All our children belong
exploring the experiences of black and minority ethnic parents of disabled children

Inclusion - time for change and action
All our children belong
Exploring the experiences of black and minority ethnic parents of disabled children

SESA Woruban -
“I change or transform my life”
An Adinkra symbol of life transformation

A report brought together by Parents for Inclusion’s Black and Minority Ethnic Reference Group

Edited and compiled by Annette Broomfield
2004
DEFINITIONS
used by the Inclusion Movement

DISABILITY
"Disability is the loss or limitation of the ability to take part in the normal life of the community on an equal level with others, due to physical and social barriers."

Adopted by Disabled Peoples International 1981

INCLUSION
"All for One and One for All"

"... a philosophy which views diversity of strengths, abilities and needs as natural and desirable, bringing to any community the opportunity to respond in ways which lead to learning and growth for the whole community and giving each and every member a valued role. Inclusion requires the restructuring of schools and communities."

Micheline Mason - Director of the Alliance for Inclusive Education

MEDICAL MODEL OF DISABILITY
The medical model sees the disabled person as the problem. We are to be adapted to fit into the world as it is. Usually the impairment is focussed on rather than the person. The power to change us seems to lie within the medical and associated professions, with their talk of cures, normalisation and science. Often our lives are handed over to them.

SOCIAL MODEL OF DISABILITY
The social model of disability identifies prejudice and discrimination in institutions, policies, structures and environments of society as the principal reason for disabled peoples’ exclusion, rather than the particular impairment of the individual.

MEDICAL MODEL OF DISABILITY

SOCIAL MODEL OF DISABILITY

Definitions
used by the Inclusion Movement

BI NKA BI - "no one should bite the other"

FUNTUNFUNEFU "siamese crocodiles" - democracy, unity in diversity
BACKGROUND TO THIS REPORT
Diana Simpson and Jo Cameron
Co-Directors, Parents for Inclusion

Our key role as an organisation is to value and celebrate all *disabled young people and to steadfastly work towards their right to belong. Parents for Inclusion (Pi) is proud to present this report ‘All our children belong’, from Black and minority ethnic parents, bringing their powerful voice to the issue of inclusion.

In the Dreaming the Dream, Inclusion: an issue of social justice 2001 report we brought together the voices of the collective community, with powerful messages for change. In ‘All our children belong’ our facilitating role has been to support the Black and Minority Ethnic (hereafter BME) group to bring specifically the voices of the BME parents of disabled children seeking inclusion, to the forefront. We believe that we all must tackle the double discrimination these families find themselves under: that of racism and disablism.

Our task was to face the challenges they gave us as an organisation, and to find a platform where their voices could be heard by parents, disabled people, professionals, and the wider community. To achieve this we have attempted to facilitate the BME reference group to make connections with all organisations, but especially those connected to BME issues and to engage in the debate about how to bring about effective change for these young disabled people to be included.

The final chapter of this report spells out very specific recommendations to take this work forward: -

- The understanding and the adoption of the Social Model of Disability (see Chapter 4) by ALL – family, community and professionals, through Disability Equality Training.
- The recognition of the impact of multiple oppression.
- The empowerment of BME parents and disabled young people to take the lead in change alongside disabled adults from the BME community and their allies.

*Disabled: This term embraces adults and young people with physical impairment, sensory impairment, young people with learning difficulties and those in distress. In the education system these young people are often referred to as having ‘special educational needs’ or ‘behaviour difficulties’
The challenge

It is an enormous challenge for an organisation, which is mainly white, to become truly representative of our diverse community, and to be trusted as an organisation that will treat the equal opportunity of their black membership with integrity. Although Pi had always supported, and continues to support black and minority ethnic parents through our work, we set ourselves the task of discovering why too few were being enabled to become leaders for inclusion.

Our Response

Through our grassroots work, we had been meeting many Black and Minority Ethnic Parents, who were all saying the same thing. They wanted to come together to explore their common concerns and to find ways with which their voice could be heard. The Pi Black and Minority Ethnic Reference Group was formed out of the black parents who had been supported through our helpline, inclusion groups and training. The reference group also drew in black disabled people and their allies. Through their sharing of their exploration of their issues they helped us to begin to understand that their children and they themselves experience a double oppression. Together we were able to explore their experience of racism, which combined with our understanding of disablism, led us to recognise the devastating effects of this 'double whammy'.

First steps

If BME parents and their disabled young peoples’ voices were to be included with integrity, the work would have to be taken forward under the leadership of a Black and Minority Ethnic Parent Development Worker. The key would be for Pi to gain a better understanding and awareness of race equality issues as a self-help, employing organisation. In 2001 the Lambeth, Southwark and Lewisham Health Action Zone gave Pi the opportunity to run a six-month BME Development Project to start this process.

A new 6 month project

The leader of the reference group Maureen Johnson, parent of a disabled young man, was confirmed in the post. Part of her remit was to report back on her findings, and to make
recommendations to the organisation to ensure inclusive participation, involvement, and a career structure for parents of disabled black and minority ethnic young people.

Insights and analysis

Maureen was able to bring the full breadth and depth of her experience as a black woman and parent of disabled young person to her work and together with the reference group helped to produce a report for Pi beyond this narrow remit. Building on this, Annette Broomfield went on to edit and compile this enormously powerful and insightful report 'All our children belong' with the support of other key members of the reference group Cynthia Unoarumhi, Christine Shekoni and June Williams. Its production has been a long, profound and important journey for us all. Time had to be taken to grow together in relationship and understanding, a necessary, painful and worthwhile process. We all hope we have now laid the foundations for us all to move forward.

What difference has the work of the BME reference group made?

The reference group made Pi take action for change. With their recommendation we brought in a Race Equality trainer, whose approach brought us face to face with the issues needing to be tackled. Pi’s key priority is to continue to seek funding for a BME parent development worker. Meanwhile some progress has been made:

• BME parents have become leaders - taking the platform in all Pi events promoting inclusion:
• Two BME parents are now paid sessional lead facilitators of inclusion groups
• 25% of parents on the Inclusion Training Pathway are from BME communities.
• 50% of graduates are BME parents.
• One of the four Disability Equality Trainers we have worked closely with is a black young woman with learning difficulties.
• Pi’s Trustee board includes 2 black parents of disabled young people, a black disabled parent and a black disabled person.
• Our key conference Action for Inclusion in 2002 gave a platform to BME parents and disabled people to address the audience of policy makers from health, education and social
services.

• Our ongoing press campaign ensures that BME parents are supported to be press spokespeople with their stories given coverage in national and local press.

• Our joint magazine with the Alliance for Inclusive Education and Disability Equality in Education features articles by BME parents, disabled adults and young people, and ensures that there are images of the whole diversity of the BMA communities.

This way we have been able to reach more and more BME families through the Helpline and Inclusion Groups in schools - approximately 56% of our callers and inclusion group attendees. This includes a growing number of refuge and asylum seeking families.

**Developing leadership**

With Pi’s grassroots work giving parents the opportunity to grow their skills and confidence there is now a growing number of BME parents to take the work forward. As we raise funds for further development workers who can take the social model of disability out into the community, there will be more and more opportunities for these BME parent leaders to bring their influence to bear.

**The way forward**

Pi recognises that these issues will always need to be at the forefront of our thinking and actions. We will always need the voice and the challenge of those who are facing the oppression to guide us. This powerful report spells out in its recommendations, messages of understanding and lessons for listening that *must* be heard, by not only our organisation, but by every individual or agency that wants to make a difference. Our hope is that funders will acknowledge this by providing the financial support needed to tackle this double oppression.
Definitions used by the Inclusion Movement 2
Background to this report 3

1 Introduction 9
2 What do we mean by ‘The Black and Minority Ethnic Community’? 11
3 What is Racism? 14
4 Different models of disability 21
5 What is Inclusion? 27
6 Why a Reference Group? 36
7 How the Black and Minority Ethnic experience differs 43
8 The challenges we face in seeking inclusion for our disabled child 48
9 Our conclusion and recommendations 66

OUR VOICES
Parents talk about:
Racism in the school system Zarah 16
Racism in the school system Marcia 24
Inclusive Education Marion 41
Accessing Services Moona 45
Accessing Inclusive Education Paulette 62
Accessing Inclusive Education Odun 64

Young people talk about:
School Ola 31
School Kareem 32
School Zainab 33
School Sau 34

Appendices:
1 Race Equality Day - recommendations 72
2 PATH - Planning Alternative Tomorrows with Hope 74
3 All our Children Belong - recommendations from workshop 76
4 Bibliography 78
5 Inclusion organisations 82
Acknowledgements 80
Colour photos including the PATH centre
Adinkra symbols from West Africa are used throughout this report, for the messages that they symbolize.

To find out more about adinkra symbols visit www.welltempered.net/adinkra.
OUR INTRODUCTION

This report is the result of a pilot project undertaken by Parents for Inclusion to investigate the issues around the experience of Black and Minority Ethnic (BME) parents/carers and their disabled children. For those who contributed to this report, it was apparent that the experience of BME families was significantly different to our white counterparts. We, as BME families, experience additional obstacles, have higher levels of unmet needs and lower access to services and information. The interplay of race, culture, religion and disability has largely been ignored by many service providers, statutory bodies, voluntary and disability organisations. This includes both organisations of and for disabled people. The impact of racial inequality upon the lives of disabled individuals and their families, whilst central to our experience is relatively marginalised or ignored. We have felt invisible. This report is a call for the acknowledgement of the diversity of experiences and needs, and an attempt to move our experiences from the margins to the centre, and an understanding of the double discrimination of race and disability.

Parents for Inclusion (Pi) is a small voluntary organisation supporting parents who seek to have their disabled children/young people included in mainstream schools and communities. In order for Parents for Inclusion's goals for all disabled individuals to be fully included and participating in society, it was felt that it is necessary for them to address the dual barriers of race and disability.

In 2000 Parents for Inclusion encouraged a group of BME parents/carers and BME disabled people to form a reference group and secured funding to employ a co-ordinator for the group. Many members of the group had arrived at Parents for Inclusion through months and even years of struggle and endeavour to make their dreams of inclusion for their disabled children a reality. Many had initially come in contact with Parents for Inclusion whilst seeking help and support in order to secure suitable educational provision for their children, or had attended Parents for Inclusion's Inclusion Groups in schools. Our reference group soon began to see the difficulties and barriers that we were experiencing could be placed within the wider context of the social exclusion of disabled people. After the initial contact with Parents for Inclusion, many of us went on to undertake Disability Equality Training, Planning Positive Futures workshops, and so on. However, we became increasingly aware that our experience as BME individuals was not reflected in Parents for Inclusion’s predominately white setting. The BME Reference Group met on a regular basis for a year in order to explore and discuss the issue of race and disability. This report and a number of workshops are some of the end results of the BME Reference Group's work.
It is assumed a wide readership will access this report, from parents, disabled people, allies, policy makers, practitioners, professionals, the voluntary sector and the community. It is hoped that this report will be accessible to all and that language will not act as a barrier, so terms and concepts will be clearly explained and defined.

This report will briefly outline the context of race and disability within British society. It will briefly outline what we mean by the term ‘Black and Minority Ethnic community’, and highlight the socio-economic inequalities which our communities experience. It will also provide a definition of the term “racism”, and briefly explore institutional racism. The report will then discuss how disability is viewed within society, outlining the different ways of understanding disability – the Medical Model that overly focuses upon the individual's impairment and sees their medical needs as paramount, and the Social Model, generated and formulated by disabled people themselves, which argues for a more holistic view of the individuals, and sees society as the source of the disabling experience. It highlights the values, the social structures and environment as the source of the “disabling” experience of individuals. We will outline what is meant by “inclusion”, with a particular focus upon the central issue of inclusive education. The report will then look at why a BME reference group was set up, and then go on to explore how our experiences differ from those of our white counterparts, and the additional challenges that we face.

The report will conclude with a celebration of the empowering process that all within the reference group have undergone and a celebration of our disabled children. We have collated recommendations for service providers and all organisations and individuals seeking to fully address the needs of all disabled young people and their families.
WHAT DO WE MEAN BY ‘BLACK AND MINORITY ETHNIC COMMUNITY’?

Within this section we will explore what is meant by the term Black and Minority Ethnic Community and Racism.

Britain has always been a mixed society, a nation peopled by migrants. Britain has benefited from ethnic diversity throughout its history. From industry and commerce, to art and dance, from sport and music to science and literature; the activities of individuals and groups from ethnic minorities have enriched life in Britain for all. Indeed, post-war Britain would not have made its rapid economic growth if immigrants from the Commonwealth had not arrived to provide the much needed human resource.

The term Black and Minority Ethnic (hereafter BME) is used to describe a significant section of the non-white British population; predominately African, Caribbean, and South Asian people. An important and recent addition to this group are refugees and asylum seekers; Eastern Europeans whilst being white, may initially experience similar experiences as the BME community, chiefly due to linguistic barriers and the current political climate of hostility towards asylum seekers. Whilst the umbrella term Black and Minority Ethnic community is useful, it is deceptive as it seeks to homogenise whole sections of society that are culturally and at times socially distinct. For example, whilst significant sections of the BME community experience greater levels of social deprivations, some sections have seen increases in wealth and social advancement. Other factors such as religion, culture, language, dialect and even the differences between those that are British born and those who have more recently settled in the UK, result in qualitatively different social experiences.

However, it has been a long established view that there is an uneven distribution of power and resources within society, and that these inequalities are reflected along lines of race as well as social class - Khan, “Minority Families in Britain” 1979. This has resulted in lower levels of opportunities for members of the BME community. It is widely recognised that black and minority ethnic groups experience social and material disadvantage in comparison to their white counterparts. This is illustrated by under representation of the BME communities in the decision making structures of society, and the over representation in other areas, such as the penal system.

