

# **About Parents for Inclusion**

# Our vision:

Our vision is a society where all children, including disabled children, are loved, feel secure, flourish, make friends and are happy at school.

Disabled children are all those children who experience discrimination as a result of their condition, whether that be a physical or sensory impairment, learning difficulties, special educational needs, emotional or behavioural difficulties, or as a result of experiencing distress.

We consult with young disabled people and disabled adults. They tell us that disabled children long to be fully included in their local community and to have access to transport, play, leisure and friends. We believe that it is physical and social barriers which prevent disabled children being included, rather than the disabled children themselves.

Children may have little power to ask for what they want. Children tell us they want to be able to make friends and be involved in their local community. They want to be able to get out and about, meet new people, enjoy their leisure time and go to their local school.

Parents and professionals have great influence over these children's futures. So we work with them to help them see children as individual people first, with human rights and preferences and a right to an optimistic and self determined future. They then go on to make sure these children are included, in all kinds of ways, in the world.

All our work is aimed at improving life chances and the quality of life for these children.

# Our mission:

### Our mission is to:

- Help disabled children be included in their schools and local communities
- Give parents the tools to plan a positive future together with their disabled children
- Bring about a change of attitudes so there is less discrimination towards young disabled people
- Provide effective advice, information and training to parents so they can help disabled children take control of their own lives
- Encourage closer working between parents and professionals to benefit as many children as possible.

1.6 million pupils are said to have Special Educational Needs but no Statement.

Audit Commission November 2002

1 in 5 of all children will have special educational needs at some time while at school.

DFEE, SEN in England 2000



Parents for Inclusion Review 2002 - 2004

## **Message from the Chair**



Parents for Inclusion has expanded its work in so many ways in the last two years. We ran two conferences on our work with families from Black and Minority Ethnic backgrounds. We trained more inclusion group facilitators than ever before and dramatically increased the number of inclusion groups we run. We grew our capacity to answer helpline calls. We are also particularly proud that our Early Years programme is making such a difference to disabled children right from the moment they are born. I am delighted to be involved with such an important organisation, which is making a real impact on disabled children's lives.

As a mother of three disabled children myself, I know only too well the dilemmas which may face a parent of a disabled child. Often parents can be very unsure whether to send their disabled child to a special school, or keep them in mainstream education and in their local community.

Parents for Inclusion has a reputation for excellent working relationships with disabled people. Prejudice against disabled people is still not recognised in the same way that other discrimination is and is therefore much harder to challenge. Children with special educational needs are frequently disadvantaged in having their needs unmet or underresourced, and often face the threat of exclusion. Disabled children are also very likely to be poor and to suffer multiple deprivation. We listen to disabled young people, and inclusion is the course of action they consistently recommend.

We know that disabled children who make a successful transition to independence in adulthood usually do so because their parents have been their advocates and been on their side. The disabled young people we talk to tell us that having supportive parents who have high expectations for their child's future is the key to a child getting the life they want.

Citospo

Catherine Hodgson

Parents for Inclusion does a brilliant job by helping parents to champion their own children's inclusion in all kinds of ways. We believe inclusion provides the best possible life outcome for all young people. It is truly amazing to hear just how our work is making such a difference to disabled children and their families. We were delighted that in April 2004 our excellence was formally recognised by the Mayor of London who made us one of his charities of the year.



# Helpline

Our helpline is used by both parents and professionals and takes calls from all over the UK. During 2002 we began to receive calls anticipating the introduction of the new Disability Discrimination Act which came into law in September 2002. Many schools were slow to implement the change in the law and this meant helpline calls were mainly about how to make reasonable adjustments to meet children's access needs. This trend has continued.

### More hours

We extended our opening hours and are now open - Monday, Tuesdays and Thursdays, 10am - 4pm and opened the line for part of the school holidays too. We also began to train up more parents of disabled children to come and work as helpliners and in 2002 took one on as a paid helpliner.

The length of an average call has also increased in the last 2 years to 20 minutes. This reflects the way we listen to the caller and carefully help them to consider various options which might

promote a child's inclusion. We encourage parents to attend our training, to pick up more strategies and we find many callers take up this offer.

### Freephone

In November 2003 we introduced a new freephone helpline number sponsored by The Goldsmiths' Company. The number is free for callers using landlines. As the majority of our callers have an annual income way below the national average. we felt this would be a very welcome improvement. We have noticed a marked increase in callers and a lot of the families we help are very poor indeed.

This means that during the last two years we have been able to offer more help and up to date advice than ever before and, as a direct result, more children have been included at school or in the community.

Pi's helpline is regularly used by members of the black and minority ethnic communities who constituted 45% of callers in 2003, rising to 57% in 2004.

### 0800 652 3145

Our helpline co-ordinator contributed to a new book for teachers: "Making It Work", which explains how teachers can make schools more inclusive for children. It includes guidance on buildings, curriculum, training and contains case histories (available from the National Children's Bureau.)

A textphone is available too.

# Callers on 100% low-income: 71% 62%



2003 2004

### The helpline is one of our core resources. We want to:

 run a helpline publicity campaign so we can reach

even more families with

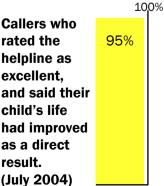
to five days a week

What we want

to do next

- disabled children extend helpline opening hours
- pilot evening sessions to reach those parents who work during the day
- encourage more parents of disabled children and disabled people to join our helpline team
- train bilingual helpliners so we can offer advice in other languages.

