

# Parents 4 Change III

## Conference Report



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

Wednesday 14<sup>th</sup> October 2009  
Riverside Stadium, Middlesbrough

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## **Welcome**

Sheila Tunney, Parent Member of the Parents 4 Change Steering Group

As chair for the day, Sheila began by thanking all those in attendance, especially parent/carers, for giving up their valuable time and coming to the third Parents 4 Change conference.

## **Aims of the conference**

Sheila outlined the main aims of the conference which were:

- To share information about what has been happening within areas of work identified by parents at previous conferences as priority areas. These were:
  - Criteria
  - Information and Engagement
  - Key working
  - Short Breaks
- To gather parent views on the work of the current focus groups
- To ask parents to identify other areas they would like to focus on, so that new groups can be created to continue to help to meet the needs of families with disabled children in Middlesbrough

## **The Story So Far**

The successes achieved so far have been accomplished through the involvement of parent/carers and through effective partnership working between parent/carers and professionals.

It is important to now build upon these successes to ensure that more parent/carers feel they can become involved; today is part of this process to give those in attendance the opportunity to get their views heard.

The more people involved, the more powerful the voice for change becomes and, as shown by the Aiming High for Disabled Children agenda, the Government listens to powerful voices and acts upon the views.

## **Parental Engagement Process**

Kathy Rist, Regional Manager Contact a Family

As a national organisation, Contact a Family is in touch with a wide range of families across all areas. Families constantly tell us they need three things:

- Information
- Support
- Help

One of the aims of Aiming High for Disabled Children is to help to get these three elements right so that families receive help, information and support at the time they need them.

We also need to ensure there is the understanding that every family is different and so their needs will be different based on a child's age, disability and individual circumstance.

Good quality partnership working and listening to parents are essential components to achieving these aims. In Middlesbrough, parent/carers are being asked to contribute to these processes through Parents 4 Change conferences and focus groups.

To build upon the successes achieved so far, we need to ensure that we all continue to listen to each other and to learn from each other which is one of the main aims for today's third conference in Middlesbrough.

## **Middlesbrough Perspective**

Ray Mallon, Mayor of Middlesbrough

Ray began by saying what a pleasure it was for him to have been invited to speak at the Parents 4 Change third conference.

From his experiences, he had heard a lot about the term "inclusion" and has learnt that this is about all communities, including children and young people with disabilities and ensuring that everyone in Middlesbrough feels included within the local community.

Ray stressed the importance of the agenda at today's conference and sees Parents 4 Change as a lobbying group seeking sensitive change and continuous progress; an agenda which should be embraced by everyone in Middlesbrough.

As elected mayor of Middlesbrough, Ray stressed his commitment to the agenda and asked those in attendance to now task him with effecting real change for disabled people within Middlesbrough. He may not be successful with every task assigned to him but he will keep people updated with what can be achieved and with the reasons why some requests can not be met.

Ray concluded by saying he wants to stay involved, come along to more meetings to hear more parent/carer's views and be kept up to date with the documentation that comes out of the Parents 4 Change process.

Ray congratulated everyone in attendance for giving up their time and contributing to this agenda and thanked the organisers again for inviting him to attend.

## **Parent Participation Grant**

Anna Taylor, parent and co-ordinator of the Main Project

The Main Project, which provides advice and support for families who have children with an Autistic Spectrum Condition in the Tees Valley area, administers the Parent Participation Grant for the Parents 4 Change steering group.

