



# Making Changes Together III

## Conference Report

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

Thursday 2<sup>nd</sup> April 2009  
Redworth Hall, County Durham



## Contents

Introduction .....	3
Making Changes Together – The Story So Far .....	3
The Durham Model .....	4
Every Disabled Child Matters (EDCM) Update .....	6
Family Matters .....	8
Come on Down – The Service is Right! .....	9
County Durham NHS Update.....	14
Making Changes Together III – Where Next?.....	14
Table Discussions.....	16
Short Breaks.....	16
Therapies .....	17
Transition .....	18
Summary .....	20
What Next? .....	20
Appendix One – Full List from Family Matters Discussions .....	21
Appendix Two – Full list of comments from afternoon sessions .....	24
Short Breaks – What should Short Breaks look like? .....	24
Therapies – What does Therapy Mean to You? .....	26
Transition – What is Transition? .....	27
Other points raised:.....	28
Appendix Three – Full List of Evaluation Comments .....	29

## **Introduction**

Marsha Dolan

Marsha is a member of the parent steering group and opened the conference by welcoming everyone to Redworth Hall, stressing how this event is for parents/carers and professionals; all about your views, your opinions, your families or your workplace.

The parent steering group hope that by parents working with service providers, they can make things better for families, children, young people and everyone's working lives. At the conference, parents were joined by invited professionals from Durham County Council and Durham NHS to ensure these changes can be made together

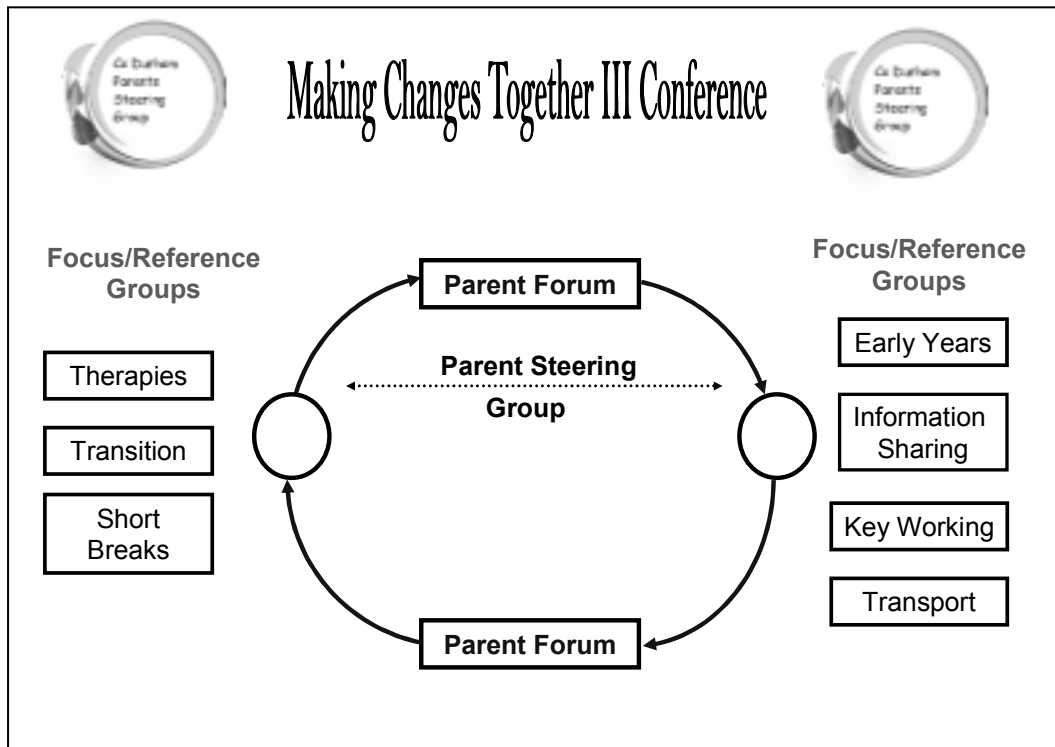
## **Making Changes Together – The Story So Far**

Since the first Making Changes Together conference held at Seaham Hall in May 2008, the Steering Group and Focus Groups created from the conferences have been working very hard alongside service providers to ensure that the expert knowledge and experiences of parents and carers is heard when it comes to planning and developing services for children and young people with special needs and disabilities in County Durham.

## The Durham Model

Janet Cummings

Janet, another parent member of the steering group gave everyone a brief background to how the Durham model was established and what the model means in practical terms, as highlighted by the following diagram:



The parent forums on the diagram are the two Making Changes Together conferences held each year. The role of the parent steering group is to organise these conferences. At these conferences, parents are able to inform services of what they need, what helps them and also discuss best practice.

The first conference was held in March last year and focus groups were established based on the priorities identified by parents as the areas of local service development that they are mostly interested and concerned about.

As a result of information gathered from the first conference, four groups were established on Early Years, Information Sharing, Key Working (Lead Professional) and Transport. From the second conference, further groups are now being established on Therapies, Transition and Short Breaks.

Focus Groups are made up of parents and invited professionals who meet regularly in between conferences to work towards developing the services in each particular area and parents are encouraged to sign up to those groups they have a specific interest in. Parents are also welcome to make suggestions for further groups.

Parents on the steering group have also been asked to inform other parents and workers around the country about the exciting things which have been happening in County Durham. Three parents have been involved with speaking at conferences in both the North East region and further afield. This has led to the adoption of the model in several of the areas parents have visited putting County Durham firmly on the map of parent participation

## Every Disabled Child Matters (EDCM) Update

Lileen Cuthbertson

Another parent steering group member, Lileen Cuthbertson gave an update on the EDCM charter

At the October 2008 conference, representatives from Durham Primary Care Trust (now NHS) and Durham Local Authority (LA) County Council alongside local parents signed the Every Disabled Child Matters Charter.