National and local government data have captured levels of inequality experienced by the BME community. These show that many sections of the BME community tend to experience lower levels of educational attainment, and experience higher levels of unemployment. We are over represented in lower
paid employment, or experience lower levels of social advancement, signified by lower levels of household income, than our white counterparts. The BME community also tends to experience poorer housing conditions and lower access to statutory services.

Education is an important area which starkly highlights the social inequality experienced by many within the BME community. Statistical indicators highlight levels of inequality for significant sectors of the BME community. Males from an African-Caribbean background are one of the lowest achievers despite having similar attainment profiles as their white counterparts on entry to the education system (“Recent Research on the Achievements of Ethnic Minority Pupils”, OFSTED 1996). Males from an African-Caribbean background are four times more likely to be excluded from school. One report (Kundnani, 1998) suggests that the:

“profile of African Caribbean children who are excluded differs from that of excluded children generally; they are usually higher than average ability, exhibit less evidence of deep-seated trauma and are less likely to have shown disruptive behaviour from early in their school career”.

Kundnani (1998) suggests that there is a problem

‘between teachers and black children and that teachers’ perceptions of black children (and vice versa) do, somehow, play a crucial role’;

Similarly, the 1985 Swann Report, “Education for All” concluded that whilst only a small minority of teachers could be described as intentionally racist it highlighted that a teacher’s attitudes towards, and expectations of, African Caribbean pupils may subconsciously be influenced by racial stereotypes, negative or patronising views of their abilities and potential based on their ethnic origin, which may prove a self-fulfilling prophecy, and can be seen as unintentional racism. It also highlighted other contributory factors such as the curriculum, books and teaching materials, links between schools and the community, special provisions and school pastoral arrangements. The report’s conclusion was that there was

“no single cause…but rather a network of widely differing attitudes on the part of teachers and the education system as a whole, and on the part of West Indian parents, which lead the West Indian child to have particular difficulties and face particular hurdles in achieving his or her full potential.”

The most recent data on achievements in schools show that African Caribbean, Pakistani and Bangladeshi children continue to under-achieve in schools, and attain the lowest GCSE levels of all groups. In 1999, OFSTED’s report “Raising the Attainment of Minority Ethnic Pupils: Schools and LEAs responses.” noted that:

“Black Caribbean students make a sound start in primary schools but their performances shows a marked decline at secondary level……In many LEAs …….there is a worrying ignorance, generally about how to raise the attainment of black Caribbean boys.”

“My experience of the British system of education is both personal and professional. As a young (black) man, I was one of those children that the system attempted to consign to the educational rubbish heap of suspensions, expulsions and failure. Labelled as “disruptive” and an “underachiever”, I was excluded five times from the schools that I attended. And now, as an older and hopefully wiser man, I continue to experience the education system, as a father of nine children and as a parent school governor. …Rather than engage and empower them (young black students), the classroom has always been a hostile and discriminating environment, denying their existence, their abilities and their potential…”

For disabled young black and minority ethnic people, they similarly inform of negative experiences in the education system. Tracey Bignall and Jabeer Butt’s investigation into the experiences of young black and Asian disabled adults highlighted that many felt unprepared for a life of adulthood. (Between ambition and achievement, Young Black disabled people’s views and experiences of independence and independent living, 2000.) They attributed this to professionals’ low expectations of their ability and potential, due to their race, culture and disability. Many felt that their education concentrated on their physical needs rather than their academic, resulting in poor academic attainment and poor employment prospects.

It is no wonder that BME parents continue to express concern about the inequalities experienced by our children.
WHAT IS RACISM?

Snapshots, Headlines and Clippings

….our young men are afraid to make that final leap
lest the gesture be mistaken as a reaching
for an imaginary
gun or blade they’re carrying
so we watch
with a mixture of dread and wonder
as they lock their hair into beautiful coils
of Afrocentric pride
knowing its yet another marker of difference
that will set them apart
label them radical=dangerous=criminal…..

For I have no cure for the disease
That will transform him from cute to criminal
In the gaze of a racist world
That both needs and creates these categories
For its own survival…

Donna M Weir
The Caribbean Writer, vol 9

“Racism is the belief that some races are superior to others based on the false
idea that different physical characteristics (like skin colour) or ethnic background
make some people better than others”

Commission for Racial Equality

Racism is an ideology which becomes realised by its practice. It is perpetuated
by a dominant group, in our case white British society, against the BME
community. Racism and racial discrimination can therefore be seen as a major
attributing factor of the inequality that the BME community experience.

Whilst individuals or groups can actively and deliberately discriminate against
different ethnic groups, institutions also commit acts of racial discrimination, and
thus reinforce inequality. This is called institutional racism, and is just as insidious
and damaging as direct racial discrimination.
Institutional racism describes forms of racial inequality which are structured into organisations and institutions. It occurs when organisations, institutions or governments discriminate, either deliberately or indirectly, against certain groups of people to limit their rights. The structures, practices, ideologies and their underlying assumptions result in the less than equal treatment of certain groups. The individuals within institutions themselves may not necessarily hold views that are racist and may even be members of the BME community. The organisations and institutions may have anti-discriminatory policies; however their actual practice may show levels of discrimination. The policies, structures, values and norms of the institution and individuals within them act as a barrier for members of the BME community, and therefore reinforce social inequalities. This was clearly evidenced by the Macpherson Report into the police force following the tragic death of Stephen Lawrence.

The importance and relevance of institutional racism to this report is that it is a form of racism that reflects the cultural assumptions of the dominant group, so that the practices of that group are seen as the norm to which other cultural practices should conform. It regularly and systematically advantages some ethnic and cultural groups and disadvantages and marginalises others. This report will explore the experiences of BME parents of disabled young people, in order to highlight the impact that institutional racism plays in acting as a barrier to social inclusion.
OUR VOICES

A Parents Voice:
“Zahrah”, talks about…..

RACISM IN THE SCHOOL SYSTEM

“Zahrah” talks about her son who has learning difficulties and has been labelled as having behavioural difficulties. She talks about her experience, especially in relation to her son’s experience of the education system and being excluded from his primary school.

Zahrah talks…..

Q What are the challenges and difficulties that you have experienced when trying to access provision that supports your disabled child to be included?

In the primary school that my son attends they were aware of his difficulties from a very early age, but it has only been quite recently that he received a statement of special educational needs. Despite being aware of his needs they still didn’t provide the appropriate levels of support to meet them.

Q In what ways do you feel that Black and Minority Ethnic People, and Parents of disabled children could be better served, by education, health and other statutory services?

They need to raise their profile more within the Black, Asian and other ethnic minority communities. They should target our communities, especially where English is a second language. I know of many black and Asian people who are not aware of some of the services they are entitled to, or aware of the help they can access from certain services. I think it is important that everyone is made aware of the services out there to support them.

Q As a black person, what are the added pressures that you have to face?

As a black person we have to try twice as hard in everything we do! You are always aware that the colour of your skin is a barrier for some people. So you have to overachieve in order for them to know that you can still do what is required.

Q Are there any instances, when you have felt you would have been better served if you were white and middle class?

I have to respond with a resounding YES! My son was labelled as
“disruptive” by his school, and in my opinion did not receive enough support to help him. I do believe that had we been white and middle class, and the school situated in a different area then the whole situation would have been quite different. He would have received the right support, and we would have received more support as a family.

Q Can you tell us more about your son’s experience at school?

One of the main problems that my son had in primary school was that he had difficulty retaining a lot of the information that seemed to just keep coming at him. He has a learning style that was not adequately catered for. He had problems keeping up, so his behaviour began to deteriorate, and he began to be labelled as being disruptive. He actually began picking up on the negative feedback that he was receiving from teachers and staff and stopped caring about trying to do well. I didn’t really get the support that I hope for from his school, and now we are in the situation where he is not actually in school.

They wanted him to go to the Pupil Referral Unit (PRU). When I went to visit it - I was shocked! I’m talking November 2003 and it was predominantly black boys.

Q What was it like?

It was incredibly structured, quite regimental in fact. It’s like they wanted to make them into little soldiers. Those children obviously have behavioural problems which is why they are there, but that kind of stamping down does not give them a way to express themselves, or their personality. I don’t think the children are given time or opportunity to talk.

I didn’t like what I saw at all, but I felt the primary school was pressurising me to send my son there – we were told either he goes to the PRU or that they will permanently expel him. We weren’t really given a choice.

Q How do you feel about the school now?

Well, when schools become negative about your child it creates a vicious circle, you become angry, the child picks up on it and feeds off it. So although I’m not pleased with my son’s school I’m trying to be supportive of the school, and talking about the school in a very positive way in front of my children. I have got another child there who is doing very well and he likes it there and he is due to leave in July. My husband and I work very hard for our sons. I keep them very positive and say “Do your best for yourself as well as us”. My eldest son has the added pressure of his
GCSE, and I say to him, “take one day at a time, relax, revise, do the best that you can and be proud of what you have achieved. When you come to that interview no matter what the results are we will still love you.” He says “that’s good mum” because you know he’s really worried.

Q Can you say 3 changes that you think would make a difference?

- High expectation of our black boys.
- More black male mentors in schools.
- An acknowledgement of children’s different learning styles, and alternative ways for children to learn.

Q Why do you think that these things will make a difference?

It has been my experience that black children, especially black boys, so easily get labelled “disruptive”, and that there is an assumption that they come from “dysfunctional” families. It is assumed that they will not really achieve because they come from a poor area. It is important that these negative attitudes are confronted.

They face so much negativity, and they pick up on it and begin to think, “Well, why should I care”. It’s scary because they are going to go through life with that attitude and it will affect them later on as they get older. As they go out to the world it is going to be even harder for them because this society is vehemently hostile to black males.

Unfortunately, for some of our black boys it’s a downwards spiral ending up in jail and a life of crime, when all it needed was some intervention.

When our black boys have special needs it’s even harder for them, they face double the discrimination.

Our black boys need more mentors and more things in place for them in schools. They shouldn’t be just written off. They need greater encouragement and positivity. I’m sure they’ll respond to it. Things like mentoring help to raise self-esteem, self-confidence and empowerment. Everyone should have higher expectations of them.

For some black children there may be added pressure and stress from home. As parents we often tell our children-“You’ve got to do better when you get out in the world - it’s going to be this and that…It’s going to be harder for you…..” It’s true, but it’s added pressure. If they have a negative teacher, or school in general, it makes it even worse. I think if they watch children as they progress in school by the time a child reaches 8, 9 -11 years at primary school you might pick something up before they
get to secondary school.

But even before that early intervention is so important; it should start at nursery or reception when signs of distress or need are evident.

Q  What are your dreams for the future?

Oh my dreams are for an inclusive society where everybody is included no matter what their difference is, everyone is accepted for who they are and what they are. To have a more multi cultural society, more ethnic minority people being represented in places and areas where very few of us are now.

Q  How has your involvement with Parents for Inclusion made a difference?

Parents for Inclusion has helped me by letting me know my rights as a parent so that I can know how to support my child and what support I should be able to access. They have given me personal support. The parents and the workers and everyone I have met there are really very friendly and open and let me feel included. There has been a real sense of belonging, for both me and my son.
When You Look At My Child

What do you see
When you look at my child?
How does he make you feel?

Yours words confirm what I see in your eyes
Confident words, so secure
In the assumptions that you make.

Which child are you speaking about?...........

When did I tell you I wanted him changed
That I would prefer him different
From as he is?
When did I tell you I wanted your help
To change him?
I longed for my child for such a long time
I met him and chose him
And held my breath for a while.
I was very lucky.
He decided I belonged to him too.

Why would I change him?

Don’t you realise that I can feel
Your need to change him
Your need for him to be other than as he is
To be “improved”
To be more or less or whatever
You are disturbed by?

Don’t you understand that
The comments you make about my child
Tell about yourself
And not about him?

And the needs we discuss
Are yours
And not his.
When you look at my child.

Jill Penman
Let our Children Be
Different Models of Disability

Within this section we will explore what we have learnt about the issue of disability.

Before looking directly at personal experiences, it is important to explore the second discrimination that BME parents of young disabled people, and in fact all disabled people, experience: that is disablism.

“Disablism is the belief that some people are superior to others – based on the false idea that different physical or intellectual characteristics make some people better than others”.

‘Dreaming the Dream. Inclusion: an issue of social justice.’
Published by Pi, 2001

Disabled people inform us that they experience discrimination, hostility, fewer opportunities and a lower quality of life than non-disabled people. Any actions taken to deal with or remove the disadvantage experienced by disabled people depend on what is believed to be the root cause.

The two dominant ways of explaining the causes of the disadvantage are called the Medical and Social Models of Disability.

The Medical Model is, by and large, the prevalent way of thinking about disabled people today. It is the way that many in the medical, educational, media and other public institutions think at this time. Indeed, it is the way society at large views disabled people. Our brief exploration will show that the Medical Model begins from the starting point that the disabled child is faulty and that the impaired body is the source of an individual’s inequality in society.

The Social Model has revolutionised our way of thinking about disability and comes from disabled people themselves in the Disability Movement. This way of thinking values the whole child, encourages explanations of inequality in terms of people’s views and values and how society is organised. It is not a denial of an individual’s impairment, but a valuing of the diversity that exists within society.

The Medical Model of Disability

Within this way of thinking, disabled people’s inability to participate in society is seen as a direct result of having an impairment and not as the result of features of our society, which can be changed. Therefore the focus of attention is placed upon the individual’s impairment, and his/her ordinary social needs are put on hold. A lot of focus is placed on trying to correct or “normalise” the functioning
of the disabled person.

