

# Parents 4 Change IV

## Conference Report



Devised **by** Parents **for** Parents with  
disabled children

Wednesday 19<sup>th</sup> May 2010  
Riverside Stadium, Middlesbrough

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## **Welcome**

**Sheila Tunney**, parent steering group member

As chair for the day, Sheila began by welcoming everyone to the fourth Parents' Conference.

The aims of the day were to update parents on the work of each of the focus groups that had been identified at previous conferences and get parent views on the next priority areas to work on.

## **Introduction**

**Councillor Mike Carr**, Executive Member for Children, Families and Learning from Middlesbrough Council.

Ray Mallon, Mayor of Middlesbrough who attended the previous conference, had intended to attend again but was unable to because of a royal visit to the area. He has given his full support to the Parents 4 Change agenda.

Mike is responsible for the children and families department within Middlesbrough Council, which includes ALL childrens' services. The Local Authority is trying to ensure that all the different services are integrated and people are talking to each other. Disabled children are particularly important to this agenda.

Parents 4 Change is vitally important, highlighted by the fact that the Aiming High for Disabled Children agenda is supported by Government money and is a strong example of parents and professionals working together which will help the process to continue moving forward in the future.

The new Government is looking to make significant cuts so it's an age of uncertainty for everyone but Parents 4 Change very much meets some of the things the new Government will be looking to do, for example more power being exercised by local people and more involvement of local people in decision making.

Mike concluded by wishing everyone involved in the Parents 4 Change process a high level of success; thanked all those who had given up their time and efforts to achieve the work already undertaken and encouraged more parents to become involved to further strengthen the work being done now and in the future.

## **Behaviour Focus Group Update**

**Kerrie Morrison**, parent steering group member

The group acknowledged the fact that challenging behaviour can mean different things to different people but all are equally valid as the group did not want to trivialise any individual parent experience. The key fact is that challenging behaviour, in whatever form, can be both emotionally and physically draining for parents to cope with.

### **What did the group do?**

- Met 5 times
- Identified the issues
- Met with providers
- Came up with ideas about the information and support that families need

It was encouraging to have other agencies such as CAMHS (Child and Adolescent Mental Health Services) and the Children's Behaviour team involved as it gave parents the opportunity to ask questions

### **What did we achieve?**

- Found out about:
  - Assessment processes
  - Parenting support and Parenting Programmes
  - Behaviour support in schools
  - Portage and Speech & Language Therapy
- Started work on a section on behaviour for the new Information Pack

### **What difference do we hope to make?**

- Parents will have more knowledge and practical advice on dealing with challenging behaviour
- Parents will know where to get professional help if they need it
- Families will be able to enjoy life more

### **Ideas for contents of the new behaviour section in the Information Pack**

1. Introduction
2. Five facts every family should know.
3. What is challenging behaviour?
4. Possible reason why a child might be 'difficult'
5. What can we do? Some practical suggestions
6. Services available
7. Physical interventions
8. Frequently asked questions
9. Further information available

This new section will be included in the pack in the autumn. It will make information more accessible and clearly signpost where parents can go to for appropriate help and support.

The work of the challenging behaviour focus group is on-going so parents were encouraged to become involved and get their views heard.

### **Table Discussions**

In tables, parents and carers were asked to look at issues around behaviour and discuss identify priorities that should be addressed within this focus group.

Discussion points made:

- The work undertaken so far has been a good start but we feel we need training to be able to make an impact in the future. The focus group needs more parents involved in order to grow and move forward
- Parents feel disempowered and blamed for their children's poor behaviour in public and by some service priorities
- Workforce Training and Development – please inform workers about what we are entitled to; they need to get their facts right and pass information on correctly about where behaviour support can be found
- Clarity about processes of investigation into things that have happened, i.e. a young person involved in an “incident” at a play centre but the parent was told nothing. After the “incident” it was reported to her and an investigation was carried out

### **Sleep Focus Group Update**

**Mary Harland**, parent steering group member

#### **What did the group do?**

- Met 5 times
- Identified the issues
- Met with providers
- Came up with ideas about the information and support that families need

#### **What did we achieve?**

- Found out what is available
- Came up with ideas for:
  - a sleep helpline
  - drop-in sessions for parents
  - training for GPs and Health Visitors
- Started work on a section on sleep for the new Information Pack

The group did organise one drop in session for parents but were disappointed with low attendance.