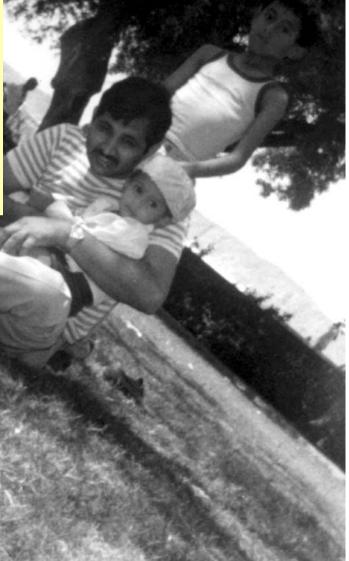
Callers who rated the helpline as excellent. and said their child's life had improved as a direct result.



### Darren's story

Jane's son Darren is a wheelchair user. He is due to start school next September but as yet his school is not accessible. The Local Education Authority has offered to initial a "cheap" option and install a lift costing £35,000, as opposed to one costing £119, 000. However the cheaper lift is unsuitable because it is away from the accessible loo. The school has an anticipatory duty under the Disability Discrimination Act to meet the needs of all children. The LEA is basing their decision on money, rather than making a reasonable adjustment to meet access needs. We had a phone call from the head teacher asking where he could get funding for this lift, as his funding budget for the whole of inclusion was £135,000. He was happy as we could refer him to a booklet produced by the DfEs called "Accessible Schools" about funding and how he could apply for it.

"They were very encouraging and pushed for the highest possible solution. I understood the trouble was not because of my child's disability but because of the people I have to deal with, which made it seem less of a problem. They gave me hope to accommodate my child into society and accepting my child as he is. I started thinking more deeply about this situation. The focus was shifted from my child to myself. I have never encountered people who knew exactly what was going on in a family like mine, I did not have to do much explaining." Parent on our training



# **Training**

All our training is designed and delivered in partnership by experienced trainers. One trainer will always be disabled themselves, the other always a parent of a disabled child.

### Parents hear from disabled adults

Listening to disabled people allows parents to step back and see the world from their child's point of view. The disabled trainers use their own real life stories to illustrate the training and they present a positive role model of how a disabled child can grow up into a successful adult. We help parents feel better equipped to take an active part in facilitating an independent life for their child. We help them think about making sure their child has access to transport, play, mainstream education. leisure and friends. Our workshops help parents and their children to plan together to come up with innovative and practical ways in which these children can be included in their everyday life. We also introduce parents to disabled people in their area.

### **Inclusion Now Summer School**

In July 2002 we participated in running a very sucessful four-day Summer School event at Nottingham University, together with disabled people's organisations; the Alliance for Inclusive Education, Disability Equality in Education, the Bolton Institute of Higher Education and Inclusive Solution's team of educational psychologists. It supported networking between different agencies and looked at all the different ways inclusion could

be supported nationally. Over 300 teachers, social service and health professionals, disabled people and parents of disabled children and allies attended it. We offered talks, workshops, and seminars, inclusion group demonstrations and networking opportunities. Suresh Grover, Chair of the National Civil Rights Movement gave a presentation on equality. We also ran a theatre forum where actors portrayed typical situations faced by disabled young people and their parents and invited the participants to share their own stories to help the group come up with inclusive solutions.

### **Demand increases with change in law**

In September 2002, the new Special Educational Needs Disability Act (Part 4) finally came into practice. This meant that schools were no longer allowed to discriminate against disabled children and had to make sure their school was ready to welcome all children. From this point on we experienced a very high demand for our training.

In 2002-2003 we trained 309 Headteachers, teachers, learning assistants and Special Educational Needs Co-ordinators who wanted our help in making their schools more inclusive. In 2003-2004, this figure rose to 365. All our training raises awareness of the Disability Equality issues that affect families in their daily lives. Professionals say our training helps them become more aware of what they can do to fully include children in their schools. We reached another 200 people through outreach events.



"What could be more powerful than to be able to release a parent from the incarceration of thinking that their disabled child has no future .... discrimination against any child is a punishment that no parent should have to bear."

Michelle Daley, Disability Equality Trainer



Parents for Inclusion Review 2002 - 2004

# ... more about training

### We begin to work with health services

2003 also saw us begin training health professionals in inclusion in response to a demand for greater understanding of how inclusion can benefit the health of patients. We trained 87 student nurses from St Thomas's Hospital, 54 student nurses at Kings College and 13 specialist health visitors in Bermondsey on good inclusive practice. We also trained parents and professionals from the South Lambeth Opportunity Group on inclusion skills and young people at Youthbank's National Conference on how they could involve more disabled children in other Youthbanks around the UK.

### Flexible ongoing training for parents

Parents of disabled children can improve their inclusion knowledge and skills by attending our Training Pathway. We run our Training Pathway flexibly so parents can easily opt in and out, as their commitments fluctuate and resume training once their individual circumstances allow. Through our Training Pathway we actively recruit parents

who feel they have the time and space to help us offer services to other parents. We train them to help deliver the helpline, our training and inclusion groups. In 2003, 27 parents began training on the pathway and in 2004, 16 more parents joined the programme. We also trained two young disabled people to deliver our training and ran a pilot project, successfully training a person with learning difficulties to deliver our training too.

### **Work with Sure Start**

Because of our high reputation, North Leyton Sure Start commissioned us to develop a new training for them "It takes a village to raise a child". We trained Sure Start parents in training and facilitation skills and helped them develop more confidence, and a greater understanding around valuing and celebrating diversity. After this training these local parents were equipped to become members of the Sure Start Board, with a clearer understanding of how they could build inclusive communities. We were also asked by Gingerbread and the British Institute for Human Rights to advise them on their disability rights training.