When people, such as policy makers, think about disability in this way they tend to concentrate their efforts on 'compensating' people with impairments for what is 'wrong' with their bodies by, for example, targeting 'special' benefits at them and providing 'special' services for them which are often segregated and set apart from everyday society.

The language of the Medical Model conveys notions of inequality, with its over focus upon the impairment with terms such as “normal”, “not normal”, “disorder”, “handicapped”, “wheelchair bound”, and using the impairment to label an individual, such as calling someone “a paraplegic” or “an autistic” and so on.

The Medical Model of disability also impacts on the way parents think about their disabled children. They internalise the negative messages believing that inequalities stem from their child not having ‘normal’ bodies. Thus they believe that it is the impairment itself that automatically prevents their children from participating in society. They are therefore less likely to challenge exclusion from mainstream society.

The Medical Model also contributes to the disabled individual’s self-perception. They may see themselves as less worthy and inferior to non-disabled people.

The Social Model of Disability

The Social Model of disability makes the important distinction between ‘impairment’ and ‘disability’.

The Social Model has been developed by disabled people who feel that the Medical Model does not provide an adequate explanation for their exclusion from mainstream society - because their experiences have shown them that in reality most of their problems are not caused by their impairments, but by the way society is organised, and its discriminatory attitudes and values.

The Social Model is a powerful new way of thinking because it values difference and diversity. It points out that impairment is a natural and totally normal part of human existence; indeed for many of us the aging process may involve impairment of one kind or another.

Rather than the focus upon the impairment, the child and individual should be central. Their needs should be viewed from the basis that they deserve to participate and have lots to contribute to society. There should therefore be no need for specialist or segregated services, but facilities should be made available
to everyday services so that they can cater for the needs of everyone. Then disabled people can, and do, participate and contribute on their own terms, benefiting to them and all those around them.

Within the Social Model an individual is disabled not by their impairment but by society's barriers: prejudice and stereotypes, inflexible organisational procedures and practices, inaccessible information, inaccessible buildings, inaccessible transport and so on.

As one person with a physical impairment commented regarding her home which had been adapted to meet her needs:

“I am not disabled within my own home – I have a slope to access my property, and the door ways are sufficiently widen. However, when I access a building that only has stepped access and narrow door ways – then I am disabled.”

Society disables; disability is therefore the loss of opportunity. Impairment is an individual's medical condition, diagnosis or description of their functioning. This is the perspective that disabled people themselves have given us over the last 20 years in identifying what the real issues are.

“Disability is the loss or limitation of the ability to take part in the normal life of the Community on an equal level with others, due to physical and social barriers”

Adopted by Disabled Peoples International, 1981

The Social Model values the individual and welcomes social diversity. Its impact upon the relationship between the parent and child is positive – it reinforces the parent's natural instinct to love and cherish her child. It celebrates the existence of her child. It can remove much of the stress and difficulties that parents experience from society. For disabled people, it can lead to empowerment and confidence – their difference is celebrated and the need for change is not placed in curing their impairment, but within society at large.
A Parents Voice:
“Marcia”, talks about….

RACISM IN THE SCHOOL SYSTEM

“Marcia” talks about her two sons, one has a learning difficulty and is in a mainstream secondary school, the other who is now in his early twenties, was labelled as “disruptive” at school.

“Marcia” talks….

Q What are the challenges and difficulties that you have experienced when trying to access provision that supports your disabled child to be included?

One of my sons was having trouble coping with the work in his primary school. I had to insist that they investigate further, but because his impairment was not obvious, and his difficulties were not resulting in behavioural issues, in fact he is quite quiet, they said that they had no concerns.

Later, when I was fighting for a statement for him I was told in the school no one else had the same impairment that he had, and that he was ok. It wasn’t until I got outside assessments that the school finally decided to help. Without that assessment I don’t know what would have happened to him. It was all because he did not have a physical disability or impairment, it wasn’t so obvious.

Q In what ways do you feel that Black and Minority Ethnic People, and Parents of disabled children could be better served, by education, health and other statutory services?

I’ve seen an excellent example of how black and minority children can be served in schools. At the secondary school which one of my children still attends, they had a fantastic service there. They had black mentors who would go out into different schools. This worked really really well in my son’s secondary school. He had this black mentor who worked with a group of children who had different needs. He was fantastic with these children! He was someone they could relate to, but then that service was withdrawn due to lack of funding. All schools need a service like this. It is amazing how children can relate to someone like that. It would be fantastic if the money was there for it to be continued.
Q As a black person, what are the added pressures that you have to face?
You have to try double hard. It’s the same for our black children – they have to work twice as hard.

Q Are there any instances, when you have felt you would have been better served if you were white and middle class?
Yes. It was an incident that is quite personal to me: my eldest son who is now 22, was seen as being disruptive and then eventually expelled from secondary school.

I felt that if I had been a white or middle class person that the situation would not have got to that stage. There would have been things put in place to prevent that happening, and the school would have worked with me to help keep my son in school.

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! It wasn’t anything in particular for some of these boys it was just an accumulation of things that needn’t have happened. They could have tackled these things. Instead of alerting the parents earlier and working with them, they waited until the very end and built up lots and lots of evidence. I’m sure if they weren’t black these boys would have received more intervention. I guess that they just conformed to someone’s stereotype as aggressive, disruptive black males.

It was awful because a lot of those boys were condemned, some of them have been in and out of prison since school.

The saddest thing is that all children are lovely. It’s a culmination of things that happens in their lives that often turns them into what, unfortunately, they are at the end. It’s good if they can stop in their tracks and look back and see that there is an alternative positive life. But that’s working in a family where there are positive circles around them. It’s those who don’t have that who cannot stop and look back and think “What have I done?” That is the hardest thing. Some black boys, if you are honest, find it difficult to talk to their parents. If they haven’t got family support, and no support in the school from Teachers or Mentors then there is no one for them.

Q How does your son feel about this experience now?
Well now my son can look back and say, “Oh my God, it was the worst thing that happen to me”. He’s so different now, but it took a long time for him to realise how serious the situation was. He tells his younger brother to try his best and work hard. He does not want what
happened to him to be repeated with my other son.

Q *Can you say any changes that you think would make a difference?*

I think that there should be provisions like mentors in schools. They should be given the freedom to be able to work in whatever ways they need just to help children stay in school. It’s important to help our Secondary aged boys to stay in school. They need extra support – but its just not there for them. For many of these boys, they are just waiting for someone to unlock them with a key. But if there is no one to do that, they are just going to end up doing nothing and will be labelled. Then a they start living up to their labels: it becomes a self-fulfilling prophecy.

The other thing they need is mentoring and extra support when they are leaving school. It’s something I’m going through right now, I don’t think my child’s being supported leaving secondary school. It’s just that they want him to get out as quickly as possible and there is nothing - no help for me or for him. There should be somebody there for me and for him to guide and advise us on what the next steps could be. It’s especially important if you have had a child who has had a difficult time at school. It’s also important if your child is not academically strong but has other potentials. There’s not much on offer for non-academic boys really.

Q *What are your dreams for the future?*

For all children no matter what their disability or need to be treated fairly. For schools not to be judgmental and assume and think that children can’t achieve and to raise their expectations.

Q *How has your involvement with Parents for Inclusion made a difference?*

I think they have helped me because they have helped me to change. I have changed. Many years ago I was rather an angry parent. I have changed – I’m empowered! I don’t know, I think if they were not there for me - especially when my child was excluded from school, I don’t know what I would have done. They supported me through all that and it does not matter what your problems are they are there for you all the way. We do go through sort of highs and lows and then there is a dip and you think, God, I really need somebody and some support. That’s what Parents for Inclusion is all about.
“Inclusion? What else should I seek? A separate existence in any sense different or apart from our family is not something any of us would automatically choose, that choice was made for us. We agreed to a separate school to her siblings and away from home as it was cruel to keep her at home all day, every day and no provision was made for her in our area. The consequences however have been devastating for our family. It has been impossible to have joint family activities without elaborate and extensive preparations, which may even then clash with her school arrangements. We rarely get to meet her friends or their family’s therefore home visits and overnight stays are out of the question. Her siblings are not conversant with her communication, social and access needs and either leave her out of their activities or politely attempt to include her as one might a stranger.”

BME Parent

In this section we will explore the issue of inclusion, focusing upon inclusive education for disabled children.

Inclusion is the full participation of all groups within society; it is the welcoming and valuing of difference. Its keystone is the building of relationships.

Inclusion therefore is an acknowledgement of difference, and more importantly it is a valuing of difference. It calls for change – change in ideas, assumptions and values. It calls for changes in policies, our constructed environment and our systems. It calls for the removal of all barriers identified by disabled people and their allies/supporters.

Inclusion is the antithesis and opposite of exclusion. As social beings all of us desire to be included; disabled peoples’ desire for inclusion can therefore be understood by everyone.

Inclusion is the underpinning goal of the Social Model of Disability. Inclusive education is seen as the key to an inclusive society where everyone is equally valued, and has access to a broad and stimulating education.

...“Inclusive education means disabled and non-disabled children and young people learning together in ordinary pre-school provision, schools, colleges and universities, with appropriate networks of support.

Inclusion means enabling pupils to participate in the life and work of mainstream institutions to the best of their abilities, whatever their needs.
For it to be effective, LEAs and ordinary schools have to adapt their approach to:

- the curriculum,
- teaching support,
- funding mechanisms
- and the built environment

Developing processes of inclusion - pre-school, school colleges/university settings - means responding to diversity. Each belongs and everyone is welcome. Processes of inclusion are wide-ranging, dynamic, and varied. They consist of:

- Forging relationships
- Building community
- Increasing participation

Inclusion in education is concerned with breaking down barriers to learning and increasing participation for all students, treating all learners on the basis of equality and non discrimination. Inclusive schools are an integral part of an inclusive society.

In education and social settings of all kinds working towards inclusion entails celebrating difference of:

- Culture
- Ethnicity
- Gender
- Sexual orientation
- Needs and abilities.

Taken from ‘Inclusive Education’ a leaflet published by CSIE (Centre for Studies on Inclusive Education.)

These changes must lead to the regaining of the essence of true education so young people can be equipped to understand and value each other, learning the importance of building relationships and becoming equipped to build the much needed inclusive communities of the future.

Many parents of disabled children are already playing their part in bringing about these changes by the simple act of refusing to stop valuing their children. These parents are revolutionaries. But even so the system can exert a powerful force to put them off their track.
“The main difference between parents and professionals is one of power. Professionals act within a system, backed up by laws, regulations, colleagues, resources, training, status, clerical support, large offices, long words and emotional distance. Parents only have their love for their child, and their desire that that child should be given the best possible chance to have a good life. How is partnership possible in such an unequal state of affairs? It is only possible if everyone involved is willing to examine the values and beliefs which lie behind all our actions”.

Micheline Mason, Parents and Partnership, 1996

“.All we want is for our children to be valued, happy, included and to be educated. We want to be able to celebrate their successes…”

Parent speaking at an Inclusion Group in school.

Parents within the BME reference group felt that their main goals were for a mainstream inclusive education for their children. We felt strongly that inclusive education benefits all children, and that inclusive processes, adaptations and systems have a positive impact for all children.
A POEM FROM BEN OKRI

Whatever the purpose or the meaning of life is, education is an important part of it. No great transformation of a people is possible without pervasive education.

It is the sustainer of civilization.

Education is one of the makers of whatever our future will be. It is the liberator of minds from the slavery of fear, evil and ignorance.

It is the Nile that turns poverty into fertility.

More than all the gold of fabled lands, education can be one of the single greatest healers of most of mankind’s ills - the perplexity of destiny, the evils of racism, the death of liberty.

For education shines a light in the darkness of our minds, and makes the world what it always was, raw material to be fashioned by our wise will and our enlightened vision into a glory land of possibilities.

But first education must itself be enlightened and must incline towards the illumination of mankind.

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OUR VOICES

A young person’s voice:
“Ola”, talks about….

SCHOOL

“Ola” is a young disabled person who attended a local mainstream nursery and now attends a local mainstream primary school. He has learning difficulties.

“Ola” talks…

Q  What are your early memories of school?
   I played with the train set in my nursery, I like train sets. I liked my nursery a lot.

Q  What is your school like?
   I like my school. I have lots of friends and I play with them. But I don’t like the bullies, they call me names. They pick on me because I am in year 3, they pick on all year 3 kids. But the bullies have gone now. No-one should be bullied.

   In school I like science the best and art and maths. I am good at maths. I wish that my school was a science school, where we got to make rockets and could use our super powers!

Q  When you grow up and move to secondary school what do you hope for?
   I hope that there are no bullies. I hope that my teacher can come with me to secondary school. I hope that my friends can come with me to my new secondary school.
OUR VOICES

A young person’s voice:
“Kareem”, talks about….

SCHOOL

“Kareem” is a young disabled person who attended a special residential. He attended this school because the local authority did not make the resources available to meet his needs locally. He now remains at home. “Kareem” talks…

Q What are your early memories of school?
A learning space, but I had a terrible experience. I was hurt every time I mention work was too easy and boring. All the teachers and carers working are evil. They do bad things to get children reaction to be violent. I watch one child kicking out at staff, they barricaded him in room let out afterward. I hated every staff and begin to feel learning not important in my life. Every day is a nightmare and I was unhappy all the time. But something I learn was to endure bad treatment I suffer which I told my mother.

Q What was the school like?
School work was too easy. I complained, teacher scolded and pull my ear that I do as am told.