**What difference do we hope to make?**

- Parents will have some tips and hints that they can try for themselves
- Parents will know where to get professional help and will be prepared to answer questions
- More people in more families can get a good night's sleep

**Ideas for contents of the new sleep section in the Information Pack**

1. Introduction
2. Why sleep might be a problem?
3. Being tired
4. The bedroom
5. The routine
6. Crying
7. Special equipment
8. Tips and hints
9. Asking for help
10. Frequently asked questions
11. Further information available

**Table Discussions**

Discussion points made:

- Good start made by focus group but more parents involved will help to expand knowledge, personal experience and information sharing
- Exhaustion makes parents desperate and desperate makes you nervous and a poor parent
- Who do you talk to about Sleep problems? Health Visitors seem to struggle to support families, teachers do not seem to know how to help families so who is there to help?
- So pleased we are looking at this big issue

## **Going Places – Every Disabled Child Matters DVD**

Attendees at the conference were shown the Going Places DVD to re-iterate why we are all here today, to improve the lives of disabled children and young people.

In 2008 the Every Disabled Child Matters (EDCM) Campaign asked disabled children and young people from all over the country the question, “**What would better places to go and things to do look like for you?**”

The DVD was made in response to this question, with the help of KIDS Hayward Adventure Playground and the Out & About group from Ipswich. It aims to give children and young people a voice and a way of expressing their needs and wants.

The Parents 4 Change steering group stressed the importance of the work they are undertaking to try and help children and young people achieve these goals and encouraged more parents to become involved to help them to do this.

The DVD is available to view on the EDCM website at [http://www.ncb.org.uk/edcm/campaigns/participation/going\\_places.aspx](http://www.ncb.org.uk/edcm/campaigns/participation/going_places.aspx)

**“DVD was very emotional and has inspired me to want to help families in the community even more”**

Parent Quote

## **Transitions Focus Group Update**

**Kerrie Morrison** and **Christine Humphreys-Middleton**, parent steering group members

Due to family commitments, Christine has been unable to attend focus group meetings but has been fully involved and kept up to date through email and receiving meeting minutes etc. This highlights how parents do not need to give up a huge amount of time to become involved in the Parents 4 Change process.

The group are aware that transition can mean different times in a child's life but as this is such a challenging and complex area they had decided that, at this time, the group would concentrate on the transition from child to adult services.

### **What did the group do?**

- Identified the issues
- Met 5 times with providers
- Talked about different sorts of transitions and differences in services
- Worked on developing a new resource pack for young people

### **What did we achieve?**

- We made a start on changing the information for young people and their families
- We contributed to a key consultation event on the development of the Path Event – Shaping the Transitions Service

### **What differences do we hope to make?**

- Taking the anxiety out of transitions
- Helping people to prepare better for the changes when your child becomes an adult and making the experience more positive
- Shaping services so they meet the needs of our children

It has been acknowledged that parents need information as early possible and definitely at the 14+ review stage of their child's life.

A Transitions team in Middlesbrough is newly in place. They can offer support to families and young people and aim to make the process a more enjoyable and easier experience for everyone concerned.

An easy read booklet is being developed for both parents and young people. It has taken a long time to get this document produced because everyone's views need to be heard and considered with regards to the content and style of the publications.

## **Examples of the content of this booklet:**

### **Introduction to Transition**

The term 'transition to adulthood' is about growing up and the experiences of children and adult services. In terms of growing up, transition to adulthood is said to involve:

- Transition from school, to post 16 choices for example: College or work based training etc.
- Moving out and into their own home
- Adult relationships, sexuality, marriage and possible parenthood

Many parents/carers of young people with disabilities, are naturally worried about their child growing up and changes that their child will face in their life, especially during this time.

Within this booklet 'Transitions' also means when there are changes from Children's to Adult services. The start of this important time is when the young person is 14 years old.