The progress made so far (EDCM Charter pledges in bold):

- **We know how many disabled children live in our area and that we are planning future services on the basis of this knowledge**  
Information is available around the number of children and young people (C&YP), demographics and age. We now have an understanding of who accesses short breaks in County Durham
- **Key Worker established (LA) and Children's Lead with specific responsibilities (NHS)**  
Lead Professional work has finished and next steps are now in place for implementation. The Lead Professional passport also now has strategic sign up.
- **Parent Partnership Service is sufficiently resourced to provide advice, information and support to parents (LA) PCT to demonstrate a close working relationship with LA and to have input in all C&YP plans and strategic sign up**  
Parent Partnership is resourced and work is on-going focussing on information and advice. The PCT are closely involved with the LA and have strategic representation. The PCT are central to the C&YP Plan
- **Parents, young people and carers are receiving accurate information that is timely to them and their families (LA)**  
The Information focus group is working on accurate information and advice including the launch of the Durham Children's Network directory in March 2009
- **All staff have received both disability equality training and training to ensure that they have core competencies to work with disabled children (LA)**  
Staff training has commenced in Children's Centres by Contact a Family and the Council for Disabled Children. The new workforce development officer is aware of the charter commitment and there is also potential to skip up parents and carers through accredited training
- **Disabled children are involved in drawing up our Disability Equality Scheme and are also monitoring its effectiveness (LA). Incorporating commissioning and health (NHS)**  
Investing in Children to be central to drawing up and monitoring a disability equality scheme to link with the wider corporate agenda chaired by Maureen Clare. This group has met and has involved a wider group including three schools

- **Our Children & Young People Plan explains how we will provide specialist services and also make all universal services including extended schools and children's centres accessible to disabled children (LA)**  
 The new C&YP plan will explain how we will provide specialist services, universal services including extended schools and children's centres especially around short breaks
- **Our Local Area Agreement includes targets for the level of Service to be delivered to families with complex needs (LA)**  
 The Local Area Agreement includes targets for the level of services to be delivered to families with a disabled child in Children & Young People's Plan
- **Disabled Children & Families are involved in the planning, commissioning and monitoring of services in our area (LA)**  
 Disabled children and their families are involved including membership of Investing in Children for all current and potential service providers, as in short break specification
- **We are working to reform our community equipment and wheelchair service to improve the quality of equipment available and to address the holistic and changing needs of children and young people (NHS)**  
 A review of current arrangements is taking place and gaps are to be identified and commissioned against appropriately
- **We are commissioning comprehensive specialist medical, nursing and therapy services for children with palliative care and complex health needs and are working with all commissioners and local authorities in our area to integrate these services into a wider children's service (NHS)**  
 Joint commissioning is taking place around short breaks, therapies are to be placed within universal surroundings, a therapies audit has commenced and joint commissioning arrangements are in place to be responsive to gaps in provision
- **We can demonstrate an effective partnership with disabled young people and adult service providers in our area to ensure a smooth transition to adult services for disabled young people (NHS)**  
 The transitions focus group commenced in January 2009 and has the full backing from the Durham Joint Commissioning Group linking into the Multi-Agency Transitions Group

## **Family Matters**

In table discussions, parents and professionals were asked to look back on the last six months of their lives and share information on both the positive and negative experiences they had had during this time. They were encouraged to share whatever information they wanted including personal triumphs, children's successes and any difficulties faced. A full list of comments made is attached as Appendix One.

The key points made were:

### **Positives**

- Individual children's development breakthroughs
- Independence of young disabled people
- New Children's Network Directory (but need loads more copies)
- The Durham Model being highlighted on the Together for Disabled Children website as an example of good practice
- National acknowledgment and pride in the achievements made so far in County Durham
- Positive experiences of social worker
- St Oswald's Park now has supported and accessible play equipment
- Finally getting equipment for children
- Opportunity for dialogue and debate between parents and professionals
- Eco Village
- Paediatric Physiotherapist
- Received more respite
- More drive
- Employers enabling parent to take time off to attend conference
- The Making Changes Together Conferences and Focus Groups and all working together
- Open referrals now to wheelchair services
- Support received through transition times including social care in the home
- Listening to parents
- Receiving a bus pass for a child and a carer
- Getting the right amount of support for teenage children (in home and in school) – the diversity of school and education received
- Having a holiday
- Children's confidence increased

### **Negatives**

- Child health difficulties
- Lack of physiotherapy provided by a hospital after a child's operation
- Need clarification on criteria (for staff as well as parents)
- Problems with getting the right equipment and the long waiting times
- The fact that there are always barriers including judgements from the general public

- Lack of confidentiality of personal information
- Difficulties in communication around hospital appointments
- Transport issues
- Transition problems
- Lack of support and advice around education and schools
- School review where a social worker promised to attend but didn't
- Frustrations at red tape
- Education issues around accessing the right education for children
- Lack of legal rights
- Staff not trained appropriately to support children effectively

The issues identified by everyone through these discussions will help to drive future work forward, giving the steering group and focus groups more ideas around the priority areas for families and professionals in the issues they face in their daily lives.

## **Come on Down – The Service is Right!**

From the previous Making Changes Together Conferences, parent's views and concerns have been used within the four focus groups that were initially established on transport, lead professional, early years and information.

Lesley Moore from the parent's steering group introduced a parent and professional representative from each of the focus groups to take part in the Service Is Right game show. The aim of the game show was to illustrate the achievements and progress been made so far in an interactive, fun way.

Teams consisted of:

Team Transport – Lileen Cuthbertson and Allen Hazlett

Team Lead Professional – Annette Doherty and Lynne Gregory

Team Early Years & Children's Centres – Michelle Cook and Caroline Richardson

Team Information – Teresa Crich and Elaine Wilson

Teams had to answer individual questions in the first round to share information about the progress made:

### **Team Transport**

#### **Q1 – What as the first thing the Transport Focus Group did?**

A1 – They did an audit of all transport in County Durham. They met with a large number of parents to get the key issues

#### **Q2 – What where the two key issues?**

A2 – Lack of flexibility in the transport and the needs of the children were being overlooked

**Q3 – What percentage of parents at the last conference were happy with their transport?**

A3 – 80%

**Q4 – What changes are happening?**

A4 – The transport focus group now has some high level transport professionals on board working with them. They now recognise and acknowledge the need for changes in policy and this is beginning to happen.