Small school size, big ground for play, good light to classroom, difficult to make friends as are speech impaired and behaviours annoying. Teachers and carers verbally abusive, harassing, provoking pupil by teasing physical appearance, facial expression, bullying children by pulling to hurt. They lock doors: toilet, bathrooms, bedroom, feed with inedible food and fruits. I was frightened, felt unsafe, I felt unloved by my mother for sending me to hostile people and school.

Q What happened as you grew older and moved to secondary education?
My mother became my teacher and my school was at home since LEA yet to fund a school placement.

Q What do you feel about your education now, and are there changes you would like to happen?
An illusion, living in a dream world waiting to wake up out of the dream. I hope I am offered the opportunity and be funded in education that are able to address my difficulty too.
OUR VOICES

A young person’s voice: “Zainab”, talks about…

SCHOOL

“Zainab” is a young disabled person who attended a mainstream primary school. She now attends a mainstream secondary school.

Zainab talks…

Q What are your early memories of primary school?
I made lots of friends but the other children wanted to know what had happened to my legs, many were quite curious. The teachers were understanding. The only bad thing about my primary school was that there was no disabled access, so it was quite difficult for me to go to certain parts of the school building.

Q What happened as you grew older and moved to secondary school?
I was happy but very nervous. I was worried because secondary school is a huge step. The work is harder. But I was happy when I started because the building has much more disabled access like lifts and ramps.

I was also thrilled to discover two more disabled kids using wheelchairs; so I wasn’t asked questions by the other pupils because they were used to it.

Q What do you feel about your education now, and are there changes that you would like to happen?
I’m happy about my education, I really enjoy being at school. But I do worry a lot about the lifts breaking down, like they did before. I need to use the lifts to get to class.

I would like other kids to stop using the lifts when they don’t really need it, so that it can be used by those that do need it.
OUR VOICES

A young person’s voice: “Sau”, talks about….

SCHOOL

“Sau” is a young disabled person who attended a mainstream primary school. He now attends a mainstream secondary school.

“Sau” talks…

Q What are your early memories of primary school?

I’ve done this drawing -

Q What was the school like?

The school is a very enjoyable school. The teachers are very nice to me even with my disability. I liked the building because its so big and it looked like it needed adventure. Most of the kids are nice to me but some just tease me about my disability and colour. Generally I loved it a lot.
Q  What happened as you grew older and moved to secondary school?

It was scary for me when I moved to Secondary School. I found out the Secondary School was going to be a whole lot harder, and the teachers are not very nice.

I find the work not that easy as well. I get homework every night, and hsp’s take the longest time because it’s the research homework.

Q  What was secondary education like?

I find that my education is running quite well and I excel in Maths and Science and RS (Religious Studies). The building is 40 times bigger than my nursery and primary schools combined, it is very tiring five minutes after each lesson because you have to move all the way from one lesson to another on the other side of the building. The teachers are nasty and they are very loud, they tell you to shut up.

I make friends very easily and because of that I’m known all the way up to Year 11. I am a popular boy. Kids are nice to me except the odd ones.

I like Secondary School a bit but not a lot.

Q  What do you feel about your education now, and are there changes that you would like to happen?

I think my education is better but a lot harder; I’d like to have another CCTV and to finally get my dictaphone.
In this section we will explore why a special Reference Group of BME parents was required.

All parents of disabled individuals experience the discrimination, isolation, anger and distress that disabled people themselves often experience. As BME parents and BME disabled people we often face more barriers due to racial inequality. When accessing support groups or services, many of us felt that we were invisible and our distinct needs and experiences marginalised within what are often predominately white middle class organisations. There is often a struggle to have our voices heard.

Like many BME families with a disabled child, it has been our experience that when we access Black or Asian or disability groups or services, we are inadequately served, as they are not able to fully address the combined issues of race and disability. We have frequently found ourselves falling between the gaps created by both groups, furthering our isolation. In 2001, the Joseph Rowntree Foundation carried out a survey of the views of Black disabled people on the services that they received: “Providing better access to short breaks for black disabled children and their parents”, May 2002. This report reiterates our experience of unmet needs and indicates that gaps are often mirrored in the priorities and remits of funding bodies, of the objectives of voluntary and statutory agencies, as well as in the gap between the disability movement and the race equality movement. The report suggests that restrictive or limited funding often results in either race or disability being the main focus for groups and organisations.

For many BME parents of disabled children, it is impossible to separate the issue of race and disability, and the apparent inability of groups and organisations to reflect the equal importance of these issues renders our experience invisible, and compounds our isolation.

White society is the main perpetrator of inequality and discrimination, thus many BME parents have also expressed their reluctance to openly and frankly discuss issues of racial or cultural discrimination with their white counterparts or with predominately white disabled organisations. For many of us, such organisations do not represent a safe place in which these issues can be fully explored, or from which we can become empowered as Black people. The lack of understanding of our experience as Black people and cultural ignorance means that the predominately white disabled movement/groups do not represent a place in which we can always feel totally welcome or comfortable.
A BME parent commented:

“I sat there listening to the facilitator. What she was saying was good, I agreed with it. But all I was thinking was that there she was, a white middle class woman with more resources at hand than me. I did not even have the support of my family or my church community, who were rejecting my son and I, because he was different.”

She later concluded:

“It seemed much easier for her to approach the professionals – she spoke their language.”

One parent confessed, when approaching Pi and faced with a predominately white and middle class organisation,

“My experience since my son's diagnosis was of ‘medical model’ professionals who were, in the main of a similar social and economic group. My assumptions lead me to believe this was not to be a place where I could be myself and find the kind of camaraderie I needed.”

The lack of awareness of the linguistic and cultural needs of BME parents means that many of us are unable or reluctant to access many organisations supporting disabled people and their families.

The specific cultural and linguistic needs of the BME community often go unacknowledged and unrecognised by many predominately white disabled groups. Indeed, in a report entitled “Double Invisibility: A Study into the needs of Black Disabled People in Warwickshire”, M. Banton and M. Hirsch, 2000 the results of a survey of over 60 organisations supporting disabled or BME groups in Warwickshire revealed widespread ignorance about the needs of BME disabled people and their carers. The report highlighted that language and communication problems make it difficult for the BME community to find out about the help on offer. This report highlights that for many organisations and service providers for disabled people, the needs of the BME community go unrecognised: this is reflected in their organisational structures and distribution of resources.

The inequalities faced by disabled people within the BME communities are further reinforced by the “invisibility” of our experience. There is very little statistical data or research to highlight the disparity experienced by disabled people within the BME community. Indeed research may even totally overlook the BME experience because it is so often colour-blind and assumes equality of access. For example, the recent PACE Tribunal Report (PACE 2002) surveyed 75 parents to highlight their experience of appealing to the SEN and Disability Tribunal regarding their child's special educational needs. The report captured the immense difficulties and challenges that parents and families face when having to resort to the Special Educational Needs and Disability Tribunal.
(SENDIST) to secure educational provision for their children who have ‘autism’. It concluded that:

“Our survey confirmed that although the right to go to SENDIST is in theory available to all, the reality is that it requires significant resources - both emotional and financial.”

It also went on to conclude:

“Given these facts, it appears that in reality those going to Tribunal represent the tip of the iceberg, because it is a process that only a minority can afford to embark on – be it emotionally or financially.”

The absence of any indication of how race and ethnicity affects the possibility of BME parents being amongst that “minority”, that is those who appeal to the SENDIST, is unfortunately never explored. Our own experience as BME parents informs us that very few BME parents are aware of their children’s educational rights, and very few resort to appealing to the SENDIST to secure more, or different educational provision.

Groups, organisations and statutory services geared to the needs of the BME communities similarly are unable to address the issue of disability. Whilst many BME groups often address the inequalities of access for statutory services and the uneven distribution of resources, the issue of disability often goes unaddressed. Indeed, it is important to recognise that people have different levels of awareness of disability issues, and attitudes vary between and within black and white communities.

Within some BME communities there is great stigma attached to disability. This can be due to religious notions of disability being a result of sin, punishment or disfavour. It can also be linked to a history of colonisation and slavery, where disabled slaves, indentured labourers and workers were killed because they were seen as non-productive. Views of disability may also be the result of widespread poverty in underdeveloped countries, where the disabled may be seen as a burden. These views may inform BME communities’ notions of disability within the UK, but the persistence of this stigmatisation of disabled people can also be attributed to the lack of services and low levels of awareness-raising work in BME communities.

Many within the BME community have not had the opportunity to explore alternative models of disability, because they are mainly informed by professionals who promulgate notions of the Medical Model. They have never been able to gain an understanding of inclusion, or the Social Model of disability. It is clear that there is much work to be done to inform and educate the BME community; to challenge attitudes, values and cultural or religious notions of the inequality of disabled people that are held within our communities.
Within our communities disabled people have typically been marginalised or their disabled status uncelebrated. For example, Black History Month in the UK and US rarely celebrates or makes explicit the contribution of black disabled people. Harriet Tubman, for example, is widely celebrated for her role in fighting against slavery in the US: she escaped slavery and helped others to do so. However the fact that she was disabled – she had a brain injury and experienced blackouts - is not celebrated.

Often when the BME community speak out against discrimination of disabled people it is predominately in terms of race – that is, they are resisting what they feel is white society’s attempt to label or categorise Black people as “different”. Due to the lack of awareness, the BME community rarely see their experience in terms of racism and disablism, that is they rarely recognise the role of disablism.

Many within our group talked about the rejection and isolation that we felt from our own communities – this was especially where our children’s impairment was less visibly obvious. One parent shared how she was unable to take her disabled child to their local centre to worship, because both she and he were being ostracised by the other worshippers because of his behaviour, which was due to his condition.

It appears that those of us with children with learning difficulties face the most lack of understanding from our own communities. For many BME communities, the need for our children to be self-reliant, or the high value placed upon academic attainment means that the abilities of our disabled children are devalued and overlooked.

As discussed previously, the barriers that many of the BME community experience when accessing disability groups, and the inability of our own communities to challenge disablism, has resulted in lower levels of awareness within our communities, and our general ignorance of disablism as an oppressive force, as we do racism. We do not always have the tools to challenge notions of disability or to break down barriers to inclusion. Thus the cycle of inequality continues.

**The Parents for Inclusion BME Reference Group** was established by BME parents of disabled young people who were accessing their Inclusion Groups or helpline. The reference group also drew in black disabled people and their allies. The group met for a year with a BME worker in place for 6 months coordinating discussion groups, workshops and training.

The key objectives of the project were:

- To contribute to the longer-term objective of the inclusion of disabled black and minority ethnic children into mainstream schools.
• To engage more black and minority ethnic parents and parents of early years children, as these groups of parents are those identified as in need of support that can be provided by Pi, and yet are under represented on Pi’s training events and in the organisation itself.

• For black and minority ethnic parents to have increased representation in Lambeth.

• To recruit more black and minority ethnic parents to build our capacity to deliver more advice and information, and training locally and nationally, and to support the formation of local inclusion groups.

The group was successful in initiating Race Equality Training for all staff within Parents for Inclusion, which resulted in recommendations for Parents for Inclusion (see appendix 1) setting up a workshop for BME parents to explore a P.A.T.H. (Planning Alternative Tomorrows with Hope) for their disabled children (see centre colour pages and appendix 2).

A PATH is a structured tool to help groups dream together and make more detailed plans in order to achieve their dreams. Also the group held a workshop for BME parents celebrating our disabled children, called “All our Children Belong” (see appendix 3).

For many of us involved in the Reference Group it was an invaluable opportunity in which we could openly and frankly work through the issues of race and disability, with a full acknowledgement of the multiple oppression that we experience. It was an opportunity to talk with and learn from disabled people, and it was an opportunity to acquire some of the tools of empowerment and inclusion.

ESE NE TEKREMA -
“the teeth and the tongue” - friendship, interdependence
A Parent’s voice: “Marion”, talks about…

INCLUSIVE EDUCATION

“Marion” talks about her daughter, a young person with a physical impairment. She insisted on an inclusive education for her daughter.

Marion talks……

Q What are the challenges and difficulties that you have experienced when trying to access provision that supports your disabled child to be included?

I felt very strongly that my daughter should have an inclusive education. I did not want her to be separated, or made to feel like she did not belong. I did not want her to be excluded. She has always been intelligent. She is much more confident due to her mainstream schooling. However, when she was young, our health visitor strongly advised me that I should place my daughter in a special school. She said that they would be able to cater for her needs more, but I was adamant that she should attend a mainstream school.

I wanted her to attend a church school, and when we initially approached the local church school they seemed quite positive. At the time my daughter used a walker. However, we were later informed that they had no places available. When I appealed I was told that this was due to the fact that we were not practising Christians. I appealed, as we had provided the necessary documentation to prove that we were in fact regular church goers. We then learnt that my daughter was not admitted because it was felt that her walker would take up too much room! I appealed on the grounds that this was discrimination.

Perhaps to appease us they said that my daughter would be placed on the waiting list. But we never heard from them again. It was clear that they did not want a disabled child in their school.

We found a different school, which was more supportive and welcoming. However, just like in my daughter’s Nursery school, there was nothing in place for a child with a physical impairment – no ramps or adjustments. Can you believe it, in the 21st century! There was even a school governor who was a wheelchair user who was unable to access many parts of the building due to the lack of access.

I initiated a campaign and with the support of the school wrote many letters to the local education authority. The former head teacher of the
primary school even threaten to go to the press as the education department were very unresponsive. Finally the ramps were put in place.

It was through my daughter that the ramps were put in place, and that school is now more accessible to more disabled children and adults.

The only thing that I found difficult to deal with was that I still had to accompany my daughter on all school trips and outings.

In year 5 we were very upset that my daughter could not attend the residential trip because the facilities had no disabled access. Both my daughter and I remember this with great indignation and sadness.

Q Tell us about your daughter's experience in her new Secondary School.