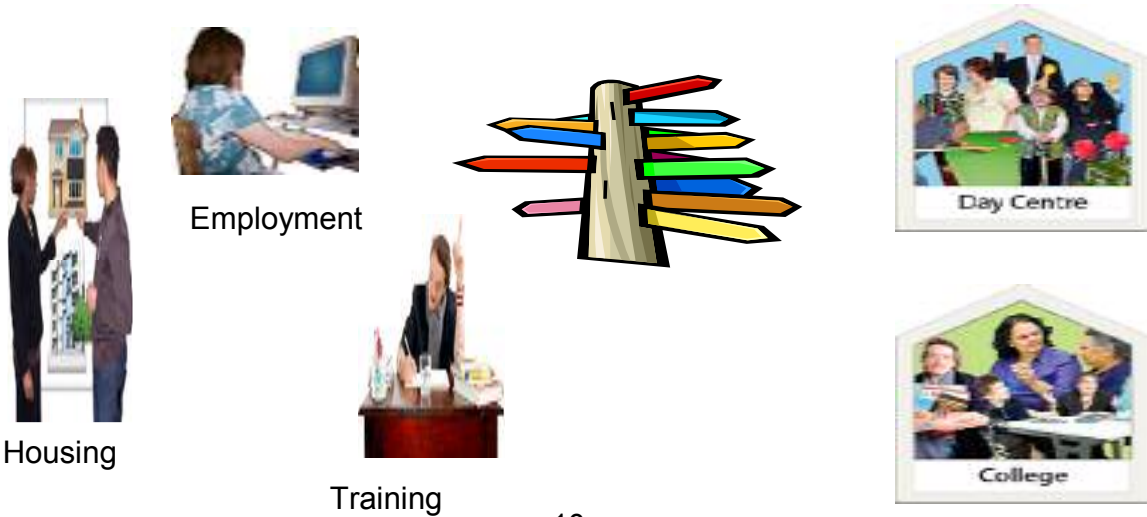
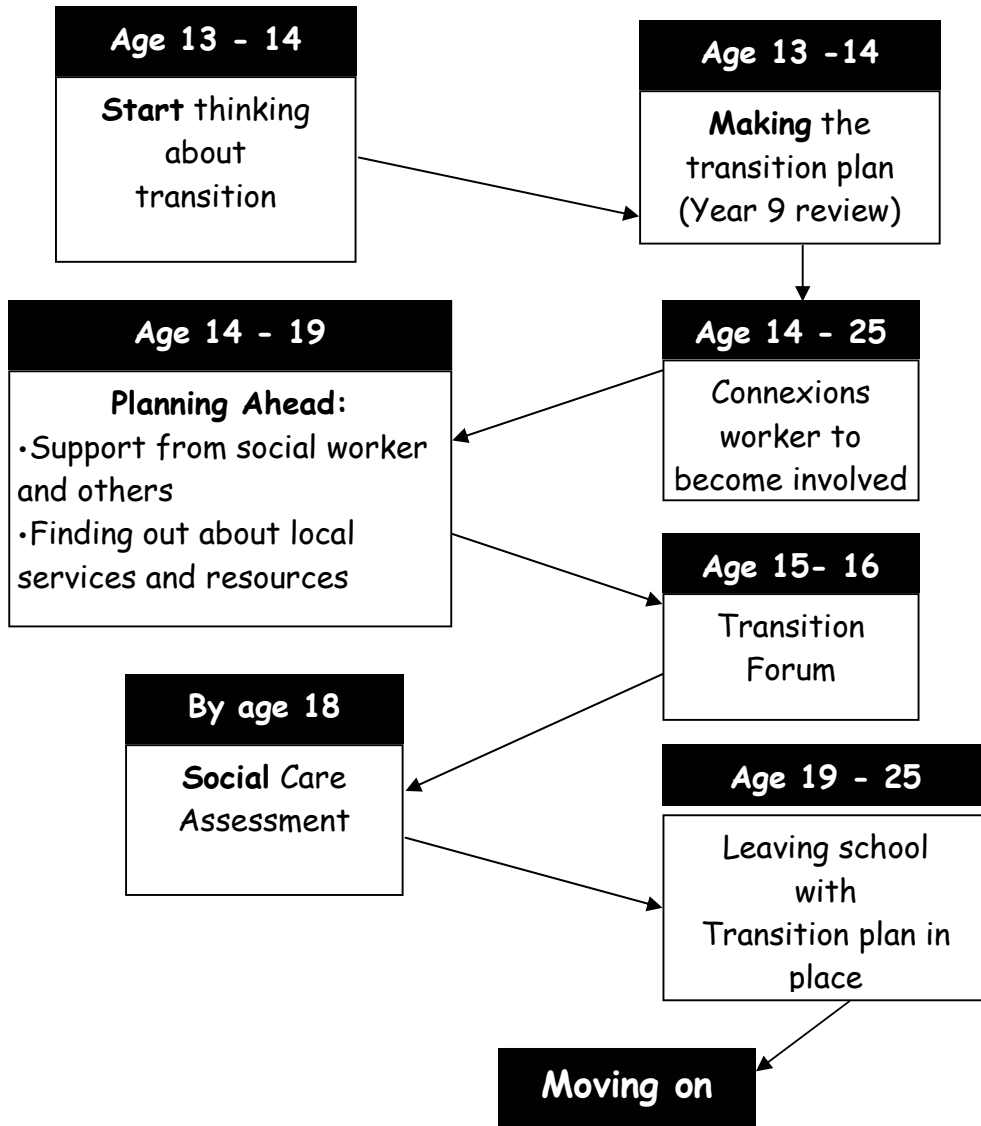
The first important meeting is called the Year 9 (14 yrs old) Transitions Review which is held by a Special Educational Needs Officer and will take place usually at the young person's School.