They now see good transport/transport providers as vital to the child's package of care and realise that poor transport affects the child, their family and the success of the placement where they are travelling to and from.

They are looking at an accreditation scheme to reward excellence, for providers who do their job well.

The Lead Professional passport is likely to have a section on the child's transport arrangements, emphasising their transport needs, e.g. any medical issues, preferences for travelling.

**Team Lead Professional**

**Q1 –Why is it just children with complex needs will get a Lead Professional?**

A1 – After listening to parent's views at the last conference and through work done in the focus group, it has been agreed that any child with a need (either identified through the Common Assessment Framework or from having more obvious needs) will be able to have a Lead Professional. It is important to realise that a family might only need a Lead Professional for a short period of time for example 6 weeks, to achieve one aim or a family may need one long term or families may choose not to have one at all

(The Common Assessment Framework (CAF) is a country wide assessment process used by practitioners across services for children and young people. The practitioners for example may be social workers, doctors, health visitors, teachers, nurses and anyone else who works with a child/young person with additional needs.

The CAF will provide a more effective way of assessing a child/young person's needs. It will take into account the child/young person's strengths and needs. It also takes into account the parent/carer's strengths and the effect of the child/young person's environment on their development. The CAF will suggest what support is needed to help the child/young person's development and will ensure joined up working across the services they use).

**Q2 – Can you name 5 things that a family would expect from their Lead Professional?**

A2 – My Lead Professional knows my child, me and my family and our history relevant to the child; that my Lead Professional will provide support and advice about my child's needs; my Lead Professional can put me in touch with relevant groups/information; my Lead Professional can signpost me to agencies/benefits etc and that I can choose my Lead Professional (within reason) and that if my Lead Professional has to change, I will be informed and consulted

**Q3 – Can you name 2 things that a Lead Professional will do for a family?**

A3 – They will co-ordinate the "Team around the Child". These being Speech Therapists, SENCOs, Short Break services for example and because the Lead Professional will be recognised and valued by the "Team around the Child" there will be more interagency working and understanding allowing the Lead Professional to carry out the role successfully

**Q4 – Who can be a Lead Professional?**

A4 – Whoever is relevant to that child and family e.g. Health Visitor, Social Worker, Occupational Therapist, SENCO etc

**Q5 – What training will be given for the role?**

A5 – There will be standardised presentation so that all professionals in County Durham will get the same information in the same way. Instead of taking all the workers/professionals out for long periods, the training will be delivered in their existing meeting/training slots. Training will also be delivered by parents alongside workers/professionals. It is expected that this training will be completed by the next conference!

**Team Early Years & Children's Centres**

**Q1 – Who is on the Early Years Focus Group?**

A1 – Parents, Children's Centre Cluster Managers, Access and Inclusion Strategy Manager for Sure Start County Durham, Senior Managers from Sure Start County Durham, colleagues from Placement and Provision, Early Years' Educational Psychologist, colleagues from NHS etc.

**Q2 – How did the group and Children's Centre Cluster Manager get information on what you need from your local Children's Centre?**

A2 – At the last conference, we asked parents to notify us of their nearest/likely to have used Children's Centre and then parents were asked to attend a meeting to discuss what would have been/would be helpful/good/user friendly. All the findings from these meetings were brought back to the focus group

**Q3 – How much money has been set aside for the Early Years Workstream Group to pay for, for example, training and setting up a parent buddy system along with other priorities as identified by the parents?**

A3 - £40,000

Parents and professionals from the conference were then asked for their suggestions about what they thought this training should be like. The following was suggested:

- Moving and Handling
- Communication issues such as PECS, Makaton, Sign Language, AAC
- Nutrition
- First Aid
- Sensory Difficulties
- Epilepsy
- Autism Awareness
- Behaviour Management
- General Public and raising awareness

**Q5 – Can you name three initiatives that are going to take part in Children’s Centres in the near future as a result of the last conference and the focus group?**

A5 – Portage group sessions and some Therapies/Therapy sessions are going to take place. Training is going to be held for both staff and parents, probably together if that is what parents want. Already parents have been invited on local management groups.

### **Team Information**

**Q1 – The team was shown a photograph of the conference steering group members receiving a text message and were asked what the message was**

A1 – They had just all received their first text message from the Children’s Network giving them up to date information

**Q2 – What are the benefits of joining County Durham’s Children’s Network?**

A2 – You get information, advice and guidance in respect of services for children with additional needs. You also get the opportunity to access fun activities such as children’s parties, sport’s days etc. And you get your own directory and monthly newsletter

**Q3 – Can you tell us how you update or add an entry in the directory?**

A3 – You can send in the tear off update sheet at the back of the directory or email Elaine Wilson, Network co-ordinator. And in the near future, when the County Durham website is up and running, there will be a children’s network part to it where you will be able to add to or change the information online. You’ll also be able to access other relevant information on that site.

**Q4 – How many children with additional needs live in County Durham?**

A4 – 3,250

**Q5 – How many of them are members of the Children’s Network?**

A5 – 903

### **General Knowledge Round**

**Q1 - When was the Every Disabled Child Matters Charter signed in County Durham?**

A1 - At the last conference on 1<sup>st</sup> October 2008

**Q2 - What is Elaine Wilson from the Children’s Network email address?**

A2 - elaine.wilson@durham.gov.uk

**Q3 - What is the Children’s Network website address?**

A3 - www.durham.gov.uk/childrensnetwork

**Q4 - How many parents signed up to Focus Groups at the last two conferences?**

A4 - 39

**Q5 - What’s the name of this conference?**

A5 - Making changes Together III

**Q6 - What do the initials DADLG stand for?**

A6 - Durham Area Disability Leisure group which is for disabled children and their families. They organise leisure and sport activities and can be contacted on 0191 389 1666

**Q7 - Can anyone name two types of transport?**

A7 – Taxi and minibus

## **County Durham NHS Update**

Anthony Prudhoe, Associate Direct Joint Commissioning, Primary Care Trust

Anthony stressed how important these conferences and the work of the focus groups are in determining the priority areas for families with disabled children in County Durham.

As a result of the hard work of parents, an additional 3.9 million pounds has now been allocated to therapies in the region, some of which will be spent on providing more therapists.