"For many non-disabled course participants, both professionals and parents, meeting a disabled professional is still an unfamiliar experience, and meeting a disabled adult who shares their insight and perception on what it was like growing up as a disabled person is even less usual. For people who mostly work with children and for parents whose children have yet to grow up, this meeting opens the door to images of positive and possible futures for young disabled people." Pi Trainer

### What we want to do next

Our training improves the knowledge and working practices on inclusion for all those who work with children. This means they can play their part by spotting discrimination early on and step in to prevent it. We want to:

- reach even more families with disabled children
- run a series of forums for parents around the country to help families recognise the power of inclusion to shape a better future for their children
- run more skills days to train even more parents to help us deliver services
- · offer some parents a bursary to train with us
- act as consultants to regional parent groups who want to learn how to build inclusive communities for all children
- employ more disabled trainers as part of our training team, including trainers with learning difficulties
- attract more fathers to our work by running twilight training sessions
- offer more training to personal assistants to young disabled people under the Direct Payments scheme
- publish training materials in different formats so they are accessible for people with learning difficulties.

### Jack's story

Jack (aged eleven) who is a wheelchair user at a mainstream primary school, applied to a mainstream secondary school in a neighbouring borough. While a place had been provisionally offered in February 2003, by June 2003 still nothing had happened. His mother attended an inclusion group and discussed her concerns. These included transport, amending hers son's statement to name the new school, changing hours, meeting new support staff, finding out about the induction days for new Year 7 pupils and how to address her fears that nothing would be done in time. The SENCO at the primary school set up a transitional review straight away in July and made sure that representatives from both LEA's were present to agree arrangements and funding. This prevented the parent from feeling caught in a 'funding sandwich' between the LEA and the school. This meant that the transition went ahead smoothly and Jack settled in straight away and is now doing well.



# **Inclusion Groups**

Under the law the Special Education Needs and Disability Act 2001, Local Education Authorities and schools have to work with parents and should find effective ways to do so. Our Inclusion Group work is an effective model which puts co-operation between schools, parents and young people into practice.

### **How Inclusion groups happen**

The first ever Inclusion Groups in schools were started by us in 1989 and we continue to run these very successfully. These meetings are open to anyone who has concerns about their child in school. We work closely with each school and invite all the parents to come and take part in an Inclusion Group meeting at the school. On average eight parents attend each meeting. The Pi facilitators are totally independent of the Local Education Authority and the school. Only parents attend the first part of the meeting, so it is possible to talk very openly. The school's Special Educational Needs Co-ordinator (SENCO) is invited in at the end of the meeting to hear in general about the issues which have been discussed and then everyone concentrates on coming up with solutions which are best for the children.

We have a whole range of tools which we can bring into a school: the concept of a Circle of Friends, Disability Equality Training, and we can work alongside schools to develop their inclusion policy by using the Index for Inclusion, and to consider implementing restorative justice.

### **Evaluating Inclusion Groups and feedback**

We regularly interview all parents, SENCOs and Headteachers who hold inclusion groups in their schools and consistently find a high degree of satisfaction with our work. Teachers tell us these groups actively prevent exclusions and improve communication and relationships between teachers, parents and children.

Over 50% of all participants come from black and minority ethnic communities and we have seen a sharp increase in the number of participants coming from refugee and asylum seeking families. Some schools provide interpreters, so participants can more freely express themselves and evaluate our work. Our Inclusion Group work always provokes a flood of calls to the helpline from parents who want in depth advice on dealing with their individual child's situation.

We rapidly increased the number of Inclusion Groups to 130 in 2003, and then 180 in 2004. We are now working in 30 London schools.



"We are delighted to inform you that we have achieved an "excellent" grading which places us in the top 5% of schools. The school could not have achieved this without the commitment and support of all our community partners. Thank you."

Lucy Whittaker, Headteacher, Ethelred Nursery School and Children's Centre

"I think Parents for Inclusion are great. They make you realise you are not on your own, and by coming to their groups it makes life do-able. By coming together we are stronger, and able to challenge the barriers created by others not by ourselves. Of course our children must be included." Parent

"We believed in her right from the beginning. We believed in her from the moment she was born – that she was going to reach her potential and have a happy full inclusive life because we have always included her from the word go. We have included her friends; we have not stopped taking her anywhere..."



# ... more about Inclusion Groups

### Reaching early years and babies

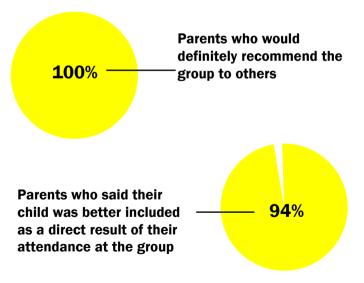
Through funding from Lambeth EYDCP, Kennington Sure Start, and Lambeth Education Business Partnership we have set up a very exciting new project running Inclusion Groups for parents of very young disabled children in pre-school settings and mainstream nurseries. This means we are now reaching much younger parents too. We offer new parents the opportunity to talk about fears that their baby will lead a segregated life. We then help them make practical plans for their child to be fully included in the world right from the start. These have been a great success. Our evaluation shows us that both families and providers have been delighted with this work which has helped make early years settings as welcoming as possible for all children and created supportive spaces for their parents too.

This work has really taken off and we are now in 11 mainstream early years' providers. We estimate we have reached 70 new families in this way.

"I am very excited about this group. The discussions this morning have been helpful on a personal level to give me clarity about my ""next step"" and also on a sharing level to hear about the kinds of issues other parents are dealing with. Inclusion group is a very welcome bridge between parents and the school, thank you." Parent

### Ayisha's story

Eight-year-old Ayisha was arriving late at her school every morning and was in danger of being excluded. We had set up an inclusion group at her school and at the very first session her mother told the group that Ayisha had recently witnessed her uncle's murder. Immediately this situation was explained to the SENCO at the end of the meeting, the school saw the girl's behaviour in a completely different light. Instead of excluding her, the school put appropriate support in place to keep Ayisha at the school and help her overcome the trauma.