It's a new school, so the building is accessible for disabled people. My daughter is quite a confident friendly child and she seems to be coping well in her new school. However, she recently mentioned that she is having some difficulty making friends, and that she is not being invited over to other students houses, like some of the other students. It seems that the other parents may feel uncomfortable about having her over. I tell her that sometimes these things take time and that she should keep positive. There are other disabled pupils at her new school so she does not feel so isolated.

Q In what ways do you feel that Black and Minority Ethnic People, and parents of disabled children could be better served, by education, health and other statutory services?

We tend to be less informed about a range of issues and alternatives. Many of the professionals that we come across have access to lots of information but do not seem to want to empower parents with it. So you see, it's really up to parents to educate themselves about their child's condition, about services, their rights and entitlements.

Q As a black person, what are the added pressures that you have to face?

You often have to try twice as hard in many things that you do.

Q Are there any instances, when you have felt you would have been better served if you were white and middle class?

Generally, no. However, I have noted that white families that I know have had better results with re-housing.

Q Can you say any changes that you think would make a difference?

Less discrimination against disabled people. Parents to be given more information and support.
How the Black and minority ethnic experience differs.

In this section we will explore how the BME experience differs from our white counterparts. It will focus mainly on BME parents of disabled young people.

Our report acknowledges that most families with disabled children experience injustices, hardships, isolation and many other difficulties. However, for many BME families the experience is qualitatively different. Our experiences are generally missing from research and data on disability, which appears to predominately capture the experience of white families and disabled people. One piece of research carried out by the Universities of Bradford and York (1999) was “one of the first to provide detailed information at a national level of the needs and circumstances of families from minority ethnic groups caring for a severely disabled child.” It compared its findings with those from an earlier survey of white families from the same database. The research by Chamba et al (On the Edge: Minority Ethnic Families caring for a severely disabled child, 1999) compared a 1995 study which explored the experiences of about 1,000 white families caring for a disabled child, with a study in 1997 of a comparable group of BME families caring for a disabled child.

The research concluded that:

“In comparing the findings, the current study (of BME families) shows that, with few exceptions, minority ethnic families were much more disadvantaged in all areas explored and had higher levels of unmet need than the white families in the 1995 study.”

The report indicates that:

“Overall, families from minority ethnic groups caring for a severely disabled child were even more disadvantaged than white families in similar situations. Families’ experiences, needs and circumstances varied across ethnic groups…….

Compared with white families, fewer families were receiving disability benefits. Those receiving benefits were less likely than white families to be awarded the higher rates of Disability Living Allowance (despite both groups having severely disabled children)”

The report goes on to cite the lower household income levels of BME families in comparison to their white counterparts:

“Most families reported incomes of less than £200 per week. Overall, families in this survey reported lower income levels than the white families in the 1995 survey. Pakistani and Bangladeshi two-parent families had much lower incomes than Black African/Caribbean and Indian two-parent families. Lone parents
Low levels of employment - especially among mothers - contributed to the difficult financial circumstances in which many families were living. Three-quarters of mothers had no paid work. Black African/Caribbean and Indian mothers were more likely than Pakistani and Bangladeshi parents to be in paid employment or to want to be working.

The report also goes on to cite the higher levels of unmet needs amongst the BME group in comparison to the white group, highlighting important issues such as unsuitable housing, unequal access to services and information by speakers of languages other than English. The other unmet needs ranged from: lack of money, support with helping their child, help with planning their child’s future, support during the school holidays, respite, and help with sleep/behaviour problems. Whilst the unmet needs were similar for both the white and BME families, the latter reported twice as many unmet needs compared to their white counterparts. The report also indicated that despite the stereotype, BME families experienced less support from their families – both immediate and extended, than their white counterparts; Black African/Caribbean and Indian families being the most vulnerable. It is also likely that with the former group more likely to be single parents, and both groups containing mothers most likely to be employed, that these families experience considerable levels of stress and pressure.

This research goes some way in highlighting the different experiences of BME parents of disabled children. However, what is known about the experiences of BME parents of disabled children remains limited, compared to our white counterparts.

Indeed, it outlines that for many BME parents per se, the daily struggle for survival is immense. For some parents the continual need, say, to attend numerous appointments and even support their child at school, seriously jeopardised their ability to remain employed and some have been forced to give up paid employment. Many parents do not discuss this with professionals for fear of being seen as not caring enough for their child. For many BME families who face lower household incomes and greater vulnerability to unemployment this can result in considerable stress for the whole family unit.

Within our group, many of us shared about the experience of anger, frustration and ultimately depression. This was often in result to our isolation from our community and the lack of support in general. Within the BME communities, many parents of disabled children go unsupported and their needs largely ignored. For certain sections of the BME community, ideals of self-reliance and
the fear of being seen as not coping is very strong. As is a reluctance to seek assistance or support from those outside of our communities. Thus service providers fail to be proactive and interpret these messages as a lack of need.

Both within our reference group and within the report cited above, the lack of information was confirmed as an important issue. Chamba et al’s (1999) research highlighted the unequal level of service received by speakers of other languages. Indeed, over one third of the families in the survey indicated that interpreting and translation would be an important requirement, however all families indicated that the provision was limited, and in respect to translated materials sometimes non-existent. This seriously impacted on parents’ ability to learn about their child’s condition and the services available for them and their child. Thus the research highlighted that they were also ignorant of their rights and the choices available to them.

Krishna Birdy’s findings in the report “Equal Education for All” (published by Disability Equality in Education, 2003), highlighted that within the group of Asian parents of disabled children attending the workshops hosted by the Asian People with Disability Alliance in North London and DEE, that the Asian parents were not aware of the options available to them regarding the education of their disabled children. Many of them were under the impression that special schooling was their only option.

Thus for many BME families, services not only fail to meet our needs, but serve to reinforce social inequality.
OUR VOICES:

A Parent’s Voice:
“Muna”, talks about….

ACCESSING SERVICES

Q What are the challenges and difficulties that you have experienced when trying to access provision that supports your disabled child to be included?

We had numerous referrals to many departments and agencies, all of which involved many different appointments and my child having to be assessed over and over again by each different one. The same questions, the same information! Added to this, each department or agency has its own special policy devised to produce a lengthy waiting process.

We have required input from many different services including medical intervention, legal involvement, education, social services and diagnosis before any action was taken.

It surprised me that even on identification, delays continue to occur and the implementation of strategies or support was very slow to be put in place.

Q In what ways do you feel that Black and Minority Ethnic People, and Parents of disabled children could be better served, by education, health and other statutory services?

Many of us need to be re-educated in all aspects of disability. We need knowledge of disability issues and an understanding of the history of disability. We need this kind of information to be delivered locally. We also may require access to counselling services to help us talk over issues and raise our confidence.

Q As a black person, what are the added pressures that you have to face?

Personally, I have had a limited knowledge of education, so I have had some problems with literacy and communication. My family has experienced upheaval and domestic turmoil. We have felt socially isolated in many ways. Economically, we experience considerable instability as our finances are not meeting the growing cost for our basic living needs, especially getting what I need for my child. I have also experienced health and mental health problems.

Q Are there any instances, when you have felt you would have been better served if
you were white and middle class?

Yes, I have felt unequipped to use information due to a language and communication barrier. I have difficulty expressing myself verbally or on paper clearly in English, so my opinions and what I would like to see happen often never really gets expressed. I often feel invisible.

Q Can you say 3 changes that you think would make a difference?

Re-organise the available services under a single department or agency with a single policy.

Early intervention and support will help to achieve adequate independence for disabled people.

Re-educating those involved in social work, education, health, welfare and society in general so that they understand the real needs of disabled people and their families.

Q What are your dreams for the future?

That the stated 3 changes might be considered not only locally but nationally as well.

Q How has your involvement in Parents for Inclusion made a difference?

I have been able to meet more parents in similar situations. I have learnt about how the system really operates for disabled people and their families. I have learnt about my son’s right to educational provision.
THE CHALLENGES WE FACE IN SEEKING INCLUSION FOR OUR DISABLED CHILDREN

Kim

When I first had Kim he was my son
A year later he was epileptic and developmentally delayed.
At eighteen months he had special needs and he was a special child. He had a mild to moderate learning difficulty. He was mentally handicapped.
I was told not to think about his future.

I struggled with all this.

By the time he was four he had special educational needs.
He was a statemented child. He was dyspraxic, epileptic, developmentally delayed and had complex communication problems.
Two years later, aged six, he was severely epileptic (EP), cerebral palsied (CP) and had complex learning difficulties.
At eight he had severe intractable epilepsy with associated communication problems. He was showing marked developmental regression.
He had severe learning difficulties.

At nine he came out of segregated schooling and he slowly became my son again. Never again will he be anything else but Kim – a son, a brother, a friend, a pupil, a teacher, a person.

Pippa Murray
Stories of Exclusion, from the book Let our Children Be

Within this section, we will explore the challenges that we have faced when seeking social inclusion for our children.

The Medical Model of Disability seems all pervasive, and at times ingrained and unchallenged in society, just as racism and sexism were a few decades ago. Therefore when BME parents seek inclusion for their disabled children, notably inclusive education, they begin to challenge deep seated and widely held views and assumptions. We may be challenging a teacher’s view of what education actually is – that education is more than literacy and numeracy, it is learning
about others and building relationships. We may be challenging a psychologist’s view about the importance for our disabled children’s social needs – the importance of them having a broad section of friends and allies situated within their local communities and neighbourhoods, something that may be difficult if a child is educated in a specialist setting. We may be challenging an officer of the LEA when we insist that high level needs can be supported within a mainstream setting, and in fact can prove an efficient and more cost effective use of local authority resources. We may be challenging general notions about the ability and potential of our disabled children, that they have a right to a broad and wide curriculum, because their potential is unknown in their early years.

We all felt that inclusive education was important for our children, because we understood that our disabled children would very soon become disabled adults. An inclusive education would facilitate their inclusion into our local communities, and society in general. For example, by being educated in their local schools our disabled children will be able to establish friendships and networks with their peers from their communities. This is very often difficult to achieve if a child receives a segregated education. They are generally unknown by local children and people because they are educated away from their peers.

We often become labelled “difficult” and “demanding”, and even conform to racial stereotypes – for example that of black people being aggressive, when indeed we are pioneers, just as our disabled children are.

Within our group, we all knew many examples of families who had experienced the oppressive forces of racism and disablism. For many of these families, we remarked on how the lack of information on the parts of the parents had resulted in inequalities for their disabled children. A number of disabled children were placed in a mainstream setting without adequate support, or parents were being placed under pressure to remove their children from mainstream schools. A number of children were being placed in a special school when a mainstream setting could have been achievable, but parents were either unaware of how to achieve this or were being hindered by the policies of the Education and/or Health services. A number of children were placed in inappropriate specialist settings and their parents were trying, unsuccessfully, for an alternative or an inclusive setting. It was also not uncommon for black and minority ethnic disabled children of school age to be without an educational setting altogether.

It is also our experience that many BME parents are not even aware of their rights for health provision, benefits or other statutory services. Many within our communities are unaware of where to go for assistance and help, or the
existence of support groups. This is especially true where English is an additional language.

Our white counterparts however are accessing and utilising services much earlier and with better outcomes than we are.

One BME parent commented that following an appointment with a community paediatrician she was informed that her son probably had autism. She was informed that this would only be confirmed after a multi-disciplinary assessment. This would take place in approximately 18 months to 2 years. The paediatrician advised her not to find out more information until the assessment had taken place, as it would only “upset” her:

“…I came across a white couple whose son was the same age as mine. They had the resources to get a diagnosis almost immediately by going private. After they had this, they were able to access all sorts of services, including requesting for a statutory assessment for statementing. They were even able to see an NHS specialist and discuss which educational approaches would best meet their son’s needs. They seemed miles ahead of me in terms of getting the right support for their son.”

BME parents within the Reference Group also noted the over representation of BME children in special or segregated educational provision – this is despite most impairments having no direct causality to ethnicity or socio-economic status. This was also noted in Krishna Birdy’s report, “An Equal Education for All” (2003) which looked specifically at Asian parents of disabled children in North London. Krishna Birdy noted that a high proportion of the children of those that attended the workshops attended special schools. Within our reference group, our experiences concur with Krishna Birdy’s findings, it is our experience also that many BME parents:

• are not aware of their rights, and their child’s right to an inclusive education
• are not aware of their options in regards to educational provision.
• have limited knowledge, or are confused by the Statementing process
• are not aware of support agencies within the statutory or voluntary sector that can support them achieve a mainstream education for their child

Indeed, many within our reference group talked of not feeling full participants in the decision making process concerning our children’s education. Many felt daunted by a room of (predominately) white middle class professionals in review meetings etc, and felt unconfident about speaking up, or questioning decisions. Parents mainly felt that the “expert’s” opinions were more valued and seen as more important than their own. Even when they disagreed with
professionals they often did not feel confident enough to challenge this, especially in meetings where they generally felt unsupported. Like the parents in Krishna Birdy’s report, many of us were made to feel that it was the professionals who knew what was best for our children.

There are often barriers to our inclusion in the decision making processes concerning our disabled child: the use of professional jargon, being invited to meetings but not being fully informed of the purpose or what to expect, lack of support and information in order to make informed decisions, and the attitudes of professionals which suggested that they know what is best. Parents that participated in Krishna Birdy’s review informed that they had not been invited to Annual Reviews or been asked to submit reports. Some were not even informed about the Annual Review until after it had already taken place!

One parent comments:

“I do not recall any one ever really explaining to me what an I.E.P (Individual Education Plan) was, or a Statement (of special educational needs)... I would be invited to meetings by my child’s school and discover that we were reviewing her IEP or the annual review of her statement. I was given little support to prepare for these meetings, so I would just sit there and listen, without having much to contribute. Afterwards, I would always have questions or things I wanted to add, but it was always too late by then.”