1.4 million has been allocated to provide additional short breaks for families and 2.4 million is available for children with complex needs.

It is important to now work on how best to spend this money effectively to have a positive outcome for families. Focus Groups set up through the Making Changes Together conferences will feed into the planning of how this money will now be spent so it is really important that as many parents as possible sign up, get involved and get their views heard.

The allocation of these funds shows the very real changes that are happening in County Durham as a direct result of effective parent participation and engagement.

## **Making Changes Together III – Where Next?**

Parents and professionals were then asked to look at each of the newly established focus group areas to help to identify key areas for each group to centre on.

### **Short Breaks**

Paul McGinnety, Integrated Service Co-ordinator for Children with Complex Needs

Before table discussions, Paul gave a brief background on the work that has already been taking place in County Durham around short breaks. The work started following the launch of Aiming High for Disabled Children (AHDC) in May 2007. This places a requirement on Local Authorities and the Primary Care Trust (now NHS) to deliver a full service offer to families around short breaks, in short a menu of options that are accessible to a wide range of children.

The first stage was the completion of readiness criteria that mapped County Durham's current position and identified targets for the next three years. This was followed by a gap analysis that compared current provision against the full service offer. Like other developments, this is a joint commitment from both the Local Authority and the NHS.

### **What is being done?**

Commissioning has commenced for technological dependant and children whose needs challenge and County Durham is looking to increase the capacity of short break services in the Autumn.

Parent groups and young people's groups have been established to feed into this commissioning activity and Durham are in the process of monitoring various contracts as they continuously ensure value, quality and safety. Local Children's Boards are involved to ensure local expertise is involved in delivering on the full service offer. Commission time has been booked so that Durham can plan, commission and deliver effectively.

### **What does this mean to families now?**

Special Schools are now being asked what extra holiday provision they can provide and how this can start to happen during the 2009 Summer holidays.

Two events have been planned for children and young people in the Summer (details will be distributed through the Children's Network).

A feasibility study is due to take place with regards to the possibility of the establishment of an Eco Village in Teesdale, as suggested by parents at the last Making Changes Together Conference.

Paul encouraged parents to sign up to the Short Breaks focus group to help everyone work together to map the future of provision in County Durham

### **How will it all be measured?**

The delivery of an increase in short breaks is part of the new Children & Young People's Plan and Local Children's Boards also have this as a major priority.

Durham will ensure that all new services seek and obtain feedback to shape future developments. They will look to increase the use of existing facilities, for example, school swimming pools and how best these can be used during school holiday periods.

This is a cultural change towards becoming more inclusive and the true test will be what happens in improving Short Break provision for families in County Durham not just over the next three years but long term.

## Table Discussions

The key points that were raised during the table discussion were as follows:

### Short Breaks

Tables were asked to focus on the question - “what do short breaks look like to you?”

Short breaks should be:

- Flexible and varied; there needs to be a menu of options available to families so they can choose what is most suitable for them. Some families may choose a holiday away together, others may want a sitting service so they can go out as a couple or with their sibling children for just a few hours
- Accessible – not just the provision itself but there may also be a need for transport to enable a family/child to access an appropriate short break provision
- Led by a family/child’s needs rather than service led
- Equally available to all families who need them
- Age appropriate

**Short breaks need to be age appropriate for example where can a teenage girl with Cerebral Palsy go to meet other teenagers and access teenage activities?**

Parent Quote

Ideas for Short Breaks:

- Sitting services
- Befriending schemes
- Pay for a family to take a carer away on holiday as an extra support
- Offer short taster sessions at leisure activities for free so families can see if they are suitable for their children to attend
- Extend existing services so they are more open and available e.g. school facilities in holiday periods and breakfast, after school clubs
- Accessible holiday venues such as Calvert Trust; Haggerston Castle, Berwick Caravan Park

**Have affordable holiday facilities targeted to families who have children with disabilities and special needs**

**Block book local caravan sites for families to all go together**

Parent Quotes

## Key issues

- Staff in short break provision need to be appropriately trained and have an understanding of a child's needs including appropriate specialist care for those with complex health needs
- Currently, many families use short breaks to enable them to have time to do practical things such as shopping, housework, looking after other children rather than having a break themselves. If there were more options and choice, they may also get a chance to relax themselves too
- Families should not be at a "crisis point" to be able to access a short break provision
- Families still need more information about what short breaks are available and how they access them

## Therapies

Table discussions centred on the question of what therapy means to people?

### **Good quality intervention at the right time**

Parent Quote

The main points that were raised were:

- Alongside the usual therapies on offer such as Speech and Language, Physiotherapy, Occupational Therapy, there should also be help and assistance with a range of other issues, including:
  - Behaviour/Anger Management
  - Emotional Wellbeing
  - Music/Art/Drama Therapy
  - Counselling
- Therapies should be available for both children and young people with disabilities and their parents/carers
- Parent/carers need to be more involved with the therapies their children are receiving and many would welcome training in the delivery of certain therapies

### **Could be linked to short breaks – i.e. support parents with therapies whilst at a weekend break so that parents can then provide their own therapy to their children**

Parent Quote

- The announcement that more funds have been made available to increase the number of therapists in County Durham is welcomed as current services are overstretched and there are often long waiting lists to access therapy services
- There is still a lack of information for families to know what therapy services are available and how they can access them; many families are not sure if they can referral themselves or if they have to access a service through an identified referral route

- Parents often struggle to access appropriate therapy services for their child where their needs are not as complex as others; many feel that children with mild needs should have equal access to therapy services as others
- There needs to be greater input when children are not in school for example during holiday periods and when they finish school as packages are often not in place during these times and there also needs to be more links made between school, parents and therapy services
- The issues around equipment are huge and parents feel there should be a further focus group established to look at the issue of specialist equipment and home loan services including wheelchairs and communication aids

## **Transition**

Frank Whitelock, Strategic Manager for Specialist Services

Frank gave the conference some background information on the issue of Transition in County Durham.

A multi-agency group has been meeting for years which includes Children's Services. The group have mostly talked about the transition from child to adult services but it is acknowledged that there are other periods of transition in a child's life which support needs should be addressed.