### **Background**

- As part of the Aiming High for Disabled Children programme the Department for Children, Schools and Families agreed to spend £5 million to support the involvement of parent carers in planning and developing services for children with disabilities
- Support groups in England were invited to apply for grants to help them work together to develop parental involvement in changing services
- Together for Disabled Children, a partnership between Contact a Family and Serco, distribute the grants and provide support to ensure groups develop parent participation activities in each local authority area in England
- £3330 was awarded for the first year which, in Middlesbrough, was spent on the Parents 4 Change Conference, flyers and printing
- Middlesbrough applied for £10,000 for year two and has been awarded the full amount

## **Year Two Grant**

Where the money is being spent:

- £4000 - Conferences and focus meetings
- £3000 - Website and information
- £2000 - Training
- £350 - Printing costs
- £350 - Expenses, childcare, travel
- £300 - Any unforeseen extras

Effective local partnership working means that the Parents 4 Change process is also supported financially by Middlesbrough's Children with Disabilities Team.

The parent participation grant supports local parent/carers in getting their voices heard through a range of formats including the Parents 4 Change website at **[www.parents4change.co.uk](http://www.parents4change.co.uk)**

This ensures that those parent/carers who are unable to attend conferences and focus groups or those who do not wish to submit their views in these environments still have the opportunity to contribute to the consultation and engagement process.

## **Focus Group Presentations**

Following the first two Parents 4 Change Conferences, focus groups had been established on the following areas:

- Eligibility Criteria
- Information and Engagement
- Key Working
- Short Breaks

Presentations followed by parent and professional members of each focus group to give feedback on what has been achieved so far.

## **Eligibility Criteria for Accessing Short Breaks**

Kerrie Morrison, parent steering group member

Parents had identified a number of problems associated with eligibility criteria:

- Lack of information about who to ask and where to go for information
- Understanding what the criteria actually was in order to access a service
- Being told your child does not meet a criteria to enable them to access much needed services
- Children with conditions such as ADHD and mild learning disabilities being excluded through eligibility criteria

Parents wanted:

- Services provided based on the child's **needs** - not on a label
- Short break services that were easily accessible
- Not to have to have a social worker if they did not want one

To help address these issues, the Criteria Focus Group:

- Talked about what was needed
- Agreed new criteria
- Planned how it would work

### **So what now will be different?**

#### **Low Level**

Parents who need a low level of service will be able to apply directly for a service using a simple application form and a letter of support from a professional person who knows the child.

This should mean that some families who have never had a short break service will now be able to have one.

#### **Medium Level**

Parents who need a medium level of service will be able to agree an application for short breaks with staff already working with them but they will not need a social worker

This means a professional such as a Parent Support Advisor, Community Nurse or Health Visitor will be able to apply for a short break service for a family

### **High Level**

Families who are in difficulty and need the highest levels of support will still be able to access social work support and be provided with services to meet their needs.

The level of support offered will also be flexible given that a family's needs can often change.

### **Summary**

Middlesbrough is working towards increasing the number of families receiving a short break from 200 to 400 between April 2009 and March 2011.

The system is now changing for the better so that more families will be able to benefit from practical help and clear criteria is laid out to allow families to access services easily and swiftly.

### **Information and Engagement**

Kath Freemantle, parent steering group member

The Information and Engagement Focus Group listened to what families said and identified that information is absolutely vital as without it, no-one can really function. Families need to know what services and supports are available to help them.

Following these discussions, the group came up with ideas for improvements and developed a strategy and an action plan.

### **So what is different now?**

- Text Alert Service – families sign up to receive texts about what local events are taking place, particularly leisure activities for their children to take part in
- Parents 4 Change Web Site now up and running at **[www.parents4change.co.uk](http://www.parents4change.co.uk)**
- Currently working on producing Fact Sheets for Families especially for families when they first receive a diagnosis for their child, to explain where you can go for help and support
- Families are influencing decision-making

Through these new initiatives, the focus group are now making a positive difference to families in Middlesbrough.

## **Keyworking**

Emma McHale, Children with Disabilities Team (as parent unable to attend on the day).