This meeting can involve the follow people depending on the young persons need;

- Young people
- Parents/carers
- Education
- Connexions Service
- Social Worker
- Forwards
- Housing
- Health Services
- Learning Skills Council
- Independent Agencies
- Voluntary Sector Organisations
- Welfare Rights

Each agency works together to provide support and/or information during the various changes taking place at this time.

## How Long Does Transition Take?



## **Person Centred Planning**

From the age of 14 years old, people or their parents/carers, can ask for a Person Centred Plan as a way of planning for their future. The Government white paper 'Valuing People' March 2001 states that a Person Centred Plan MUST be offered as a way of planning for the young person's future.

Plans are carried out by a trained facilitator and can be drawn as well as written and involve everyone that the young person feels are important in their life.

For more information on Person Centred Plans, telephone 01642 851717 or contact the young person's school.

## **Assessment of Need**

The assessment looks at all areas of a young person's life and aims to identify what needs they have.

A Social Worker, Community Nurse, Occupational Therapist, Physiotherapist or a Speech and Language Therapist (SALT) can complete the assessment. The Health Service transfers from children's services to adult health services at 18.

## **Carer's Assessment**

A carer spends a significant proportion of their life providing unpaid support to family or potentially friends. This could be caring for a relative, partner or friend who is ill, frail, disabled or has mental health or substance misuse problems.'

Some people say 'I'm not a carer I am a mother/ son/ friend etc. However, research shows that carers are more likely to experience physical illness or emotional stress than other relations or friends who do not have a caring role.

The Carers and Disabled Children's Act 2000 says that a carer has a right to ask for a talk with a worker to talk about their needs as a carer. This is called a carer support plan (also known as a carer's assessment). This includes persons with parental responsibility for a young person with a disability (parents or other carers) and young carers. Even if the person cared for does not want to have a community care services assessment carers have a right to a carer's support plan. The Act also says that it is important for the carer to have the opportunity to have their carer support plan away from the person they care for if they would prefer this.

The Carers and Disabled Children's Act 2000 says that workers should talk to the carer so they understand the impact of the caring role on the carer. Good practice would say that carers should be able to discuss their choice in the nature and range of the caring they feel able to provide.

The Carers Equal Opportunities Act 2004 also says that a carer's need to keep or get education or work and their social and leisure needs should be considered.

Carers may also value the following support

- Help to get services for the person they care for
- Information about Benefits
- Information about Caring (medical conditions, medicines, using wheelchairs or other equipment, helping people get out of bed, up from chairs, managing behaviours or any other general information)
- Someone to talk to about how they feel about their caring role
- Quality time for themselves away from their caring role (a break for caring)
- Carer Direct Payments
- Holistic Therapies (e.g. a free course of massage)
- Carers Breaks (e.g. a free short break away at a caravan or log-cabin)
- Carelink (pendant alarms) or Telecare (equipment to support people live independently)
- Carers Emergency Card
- Carers Leisure Link Card
- Carers Writing Group
- MY Time (was called Looking After Me Course- helps carers support each other to think of their own needs)
- Or discuss any other ideas you have about support that would help you

If carers would like a carer support plan they should contact the social worker of the person they care for or ring the Middlesbrough Council Contact Centre 01642-726004.

If carers would like any other information to support them they could contact Carr Gomm the Middlesbrough Carers Outreach Service. A carer's worker from Carr Gomm is based at Lifestore (Monday to Friday 9.30am to 4pm, next to BHS in the Cleveland Centre). They can ring the carer's worker on 01642-737884 or drop-in to the Lifestore. The carer's worker can also arrange to meet with the carers at another agreed meeting place.

If the carer is under 18 years old they could contact The Junction, Young Carers Project (01642-756000).