Protocols are currently being reviewed with regards to what parents and young people can expect from the transition process.

The Aiming High for Disabled Children (AHDC) National Transitions programme has provided some funds but not as much as in other areas. A self assessment audit has been undertaken in County Durham led by the Council for the Disabled Children. Once the results of this audit are known, Durham will be offered support and funds based on the outcome. The Government have identified five main areas to focus on in the areas of transition which are:

1. Participation
2. Personalised approaches
3. Joint assessments
4. Post 16 opportunities
5. Strategic approach to commissioning services

There now needs to be greater parental involvement through the development of the focus group to help to drive this work forward and ensure a smoother transitions process for disabled children and young people in County Durham.

In tables, parents and professionals were then asked to think about Transition and discuss what the term means to them.

It became apparent that there are many periods of transition in a child's life which may include the following:

- Pre-school to infants
- Infants to primary
- Primary to Secondary
- Child to adult services
- Special school to mainstream and vice versa
- Post 16/Post 19 opportunities

Key issues raised during discussions were as follows:

- The transition process from child to adult services is obviously a very difficult time for families but difficulties are often needlessly increased because of the lack of information, support and services available through this time and the lack of understanding around parents' worries and concerns

**Because of the changes there's a huge amount of anxiety caused by not knowing what's out there and available, there are no clear directives**

Parent Quote

- Parents want to be closely involved with all issues through any transition process
- Preparation and early intervention are key
- Transition needs to be tailored to an individual child's/young person's needs
- There needs to be more options for independence for disabled young people

**Let's turn the fear and panic of transition into a time of celebration**

Quote from the day

## Summary

### Acknowledgements

The continued enthusiasm of the parents on the steering group in pulling together the Making Changes Together conferences and the support from Elaine Chandler, Elaine Wilson and Jeanette Browell.

Marsha Dolan for chairing the conference alongside Janet Cummings, Lileen Cuthbertson and Lesley Moore for their contributions on the day.

Contact a Family for help and support.

All parents/carers and professionals for giving up their time to attend the conference.

### What Next?

From evaluation sheets completed by those in attendance (Appendix Three has a full list of comments) it is obvious that everyone continues to welcome the opportunities to come together at the Making Changes Together conferences to meet others, share information and hear updates on what is happening in the region.

Participants particularly welcome the fact that each conference is attended by both parents and professionals as it is clear that by working alongside each other as equal partners is helping to effect real change for families with disabled children in County Durham.

Parents are encouraged to continue to be involved through their attendance at the conferences and by signing up to join the focus groups which will continue to meet on a regular basis to drive forward the work planned in each area.

The next conference has therefore already been arranged to take place on 12<sup>th</sup> November 2009, venue to be confirmed.

**The conference was wonderful as we have moved on so much from the first conference. At the first conference, many people were angry; now we have a voice and people who are listening and understanding and help is starting to come**

Parent Quote

## Appendix One – Full List from Family Matters Discussions

### Positive Experiences

- St Oswald's Park in Newton Aycliffe has big supportive swings and roundabouts accessible for disabled children to use
- Woodham Park for wheelchair users
- Good Occupational Therapy input
- Bus pass for both child and carer
- My son with Autism thought a man with a black beard was a terrorist – highly funny. Could have been a negative but the parent turned it around
- Occupational Therapy for my son with Dyspraxia; he looks forward to these sessions and the family notices the difference they make
- The positive outcomes from discussions and dialogue opportunities between parents and professionals in County Durham
- Became a grandma for the first time.
- My daughter jumped so high she jumped out of her cot and has a big carpet burn on her face! Expectations of her development had been so low
- A parent's daughter starting to walk in the last couple of months when professionals said she would never walk
- A child starting to smile and crawl through conductive education
- Another child having a speech breakthrough and communicating now
- One parent's son became a reporter on the Diana Award Radio Channel. The Diana team will help him take his campaigns nationally during the summer as he is campaigning for all disabled people to be given a way to say the 400 words everyone else says the most AND to be taught to read and write AND for the rights of everyone with communication disabilities to meet an AAC role model who is a fluent AAC communicator
- My son is an MP on the Learning Disability Parliament giving him a platform where he can communicate as he is better at presentations than spontaneous communication. Being with the parliament is good as he meets the adults he will have more to do with when he leaves school this year and also learn a lot by guest speakers at the Parliament on all the issues affecting people with disabilities and learning disabilities.
- Princes Trust, Cavos and Artists make communication aids free, tutorials and animations
- Have booked a holiday and this is the second ever without my son who has severe learning difficulties, Autism and some physical difficulties. Grandmother said she would look after my son for a week for us and that is a first. I will be a grandmother in November
- First grandchild was born
- Millions of meetings
- Made new friends
- Increased Confidence
- Paediatric physiotherapy in North Durham
- Invest in therapy services
- Launch of Information Directory at County Hall

- Alan Shearer centre opening in Newcastle
- 4 nights of respite a month
- Parent's 10 year old son going to Haggerston Castle for 2<sup>nd</sup> night
- Eco Village was discussed at the last conference and things seem to be on track
- A lot more drive for professionals to get things done, how do we involve more parents? Parents now have a voice to talk to anyone on the professional side
- New dads at the conference
- A parent's employers/management has allowed them time off from work to attend the conference
- New directory of information - Small charities getting their information in there, a resource with everything in it is useful for parents and all the professionals involved, really needs tons more for distribution
- A parent's son with Down Syndrome is now talking which is a massive step forward
- There is now better, clearer information available for parents
- Support from local Carers Centres is brilliant
- Elaine Chandler and Joan Temple from Parent Partnership are brilliant
- Good experience at James Cook Hospital
- Durham Model listed as a key model on the Together for Disabled Children website
- Things have been great post 18, my social worker has been great