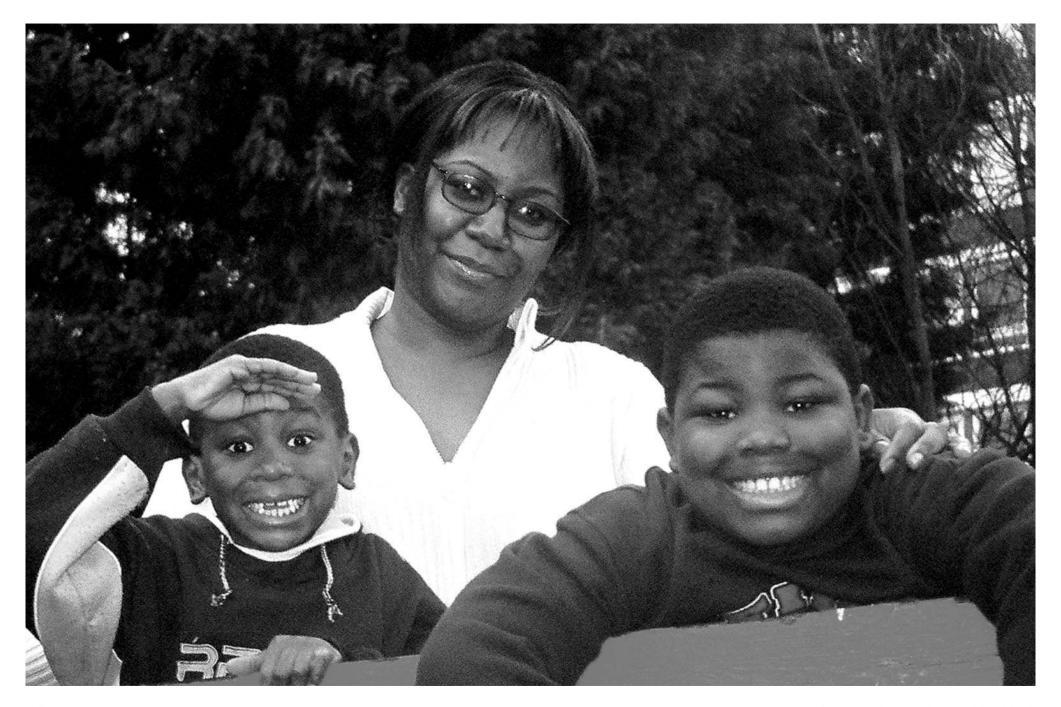


From an evaluation of Inclusion Groups, July 2004

# What we want to do next

Inclusion Groups have a hugely beneficial effect on children and their families. We have daily contact with parents and disabled children and so have built up an excellent knowledge base to draw on. We want to:

- employ more multi-lingual inclusion facilitators
- expand Inclusion Groups to other areas
- work in more secondary schools
- make our material accessible to all parents
- offer training on running Inclusion Groups so that this practice becomes UK-wide
- write guidelines for parents on working with professionals in schools.



# All our children belong

# Exploring the experiences of black and minority ethnic parents of disabled children

Lots of parents from black and minority ethnic (BME) communities who we met at our Inclusion Groups began to ask Pi to bring together other parents from local BME communities to collectively discuss their disabled children's needs. Health Action Zone Lambeth funded a co-ordinator post to meet with these parents and work towards compiling a report with their recommendations for change.

### **Listening to families**

We undertook a series of consultations with these families, running an informal drop-in cafe and facilitating focus groups. We wanted to know how they felt their needs were currently being met and in particular, what issues faced disabled children who came from BME backgrounds. We discovered that racism and disabilism are profoundly affecting these families' lives. One of the parents, Annette Broomfield, then wrote up the findings into our report "All Our Children Belong."

### Racism and disabilism explored

We found that while most families with disabled children experience injustices, hardships and isolation, for BME families the experience is made much harder by the double prejudice of racism and disabilism. This is having a devastating effect upon the lives of these children.

### **Segregation**

BME children with disabilities are still overrepresented in special schools and segregated education. Black boys are still four times more likely to be excluded from school than any other group even though most impairments are not directly caused by ethnicity or socio-economic status. We found that compared to white disabled children, black disabled children are more likely to be excluded from school, be poorer, have less of their social, educational and health needs met, and to face a bleak future segregated from the rest of society with limited independence and employment opportunities. Despite having similar needs: e.g. for housing, access to services and information, more money, more support with helping their child and planning their child's future, support during the school holidays, respite, and help with sleep/behaviour problems, BME families had twice as many unmet needs compared to white families.

### **Discrimination**

BME parents also reported being subjected to discrimination and negative stereotyping themselves when trying to access services, information or support.

For certain sections of the BME community ideals of self-reliance, and the fear of being seen as not coping, is very strong and there is a reluctance to seek assistance or support from those outside of their communities. Service providers who fail to be proactive may interpret these messages as a lack of need.

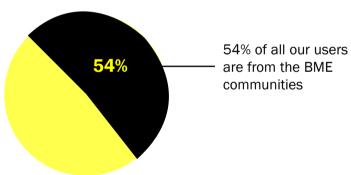


"Having been excluded myself 5 times from school, I warmly welcome this report and the fantastic new work Parents for Inclusion are doing. This is especially important at this moment, as there is crisis point for exclusion in our community, especially for black boys. As a father of nine children myself, I agree that professionals ought to listen more to parents and I urge everyone to read this powerful report."

Lee Jasper, Policy Advisor, Equalities and Policing, Greater London Assembly

### **Augusta's story**

"My eldest son ... was seen as being disruptive and then eventually expelled from secondary school. I felt that if I had been a white or a middle class person that the situation would not have got to that stage... in fact there was a group of black boys in this secondary school and one by one they got rid of all of them. They wanted to get rid of the lot and they did!" Parent, All Our Children Belong report, 2004



### **Oona's story**

"My son's father is very religious and finds it hard to accept him as disabled. "A disabled child was not part of God's plan for me" he says. He prays for "healing" all the time..." All Our Children Belong report, 2004.