## **Table Discussions**

Discussion points made:

- Even though our table had children aged 6 years old, our thoughts are for the future, what will happen as he or she grows? Through this focus group, more information is there to access
- What happens to children who go from junior school to senior school? Is this transition for my child? Mainly important for child in mainstream primary who might have to go to a special school for seniors, need help to make decision to stay in mainstream or go to special school
- Transition relates to junior to senior school so need to look at this as well

## **Sport and Leisure Focus Group Update**

**Bernard Harland**, parent steering group member

### **What did the group do?**

- Identified the issues
- Met with providers
- Talked about gaps in provision
- Worked on developing new opportunities

### **What did we achieve?**

- Event at Ormesby Sports Complex
- New activities kick started at the Big Event
- New Youth Club at Kader Youth & Community Centre (Acklam)
- A checklist for providers
- A pampering day for parents

### **What difference has it made?**

- More fun for children, young people and their parents/families
- Chance for children to try something different
- Providers will have a better idea of what our children need

### **Providers' Check List**

- Is your building accessible (this is about more than just ramps – think about wide doorways, quiet areas, changing space, security)? How safe are your exit doors?
- Is there a waiting area for parents? Do parents have to stay with their children?
- Do you employ staff who have knowledge and understanding of how to work with children with a wide range of disabilities?
- Do you employ staff who can use sign language?

- Do you employ staff who can work with children who have challenging behaviour?
- Do you employ staff who can support vulnerable children and understand bullying and discrimination?
- Do you employ staff trained to deal with emergencies?
- Do your staff understand the difficulties experienced by parents of children with disabilities?

### **Table Discussions**

Discussion points made:

- Lots of good news regarding sport and activities for all ages and abilities
- A variety of leisure activities with mutual support groups for parents including sports that are new and innovative

### **Parent Reflections on Aiming High**

**Lileen Cuthbertson**, parent member of Making Changes Together Durham Steering Group

Lileen is a member of the Durham steering group and like the Parents 4 Change group, has been working alongside other parents and professionals in focus groups to improve and develop local services for disabled children.

Because of the significant changes Lileen has seen happening already in County Durham, she wanted to encourage parents in Middlesbrough to become more involved to help strengthen the process locally and ensure parental views and voices continue to be heard and listened to with regards to improving the lives of local children and families.

Lileen introduced a short video of “Talking Heads” – parents and professionals from County Durham sharing their thoughts around their own experiences of being part of the Making Changes Together agenda.

## **National Update**

**Kathy Rist**, Regional Manager Contact a Family North East and Together for Disabled Children Parent Participation Advisor

Aiming High for Disabled Children (AHDC) funding has been made available for a three year period until March 2011. Following recent Government changes, the Coalition Government has yet to make its plans clear for Aiming High and so we are currently living in an age of uncertainty but one thing we do know is that there are going to be drastic cuts in services and funding.

Because of this, it is more important than ever for local parents to become involved in the Parents 4 Change process. We need to ensure that politicians on both a local and national level hear that Aiming High for Disabled Children has worked and has been successful to help to strengthen the position of Parental Participation.

Kathy therefore asked as many parents as possible to:

- Strengthen their involvement in the Parents 4 Change process
- Lobby their MPs and sign up to campaigns – the more parent views, the greater the voice and the harder it will be for Government to ignore
- Influence Ray Mallon, your local mayor as much as possible. He has already stressed his commitment to this process so parents need to ensure this continues
- Stress how successes have already been achieved – where costs have already been saved, where services have been developed and how they are significantly helping to improve the lives of local disabled children and families

Kathy praised the work already undertaken throughout Middlesbrough, thanked all the parents and professionals involved for their hard work and encouraged new parents to sign up and become involved.

## **Parents 4 Change – Two Years on**

**Ruth Johnson**, parent steering group member

**Jenny Dalby**, Middlesbrough Children with Disabilities Team

Parents 4 Change is now two years old; so what have we done and what difference has it made?

### **Information**

We wanted to be better informed.

Now we have

- An information officer
- A texting service
- Leaflets for new families
- Better communication with staff

Jen Whitehead was recently appointed as Information Officer.

Contact details are:

01642 354201

[disabilitymatters@middlesbrough.gov.uk](mailto:disabilitymatters@middlesbrough.gov.uk)

### **Involvement**

We wanted to be more involved.