### **Negative Experiences**

- Bishop Auckland General Hospital closure. No doctors on A&E department, children's ward 7 after 5.00 p.m.
- My daughter has medical problems and if she becomes ill have to call 999 to give her an injection immediately.
- Bad experience at the eye testing centre at Asda in Bishop Auckland who use employment agencies for their staff. The person who tested eyes was so angry when my child cried and swore. We reported him and Asda won't let him work in their store again but it should never have happened.
- Waiting for a commode from June to January
- Changes in staffing
- No choices made available
- Finances
- Social Services – no Social Worker for a deaf child
- No information available through Social Care Direct
- More support needed through transition
- Social Workers should be generic
- Workers coming to see parents and not leaving a business card or contact details
- Parents get frustrated at not getting answers or clarity
- 16-18 service provision
- School issues

- Parents sometimes look for the negatives as they get so many knock backs
- My daughter had a review at school and the Social Worker promised to attend but didn't as she needed a specific Social Worker for the deaf so nothing was set up.
- Whatever you try to do you have barriers i.e. judgements made by the public when no obvious outer signs of disability
- One parent's daughter was taken to hospital when she couldn't breathe. They couldn't find a reason but the next morning a piece of pink chalk was found, soaked through.
- School wasn't trained to use my son's communication aid even though the SENDIST (Special Educational Needs Disability Tribunal) told them to be
- School cannot give my son literacy instruction; they say they don't have to now he is over 16 and there is no law to say they have to
- Head teacher union threatened the parent that she is an inaccurate, persistent, vexatious complainant
- No transition plan in place
- No liaising or communication
- Getting funding for my son to continue in education. I find it important for my son to continue his education
- Hospitals don't understand the needs of disabled people
- Daughter's school
- My medical problems
- Stress, stress and more stress
- Appointments for my son's operation – having to ring for all the appointments
- Cannot get booked for a break at Kielder at Easter
- During the last few weeks, the personal papers of a girl was taken out of a post box and found in a field. The school has now changed the ways of posting mail. There are still papers missing
- Frustrated by red tape trying to get things done
- Access to hydrotherapy pool after school has gone
- One parent's daughter has just had a massive operation at the Freeman Hospital. She was told that she needed intensive therapy following the operation as she cannot walk but she has been given nothing officially; unofficially one of the wonderful local physiotherapists is managing to give her half hour hydrotherapy in South Durham.
- Awareness still not reaching front line staff
- Confusion about who, what, how, when and where – panels! Who is advising? Who is the Lead Professional in all of this?
- Muddles pathways to access services
- Clarity still required for staff to understand criteria

## **Appendix Two – Full list of comments from afternoon sessions**

### **Short Breaks – What should Short Breaks look like?**

- Support in the home around weekend and holidays with the child. Could be student support worker
- Support to assist on holidays/breaks with Single Parent Families
- Butterwick Hospice for 2 weeks per year, arranged easily through a Specialist Health Visitor
- Initial reluctance to leave child with someone else
- School holidays are difficult
- Siblings should also be included, there is often provision for the disabled child but not for other children
- Age restrictions in younger years
- Parents need time to spend with each other as there are many strains on relationships
- Assumption that care for younger children should come from extended family – often relatives are reluctant/afraid to take a child overnight in case something happens
- Can't access services until you are in crisis point when a short break could avoid a family reaching this point
- Don't know what's available so struggle on alone. Don't know what I am entitled to or who pays for it.
- Issues accessing services via a Common Assessment Framework; will it be effective? How much time will it take?
- Parents spending short break time doing practical things
- Is a short break for the parents or for a child's development?
- Options need for accommodation including adapted static caravans, smaller touring caravans, wooden lodges placed in sites, eco village, build up existing sites
- Fun and fitness weekends; sea cadets, ocean trust (sailing for disabled children)
- Cookery, healthy eating
- Pioneering Centre
- Art and music
- Sports – make them more accessible e.g. yoga, tai chi
- Sportability at Spennymoor Leisure Centre
- Bikeability
- Centreparks in the Lakes or Nottingham; Hamsterley; Kielder Forest; Berwick Holiday Centre – give parents access to a carer who could go on holiday with a family as support
- Offer more play schemes during holidays and provide transport to help families get their children to the play schemes
- Offer group holidays where families can go away with each other
- More caravans made available for children with disabilities
- Disneyland in Paris
- Haven Holiday Parks and Butlins

- Interactive activities/education e.g. horse riding, farms, water parks
- Offer families specialised sessions in sensory rooms and hydrotherapy pools
- Families to choose a well trusted person to either take children out for a few hours or accompany them on holiday
- Parents should be given money to use as they need, should be more flexible
- Tailored to individual families needs
- Change already existing places so that everyone can access them
- Short breaks offered around a family, not around a service
- Across school holiday times there needs to be places for children with disabilities to go to mix with ALL children where the staff are trained and able to support (such as the Calvert Trust but for birth to 19)
- Major staff training and equipment issues. Need to know what is available now and in the very near future (Summer 09)
- Families need to know what the criteria is for accessing short breaks
- Short breaks need to be age appropriate for example where can a teenage girl with Cerebral Palsy go to meet other teenagers and access teenage activities
- There needs to be better access to facilities so that we can all go out as a family e.g. changing facilities
- Offer a carers card for leisure facilities
- Have affordable holiday facilities targeted to families who have children with disabilities and special needs
- Block book local caravan sites for families to all go together
- Offer babysitting services including over night support to enable couples to have time together where a support worker could take a child out too
- Out of school and breakfast clubs in holiday times
- Weekend respite for child and family
- Someone to take child out to events, guides, leisure activities
- Respite/overnight care for child linked to school placement
- Tailored to child's and family's needs
- Provide access to short break services in alternative ways e.g. through charities, with or without social worker involvement
- Awareness of workers to make short break services more accessible
- "Child" sitting
- Befriending services
- Specialist care to meet health needs in hospices or units in home care
- Money for equipment for carer's homes
- Offer taxi fares to activities
- Everything is currently means tested and you have to use your own money to pay for things which could be a struggle for some families
- Funding for school trips/family activities
- Specific groups for children's disabilities
- Staff to be more aware and receive adequate training
- Hold a pamper day for parents – something to de-stress
- Hold a Family Day – where children can do activities whilst parents can relax

- Hold activity breaks for example PGL (company that specialise in this)
- Put funding into mainstream services so they understand disabilities ensuring all children can access these