## **Background**

A Key worker would be:

- Someone already working with the family or someone who just has that role and knows the family well
- Someone who has special training
- Someone who is acknowledged by everyone as the key worker

We know that families feel that key working could be important for them because parent/carers at the Parents 4 Change Conference held in November 2008 said they would want:

- One stop key worker
- A named person from the start to help and support
- One central link point to key workers

## **Where are we now?**

Parents at the Conference in March 2009 signed up to the focus group for Key working

A focus group of parents, grandparents, carers and professionals have worked on a plan for the introduction of key working in Middlesbrough.

## **Vision Statement**

Within this plan, the following vision statement was compiled:

**Families who have a child with a disability or complex need, and who need support from more than one specialist service, can ( if they wish) have a key worker who will act as a main point of contact and co-ordinate the services they receive**

This plan has been shared with the Senior Management Team for Children Families and Learning and the Be Healthy Sub Group of the Children's Trust

It is proposed that Middlesbrough initially adopts the non-designated Key worker model. Non-designated key workers would be expected to work with a maximum of three families at any one time

Non-designated key workers are those who are not employed just to be key workers but who act as key workers for a small number of families on a voluntary basis or as part of their permanent post.

It is also important to remember that a family do not have to accept key working if they do not want to access this service.

### **Next Steps**

- Funding for the pilot needs to be agreed
- A Key Worker co-ordinator to be identified
- Launch of Key working in Middlesbrough
- Identify families willing to take part in the pilot
- Training for Key Workers  
Identify individuals willing to be Key workers, not just professionals - proposing that parents interested in being a Key Worker participate in the same training too

Any updates on the key working plan will be included in the Disability Matters newsletter so families are kept up to date with progress and developments.

## **Short Breaks**

Bernard Harland, parent steering group member and Gail Humphrey, Primary Care Trust

The job of the short break focus group was to look at the vision that parents came up with at the Visioning Event that was held in Middlesbrough in December 2008:

**Disabled Children, young people and their families are involved in developing a range of flexible, and easily accessible, high quality short break services and activities, enabling them to reach their full potential and maintain family stability. Make it so.....**

It is clear that families need a menu of services available to them so that they have a choice when it comes to accessible short break provision they can apply for.

The range of services identified through discussions with families includes:

- Youth groups
- Groups for children with disabilities
- For children by themselves
- To support families to spend time together
- In the community
- In the child's home
- Through the day
- Overnight

### **What has been achieved so far?**

- Youth Clubs and Youth Groups –support from the Children with Disabilities team to make sure that universal services are accessible for disabled children and their families
- Trips and Outings - organised through the Children with Disabilities team and advertised through the Disability Matters newsletter and the new texting service
- Extended Schools - work has been undertaken around having services available out of school hours and an audit has been completed to ensure that disabled children are included within these plans
- Girls Group – a new group starting in October 2009
- STARS service – South Tees Activities and Resource Services that will work flexibly with families
- Shared Care – joint partnership with fostering team to help share the care and support

- Small grant fund & Community grants of £3000 to provide additional short break services – through money made available through Aiming High
- Children with very complex physical health care needs – a service that although not in area (it's in Newcastle) it is available and can meet families needs

By listening to families, the focus group are now working towards the following:

- Criteria broadened
- Greater flexibility
- Raised awareness of what is available
- More direct route to services
- People from different services/agencies are around the table listening and talking
- On the road to making it so.....?

## **Table Discussions**

In tables, and with reference to update reports that were included within Conference Packs, parent/carers were asked to discuss the issues around the four current focus group areas. Each table was asked to identify 2 questions for each area that were then delivered to a panel made up of those parents and professionals who had been involved in the groups.