### At the launch of All our Children Belong

Clockwise from top left: Christine Shekoni - Pi Trustee. Annette Broomfield - compiler of this report, Anne Marie Johnson - Pi Trustee, June Williams - Pi Inclusion Group facilitator, Haq Ismail - Disability Equality Trainer, Michelle Daley - Disability Equality Trainer, Cynthia Unoarumhi - Co-optee to Pi Board of Trustees

The launch of this report in March 2004 was attended by 113 people: parents of disabled children, teachers, nursery nurses, health, social services and voluntary sector professionals, disabled people and children, an MP. Councillors and Lee Jaspar, who was one of the speakers.

# ... all our children belong

### **Institutional Racism**

Many BME parents were given the impression that special schooling was the only option for their disabled children, when this was simply not the case.

Some disabled black children were placed in a mainstream setting without adequate support. Parents reported being put under intense pressure to remove their children from mainstream schools.

Sometimes the only option left was to go to an educational tribunal but because of the emotional or financial costs only a minority of parents ever embarked on this course. This meant that many children who by law should have been in a mainstream school were denied this opportunity.

We concluded that the way BME disabled children are treated within the education system is probably the result of unintentional racism with people subconsciously influenced by negative stereotypes. Institutional racism is therefore acting as a huge barrier to social inclusion for these disabled children.

### All our Children Belong - findings

Parents and children involved in this project recommended that:

- Education, health and social services professionals should become aware of the destructive impact racism and disabilism is having on these children. They need to find out what black disabled children and their families actually want provided and do more to raise awareness in BME communities of what help these families are entitled to.
- Parents need to be provided with accessible information about their child's rights under the law and about services available to them. There is a need to specifically target information at different BME communities, especially where English is a second language.
- Black disabled children's achievements across the whole curriculum are limited by too low expectations from professionals and sometimes parents. It is important to promote a "can do" attitude amongst teachers and parents.
- Early inclusion is very important and should start at pre-school and nursery.
- Schools need to be equipped and willing to welcome all children in their community.
- More black professionals should be employed in education, health and social services.
- Mentoring helps to raise children's self-esteem and confidence and more black male mentors could help children stay in schools.

### What we want to do next

Significant numbers of disabled children from BME families are suffering disproportionate rates of exclusion. We want to:

- run a conference for professionals and parents to explain how they can have a positive impact on these children's lives
- reach more families from different communities and encourage them to stand up for their disabled children
- translate our materials so parents know what support is available
- offer training to professionals to make them aware of how discrimination and negative assumptions blight children's futures
- employ multi language facilitators to run inclusion groups in different parts of London
- promote the mentoring of black disabled children by black disabled adults
- reach out to the disproportionate amount of looked after children from BME backgrounds and the professionals who care for them
- capitalise on the enormous interest different Asian communities have expressed in this work.



# **Early years**

Ever since Parents for Inclusion began there has been a real sense that we should be looking at the 'welcome' of disabled babies at their birth and young disabled children during their early years. Our work has always covered education and community development, but now we have the clear mandate to address the welcoming of all babies and children in an inclusive way right from the start.

In July 2002, as part of the Government's research into devising its new National Service Framework for children, we were asked to consult widely with families of disabled children and ask them how statutory services to them could be improved.

### **Welcoming all babies**

Society typically sees a disabled baby as somehow "faulty" and that it is the child's "disordered" body, which is the source of all the difficulties. We are asking everyone to recognise that it is in our power to change the medicalisation of disabled babies and very young children. They have the right to be welcomed into the world, and to be celebrated. Professionals need to understand that the relationship between the parents and the disabled child is paramount, and messages of inclusion should be there right from the start. We were concerned that the opportunity for effective change had not been properly addressed.

We felt strongly that the voice of very young disabled children should be represented in services for children and decided to find a way this could be done. We set up a reference group of disabled parents, parents of young disabled babies and young disabled children, and professional allies working in early years settings such as preschool settings, to find out what they thought these young babies most needed.

### At birth

We heard that often the people around new parents, both medical professionals and their families and friends, saw the birth of a disabled baby as a tragedy. Parents told us that people commiserated with them on the birth of their baby or felt awkward and didn't know what to say. These families then experienced profound feelings of isolation and exclusion from the world as if they and their new-born had done something wrong.

But these parents told us that they loved their children as much as any other parent loves their child. Rather than have everyone focussing on the child's impairment and how to make the child "better" to fit in with the world, they wanted their child's birth to be a welcoming occasion as it is for any other family. They wanted us to help find new ways to welcome disabled babies, and young children with a mild or serious condition and their families.