## **Therapies – What does Therapy Mean to You?**

- There are not enough therapists; individuals are fabulous but they are all so overstretched.
- Parents don't have contact or access to services (although there is some information in the network directory)
- Current and forthcoming changes in place but these have not yet been filtered out to parents.
- Children with complex needs seem to be automatically able to access all therapies but other children seem to struggle to get a referral
- Need more equal access to therapies based on severity of need – some children get a lot; others get very little and it doesn't seem to make sense.
- Conductive Education makes a big difference compared to physiotherapy (20 minutes physio at school compared to 8 hours of Conductive Education at Step Together)
- Therapy in nursery settings has cross-border/county issues. The Early Language group is good
- Speech and Language Therapy (SALT) is very varied from excellent to terrible. Breaking promises, parents having to do things themselves e.g. find Makaton lessons. Even when it is excellent, accessing services is a battle
- Child is very bright and surpassing SALT so is ahead of peers and bored in groups
- Location needs to be more community based
- There are gaps in the therapies available in special schools; they are not providing the full range. Need equity of provision.
- Professionals, e.g. at schools, need to be aware of children's needs and trained appropriately
- Training of parents – family and relatives have to pay to learn British Sign Language for example
- Anger and frustration management for children with Autistic Spectrum Disorder and other disorders.
- Music therapy
- Relaxation therapy and techniques – inc aromatherapy, emotional well being as well as the physical and communication therapies
- Management/working with teenagers with disabilities i.e. hormones of a 16 year old but capabilities of a 6 year old
- Carers Support
- Language & communication therapies
- Better links between schools, communities and home – need continuity, avoidance of duplication
- Priority is more support in schools (including so parents don't get called in several times a week)

- Need fun therapies to engage with children and enhance their progress doing something they enjoy
- Counselling
- Should be therapy provision available after children leave school as there are packages available whilst they are in school but then what? Including during holiday periods
- Parents need to be included and involved and trained in understanding the whole process
- Could be linked to short breaks – i.e. support parents with therapies whilst at a weekend break so that parents can then provide their own therapy to their children
- Are sufficient staff available to provide therapies in schools?
- When therapies start, it is often unclear where the service is coming from
- Sessions are often agreed without the parent's input
- Services are very different across the county and too stretched
- Not enough equipment to support therapies is available
- Rolls Royce equipment has to be additionally funded by parents
- Assessments do not lead to therapy and equipment and there is often too much time between an assessment and then waiting for equipment to arrive
- It would be good if all the different types of therapy are in one central place
- Need more clinics at schools, would be less disruptive to have them in a familiar environment
- Timescales for things; sometimes you have to wait a long time for equipment and parents need to be better informed about what is happening
- Good quality intervention at the right time
- Accessible therapy to maximise input
- On-going, consistent input and flexible to meet the needs of the family and child
- Should be joint working between therapy services and the school and parent including training
- Increase the universal level of therapy services
- Provide permanent funding for posts
- Offer therapies such as Reiki for parents at carers centres
- Add a separate focus group around specialist equipment/home loan services including wheelchairs and communication aids.

## **Transition – What is Transition?**

- Parents of children with disabilities are very concerned about ALL periods of transition; from nursery, school, infants, juniors, secondary and post 16. Whatever the age of the child it is the most important transition period for THEM.
- It is most effective when families are dealing with a pro-active setting with good professionals
- Parents go year to year worrying if this will be the years when they have to leave mainstream and move into a special school.

- At ages 16 to 18 there is a black hole of services
- Structure – because of the changes there's a huge amount of anxiety caused by not knowing what's out there and available, there are no clear directives
- Health assessments – go back to GPs
- Transition planning should start earlier although it's talked about it doesn't happen in practice
- Need a Social Worker available earlier
- Post 16 but other transitions are also significant and shouldn't be ignored. Preparation is important. Work experience for all and job opportunities
- Need information on what is available and where
- Work on structures already there
- Hold a "moving on" celebration
- Offer more support to families
- For some children. transition can even mean changing a class or a teacher
- Need to provide disabled young people with a quality independence where possible
- Parents need information and understanding of their fears and needs
- A time of anxiety, stress, upset and change
- Need early intervention
- Increase in workers and more skilled workers need to be available to support families
- Independence factors need to be considered
- Services need to be more co-ordinated/ more multi-agency working is required
- Always keep the parent involved in what preparation is being done for the child
- Transition needs to be specific to the child's needs and disabilities

## **Other points raised:**

### **General**

- Common Assessment Framework
- Need a Nutritionist and assistance with providing a Gluten Free Diet
- Behaviour Management training for parent/carers is needed
- Should have an equipment user group for service users to work together on issues such as wheelchair and home loans. Should include parents and representatives from HELS (Home Equipment Loans Service)

### **Transport**

- Taxi – quality and feedback, worries with the change in drivers and escorts without any warning provided
- Are badges given to drivers and escorts? They are not always badged up
- Is the escort first aid trained?
- Do they (escort and driver) go on awareness training so they can deal with a potential situation if it arises

## Appendix Three – Full List of Evaluation Comments

A total of 42 evaluation forms were completed by parent/carers and professionals attending the Making Changes Together III Conference.

---

The majority of people were happy with the venue but 7 said they were not happy. Their comments were:

- Too many stairs to climb
- Should have been on the ground floor as I had to hump my daughter upstairs in her pushchair
- Ground floor would have been better – pushchairs were carried up the stairs; if I had brought my 3 year old disabled child I would have had to stay downstairs at lunch
- Difficult to find
- Room too dark, air conditioning was noisy
- No lift, the crèche downstairs made it difficult to access with buggies. No PA, poor acoustics, noisy room, couldn't hear people. No toilets on the same floor so a lot of up and down<sup>1</sup>
- Too out of the way with stairs to climb

Other comments made were:

- The food could have been better; tea and coffee were not replenished quickly enough
- It was often very difficult to hear
- Noisy

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

- Opportunities to discuss things with parents
- Parent contribution
- Table based discussions and having a real input into processes
- Hearing a few positive stories and sharing good information
- Hearing from so many parents and professionals; spending time celebrating change and developing new actions
- Everything
- Gaining contacts
- Sharing information
- Food
- The game show was an excellent idea; well done to all who took part
- All; general networking, the food and the enthusiasm of everyone

