### **MERENISHA**

They feel like we are not only disabled, we can play with them and we can mix with other children as well, and we can like enjoy ourselves with them as well, they think we are not like, visible and we don't need for somebody's caring all the time you know, that's what they think if they mix with other children.

### **ANNETTE**

I do think that some things need to be separate but on the whole as much as you can, I think children need to be included as much as possible. There are some things that they might have to be exclude, or might have to have one to one for, but if children aren't given other role models, then you know, they're never going to be able to develop, you know to to help their communication, to help their physical skills and their other needs. They definitely need, you know, mainstream children around them as well, and other role models to help them in their development.

### **RONNIE FLYNN**

Partners in Play is an after school and holiday project that includes both disabled and non-disabled children. A parent, a worker, and some children who make use of the project, discuss the advantages of its inclusive nature.

### **JANET**

The advantage of it is that it breaks down barriers to disability and it provides a model that can be adopted widely. I think Francis could give you quite a good example of children who are now part of their own communities because, for different reasons children do go to separate and special schools or are sent outside their communities. So by having something in their communities, they're part of that community. They've also got the advantage in that, they're going to the same groups and the same activities as their brothers and sisters, and they're not seen as separate and very different, and it's recognised that they do have rights. I

think the project has proved that that has been successful, and that, you know, families are saying to us, it's absolutely great you know, so-and-so's recognised now and people are actually saying hello. So that's the one big advantage. Plus for a parent it's down the road, you're meeting other parents. You're accessing something on the same level as everyone else, an out of school club. It also gives you the opportunity to have some time to yourself, and huge benefits and huge barriers have been broken down by having this kind of provision in local communities rather than specialist, separate, which you know just compounds the differences.

### **FRANCIS**

I think that for a lot of us whose children have, need special education to be delivered away from their local communities, we find our children are very isolated little beings, and that, the project offers within our community a chance for other children to become aware that our child is not so different, is not so disabled as they may think. I've had experiences of children walking round and round my wee boy in a supermarket because he just looks so different, but if I met a child who's been to a play scheme with him, the experience is totally different, they just run up and, they know he can't see so they come and they touch and they've learned by watching adults handling him, how they may handle him. So the inclusion comes from people seeing our children as just a normal part of the community, instead of everything that he has to go to having to be a separate provision.

I think there are barriers that still have to be broken down. I think that we're dealing with after school clubs who are willing to have our children with the additional support, but still lack the confidence in many instances, to take over that role. That is our job as a scheme, to build bridges to help them realise that they can handle children regardless of their needs. That hasn't come to full fruition, but we're working towards it.

I think that, regarding other disadvantages not socially for the children, I can't think of any, I just think that you have got to be realistic and say 'right at the stage we're at just now, we're going through a process, we're knocking the bricks out of the wall, but the wall isn't completely broken down yet'. So I would rather be realistic about it than just assume that everything is rosy because it's hard work. But that's why we as parents are willing to give our time because we think it's worthwhile.

### **CHILD**

There shouldn't be a club without disabled children because they're just the same as everybody else, and they should be treated the same as everybody else, because they're no different.

### **CHILD**

I don't know another reason why I'm special, it's usually other people that tell me, but I think I'm special because I've got a loud voice!

### **CHILD**

I think playing with disabled children is just the same as playing with other children, non-disabled, because they're just really the same only, they've got maybe something wrong with their eyes or their hands or anything like that. So, I don't really care who I'm playing with, I'll play with disabled or non-disabled children.

### **CHILD**

Everybody's just the same, they're not, whoever's disabled or non-disabled, they're just the same as other people who are non-disabled and they can, they can do what other people do.

### **RONNIE FLYNN**

Philippa Russell's experiences with her son reinforce her belief in inclusion.

### **PHILIPPA RUSSELL**

I well remember when my son was four years old, the children in this road all had wonderful birthday parties, and Simon had a brother nine months younger, ten months younger than he did, and Christopher was always asked to the parties and Simon wasn't. And I decided that I

would, that I would actually set an example for inclusion, so I gave the best and biggest parties in the road, and I knew the parents were much too polite not to invite Simon back. But the interesting thing was that when they invited Simon back, their comments - notwithstanding their nervousness - were all extremely positive. They said how guilty they felt, they hadn't realised that Simon was such an attractive, friendly little boy, that Simon actually behaved a whole lot better than a lot of the other children at the parties. And when they saw him enjoying himself, and doing the things that other children enjoyed, they suddenly realised that inclusion was possible.

### **RONNIE FLYNN**

She goes on to give an example of the benefits of inclusion to the community as a whole.

### **PHILLIPPA RUSSELL**

There have been some very interesting developments in making services accessible to disabled children. I can think of one example where the local authority and a local organisation of disabled people, and a local community group, Bangladeshi parents, all worked together to see how the local leisure centre could become more accessible to disabled children, because a lot of the disabled children and the parents were saying 'we don't want separate provision for our children. What we would like was some additional support and some adaptations to the leisure centre so that everybody can go together, but we have to feel that our children are safe'

And those three groups working together, disabled people, parents from the Bangladeshi community and another parents organisation and the local authority, and the, of course the leisure service, really were able to introduce a very good access programme. They provided a number of different supports. They recruited and trained some what they called 'specialist child minders', and the specialist child minders were not child minders in the usual sense of their word but their role was to be an outreach worker or support worker to individual children, to introduce them to leisure activities, to support them as intensively as possible but with the hope that a lighter touch support would work in the end. They worked with a local community nurse from the community learning disability team to provide very specialist personal support for two children with very challenging behaviour and autism, and they liaised with a local organisation of physically disabled people about introducing a three year plan to improve the physical access within the leisure centre.

Some of the short term measures simply involved using another door to get into the gym, installing some portable ramps whilst the money was raised and planning permission sought to introduce more permanent access, and looking at the colour schemes to help a significant number of visually impaired children who happen to live in that particular authority. So it was a corporate effort. A lot of the initiatives to make that leisure service accessible were really quite low cost, but it was beneficial to everybody.