Krishna Birdy’s report indicated that many parents felt that professionals often had a hidden agenda. This concurred with the experience of many within the reference group who felt that this was mainly attributed to issues around resources, but also to professionals’ perceptions of us as parents. We felt that these perceptions were often underwritten with cultural stereotypes, that we were “bad parents”, had poor parenting skills or capacity, or that we were being aggressive or overly demanding. Some of us also felt patronised or pitied by professionals. Many of us have had the feeling of being discussed and talked about by professionals behind our backs in what we suspect is less than positive terms!

It is clear that the failure of statutory bodies to appropriately inform, support and educate parents in the workings of their systems has resulted in the lack of parental participation in the decision making processes and therefore the perpetuation of social inequality for our children.

Within the BME communities, there are lower levels of awareness, information and education around issues of inclusion and disability than there is within white society. BME families with disabled young people require a greater understanding of inclusion and the history of disabled people. However, it is
important to recognise that inclusion is still a battleground yet to be won, and that the BME community is itself already engaged in battles on several fronts already. For many parents, inclusive education often entails fighting for correct levels of provision and adequate support. These struggles are often against the very institutions that we feel are already poorly meeting our needs, our communities needs as a whole, or are perpetuating social inequalities.

Within many special schools, BME parents may be isolated by the organisation of the school. Most children within special schools are transported to school by community transport, therefore parents rarely get to meet and form relationships with each other. As it has been widely acknowledged that parents of disabled young people actively benefit from the support and often first hand advice of other parents, many of these parents are denied a rich source of assistance and support.

Many of the structures within Education and Health prove to be the greatest barrier to inclusion, and can often reinforce inequality.

For some of us they also act as a cohesive force against inclusive education for our children. This can be attributed to what is seen as a conflict between parents demanding better services and the public bodies seeking to limit expenditure. This is of course a false economy, as many parents recognise, because early intervention, inclusive education and appropriate support can often result in confident disabled people leading productive lives and contributing to society.

All parents within our Reference Group shared about their need to “fight” for their children's educational and health rights. Almost all of us within our groups had experienced considerable difficulties when attempting to place our children in mainstream education. The difficulties we experienced were discriminatory attitudes from both the schools and the education authority. One parent relays a common experience:

“I visited about ten local mainstream schools within my area – only one was happy to accept my child. They all knew that they could not openly deny him access, but they made us feel very unwelcome. The experience was totally different for my non-disabled child – he was welcomed without reservation.”

A number of us have had to resort to going into dispute with both the LEA and/or schools. The parent continues:

“The LEA said that they would only offer 15 hours of support - my son had high support needs and would require about 30 hours. The LEA informed me that if my child required 30 hours he should be placed in a special school.

The mainstream schools were saying that they would not accept my son
because they were not prepared to supplement the 15 hours. Although I wanted my son to go to a mainstream school, I felt that my only option would be to send him to a special school....”

Many of us experienced local mainstream schools discouraging us from admitting our children to their schools, even when we were within their catchment area. We were often encouraged to seek special schools, or to re-contact the LEA. Where our children have high level support needs and may require full time support, it is common for LEA officers to inform parents that full time support cannot be met within an inclusive setting, and that parents had to opt for a specialist one instead.

Even where schools were already supporting children with special needs, many Head Teachers, SENCOs and so on expressed a reluctance to “take in any more”. We were also aware of parents whose disabled children were already placed in schools, for example in a Nursery class due to move to a Reception class, who faced intense pressure from schools to remove their child, or were actually denied a school place.

If school admissions were not an area of difficulty, then for most of us, the correct level of provision and support certainly was, and often remains so. All members of the Reference Group have statemented children, but many of us experienced the failure of the LEA or schools to make realistic and appropriate provision for our disabled children to be either sufficiently educated or included. Also, many other aspects of the statutory assessment and statementing process remain ambiguous and beguiling. LEA officers and other professionals often give incorrect or unhelpful information. We are often bounced between different agencies, with a failure of all to take appropriate responsibility and action to resolve problems. One parent described her experience when attempting to resolve the exclusion of her daughter, who has a physical impairment, from attending the school’s residential trip:

“I am still upset by what happened to my daughter in year 5. In year 5 pupils go away for a week’s residential, we were told that she would not be able to attend because the accommodation was unsuitable, that is, inaccessible. I complained and made strenuous efforts to reverse this decision. However, I was pushed from pillar to post – no-one wanted to take responsibility for resolving this. The Education Department of the Local Authority said that it was the school’s responsibility, and the school said that it was the responsibility of the Education Department. It was exasperating and tiring. In the end, she was excluded from an activity that all her peers were able to attend.”

This failure of agencies to work co-operatively is a common experience that many parents talked about.

For a number of the group, accessing support groups meant that we were able
to challenge the system, as one parent continues:

“I received a lot of support from Pi, IPSEA* and other groups …..In the end I went to the SEN Tribunal and the case was decided in favour of my appeal – my son was awarded 30 hours for support at a mainstream school.

He has made great progress at his mainstream school, and is extremely happy there. Everyone agrees that he would not have made this progress if he did not have the appropriate level of support.”

*IPSEA - Independent Panel for Special Educational Advice

For all of us who resorted to taking the LEA to a Tribunal or threatening to do so, it was an exhausting and expensive process. However, we agreed that is seemed the only channel left available to us.

Within our group we recognised that for the vast majority of BME parents this action is well beyond their means, but we also felt it should not be a necessary step to secure provision.

Within our group, we also shared our experiences of the cohesive pressure we experienced when seeking social inclusion via the views and opinions of professionals, other parents, friends and family. The messages that we receive are all underpinned by notions of what is good parenting; thus to disagree and to challenge was to seen as not being a good parent. We were often being told that we were harming our disabled children by placing them into a mainstream school.

However, messages of social exclusion and inequality begin very early on in the lives of some of our children. When an impairment begins at birth or in the very early stages of development, it is invariably communicated to parents via the Medical Model. It encourages parents to think of their child as “imperfect ” “faulty ” and “impaired”, rather than a child with impairments. It places the child outside of the realm of what is considered “normal”, positing a false notion of humanity which fails to acknowledge the existence of impairment all around us.

For parents the whole process of assessment and diagnosis focuses almost exclusively on what the child is unable to do, how different they are, and what is “lacking”. As one parent commented:

“The whole process constantly forces one’s attention to what my child cannot do. I began to see my child in terms of his inability and not his ability.”

Another parent commented

“..we received a 5 page report that described in some detail all my daughter’s
difficulties. In a very brief paragraph it mentioned the things that she was able to do. I almost did not recognise my own child.“

The Medical Model is wholly destructive in the parent-child relationship. Its notion of human perfection encourages many parents to grieve for the “loss” of their, perhaps, once perfect child rather than encourage an acceptance of his/her difference. Many parents therefore find it necessary to emotionally re-acquaint themselves with their child. Parents go on to grieve this “loss” for a considerable time, and some may never really accept their disabled child. Within the Reference Group we all openly shared that we had indeed undergone this painful and often destructive emotional journey.

One parent shared her story:

“It took me many 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 loved and 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.

Throughout those months I cried every morning, each day I woke up with a deep sense of hopelessness. As I dressed for work, I put on this façade of confidence – but deep down inside I was crumbling.

It became impossible for me to discuss it – like I had become the keeper of a dreadful secret. In fact, I very quickly refused to discuss it at all, and even censored my own thoughts. It was like, if I did not talk about it, then it would somehow not be true – that it would somehow go away.

It was the worst time of my life…..”

The impact upon the parent–child relations of viewing the disabled individual through a Medical Model is immense. Many of us expressed some difficulties in identifying with our disabled child. We felt somehow estranged from them as we too saw them as problematic and their “faulty” and “disordered” body as the source of all their difficulties.

Within our group we confessed to feelings of shame, anger and guilt towards our children. Many of us talked of the low expectations we had had of our children, or of our over protectiveness, and inability to “let go”. We all expressed great fear and anxiety about our children’s future, especially adulthood.

This is in acknowledgement that within many sections of the BME community, notions of self-reliance, or educational achievement or strict codes surrounding
behaviour are important. For several of us, our religious faith and belief also deepen this gulf between us and our disabled children:

One parent shared:

“In my church when I told them that my son may have autism they told me to refuse the pronouncement as it was a Lie. I was told that my son needed healing, that God would work a miracle…..”

We shared the deep sense of guilt that has come to pervade our relationship with our disabled children – guilt that somehow we may have caused or contributed to their condition, or that we are not doing enough for them, or that we are not parenting them in the right way. We tended to be overprotective and overanxious about them, more so than their siblings.

Not only does the Medical Model way of viewing disability adversely impact upon the parent/child relationship, it can also place considerable strain upon other family relationships – notably the partnership between both parents. Many BME women expressed their concern about the inability of their male partners’ to come to terms with their child’s condition.

Another parent talked of her ex-husband:

“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.”

Many of our sexual relationships are already under considerable strain, having a disabled child can result in the total collapse of the relationship.

As our children grow and develop, the focus continues to be placed on their inability. This is underlined in the language that is used: words such as “disorder”, “handicap”, and “retardation”. The language of the Medical Model reinforces ideas that our children somehow occupy a space outside of ordered, normal functioning humanity. This therefore legitimises keeping them separate and apart from the rest of society.

The BME Reference Group discussed at length our common and daily experience of the excluding and discriminatory ways of thinking from those within our families, communities, those providing services and within society at large. These range from:

- They are disabled and are understandably (even if illegally), discriminated against. When we do so it is their interests we are thinking of.

- They are not the same as us, not equal in ability and they are therefore
not deserving of full equality or rights. Surely we all know and accept this as simple common sense.

• They do not have the wit and the intelligence that we have, and for these and other reasons are a burden to society, which we are not. It therefore follows that they should be subject and subjected (albeit gently if possible) to our decisions and dictates.

• They genuinely prefer to be with their own ‘kind’. We don’t of course mean that in an unpleasant or unkind way but let’s face it their difference can only lead to trouble if we try to mix. I could take it but some couldn’t because they are too weak and vulnerable as they are.

• They have different needs and different requirements than the rest of us. They deserve and need to be kept separate in protected and comfortable environments for all of our sakes but particularly for theirs.

• They would find normality too stressful/painful/harmful, and may eventually become so distressed that they may lash out and harm a normal person.

• They would become distressed and disorientated in our normal environments. It would be too difficult and unrealistic to expect or require us to make changes. Why should we be expected to go to the limitless lengths of making our society accepting and accessible to them?

• What about the expense and the disruption. What would we do whilst this upheaval was happening? How could we normal people go about our daily lives? The effort would really not be worth it the consequences too disruptive. They would not or could not anyway appreciate the changes.

Thus we receive messages suggesting that our disabled children are not as valued, cherished or welcomed as their non-disabled brothers and sisters, or peers. Indeed, our parenting role comes to be characterised as arduous, and we are widely pitied and patronised. Whilst many of us would openly acknowledge the challenges that our parenting roles represents, many factors external to our children as discussed above exert considerable, if not more, levels of stress and pressure.

One parent shared her experience:

“Odun” has three albino children and has been the victim of verbal taunting and isolation. As black parents of ‘white’ children she and her partner have had much to cope with. But she knows that her children must not be protected from other children. Her seven year old is the brightest in his mainstream class.
In her own words:

“So it was very, very difficult for us, when I had him I didn’t want to go out, because when we went out everybody stared, they called him a freak, an alien, things like that - it was very, very difficult. And when I had my second child he came out an albino as well ... We just wanted to stay in the house and not go out because of people staring and so on. When I had my third one, she was an albino as well, and a girl. The medical people said it was very, very unusual to have an albino; its one in five million to have an albino child, and I’ve got three, ... but we try to be strong for them…..”

Another parent shared her story of trying to access leisure facilities for her disabled child:

“I almost expect it now – I’ll call up a local drama group or art workshop or whatever, and enquire about available spaces and so on. I normally feel that it is appropriate to mention to them that my son has special needs – this is purely to discuss with them that he may need extra clarification with verbal instructions and so on. On hearing this, they invariably begin to freak out and ask “What’s wrong with him?”; of course I inform them that there is nothing wrong with him, it just that he has autism. “Sorry”, they will often reply “we don’t think that we can cater for him……”. I might inform them that my son will be disappointed that he will not be able to go, but that his brother can because I have had to discriminate against him!

It always ends up with them apologising, but then offering to accept him on a trial basis. Of course my other non-disabled child is totally welcome to participate without any questions asked – except my ability to pay.”

For many parents, their disabled child may often be the first disabled person that they have come into contact with on a personal level. Our parenting role exposes us to the discriminatory attitudes and barriers that disabled people experience as part of their every day life. We all have painful memories of becoming marginalised, isolated, ignored, vilified and even pathologised. Dobson et al’s survey, “The Impact of Childhood Disability on Family Life” 2001 looked at approximately 200 families with a disabled child and highlighted that families felt that they were no longer seen as an “ordinary” family with the same aspirations and rights as families who did not have a disabled child.

Many BME parents experience a sense of double disempowerment due to racism and disablism. The power structure inherent within the Medical Model of disability, posits the child and family at the bottom levels of power and influence. Professionals presume and profligate ideas of superior expertise. Many parents do not recognise that whilst a professional’s training and experience is to be valued, they, as parents are also experts. This often results in parents viewing the opinions of others about the needs of their child as being more informed or
even superior than their own. Considering the inherent power structure within
the Medical Model of disability, which is then compounded by a social structure
in which power, prestige and wealth are mainly focused outside of many sections
of the BME communities, it is no wonder that many BME parents feel that the
opinions and views of predominately white professionals are superior to their
own.