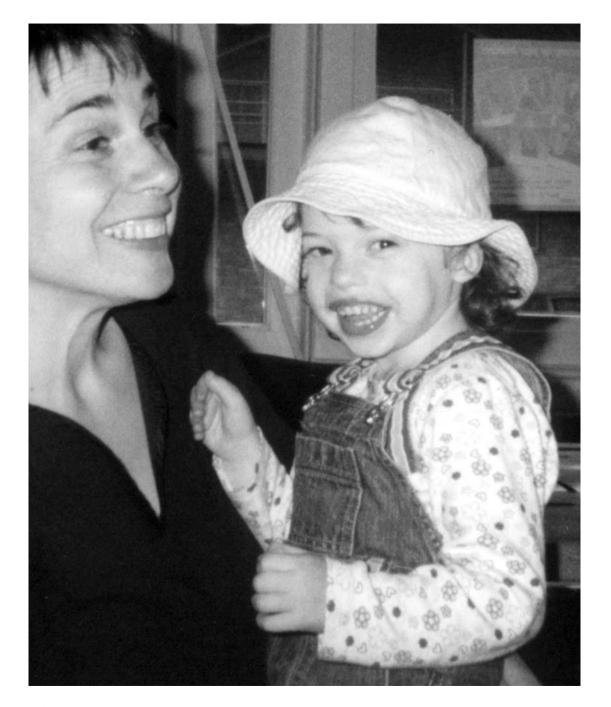
### **Integrating services**

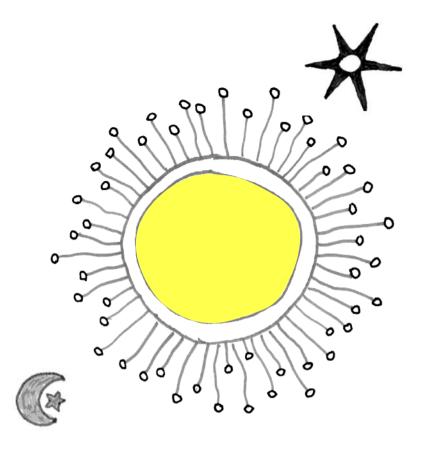
In line with the National Service Framework and the Government's new programme of reform "Every Child Matters: Change for Children", we want to create a welcome pack to make sure that support

### **Helena's story**

"It took me months to even begin to come to terms with the fact that they suspected that my child had autism. I just kept replaying the day of the assessment over and over again in my head- it can't be true! Somehow this child that I cherished more than anything in the world was someone else. He wasn't my perfect child anymore. I grieved for the child that I thought I had lost... It became impossible for me to discuss it - like I had become the keeper of a dreadful secret...!" Parent

for these families is integrated across all statutory services to ensure all children are reached. So in partnership with Lambeth's Early Years Development and Childcare Partnership (EYDCP) team we began to design and produce our Welcome pack of new materials for these babies, very young children and their families.





Your child is a brilliant star!

# ... more about early years

### **The Welcome Pack**

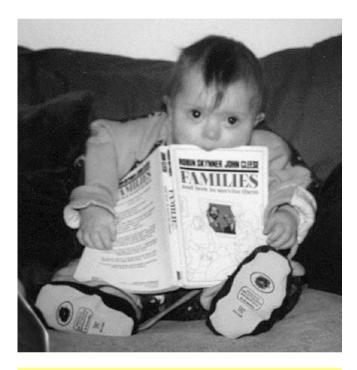
The Welcome Pack will contain a welcome letter written to 'dear little one', a specially recorded song on CD to welcome the child, and a leaflet giving information on how a parent can contact our helpline and talk to another parent of a disabled child if they want to. The message in the information will value the baby or young child unconditionally. We hope that this message be will be embraced by the extended family and community.

Our parents will continue to advise and contribute to this development, and we have plans to run a Welcome pilot project called 'Welcome - inclusion right from the start' which will directly influence the proposed national initiative.

The Lambeth EYDCP team has given us brilliant support, working very closely with us on the original idea and funding the pilot project.

The Pre-school and nursery inclusion groups as described under the Inclusion Groups section, are very much part of this early years strategy.





### Dear Little One,

Welcome to the world! You have a right to be here and to belong. You belong to your family, your community, your culture, your country, this world which we share together. How wonderful to have you here. ...

from the Welcome Pack

# What we want to do next

We know how important it is to the future of disabled children that we reach every parent who has a disabled baby and let them know how they can plan a great inclusive future for their child. We want to:

- develop a pilot project to feed into a national initiative, in collaboration with EYDCP and Sure Start
- launch the welcome pack nationally to GPs, hospital professionals, obstetricians, paediatricians, health visitors, therapists, midwives and early years centres
- appoint an early years development worker to promote this work across agencies which work with disabled babies and children
- put specialised training in place to support our staff and other professionals to develop the welcome project further
- recruit a committee of young disabled people to advise us on our work
- devise a set of early years welcome standards so parents understand what sort of support their child is entitled to receive.



"We value and love our children for exactly who they are. They have taught us much and demanded only our love and acceptance: that we be on their side."

# Reaching people

During this time we produced the "All Our Children Belong" report on disabled children from black and minority ethnic communities and 'Best Done Together!" report on innovative strategies for including disabled children aimed at health, education and social services professionals.

### **Parents for Inclusion online**

We receive many enquiries and requests for helpline help through our website. 60% of new members join via the website and many use the joining form to share their stories. We hear from people all over the world. Donors can now make a secure online donation to Pi and individuals raising money for Pi can have their own donations page. Some website visits were followed up by personal visits from inclusion workers in Mongolia, Australia, Uganda, Turkey and Slovenia.

The Open University's Rights Department runs an online course, which provides continuing professional development for teachers and other educational staff in primary and secondary schools. They use our materials to further their students' professional development.

### **Press campaigns**

In August 2002 we decided to run our first ever press campaign. We promoted the introduction of the new Disability Discrimination Act as fantastic news for disabled children and their parents, as it meant that institutionalised discrimination and prejudice against disabled children would now be

much harder for schools to maintain and more disabled children would be included in their local communities. We were delighted that Dame Tanni Grey Thompson, the paralympic athlete, agreed to endorse our campaign. The Disability Rights Commission also asked us to support their press campaign by providing family case studies for them.

In 2003 we began to contribute answers regularly to the Guardian newspaper's education section problem page. In 2004 we also ran a second campaign publicising the findings of our work with families from black and minority ethnic communities and gained an enormous amount of coverage in print, radio and TV. We have began to be regularly contacted by journalists asking us to give the parent's perspective on the importance of including disabled children in mainstream schools and we ended the year approached by two documentary makers who want to show the general public what inclusion means.