Parents have:

- Worked in partnership with staff in focus groups
- Worked with staff at planning days concerning short breaks, key working and transitions
- Taken part in interviews for staff
- Taken part in tendering for new services
- Selected which organisations received small grants

### **Key Working**

We wanted a key worker service:

Now we have:

- Agreed what we want the service to look like
- Taken part in a planning day
- Taken part in appointing a Key Worker Manager (Maria Bage has recently been appointed to this role)

## **Short Breaks**

We wanted better access to Short Break Services:

Now we have:

- New criteria
- A Short Break Facilitator
- Direct Applications from Parents

We wanted a greater range of short break services:

Now we have:

- More groups and clubs
- A STARS service
- An Individualised Budget Pilot
- More families receiving a short break service

Local parent Jane Coakley gave brief feedback on her experience of being part of the Individualised Budget pilot. Her family received money into their bank to use to then pay for support or services for 18 hours per week for her son. The family could then decide how to spend this money; whether to use all their weekly hours for a service or save the hours/money up which could then be used to pay for a family holiday. The flexibility of the pilot is a huge benefit to help to ensure that an individual family's needs are met.

### **Family Activities and Events**

We wanted more activities for the whole family:

We are enjoying:

- Soft Play Nights
- Activity days
- Trips and Outings

Because of the changes made to criteria, a significant number of new families have been able to access a short break for the first time which is making a big difference to their quality of life.

To highlight this, two years ago 170 families in Middlesbrough accessed a Short Break; 270 are now getting a Short Break and it is hoped that up to 400 will be by the end of this year.

This improvement highlights how successful Aiming High for Disabled Children (AHDC) has been with developing flexible, accessible services that families have asked for and helped to design themselves. Middlesbrough has been able to do this because of the additional funding made available through AHDC; without this it would not have been possible so yet another reason for more parents to become involved and ensure that the Government continues to support this process with financial backing.

## **Things are changing**

Families are:

- Getting more information
- Being more involved
- Receiving more services
- Having a better time

We need to keep it going!!!!

## **Focus Groups – The Next Steps**

In tables, parents were asked to think about the next steps and identify their priorities to determine the topics for future focus groups. A full list of points made during these table discussions is attached to this report as Appendix One.

Following these discussions, the following range of topics was suggested:

- Transition for Key Stage 2/3
- Speech and Language Therapy Services
- Wheelchair Services
- Summer Play Schemes
- Short Breaks
- Changing Places (Toilet facilities)
- Behaviour
- Information
- Sport and Leisure
- Training for parents in using equipment, lifting and handling
- Physiotherapy Services
- Transport

Parents were then asked to vote for the topics they thought were most important to them. The four identified were:

- **Short Breaks**
- **Information**
- **Sports and Leisure**
- **Speech and Language Therapy Services**

The work of the three existing groups will therefore continue and a new focus group will be set up on Speech and Language.

Within conference packs, parents were given Sign up, Get Involved sheets and were encouraged to add their names and identify which of these focus groups they would be interested in joining.

## **The Evening Session**

The purpose of holding an evening session is to engage with more parents to further and strengthen links with the Parents 4 Change agenda with those who work so cannot attend daytime conferences and meetings.

A shorter, more informal session took place where parents were given an overview of the Parents 4 Change process, summaries of the morning presentations and the chance to ask questions and share their views on next steps and future developments.

Sheila gave a brief overview of the aims of the Parents 4 Change process and Kathy gave the group information on the Aiming High for Disabled Children agenda and how influential parent participation work has been on both a local and national level.

The EDCM Going Places DVD was also shown to highlight how important it is for parents/carers to become more involved in the Parents 4 Change process – to help children and young people get the most of their lives.

## **Overview of Parents 4 Change**

There are two conferences held each year, where the content is decided upon by parents on the steering group. From each conference, parents identify priority areas. Focus groups are then established that meet regularly between each conference where parents/professionals work together to identify issues and solutions.

At each conference, parents in attendance receive feedback from each focus group to find out what has been happening and look at the next steps.

We are all aware that parents are time poor which is why focus groups have been set up so that parents who have particular issues that they are interested in, can just attend those particular groups.

If parents are unable to attend meetings, they can still become fully involved in the Parents 4 Change process by keeping up to date with everything through email and receiving minutes of meetings etc. On sign up sheets available at conferences, parents are given the option of ticking “information only” which means they will be kept fully informed but will not be expected to attend meetings.

The current Parents 4 Change Website ([www.parents4change.co.uk](http://www.parents4change.co.uk)) will be developed so that parents have another option for contributing their views and finding out about relevant information.

It is important that there is a range of options available to help more parents become involved; so for those who work and are therefore unable to attend meetings have an opportunity to contribute and get involved.

Different meeting times will also be considered including holding more in the evenings and at weekends.