## **Eligibility Criteria for Accessing Short Breaks**

**Q. How can parents/carers find out what the criteria are?**

A. Criteria for access to services is currently being updated as it has now been approved by the senior management team.

Information about criteria will be distributed to schools and will be sent to parent/carers who are on the Disability Matters Mailing List

**Q What about families that are non typical – residency orders, adoptions, fostering, shared care – who are already known to social services are they eligible to access the same services if the child were your own child?**

A. Yes, all families you would be eligible for the same services irrespective of how the family is made up

**Q - Who decides the criteria and is there an opportunity to appeal decisions?**

A. Within the focus group, parents have worked alongside professionals to decide on what should be included within criteria. As a result, there is now no mention of disabilities within criteria, the focus is on children's needs

There will be opportunities to appeal decisions made and an appeals process has been included within the new guidance

**Q. If a family are awaiting a second opinion with regards to their child's diagnosis, will this mean they do not meet the criteria to access a service?**

A. No as the new criteria guidelines do not mention disabilities and diagnosis, they focus on a child's needs. If a child has an additional need, they will need support no matter what the "diagnosis" of that child

**Q. How do you know which level of support you might need within a criteria?**

A family can initially access a low level of service but this will be flexible and subject to change following reviews and depending on if that family's needs change

**Q. Will the criteria be public so that families are empowered and aware of whether they meet the criteria or not?**

A. Yes, as previously outlined, information about criteria will be available to families in a number of formats

**Q. How long will it take to find out if families meet the criteria for accessing services and for reviews, e.g. if there is a change to your family circumstances**

A. Timescales will be included within the new guidance

## **Information and Engagement**

**Q. What's going to be put in place to help parents/carers understand the information they receive and to make it easy to understand? E.g. what to ask, what information is relevant etc.**

**Q. Will information be in all languages and easily accessible, in various formats**

**Q. Is it possible for information already available to be made more user friendly, jargon free and easily accessible?**

A. It is hoped that professionals working with families will help them to access information. Information will be reviewed to ensure it is user friendly and easy to read and will be available in a range of formats to ensure it is as widely accessible as possible

**Q. After a diagnosis, how do you find out further information about your child's needs?**

A. The development of the new fact sheet for families will hopefully be really useful for families in this situation. It is hoped that professionals will have access to this information too so that they can pass it onto families and talk to them about it so that any questions can be answered and a family is clear about the information they are receiving

**Q. Other than Disability Matters, the computer and the telephone are there any other routes for parents/carers to access information?**

A. A number of avenues have been identified:

- Text alerts
- Disability Matters newsletters
- Information Directory
- Website
- Personal contact through members of the Disabled Children's team getting out and about to a range of local events including information days, the Mela and local carers events
- Parent/carers need to also take some responsibility to ensure they pass information on to other parents as this is the most effective way of spreading the word about local services and support networks

**Q. Why does it take so long to get relevant information?**

**Q. Can we have a one stop shop?**

A. To try and address issues such as these, the Information Worker post that was previously in place is to be reinstated following requests from the Information and Engagement Focus Group. This person will be recruited shortly and will be based within the bus station.

**Q. Can we improve the cascading of information about individual children with disabilities into mainstream education, particularly secondary schools?**

Paediatricians at James Cook Hospital have signed up to using a template which can then be used to share information with others so this would be available for families to take into mainstream education settings.

Given that this will not help families whose children attend West Lane Hospital, the focus group will now take this on and look into it so that it's used at this hospital too.

## **Key Working**

**Q. How do parents/carers get more information about becoming a key worker?**

A. By sharing information as wide as possible when the pilot is up and running through all the information formats previously mentioned.

**Q. Why can't a key worker access services directly for a family without the need for a social worker?**

A. They will be able to once the process is up and running

**Q. What is the difference between a key worker and a social worker?**

A. A Key Worker can come from any service or can be another parent too. Sometimes a Social Worker may also be a Key Worker for a family as some already work in this way

**Q. Why is the service only open to families with children aged 0 to 18 and what is the eligibility criteria?**

A. This was agreed within the focus group by parents alongside professional workers. The key worker guidance outlines that children **may** be eligible – this is because some families may not actually want a key worker

**Q. Can a key worker liaise for a family with ALL the professionals you need to talk to?**

A. Yes, this will be one of the main tasks of a key worker to cut down on the need for a family to make numerous calls and to tell their story over and over again