---

<sup>1</sup> The steering group are aware that the Conference Crèche did not completely suit all the needs of the parents/children at the conference. As it was the first crèche that the steering group organised we had not fully thought out how it would work. We have taken your evaluations and feedback on board and will be arranging future crèches to meet those needs. Thank You. The County Durham Parents' Forum Steering Group

- The whole thing was fantastic; good speakers and very informative
- All
- Enjoyed the whole day; great
- Being with parents and professionals
- The table/group discussions about different subjects; good to communicate with other people who have the same problems and issues etc. Also the food was great
- I work with adult and community services; it is very interesting to hear what is happening in children's services and of the successes they are achieving. Excellent parent representatives; good work
- Was informative and well structured
- Discussions with all different parties i.e. parents and professionals
- All of it; first time I have been to one
- "Come on down, the service is right" an interesting way of providing feedback
- Enjoyed it, it was interesting
- Talking about focus groups and what other people want out of these groups. This is an important part for me because I would like to be more involved with the focus groups in the future
- Updates and discussion
- The come on down quiz was a good way to give feedback
- Being able to network with other professionals and parents
- The afternoon; discussions around short breaks and therapies
- The come on down quiz; an enjoyable way of delivering information
- Finding out information on what's available and who to Contact
- Wealth of information given by all
- Listening and being with other carers and professionals because I think it needs a joint effort to help our children
- Meeting parents and professionals together on an equal footing and being able to share our views and ideas about moving services forward
- Listening to parents' this is the only way we can check out if we are meeting family needs
- Learning about other people's problems
- Enjoyed all of it
- Meeting many other people; participation in groups was useful and an excellent lunch!
- Networking and meeting lots of useful contacts and learning what is happening in County Durham
- Everything; lots of information
- All of the event was informative and enlightening
- It was all very interesting and relaxing; meeting people with the same problems

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

- Not being able to sit with the person I came with and being told that people/partners don't always have a voice. This is not true; we both speak. All you are doing is moving some people who then feel ill at ease
- Noise from the bar and not being able to hear all the speakers
- Transition; very boring and not very interesting. I did not understand it
- Parents needing to collect children to have lunch with them. I feel parents would have liked to network and have at least one meal uninterrupted
- Air conditioning as the room was too warm
- Short of time to discuss all the issues
- The come on down, the service is right quiz was flippant
- Pushed for time
- Waiting in the morning
- Time ran out, we needed more time
- The start was delayed<sup>2</sup>
- Nothing; it was a very well planned day. It was good to hear about the work within adult services and the good work they are doing
- The service is right game seemed a bit pointless and not very useful
- Unable to hear speaker
- Air conditioning
- Eating too much
- Being separated from my wife as we work better together
- Not enough time
- Not being able to hear everything said
- Starting late but the day still went well
- Venue; room layout as I couldn't hear
- Lunch was poor quality and certainly not up to the standards of previous venues
- Hearing personal situations i.e. no physio, no OT, no SALT services. Where are the changes if these services are not in place to be accessed?

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

- Role models of children and adults using specialist equipment i.e. VOCA aids and powered wheelchairs. This is the third meeting and still no actual role models
- More time
- As always, hard to get everything in and talked about
- More time to chat to other parents
- More interaction
- Workshops
- Where to find information on support groups for parents who have children with additional needs

---

<sup>2</sup> There had been a road traffic accident on the A1 on the morning of the conference which meant many people were delayed in getting to the venue. The start of the conference was delayed as a result

- More break to chat to other professionals and parents as lunchtime I had to deal with my daughter
- Longer time!
- Support service directory to help parents and carers
- Directory being available to take away
- Presentation on behaviour management or some other issue which affects families

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

- Very good, good seating met a deaf friend
- Excellent
- Very informative, timed well a useful exercise and time well spent
- Excellent; very useful information sharing and hearing parent's views
- Thought the day was very informative and inspiring. It's good to know that parents are finally being listened to and that we can make a difference
- I thought it was quite an interesting day and relaxing. It is the first conference I have been to
- Great day; informative as ever. Great parents and professionals are working together and making changes together
- I thought it was very good to hear something is being done to help our children and that working together with professionals is needed very much
- Brilliant day; meeting all sorts of people; parents, professionals all fighting for the good of our children and getting the services we need and want
- Very good overall
- First conference I have attended and would like to attend further
- An event that made everyone feel valued and included, lots of discussion and not being "talked at." In my new role I will have a greater understanding of the difficulties parents endure. Extremely well organised – thank you
- Overall was enjoyable and informative
- Very useful and pleased to see progress; all children with a disability receiving attention and focus for their future with improvement in the transition process
- Liked the game format; very enjoyable
- Very enlightening, more information on help groups and support groups
- Good
- Wonderful as we have moved on so much from the first conference. At the first conference, many people were angry now we have a voice and people who are listening and understanding and help is starting to come
- Really exciting to be able to be present
- The day was well structured; the pace was just right and the themes were very timely to help the Primary Care Trust plan. A great session
- Very good day for information and to take back to the family
- Enjoyable
- It was really important that links are made with adult services. This enables a smooth transition into adult services (hopefully) but it also helps

adult services plan for the children when they reach their teens so that services are available and accessible for all

- Enjoyable and beneficial
- Thank you
- Very informative, uplifting and inspirational
- Excellent
- A well organised/run conference; well done to all concerned
- It's starting to really come together!
- Nice to see so many familiar faces but need more parents
- I thought it was a brilliant day. Well done to all who organised it. The steering group is fab! That Theresa one is lush!!!
- Enjoyed it immensely
- Brilliant again. Well balanced; loved the morning very good use of time
- Hard to hear people; bit rushed and not long enough. Parent question/answers. The professionals in the room should answer more of our queries. A lot of people want the new "find it guide" more need to be printed and distributed to hospitals, professionals etc.
- Very good. Useful to ground developments with real comments from parents
- Comprehensive, excellent to get together to discuss the way forward
- Well done; these events are getting even better