Indeed, many BME parents do not have the knowledge to challenge or question
and are often unaware of alternative models of disability.

However, one parent describes the process whereby she began to recognise that
many professionals hold incorrect assumptions about disabled people, and that
their decisions are often based upon these. 

A parent in the reference group says:

“I began looking for primary mainstream schools for my son who has a learning
difficulty. I approached many mainstream schools. All but two schools were
hostile to the idea of admitting my son. I spoke to the Deputy Head of the local
curch school who suggested that I try Clapham Park. When I indicated that
Clapham Park catered for children with visual impairment, she said that she was
aware of that, but that it would be a more suitable placement than her school!”

Another parent goes on to say:

“...I approached a few local mainstream schools for my disabled child; they all said
that their school was not suitable for her. However, when pressed they all
displayed a total lack of understanding of the needs of a child on the autistic
spectrum. How are they then able to know if their school is suitable, or not?”

Another parent commented on the refusal of her local church primary school
to admit her daughter who has a physical impairment:

“We then learnt that my daughter was not admitted because it was felt that her
walker would take up too much room!”

Many parents begin to grow with confidence, and some will want to challenge
decisions made about their child’s future or confront discriminatory attitudes.
When parents are introduced to the Social Model of Disability it can have a
powerful impact on their lives. Within our reference group we discussed how
our new understanding of disability via the Social Model helped to nurture a
more positive relationship with our disabled child. We came to see society as
the source of the disabling experience both our children and our family as a
whole were experiencing. This did not eradicate our child’s condition or need,
but it focused our attention on where the real change was needed – within
society.

Many of us talked about the liberating feeling that we experienced, both
recognising and understanding the source of oppression, and at last being given
the opportunity to celebrate our children!

For all of us, experiencing the Social Model of disability has been revolutionary. Not only do we begin to see our experiences within a wider context of social injustice, but we also begin to equip ourselves with tools of empowerment, the primary one being creating a PATH (Planning Alternative Tomorrows with Hope). Creating a PATH is a bold step, as often we are actively discouraged from having positive aspirations for our disabled children. The PATH gives us a vehicle to dream positive futures for our disabled children and to start making concrete and detailed plans to move towards our goal.

One parent commented on creating a PATH:

“I felt like I was reclaiming my daughter back. No-one seemed to have any dreams, hopes or ambitions for her – including me. The focus has always been on what she will never be able to do. I was always encouraged not to hope too much for her future in case I became disappointed. Or I was told that my expectations were too high and unrealistic. But every parent has great dreams for their child. Now, at last, I can just do what comes natural to me as a mother.”

With a new sense of empowerment, and a support network, many of us now feel more prepared to face the challenges that we continue to experience, and to be allies to all disabled people. We are now able to challenge barriers – be they attitudes and assumptions, practices, policies or physical barriers. We are better informed, with a greater understanding of issues concerning education and health provision. We are therefore altogether more active participants in the decision making processes that affect our children’s future. In some instances we feel that we have wrestled and won control out of the hands of others.

Within our reference groups we would always close our meetings with a celebration of our disabled child. We would often talk of our deep love for our children, our pride in their achievements – both academic and social, of the fun and laughter that they have brought to our lives, and of the simple things that they do which have such profound meaning. We have all felt deeply privileged to parent such wonderful children who teach us so much. It is our dream that everyone will value their difference and uniqueness just as much as we do.
Our deepest fear is not that we are inadequate.
Our deepest fear is that we are powerful beyond measure.
It is our light, not our darkness, that most frightens us.

We ask ourselves, who am I to be brilliant, gorgeous, talented and fabulous?
Actually, who are you NOT to be? You are a child of God.
Your playing small does not serve the world.
There is nothing enlightened about shrinking so that other people won’t feel insecure around you.

We are born to make manifest the glory of God that is within us.
It’s not just within some of us; its in EVERYONE!
And as we let our own light shine, we unconsciously give other people permission to do the same.
As we are liberated from our own fears, our presence automatically liberates others!

_Nelson Mandela, Inaugural speech 1994_ (adapted from Marianne Williamson’s novel ‘A return to love’)
A PARENT TALKS ABOUT ACCESSING INCLUSIVE EDUCATION

OUR VOICES:

A Parent’s Voice:
“Paulette”, talks about…

ACCESSING INCLUSIVE EDUCATION

“Paulette” is a parent of a child with learning difficulties. She talks about the barriers that she experienced when seeking inclusive education for her son.

Q What are the challenges and difficulties that you have experienced when trying to access provision that supports your disabled child to be included?

Well my son had attended an excellent nursery that was very inclusive, they were very positive about inclusion. My son was welcomed, and I was supported and made to feel very safe. But when I approached local primary schools to admit my child, I was appalled by their responses. I was very honest and open, and would always mention that my child is on the autistic spectrum and would require additional support. It was extremely disheartening – depressing even. My child was not welcomed anywhere! Almost all of them did not want to admit my son. I was told by one deputy head teacher that “if I were the parent of a child with autism I certainly would not be thinking of placing him/her in a school like ours!” School secretaries were informing me that “we don’t need any more problem children in our schools!” I was asked by one headteacher why I had chosen her school, when I informed her that it was because they was on my door step she fell silent. She then went on to talk in very derogative terms about the special needs children that attended her school.

Some of the responses I met were very hostile and discriminatory, others were polite but still very resistant. At that time I did not feel empowered enough to challenge these attitudes and I was not aware of the support that was out there, I felt very isolated.

The other challenge I faced was getting a statement for my child, and getting the correct level of provision. That was a huge battle because the whole process was beguiling. The placement officer at the LEA gave me incorrect information about my son’s rights, for example telling me that it did not matter if provision was placed in different parts of the statement, and that certain provision did not need to be quantified and so on. I wrote so many letters, sent in reports, had many meetings with LEA officers, but in the end it was like interacting with a brick wall! They
seem to be a faceless bureaucracy that made these important decisions about our children without having to be accountable to anyone.

It was a learning process, because in the end I became engaged with support networks like PI and understood what my son’s rights were. I became empowered.

Q In what ways do you feel that Black and Minority Ethnic People, and Parents of disabled children could be better served, by education, health and other statutory services?

Firstly, there needs to be the recognition that we are often badly served by these services, and that the reality is that there is not equality of access to services. Because many services have to be fought for, many of us do not have the resources or tools to undertake this.

Service providers should really undertake grass roots work to find out what Black disabled people and their families actually want and find important. Providers also must recognise that they actually create many of the barriers for us and that these should be demolished.

Some of us do not question, or do not feel confident enough to challenge how the system operates, or we become angry and isolated. As a community we have work to do, we need to be better educated and more informed, and importantly, united. I’ve seen some encouraging signs, like Black parents and disabled people becoming organised to inform and serve the community.

Q Can you say 3 changes that you think would make a difference?

Schools should welcome all children – if that child is part of the surrounding community, then that child has a right to receive his/her education in her local area.

Everyone should receive disability and race equality training so that society can move beyond ignorance and prejudice.

Health, Education and Social services should provide a more unified service offering a more holistic approach, based on what disabled people and their families feel is relevant and important.

Q What are your dreams for the future?

For a society that welcomes and values everyone, no matter what their difference.
Our Voices:

A Parent’s Voice:
“Odun”, talks about….

Accessing Inclusive Education

“Odun” is a parent of three children with albinism. She talks about the barriers that she experienced when seeking inclusive education for her children.

Q What are the challenges and difficulties that you have experienced when trying to access provision that supports your disabled child to be included?

Right from the start, my children have not been respected by professionals or the community, and this has been very challenging because we love them for who they are.

The difficulties, or let’s say challenges, are that I find it hard to get anything that is my children’s right unless I fight for it. For example, getting the Disability Living Allowance was very time consuming and difficult to get. Getting information for anything is so hard especially if you don’t know that you are entitled to it. I had to fight to get my children included into mainstream schools. I believe we should not protect them from other children. They are born like anybody else: wanting to be included and with great potential.

Q In what ways do you feel that Black and Minority Ethnic People, and Parents of disabled children could be better served, by education, health and other statutory services?

I think we should be better served by education, health and other statutory services. The country is diverse, and as we have so many cultures and backgrounds I think we should address translation and cultural differences.

The support that children get from primary school should be in place at secondary school and University as well.

Q As a black person, what are the added pressures that you have to face?

Where do I start from - I’m a black parent but my children are albinos which people consider as white. It’s very hard to explain to people about my children’s condition. It is not that I mind, but how many people do I have to explain to and how many times? Why do I have to explain
to anyone, why can’t society take us as we are?

Q Are there any instances, when you have felt you would have been better served if you were white and middle class?

I feel that if I was white and my children were albinos I don’t think that people would ask questions.

Q Can you say 3 changes that you think would make a difference?

Getting information on where to get funding for my kids for after school activities.

For necessary help to be there in mainstream schools for disabled children and those with special needs. Instead of giving all the money to special schools, the money should be re-directed to small organisations that are empowering disabled young people, and their parents.

Live and let’s live: why can’t we get along.

Q What are your dreams for the future?

My dreams are for my children to reach their potential, socially and educationally.

Q How has Parents for Inclusion helped you?

Parent for inclusion has been like a backbone for me, they helped me during my difficult times with all the information that I needed, and armed me with all the information that I asked them for. They have been fantastic and wonderful people.

It's a shock to me to know that organisations supporting inclusion are not getting enough funding, as they should, because they are helping desperate people and empowering them to do what they are supposed to do for their kids.
Our conclusion and recommendations

In conclusion we have explored our experiences as BME parents of disabled children and young people. We have explored how racism and ableism have contributed to the exclusion and inequalities that we and our children experience. We explored the different views of disability, the Medical and Social Model and argued that the former contributes to and reinforces inequality. We have looked at how organisations and services that focus almost exclusively upon race or disability are unable to adequately reflect our experiences and meet our needs as BME parents. We have explored the experiences of BME parents and then gone on to look at some of the challenges that we face when seeking inclusive education.

The report acknowledges its inability to fully address the needs of refugees and asylum seekers and recognises their unmet needs are often very acute. We also recognise our inability to fully represent the Asian experience, or disabled parents, as they were largely unrepresented in our Reference Group.

However, we would wish to assert that despite our ethnic and cultural differences, that these differences serve to enrich us all and as parents of disabled people we all share common experiences of oppression and discrimination which unify us, irrespective of race or culture.

We have endeavoured to enter into a dialogue with all sections of society, in particular other BME parents of disabled young people, our white counterparts, those involved in the disabled people’s movement and groups supporting the BME communities. We have also sought to enter into dialogue with professionals and policy makers – some of whom have been supporters and allies, who have worked with parents and young disabled people to realise their dreams. However, we would also urge many to reflect upon their practice especially in regards to the BME community, and consider our recommendations and thoughts:

Overarching demands

- The social model should be adopted. Not only is it a more accurate and humane way of understanding disability, it also fosters a more positive parent-child relationship.
- Celebration of the diversity of British culture today.
- The empowerment of BME parents and disabled young people to take the lead in change on the issue of inclusion together with disabled adults from BME communities and their allies.
OUR CONCLUSION AND RECOMMENDATIONS

Recognition of the real issues

• The recognition of the impact of multiple oppression.
• Recognising that parents often feel unconfident about meeting large groups of people, or speaking up in meetings
• Recognition of inequality of access experienced by BME parents, and deliberate steps to encourage more access.
• Recognition that for many within the BME community, our experiences of the education, health or social care systems have been negative, and that active engagement is essential.
• Recognition that for many BME parents, the daily struggle for survival is immense
• Recognition that parents have dual roles of parent and carer and that parenting is done in the context of other relationships and responsibilities – such as partners, other children, caring for other relatives, their employment, studies etc.
• An awareness that BME children are overrepresented in special schools, behavioural units or are excluded. Recognition of the need to reach out to these parents and support them to break the double oppression.
• Use of BME press to encourage and inform parents and our communities at large.
• Recognition of the need to work with Disability Equality in Education (DEE) to contact black disability equality trainers to be part of the team.
• Workshops led by BME parents on specific topics.

Parental needs acknowledged

• Professionals are urged to value and respect parents
• Parents love and cherish their disabled child, and want them to be celebrated and their potential nurtured
• Parents should be actively empowered, and should be made aware of statutory and voluntary bodies which are in place to support them

Support where it is needed

• Parents need to be actively supported in very practical ways – accessible information about services, their child’s condition, and lots of support to understand their child’s educational rights
• Interpreters and accessible information
OUR CONCLUSION AND RECOMMENDATIONS

- Additional support is needed for disabled parents
- Actively inviting parents’ opinions by making sure that they understand the purpose of meetings, helping them to prepare for meetings beforehand, not using jargon or technical terms, providing support when attending decision making meetings
- Recognising that parents often do not feel confident about meeting large groups of people, or speaking up in meetings
- Services need to be more culturally aware, parents should be actively asked what services are most helpful
- Co-ordinated approach by all agencies to reduce the burden on parents to “fight” for and negotiate the maze of services and appointments. A key or link worker to support parents.
- Co-ordinated appointments and meetings
- Recognition that for many families conditions co-exist so that there is often more than one child with a condition. Services and scheduling appointments need to take account of this.
- The social model should be adopted, not only is it a more accurate and humane way of understanding disability, it also fosters a more positive parent-child relationship.
- Consulting with BME parents and disabled people about their needs
- Eradication of linguistic barriers – translation of materials.
- Support for Asian groups.
- In our planning of dates be respectful of cultural/religious festivals.
- Joint-agency working across black organisations and disability organisations.
- Pro-active attitudes and an awareness of the issues across the organisation,
- Developing training and workshops to address race as well as disability.