**Q. Can families have a choice about who becomes a key worker?**

A. Yes, this is vital as it has to be someone a family feels comfortable with and trusts

**Q. How long does it take to train to become a key worker?**

A. A day's training was delivered in another Local Authority by a parent with a professional that was very successful so Middlesbrough would be looking at offering this alongside on-going support

**Q. Will parents be paid for their time?**

A. Expenses would be reimbursed to ensure parents are valued and appreciated for giving up their time

## **Short Breaks**

**Q. What range of short breaks is available?**

The range outlined in the Short Breaks presentation will be available including helping children access universal services, groups for children with specific disabilities, residential services and using Direct Payments to access services too

**Q. How are we going to get time to spend with our sibling children?**

**Q. Can parents have time with their disabled child with someone available to look after their sibling children?**

**Q. What happens if there is more than one disabled child in a family?**

**Q. Can short breaks be more co-ordinated?**

Historically, parents were TOLD "here's a service, take it or leave it" – now parents are asked about their needs and services are offered based on these needs so the needs of siblings children will also be met

Information about a family's requirements and specific needs should be included within the application form so that they can be met with a menu of services.

**Q. How can parents make people aware of their needs within the short breaks process?**

The criteria for accessing a short break service will be far more open and families will be also able to self-refer

**Q. Can families with more demanding needs have longer breaks?**

Yes because a family's needs will be taken into account when determining the level of support and services that is required

**Q. How do families get a short break – what is the assessment processes and how long does it take?**

For low level needs, a family would just need to have a letter of support to accompany their application form. For a higher level of need it will take longer but timescales will be included in new guidance

**Q. How long is it going to take to move to Individualised Budgets?**

5 families have been receiving Individualised Budgets as a pilot. The pilot will be reviewed and following this review, the short breaks services will be looked at so that families can arrange their own support through this process

**Q. How can parents be supported to ensure children move away safely and with support to university or college?**

Although in the very early stage of development, Middlesbrough does now have a transition service so these needs should be recognised within this.

With appropriate help and support, parents will be asked to support young people to have a person centered plan which will help with access to colleges, supported living, independent living etc

## **Interactive Session – Wheelchair Services**

Conference attendees took part in a question and answer session around wheelchair services in the form of an interactive session; designed to gather information in an interactive, instant way. From individual handsets, attendees were able to choose their responses to a range of questions which will help to inform future developments within this service.

A full list of the results is attached as Appendix One to this report.

## **What Next? Future Focus Groups**

In table discussions, parent/carers were asked to think about the subjects they wanted to look at, in addition to the groups that had already been established through previous conferences.

Tables were asked to each identify 2 areas that they would like to see focus groups established on. Through interactive voting, parent/carers were then asked to pick from the list of those identified so that a top four could be agreed upon.

This meant that immediate results were given to parent/carers so they could see how their views were being listened to and acted upon.

Following the voting, the four areas that were agreed as new focus groups were:

- Behaviour
- Transitions
- Sleep
- Sport and Leisure

Parents were then given details of the first meeting dates for each of these focus groups and were asked to sign up to those they are particularly interested in to ensure that more views are heard and a wider range of parent/carers are involved in future work. .

## **Parents 4 Change – Keep or Change?**

The name Parents 4 Change was agreed upon quite quickly to ensure there was an identity for the steering group, the website and the conferences. However, since this time there have been some suggestions from parent/carers that the name should be changed to reflect the fact that there are all carers involved in the processes and not just parents.

Due to a lack of time however, the discussions planned about these proposals will now take place at the next conference. Parent/carers were asked to add any views they have at this stage to their evaluation forms. Those received were:

- Change name to Families 4 Change
- Name change, it should be Families 4 Change
- The name should stay the same as it has been in place for so long
- Not great idea to change as the identity has been set. Perhaps an additional word could be added with lower case scrolling down into the A's of 1st and 2nd words

## **Stress Management**

Jacqueline Berry, Stress Management Consultant

There is recognition that because of the very stressful lives they lead, parent/carers need to ensure they take time out to look after their own health to help them to provide the best care they can for their children and families.