"My parents had to fight hard to get me included in mainstream school and I am very glad they did. I am delighted that this new Act means more disabled children will be given the opportunity to be included in society."

Dame Tanni Grey Thompson



2000 -

visitors per

website

month to our

# What we want to do next

We were very pleased that our first forays into press work had such a positive result, especially as we do not have any dedicated press office staff. We want to:

- produce training materials in different languages and different formats so they are accessible to parents with learning difficulties
- build an online resource library of our materials
- make our website more accessible
- set up an online chat room for families to swap experiences and information
- employ an information officer who can offer in-depth advice
- offer an inclusion pack for schools which teachers can download
- run more campaigns promoting the real benefits of including children
- fund a new press and campaigning post to help us develop this work.

# Please support our work

Financially, we have faced a very tough time over the past 2 years. Global events such as SARS and the war in Iraq stopped some fundraising treks taking place. The Barrow Cadbury Trust, which had been a long-term funder of ours, decided to review all their funding and effectively shut their fund for a year. This left us with an unexpected shortfall.

At the same time our premises were taken over by a new landlord who decided they needed to repair the building and refurbish empty units for re-sale. They charged each tenant approximately £16,450 to cover the expenses. Our annual service charge also rose by 89%. We decided to give up our own training space in order to save rent costs.

However we are very grateful to all the funders which supported us and allowed us to continue our precious work. This was also a great 2 years for developing partnership work with the Lambeth Early Years Development Childcare Partnership, and Kennington Sure Start and North Leyton Sure Start.



You can help with a monthly donation by direct debit. Please call our offices on 020 7735 7735 or email info@parentsforinclusion.org

# **Finance**

### **Annual Report Statistics**

MONEY COMING IN	2003 Accounts		2004 Accounts	
Grants and donations £	057 447	% ee a	202.054	% 01 1
Training and consultancy fees	257,447 16,758	88.3 5.7	203,954 9,812	81.1 - 3.9 -
Subscriptions and sales	1,427	0.5	9,812 587	0.2 -
Fundraising events and recharges	14,821	5.1	36,138	14.4 -
Bank interest	1,199	0.4	1,098	0.4
_	2,200	0	2,000	0
£	291,652	100	251,589	100
MONEY GOING OUT				
Cost of generating funds	18,169	5.5	34,651	12.8 -
Direct charitable expenditure	310,098	93.2	230,117	84.8 -
Charity admin costs	4,600	1.4	6,356	2.4
<del>-</del>	332,867	100	271,124	100

### Trustees' Statement

These summarised accounts are extracted from the full unqualified audited accounts for the years ending 31 March 2003 and 31 March 2004, which were approved by the Trustees on 17 Nov 2003 and 29 Nov 2004 and subsequently submitted to the Charity Commission. They may not contain sufficient information to allow for a complete understanding of the financial affairs of the charity. For further information the full annual accounts, the auditor's report on these accounts and the Trustees Annual Report should be consulted. Copies of this information can be obtained from Parents for Inclusion, Unit 2, 70 South Lambeth Road, London SW8 1RL Signed on behalf of the Trustees, Michael Walton, Treasurer

### Auditors' Statement to the Trustees of PARENTS FOR INCLUSION

We have examined the summarised financial statements set out on this page. Respective responsibilities of trustees and auditors: you are responsible as trustees for the preparation of the annual review and summarised financial statements. We have agreed to report to you our opinion of the summarised statement's consistency with the full financial statements, on which we reported to you on 30 Nov 2003 and 13 Dec 2004. Basis of opinion: we have carried out the procedures we consider necessary to ascertain whether the summarised financial statements are consistent with the full financial statements from which they have been prepared. Opinion: the summarised statements are consistent with the full financial statements for the year ending 31 March 2003 and 31 March 2004. Gotham Erskine. Registered Auditors

# How funding could help

We need funding for

- £ 1,000 for a publicity campaign for our helpline
- £ 2,000 to train 15 parents in planning positive futures for their children
- £ 5,000 to run Inclusion Groups in 2 schools for a year
- £ 10,000 for a press campaign to change attitudes
- £ 15,000 for an increase in helpline hours
- £ 20,000 to develop and expand our website
- £ 25,000 for an early years development worker post
- £ 60,000 for core costs, including our rent



# **Summing up**

Under the theme "Celebrating Diversity" and as this Review shows, Pi has enabled a powerful network of parents of disabled young people from diverse backgrounds to find their voice and to take action to change their lives and that of their disabled child. Together we have been making a difference in our own children's lives and in our wider community. There has been much learning from each other and bringing of fresh insights and understanding to what we mean by inclusion.

The clearest message has been one of celebration. By having pride in our children, and complete confidence that their very existence demands their inclusion in every aspect of community life, we have been able to experience whole communities benefiting and growing. Many of our disabled young people are taking control of their lives as never before, as seen in "Where are they now". We invite all readers of our report to join us in this celebration and to help us keep the momentum going.

All the evidence gathered in our reports and activity statistics shows that bringing down barriers to inclusion within mainstream provision is essential if we are going to create an equal and just society where all people have a right to belong. Listening to disabled children, building equal relationships and valuing difference is the only way forward. We need to "unfreeze" all the frozen attitudes which belong to a past era and which remain so destructive to so many lives.

Uniquely, we strive to work as allies to disabled people, this means as a parent organisation we are always advised by and train with disabled people.

Through our work, we know that once people fully understand the experience of disabled people themselves, they find they cannot step back into believing that protecting and separating people from each other will achieve a safer and a better quality of life. People who hear and understand this message, very quickly move forward and change their goals for disabled young people. Many professionals have now put into place useful tools for inclusive practice across the country, as shown in "Snapshots of Possibility". Many parents now have a deeper sense of who their children are and a greater understanding of how to be their ally.