For all within our group, our involvement with Parents for Inclusion, and the support we received when seeking inclusion for our children has been invaluable. Moreover, the empowerment we experience from learning about the history of disability, learning about the different models of disability and placing our experiences within this context has been life changing.

For many of us, our disabled child was the first disabled person that we had come into close contact with. We learnt not only about disabled people, but from them as facilitators and fellow allies. For many of us, these educative
processes have given us the ability to dream dreams for our disabled children, something many of us had been unable to do since learning of our children’s impairment. These dreams were explored and captured in the three key events organised by the Reference group. They were the PATH, the Race Equality Day held for Pi staff, trustees and other allies and the workshop called ‘All our children belong – celebrating diversity’, from which this report gets its title. The full recommendations from these events can be found in Appendices 1-3.

Our group sought to challenge organisations and services about their failure to address the needs of a large section of the community. We wanted to move from the periphery to the centre, and we called for the double oppression of race and disability to be addressed. The report also aims to inform Parents for Inclusion’s policy and practice as it is situated within the borough of Lambeth which has a 40% population of non-white residents, with a higher than national average of statemented young people and pupils attending specialist provision, and a large exodus of white pupils from our schools. The following are recommendations that our Reference Group have highlighted:

**For Parents for Inclusion and ALL organisations**

- To change the first impression that Pi is a predominately white organisation, by continuing to actively seek to employ training facilitators, Inclusion Group facilitators, staff and trustees from the BME communities.
- Securing long term funding for a BME worker in order to address the specific needs of the BME communities.
- An organisational structure that supports the involvement of BME individuals – i.e. childcare provision, the possible need for part-time or flexible working, the need for training and so on.
- Eradication of linguistic barriers – translation of materials.
- Training all staff on race and disability.
- Consulting with black disabled people about their needs.
- To continue and develop the black and minority ethnic parents’ Reference Group and to incorporate an Inclusion group for those parents who want to attend.
- Support for Asian groups.
- Support for refugees and asylum seekers
- Review of Parents for Inclusion’s Equal Opportunities Policy.
- Developing training and workshops to address race as well as disability.
• Joint-agency working across black organisations and disability organisations.
• Pro-active attitudes and an awareness of the issues across the organisation
• To work with Disability Equality in Education (DEE) to contact black disability equality trainers to be part of the team.
• Workshops led by BME parents on specific topics.
• In our planning of dates be respectful of cultural/religious festivals.

Our journey is not complete, and our battle not yet won – we have, as the song goes “many rivers to cross”. We would like to conclude with a celebration of all our children and young people, disabled and non-disabled.

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.

ODO NNYEW FIE KWAN - “love never loses its way home” - the power of love

AKOMA - “the heart” - patience and tolerance
SANKOFA - “return and get it” - learn from the past

NKYINKYIM - “twisting” - initiative, dynamism and versatility

HYE WON HYE - “that which does not burn” - endurance and overcoming difficulties

AKOMA NTOSO - “linked hearts” - understanding and agreement

SESA WORUBAN - “I change or transform my life” - transformation
RACE EQUALITY TRAINING

A workshop run by Jackie Lewis, Race Equality Trainer.

Race Equality Training in which these and many other views were explored and in relationship with each other a process of awareness begun:

One of the first exercises involved us honestly describing in detail some of society's stereotypical views of ethnic minority and white groups and individuals. We then explored possible origins of some these views and what may be our relationship to their origins and present use.

The conclusion to the day was an exciting exercise, which helped us to share our individual dreams and desires for PI in relation to the ethnic minority community.

Everyone who attended seemed to agree that the day was expertly facilitated with great warmth and compassion, whilst enabling us to look at some of the more difficult and painful issues.

Points to consider after the Race Equality training day:

• Support for Asian and asylum seekers groups

• To change first impression that PI is a white dominant organisation, to see two black workers at least when I come into the office. (See Background to the report - what difference has the BME reference group made?)

• To aim for black workers on the helpline, Inclusion groups, as trainers and as part of the organisation.

• Materials available in different languages and styles - clarity

• Recruit or invite trustees who represent different ethnic groups.

• To continue to build an increasing number of black and ethnic minority workers at PI in all areas including the helpline.

• To develop the black and minority ethnic parents' reference group to include an inclusion group for those parents who attend. This would be in unit 1 at PI.

• To increase the support for black and minority ethnic parents in schools through more inclusion groups for parents to reduce tension, anxiety and stress.

• Sharing of life story meetings
• Staff lunch to share poems, books, films, stories on race issues and celebrating black writers etc

• Rewrite the EOPs policy using work from today to help black parents

• Secure funding for black and minority ethnic worker

• To work with DEE to contact black disability equality trainers to be part of the team.

• To find two black and minority ethnic parents of disabled children to join Pl's trustees board

• Black disabled people as trainers

• Celebration of culture

• Short workshop and cafe Inclusion led by black parents/workers on specific topics

• In our planning of dates be respectful of cultural/religious festivals

• Forming/inviting a focus group of black parents to look at our literature/training/questionnaires etc.

• Awareness of the fact that many more black children are in special schools. How can we reach out their parents and support them to break the double oppression.

• Regional development into areas with diverse cultures

• Use of black press to encourage and inform black parents

• How we support black and minority ethnic parents to be part of the struggle and bring about community changes.

• Support black people into leadership.

• Black parents on board of trustees

• Translating more literature into different languages.

• Making the time to get to know each other

• Developing our training to include all equality issues.

• Time to listen and support each other and our building of relationships in equality.
BLACK AND ETHNIC MINORITY PATH

POSITIVE AND ACHIEVABLE GOALS/ 5 YEAR PLAN
(see PATH graphic on centre pages)

EDUCATION

- Local schools for local children
- Statements, person centred plans, done in partnership with parents.
- Less bureaucracy for children to attend mainstream school
- Set targets for school to ensure inclusion
- Schools built for inclusion, accessible in every way
- Admission criteria for schools are positively discriminating to include disabled children
- Inclusion with correct support - all needs met as a right not a fight - speech therapy occupational therapy
- Attendance at school not dependent on resources
- Influence curriculum and make citizenship more central
- Parent and school partnership - improve communication
- Training for black parents to become councillors
- All children to have a circle of friends
- Parent involvement in measuring performance in schools
- Campaign for schools to take responsibility for building relationships
- Change demand on schools not to be measured on league tables alone Create separate league tables that include our children inclusively
- Each child having his/her own performance standards which measures school on how far they have achieved

MEDIA AND PUBLICITY

- Public visibility and media portrayal of disabled people improved - positive role models
- Positive images of children and adults

WIDER GOALS

- Less professional led, more child, parent and person led
- Training for parents
- Policy makers listening - representation at government level/ Legislative and policy level
- Educate society- Disability equality training in schools and all other areas
- Support parents to celebrate their children
- Plan a national celebration of gifts and inclusion
- Campaign for employers to recognise gifts and experience, not just certificates.
COMMUNITY

- Powerful group of parents organised informed active and listened to.
- Support black people in power to keep in touch with the need of their culture.
- Government listening and acting. Necessary legislation in place.

FIRST STEPS

- More workshops
- Organise as a group
- Design a flexible strong group under Pi umbrella
- Develop ourselves as a strong group in order to gain strength
- First meeting Black and minority ethnic group for inclusion
- Develop our relationship with Pi
- Learn about circles
- Develop a plan for our future - do we need black workers in Pi?
- List of events to promote images - Lambeth Show, Nottinghill Carnival
- Lobby Government and policy-making bodies
- Lobby education departments on Inclusion
- Circulate PATH
- Be involved in all Pi and Alliance for Inclusive Education campaigns to reverse discrimination and injustice

NEXT YEAR

- Training on DET, advocacy, lobbying. Partners in policy
- Organise training for teacher on Inclusion
- Look at complaints procedure for bad practice in schools
- Organise training and instruction for parents to be enabled to be more assertive in school and to become governors
- Agree and develop and build on our plan
- Develop a circle of support for children of the leaders of inclusion
- Get Circles Network to run another Partners course in London and include people here
- Attend events to celebrate children
- Representation on policy making bodies
- Get representation on school governing boards

THE NEXT FEW YEARS

- Positive media coverage
- Be involved in assessing teachers
- Set up Pi Inclusion groups in schools
- Be involved in campaigns for inclusion
- Action. Implement the agreed plan
- Circles Network - bring Dan Hobbs for training
- Run courses and training for professionals-
- Put in place employment legislation
ALL OUR CHILDREN BELONG WORKSHOP

A workshop for Black and Minority Ethnic Parents celebrating diversity - Sept 2001

This workshop called All Our Children Belong was funded by Lambeth Education. The remit was to look at the importance of celebration, and to revisit what had been achieved since the last Path and make new recommendations for the next step. Jackie Lewis (a Race Equality Trainer) led the day, Micheline Mason (Alliance for Inclusive Education) discussed 'Why Inclusion', and Christine Burke (Circles Network) evaluated the achievements since the 2000 Path.

These were their celebrations

Everyone was asked to say what they celebrated, despite the barriers they had faced: This is what they said:

“I celebrate the joy my daughter brings into my life, her beauty, affection and caring."

“I celebrate recognising my own disability.”

“I celebrate the strength to fight for our children’s rights.”

“I celebrate my children who are who they are including and because of their disabilities”

"I celebrate my Goddaughter. For her family surviving the struggle, and her disabled goddaughter’s gifts."

These were the group’s achievements

- Disabled people valued
- Lack of embarrassment of our children
- Acceptance of difference
- Our children are motivated
- Parents recognised as an asset
- Visibility of children
- A clear Voice
- Meeting regularly

AKOMA NTOSO - “linked hearts - understanding and agreement
• Appointed paid black worker funded by HAZ
• Meetings providing a forum for black parents of disabled children
• Parents Involved in all areas of Pi and Alliance campaigns
• The group co-ordinated a race equality training day for Parents for Inclusion which was very useful

These were their recommendations

• To have more training days on disability, race and equality
• To get more people to join the group and to join in the broader struggle for the group
• To write up our stories and articles for the Inclusion Now Magazines
• To make meeting more flexible e.g. Childcare
• For disabled people and parents to become allies and to have allies
• To create more understanding between parents and children:
  • A voice for parents
  • A voice for children
• To fundraise for a development worker
• To continue the group meetings until a co-ordinator is appointed
• To recognise the need to network
• To design and distribute publicity materials
• To train more Black and minority ethnic facilitators
• To have more Cafe Inclusions
• Funding to be sought
• To connect in with Black and minority Ethnic and DEE Trainers
• To research how to get more parents involved
• To have more DET Training within schools
• Training for professionals by the people they serve
• To organise inclusive after-school clubs and holiday play centres
• To improve communication within the black community
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Pi would like to thank and to celebrate the following people and their children for their generosity and their commitment. We would like to acknowledge that it is all our young people who have been the real pioneers in this whole development. We recognise that this report has been brought together through enormous effort, and time, by the members of the Black and Minority Ethnic reference group, and many other parents through various consultations we have held over the past three years. If we have left anyone off our list, apologies, but do please remember you were equally important to this process.

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ORGANISATIONS FOR INCLUSION

We are disabled people, parents of disabled young people and allies, working together:

"We are working together to educate, facilitate and empower everyone who wants to be part of the growing inclusion movement. Together we want to bring down the barriers so all young people can learn, make friends and have a voice in ordinary school and throughout life. For each and every young person, this is an essential human right.:- All our children belong together"

Parents for Inclusion

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info@parentsforinclusion.org
www.parentsforinclusion.org

Pi is a national network of parents of disabled children and young people. Pi runs a national helpline and a leadership programme for parents. Pi's in-school model of parent support - Inclusion Groups - now runs in 20+ South London schools and is being developed in other regions.

The Alliance for Inclusive Education

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The Alliance is a national campaigning organisation led by disabled people. The Alliance works to change laws, practices and procedures which discriminate against young people and prevent inclusion.

Disability Equality in Education

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DEE is run by disabled people, who deliver INSET training on Disability Equality and Inclusion to schools, and training and consultancy to Local Education Authorities.
Circles Network

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Circles Network aims to support people who are either experiencing social exclusion or are at risk of being isolated through disability or long term illness, to become and remain included in community life. Circles Network facilitated the PATHs in this report, and created the PATH graphics.

Centre for Studies on Inclusive Education

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CSIE is an independent organisation working towards the inclusion of all pupils with disabilities or learning difficulties in ordinary schools and the gradual closure of all special schools.

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Inclusive Solutions makes available cutting edge practical strategies and ideas for developing effective inclusion in local mainstream classrooms, schools, colleges and communities. We are experienced educational psychologists who specialize in mainstream inclusion, learning from our international links.”

Communities Empowerment Network

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CEN intervenes on a partnership basis in support of children and young people and their parents as well as students and others experiencing problems with institutions, local education authorities and the Department of Education and Skills. Also provides advice, counselling, support, representation and training.
Parents for Inclusion’s Black and Minority Ethnic Parents project has been supported by:

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• Lambeth Education Business Partnership
• The Stone Ashdown Trust
• Walcot Educational Foundation (Lambeth Endowed Charities)
• Esmee Fairbairn Foundation
• Paul Hamlyn Foundation
All our Children Belong

A report that explores the experiences of black and minority ethnic parents of disabled children, seeking inclusion in mainstream schools and communities.

The impact of the double discrimination of racism and disabilism is exposed, and powerful recommendations for action and change are made.

This report is also available on tape, disc, CD Rom and simple text with pictures, from:

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email: info@parentsforinclusion.org
post: Parents for Inclusion
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