This recognition of parents/carers own needs also reinforces the issues discussed throughout the day around how vital short breaks, information and key working are to families.

Jacqueline therefore closed the conference with a stress release session where parent/carers took part in an interactive question section, a stress release exercise and some tips to take away from the day.

A full list of answers to the interactive session is attached as Appendix Two to this report.

The simple techniques parent/carers were asked to take away from the conference were:

1. Drink more water for the next seven days
2. Take Omega 369 oils
3. Green Barley Grass – for vitamins and nutrients (half a teaspoon in the morning) Readjusts your metabolism Sold by druhealth.com as a not for profit organisation

## **Summary**

Sheila Tunney thanked everyone for attending and for contributing their views to the day.

New Focus Group meetings will now be taking place to start discussions on each of these new areas. Feedback from these will be given at the next Parents 4 Change conference which will take place in Spring 2010.

From completed evaluation forms, it is clear that the majority of parents welcome the opportunity to attend these conferences. They primarily enjoy meeting up with other parent/carers and sharing views and concerns and they also find the days very informative.

A full list of evaluation comments is attached as Appendix Three to this report.

## Appendix One – Wheelchair Services Results

### What type of wheelchair does your child use?

My child does not use a wheelchair	64%
Specialist Buggy	11%
Manual Chair	21%
Electric Chair	4%

### Thinking about the information you received from the wheelchair service, was it?

(Respondents could pick all that apply)

Verbal	23%
Written	27%
Not Enough	23%
Too Much	0%
Difficult to Understand	0%
Easy to Understand	18%
I didn't receive any information	9%

### Overall, how do you rate the INFORMATION given to you by the wheelchair service?

(1 being poor and 10 being excellent)

1	15%
2	8%
3	15%
4	15%
5	8%
6	0%
7	23%
8	8%
9	0%
10	8%

**Overall, how do you rate the SERVICE given to you by the wheelchair service? (1 being poor and 10 being excellent)**

1	0%
2	8%
3	0%
4	0%
5	17%
6	17%
7	17%
8	17%
9	0%
10	24%

**What do you think the wheelchair service do well?**

(Respondents could pick all that apply)

Waiting time for a clinic appointment	14%
Range of equipment available at the clinic appointment	19%
Explanation of what equipment & accessories you are entitled to	10%
Frequency of reviews	19%
Arrangement for repair of chairs	28%
Communication with other services e.g. schools, transport	10%

**Is there a way in which the wheelchair service could do better?**

(Respondents could pick all that apply)

Waiting time for a clinic appointment	20%
Range of equipment available at the clinic appointment	16%
Explanation of what equipment & accessories you are entitled to	20%
Frequency of reviews	16%
Arrangement for repair of chairs	8%
Communication with other services e.g. schools, transport	20%

## **Appendix Two – Stress Management Results**

### **Am I late for appointments?**

Never	26%
Almost Never	26%
Sometimes	30%
Usually	9%
Almost Always	9%
Always	0%

### **Am I competitive in the games I play at home or at work?**

Never	10%
Almost Never	10%
Sometimes	46%
Usually	20%
Almost Always	7%
Always	7%

### **In conversations, do I anticipate what others are going to say? (interrupt or finish their sentences)**

Never	21%
Almost Never	7%
Sometimes	57%
Usually	0%
Almost Always	11%
Always	4%

### **Do I do things in a hurry?**

Never	7%
Almost Never	0%
Sometimes	22%
Usually	26%
Almost Always	19%
Always	26%

### **Do I get impatient in queues or traffic jams?**

Never	13%
Almost Never	10%
Sometimes	20%
Usually	7%
Almost Always	10%
Always	40%

**Do I do several things at once and think about what I am about to do next?**

Never	11%
Almost Never	0%
Sometimes	18%
Usually	21%
Almost Always	21%
Always	29%

**Do I feel that I do most things quickly? (eating, walking, talking, driving)**

Never	10%
Almost Never	10%
Sometimes	10%
Usually	32%
Almost Always	17%
Always	21%