### **Why Get Involved?**

- A number of achievements have been made so far, but we need to develop these further and increase parental involvement in the process as it is important to have a wider representation from more local families with children with a range of different disabilities and from different age groups
- From a professional viewpoint, Aiming High for Disabled Children has been really important as effectively listening to parent views helps to develop services that really work for families
- As well as influencing change, by being part of this process, parents have also developed their own skills and experiences which has helped them in their every day lives.
- To ensure changes happen not only for children now but for children in the future, it is important to recognise that parents involved in this process see the bigger picture and understand that they are not there for their own individual needs – though these are often met because of the work and changes already taking place
- Be more informed about the services available for families and have an opportunity to be involved in the services that are directly involved with children in the area

### **Group Discussions**

#### Sports and Leisure

- Often advertised as “all ages, all abilities” but parents with disabled children find that this is not the case and their children are excluded; people need to know why this is and what solutions can be made available to enable them to access a leisure activity
- Can parents use the service provider check list? There are plans to get this sent out to all leisure providers across Middlesbrough. Copies for parents will be available and if they hear about an activity that their child may be interested in, they can use the list as a prompt when asking the leisure service if they can meet their child’s needs. Providers are also aware that parents will be aware of this checklist and will be using it to ensure facilities are suitable and accessible for their children

- Is there training available for service providers if they cannot meet the checklist? The workforce development strategy includes training and the sport and leisure focus group has fed into this strategy. Awareness training is being offered to a team of Youth Workers, play leaders and to nurseries.

It will take time for each provider to be able to meet the needs of all children; they want to provide accessible activities but are often not confident about doing this so workers from the Children with Disabilities team get involved, provide staff to help others get skilled up and after time, children can be left with providers who can then fully meet their needs

Training is fine but practical experience is also vital so that it eases fears and helps improve confidence.

The work is on-going and in development

Parent steering group members closed the session by giving verbal feedback on their experiences of being part of the Parents 4 Change process, stressing how changes are being made and the more views, more comments that can be gathered can only increase the strength of parental influence in Middlesbrough.

It is a great opportunity for families to shape services and get involved and all those in attendance were encouraged to do so.

## Summary and Next Steps

Evaluation comments from both day and night sessions highlight how parents continue to enjoy attending these conferences and receiving feedback from focus groups. Many wanted to acknowledge the success of the work already undertaken.

**Excellent to hear what the focus groups have been discussing. They should be really proud of what they have achieved so far**

Parent Quote

It is really important to now continue and strengthen the work of the Focus Groups to ensure parental influence and engagement remains high on the agenda in Middlesbrough. All parent views, comments and ideas will now be used to feed into the work of each of these groups.

A full list of evaluation comments can be found as Appendix Two to this report.

## Appendix One – Full List of Next Steps Table Discussions

- People with older children are still experiencing emotions and upset due to their past experiences with other disabled children
  - Parents with older children are able to bring their coping strategies to the focus groups
  - People feel let down by professional people when they don't turn up. Children and young people find this triggers aggressive and emotional behaviour which means the family are left to deal with the "fallout"
  - Information is needed about any changes – seen or unforeseen
  - Promises made by professionals should be kept or at least families should be given an explanation of why this has happened
  - Sharing experiences with others, parent/carers or professionals, helps stop the "them and us" and becomes "us" working together
  - People need to report any worries or concerns, however big or small.
  - Communication between "us" on all levels is the key to improving the lives of children and their families
  - An updated list of things available in the Sports and Leisure area would be great
  - Parents have a limited awareness of things in their area
  - Funding for sports equipment should be available for centres which to enable them to offer new sports
- 

- Parents want to have more training such as lifting and handling, physiotherapy, coping with behaviour problems
  - More physiotherapy needs to be available to those children that need it
  - Groups for children who are wheelchair users that want to take part in teenage activities and don't have learning difficulties.
  - Transport for school trips when child is a wheelchair user and attends mainstream school so parents do not have to go with them
- 

- One sport that can be played by most children (i.e. console games) should be available at club levels so that children can play and interact together even if they cannot run around
- Holiday activities should be improved and expanded upon. Things that suit various groups, age, disabilities etc could be discussed. The amount available is very limited
- Education of children in schools about disability would help combat prejudice

### Lobbying MPs

- Knowing what to say and how to communicate that is my problem
- If I had a clearer idea of how to phrase what I want I would probably do it
- Am not too hot on computers but I would consider writing a letter
- Having time to attend meetings is hard so lobbying an MP would be even more difficult to get around to