The Special Educational Needs and Disability Act 2001, which came into effect in September 2002 has supported our work in upholding the rights of disabled young people. Sadly, the calls on our helpline alert us to the fact that there still remains a deeply worrying lack of understanding - and in some areas, a lack of political will - to recognise that disabled young people have the right to be included in mainstream.

We appeal to funders reading this annual review to support our work. We ask you to recognise the value of continuing to build upon the work achieved by a growing group of people, who are committed to celebrating diversity across the board and to the creation of inclusive communities.



Jo Cameron, Diana Simpson

Co-directors

10 Church Brons

These booklets are published by and available from The Alliance for Inclusive Education, email: info@allfie.org.uk

# **Our thanks to:**

### **Thanks to our Patrons**

Phillippa Russell CBE Louise Clifford

### **Thanks to our Funders**

in April 2002 - April 2004:

Association of London Government **Baily Thomas Charitable Fund Barrow Cadbury Bridge House Estates Trust** City Parochial Foundation **Clapham Park Regeneration Project Community Fund Esmee Fairbairn Foundation** The Goldsmiths Company Health Action Zone Lambeth **Henry Smith Charity Kennington Sure Start** Lambeth Early Years Childcare -**Development Partnership** The Lambeth Education Business Partnership Leicester City Council Lloyds TSB Foundation Marks & Spencer Mercers Company Paul Hamlyn Foundation **Platinum Trust** Sobell Fund Stone Ashdown Trust

Walcot Educational Foundation

**Trusthouse** 

### Thanks to our Trustees

We try to ensure that our trustee board is as representative as possible, so they can effectively lead the organisation. Our trustees are parents of disabled children and disabled people and come from a variety of backgrounds.

Dick Cridlan
Catherine Hodgson: Chair
Ann Marie Johnson
Bidge Jugnauth
Simon Gardner
Wendy Greenwell
Mark Mansell
Sue Newbigin
Angie Northwood
Sarah Samuel
Nick Saunders
Christine Shekoni
Mike Walton: Treasurer and
Company Secretary

### Thanks to our Advisors

Our trustees also are advised by other disabled people and parents of disabled people.

Mole Chapman
Jackie Downer MBE
Lucy Mason
Cynthia Unoarumhi

### Thanks to our Staff

Parents for Inclusion has 12 staff, most of whom work part time. In terms of hours the organisation has the equivalent of 6.5 full time posts. Most staff are also parents of disabled children and some are disabled themselves.

Lorna Bowden - Office Manager Cornelia Broesskamp - Training Co-ordinator Jo Cameron - Joint Director Caroline Goffe - Helpline and inclusion Group Co-ordinator Pam Hall - Training and Events Administrator Kea Horvers - Operations Director Maureen Johnson - BME Community Co-ordinator (6 months post) Janet Mearns - Finance Officer Miranda Payne - Marketing Officer Diana Simpson - Joint Director Phil Walton - Helpline Worker June Williams - Inclusion Group

### Thanks to our Marathon Runners

Facilitator

George Davidson Theresa Delaney Jack Hodkin Sean Lawlor Ian Maris Duncan Peagram Melanie Young Mike Walton Michael Warner

### Thanks to our Inclusion Group Facilitators, Parent Trainers and Helpline Apprentices

Lucy Bartley

Heidi Boxall

Julie Billingham

Angela Brockwell

Sally Bell

Kadie Chapman Katie Clarke Anne Darby Jeanette Delaney Angela Denni Udega Jenny Dine Heiner Eisenbarth Kerry Fox Patricia Iyoha Alison Jones Jenny Killick **Bridget McCabe** Carol McDonagh Caroline Mackeith Dee Nash Ignatia Oparaji Alison Orphan Minaxi Patel Sue Parfitt Mary Powell Alison Reed Sarah Santos **Sharon Scoffings** Rodney Seetal Christine Shekoni Melanie Summer Lisa Toomey Cvnthia Unoarumhi Tracy Upton Emma Wade Karen Weare Linda Whitehead

Cornelia Wilson

### Thanks to our Disability Equality Trainers

Eva Adom
Mole Chapman
Michelle Daley
Jackie Downer MBE
Haq Ismail
Maresa MacKeith
Lucy Mason
Micheline Mason
Chris O'Mahoney
Jenny Orpwood
Jeni Price
Mo Reece

# Thanks to others for their support

**Archbishop Sumner School Steel** Band Brenda Boyd Max Clifford Claudette Hewitt, Mayor of Lambeth Dame Tanni Grey Thomson Church of the Holy Spirit Abbeville Fete Marc Jefferies Lee Jasper Lawworks Linklaters Redweather Debra Singmaster Alan Sprung David Morris, Disabilities Senior Co- ordinator at the Greater London Assembly Ken Livingstone. Mayor of the Greater London Assembly **Gotham Erskine Accountants** Mark Taylor

SSH Associates

### Thanks to all the schools and nurseries which host our Inclusion Groups

Allen Edwards Primary School Archbishop Sumner Church of **England Primary School Asquith Court Nursery** Bonneville Primary School Charter Secondary School Clapham Manor Primary School **Ethelred Nursery School** Fenstanton School **Glenbrook Primary School** Herbert Morrison School Honeywell Junior School **Hurley Pre School** James Kane Nursery Jessop School Jubilee Primary School Kennington Children's Centre **Kings Avenue Primary School** Maytree Nursery Paxton School South Lambeth Opportunity Group Streatham Children's Centre Triangle Nursery **Vauxhall Christian Centre** White House Pre School **Woodentops Kindergarten** 

### The photos

Thanks to parents and their children for lending us photos for this review.

### 2002 - 2004



















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