**Do I get easily irritated over trivia?**

Never	8%
Almost Never	27%
Sometimes	41%
Usually	8%
Almost Always	8%
Always	8%

**If I make a mistake, do I get angry?**

Never	11%
Almost Never	22%
Sometimes	59%
Usually	4%
Almost Always	0%
Always	4%

**Do I find fault with, and criticise myself and/or other people?**

Never	4%
Almost Never	14%
Sometimes	47%
Usually	21%
Almost Always	21%
Always	7%

**Do I make negative comments about myself and/or others?**

Never	4%
Almost Never	28%
Sometimes	56%
Usually	0%
Almost Always	12%
Always	0%

**Do I ever feel unable to cope?**

Often	21%
Sometimes	48%
Rarely	28%
Never	3%

**Do I find it difficult to relax?**

Often	48%
Sometimes	38%
Rarely	7%
Never	7%

**Do I ever feel anxious for no reason?**

Often	11%
Sometimes	60%
Rarely	18%
Never	11%

**Do I find it hard to show my true feelings?**

Often	27%
Sometimes	53%
Rarely	13%
Never	7%

**Do I find it hard to make decisions?**

Often	21%
Sometimes	48%
Rarely	28%
Never	3%

**Am I often irritable for no reason?**

Often	10%
Sometimes	50%
Rarely	33%
Never	7%

**Do I worry about the future?**

Often	52%
Sometimes	48%
Rarely	0%
Never	0%

**Do I feel isolated and misunderstood?**

Often	28%
Sometimes	48%
Rarely	17%
Never	7%

**Do I dislike myself?**

Often	23%
Sometimes	12%
Rarely	42%
Never	23%

**Do I find it hard to concentrate?**

Often	26%
Sometimes	59%
Rarely	15%
Never	0%

**Am I worried about my health?**

Often	25%
Sometimes	35%
Rarely	29%
Never	11%

**Do I feel that life has lost its sparkle?**

Often	18%
Sometimes	57%
Rarely	14%
Never	11%

**Do I always feel in a “rush?”**

Often	63%
Sometimes	29%
Rarely	4%
Never	4%

**Do I ever have aching neck or shoulder muscles?**

Often	65%
Sometimes	21%
Rarely	7%
Never	7%

**Do I have trouble sleeping?**

Often	54%
Sometimes	21%
Rarely	11%
Never	14%

**Do I have persistent indigestion?**

Often	28%
Sometimes	10%
Rarely	17%
Never	45%

**Do I feel unusually tired?**

Often	55%
Sometimes	31%
Rarely	14%
Never	0%

**Do I have frequent headaches?**

Often	38%
Sometimes	24%
Rarely	24%
Never	14%

**Is my blood pressure too high?**

Often	3%
Sometimes	7%
Rarely	24%
Never	66%

**Do I have dizzy spells?**

Often	12%
Sometimes	35%
Rarely	8%
Never	45%

**Do I smoke to calm my nerves?**

Often	14%
Sometimes	0%
Rarely	3%
Never	83%

**Do I eat erratically? Over eat/Under eat?**

Often	37%
Sometimes	33%
Rarely	15%
Never	15%

**Do I drink (or eat) to unwind?**

Often	33%
Sometimes	22%
Rarely	7%
Never	38%

**Do I have unexplained skin rashes?**

Often	17%
Sometimes	0%
Rarely	7%
Never	76%

**Am I over weight or under weight?**

Often	59%
Sometimes	24%
Rarely	3%
Never	14%

## **Appendix Three - Full list of Evaluation Comments**

A total of 28 evaluation forms were completed by parent/carers at the conference.