### Individual Payments

- What is the truth? Can I save the money towards a holiday? I have been told no but another parent at the conference said she did
- 

- Speech and Language
  - Physiotherapy
  - More summer play schemes
  - Information on all topics
  - Transport for “older” young people
  - Behaviour – help with older children
  - Health service support
  - Respite care not relating to health
  - Individual payments – can it be saved towards holidays?
  - Sport
- 

- Fostering disabled children
  - Changing places – increased facilities such as hoists in changing rooms, at pools and in disabled toilets
  - Extend transitions to include moving from Keystage 2 to Keystage 3
  - Further improvements to Short Breaks
  - Speech and Language Therapy
-

## **Appendix Two – Evaluation Comments**

### **Something I've learnt from today**

#### Day Session

- That there are a lot of focus groups available that I knew nothing about
- Things are changing
- No matter who you are or what you do, if you have a child with a disability you have a connection, our aim is the same – a happy child. Also the website for special chew washing line
- Funding format and availability is changing with government
- Cut backs and that it is important to fight even harder for our children and families
- Due to government changes, there could be cut backs
- Due to new government, once this pot of money is used, there will be no more funds available
- Excellent to hear what the focus groups have been discussing. They should be really proud of what they have achieved so far
- Not respite now but short breaks
- That the parents in Middlesbrough have the same needs and wants as we do and the same worries
- New group for young people
- A positive move towards teamwork for action, for children and young people supporting parents and carers and making positive changes
- I have learnt that I am not alone no more and there is loads of help and support here. Where in Gloucester there was help but not like there is here
- That parents in Middlesbrough have the same needs , worries and wants as others
- Need to get more information about Parents 4 Change filtered into mainstream schools and groups

#### Evening Session

- Minutes of meetings can be sent via email for us to feedback on. Information received on other sports/leisure activities
- Where I'm able to get help and support for my child
- Parents who work are also wanting to be involved
- The new focus groups that have been set up and the possibility of receiving information via minutes/packs if you cannot attend the meeting

## **Something I've felt/experienced today**

### Day Session

- Other people's passion, warmth that we can make a difference
- Empathy with other parents in similar situations
- DVD very emotional and has inspired me to want to help families in the community even more
- Was when the DVD was on it was very emotional
- More parents are needed in the steering groups
- Friendship
- I have experienced today that there is all sorts of help for behavioural and sleep problems
- People with like minds are willing to work together getting close to Asian women that want to make changes in breaking down walls
- DVD – children wanting places to go like any other child
- The DVDs go straight to the heart
- I was touched by the DVD of the children talking
- The emotional effect of the DVDs of disabled children and how happy small things make them
- Felt very moved by other parent's stories

### Evening Session

- The wide range of issues and needs that different children and parents/carers face. There needs to be an associated wide range of services to cope with these
- DVD – very moving, fantastic little boy, so sincere and heartfelt
- Listening to the ladies talking about what there is out there for us
- Knowledge that other parents are going through the same difficulties

## **Something I'll take away from today**

### Day Session

- Encouragement from other parents to apply for short breaks service for my son
- All of today's handouts and views of carers
- The positive feeling amongst parents
- There is strength in numbers
- Networking and we need to lobby
- I would like to meet with you all again and consider where I may be involved

- To pull my finger out and go on courses and join groups to try and help to make a difference. Also to help me learn to deal with my two boys who have learning problems
- Advice on sleep
- Get more involved
- Lots of interesting information
- Enthusiasm to keep trying to make positive changes for our children
- Good feeling, happy and have enjoyed the day

### Evening Session

- Motivation to get more involved in whatever way I can
- Some of the paperwork to look at and read with information to help us
- More motivated, lots of paper
- Having an evening meeting is an excellent idea. The importance of raising awareness of what a difference can be made at a local level through small changes and additional funding. Pressure needs to be maintained and co-ordinated on government

### **Something that was not so good about today**

#### Day Session

- More parents to be involved and take part in these groups
- Budgeting unfortunately!
- Nothing all good
- One table had no people on it. I'd like a fuller house next conference. The Durham DVD was hard to understand (kept sticking)
- Nothing
- Maybe calories – food was great
- More parents would be great
- Attendance could have been better
- Empty
- DVDs – positive voices for different languages and cultures. A lot of parents have difficulty understanding English so this isolates them from joining in. More interpreters needed please.

#### Evening Session

- I think that the wins/successes achieved so far could have been highlighted more clearly from what is on-going discussion at the focus groups
- More needs to be done to accommodate people who struggle to get to day meetings, varying times