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### **Was the venue okay for the day?**

All respondents said yes, the venue was okay.

### **What do you think was the best part of the day?**

- Talking to and meeting other parents
- Meeting other families and lunch
- Talking to other parents
- Talking to other parents about problems with your child
- Meeting other families and discussing problems with children
- The stress release as this was very helpful
- It was all very good
- Enjoyed all of the day, mostly the last de-stressing presentation
- I enjoyed the full day
- Meeting and talking to other parents and professionals. It is good to exchange views and ideas
- All agencies getting together and getting answers to questions
- Information sharing from all parent/carers
- Stress release session
- The voting system as it was easy and to the point and you saw quick results
- Discussions as you have the chance to hear other parents' problems
- Realising that there is help available because sometimes it feels very lonely to be a carer
- The discussions around the table as they give everyone a chance to put their views forward and voice their concerns
- Finding out what focus groups have achieved. I am interested in future changes
- Meeting other parents and getting to know more about what has changed since the first conference
- Carers asking questions on Focus Groups as we managed to get a few answers
- The discussions and meeting people in the same situation
- Everything, I really enjoyed it as it was very informative
- The parent/carer table discussions and exercises that allowed my personal experience to be of relevance to the Parent Participation process

### **What do you think was the worst part of the day?**

- Stress questions
- Lunch was rushed
- The new focus group exercise. It was very restrictive as childcare, summer playschemes, extended schools and sport and leisure are all short breaks. The poor exercise diluted the potential of the exercise. Wheelchairs, speech and language etc were all PCT stuff
- Speed of events as the rush was rather stressful
- Very formal
- Not enough time allowed for table discussions and structured guidance given for table exercises

### **Is there anything that you would have liked to see included in the day that wasn't?**

- Update from PCT spend and it's transparency – what is going on with it? What is its' role? Lots of comments like “we are interested in hearing from parents” which is not very encouraging
- I have worked with parents that are unable to read and would have not been able to vote in the wheelchair questions
- There were ethnic minority people at the conference and everything was in English. There should have been some kind of translation
- Fruit juice to have with lunch
- Rather than the written documentation of the focus areas which was time consuming and not easy to refer to in multiple pages (however the individual colour coding for each focus area was beneficial) there should have been bullet point and diagrammatic documentation specific to focus area so at a glance "actual change" of past to present in that specific service is noted and is easy to reference

### **Please give a brief comment on what you thought of the day**

- Exciting, getting a laugh
- I thought today's conference was very interesting and useful
- The day was interesting and rewarding
- Informative, friendly and lovely food
- Relaxed, funny, good chat and good food. I will come again
- Very interesting and informative
- We got really good information
- Very informative and enjoyable; relaxing and got useful information
- Very good friendly atmosphere. It was good to be with other parents who are all going through similar problems. Parents 4 Change is an excellent organisation

- Very professional led – not sure about this being as parent led as we are told it is and there was the same chair as last time
- Excellent
- Very informative
- It was a good day and well organised
- Excellent
- Networking between parents and professionals was so helpful and informative
- It was an improvement on the first conference
- Excellent
- First time and it's been really good with lots of information
- Excellent – every conference is better than the last
- I totally enjoyed today
- Overall it was a success as there were burning issues that were addressed. It was also more informative than the previous conferences have been
- It was interesting to hear the mayor speak of his interest of inclusion for all children
- Really enjoyed the day and hope to be involved again
- It was my first conference and I really enjoyed it. It was very informative and I would love to be part of it
- Delighted to be brought together with fellow parent/carers with the purpose of initiating positive relative change for the lives of our children and also the stress exercise for ourselves. A Win Win situation.
- I find the consistency of the Parents 4 Change members present again not only comforting but encouraging