



# Making Changes Together II

## Conference Report including Charter Signing



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

Wednesday 1<sup>st</sup> October 2008  
Beamish Hall Hotel, County Durham

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## Introduction

Janet Cummings and Lesley Moore, Co-Chairs for the day

Janet and Lesley, both parents of children with disabilities, opened the conference by welcoming everyone to Beamish Hall Hotel.

The idea for holding conferences designed **by** parents **for** parents had initially originated at the first local Every Disabled Child Matters (EDCM) Conference held in Durham in October 2007. EDCM is a nationwide campaign to get 'rights and justice' for every disabled child. The campaign includes a strong message around getting parents involved right from the start with planning, changing, monitoring and evaluating services across the board in Health, Social Care and Education.

Following the formation of a parents steering group, and with the assistance of Contact a Family and the Parent Partnership service, a first Making Changes Together conference was held at Seaham Hall in May 2008. Janet and Lesley are both members of this steering group.

This initial conference included a national perspective from Helen Wheatley who is the Policy Advisor for the Council for Disabled Children. On this day, parent/carers were asked to identify what they wanted to see happen in County Durham and what changes would need to be made to make this work. Parent/carers were also asked to sign up to one of the following four focus groups:

- Lead Professional
- Transport
- Early Years
- Information

Each group has now met on a number of occasions and have used the conference findings as a basis for their way of working. They are all made up of parents who attended the conference and professionals who sit on the Implementation Group, which is made up of senior management who create the services that are used by families who have disabled children.

It has become very clear that these focus groups will be ongoing and will develop within themselves as this way of working - **parents and professionals together** - develops.

Aims of the Making Changes Together II conference include:

- Raise awareness of the work that is taking place
- Invite more parent/carers to become involved
- Increase the range of focus groups. New groups are being established on therapies and short breaks and parent/carers are also being asked to suggest ideas for a third new group too.

# Focus Group Updates

## Lead Professional

Annette Doherty, Clare Iddon and Glynis Barron

The Lead Professional focus group has made impressive progress since the last conference in May with its key objective to deliver an effective lead professional to every child, young person and family with complex needs in County Durham.

Parent's views and expectations around what a lead professional should be and should do were compiled by Lesley Moore and included the views of numerous families that she contacted. Thanks to all those families who participated. These were placed alongside the excellent work of Investing in Children who provided the focus group with the views of children and young people which matched perfectly with the expectations that parents have.

The focus group has worked to develop what a Lead Professional's role is and the expectations and responsibilities that it places on professionals to provide a coordinated team around the child and family. To progress the development, it was agreed that a discovery route would take place to improve learning and see how the Lead Professional would transfer from paper to reality.

Five families were identified and were asked to choose who they would like to be their Lead Professional. The eclectic mix that the parents chose demonstrates some of the challenges that are faced to implement the Lead Professional role in County Durham. The mix included health professionals, carers and professionals from children and young people's services.

It was decided by the group that to empower all potential Lead Professionals a delivery champion should be identified, which would also help when staff are away on leave or are absent. This person is the Lead Professional's manager who can offer support and guidance through the discovery route and feedback with the learning outcomes.

It was agreed that as every child, young person and family are different, so would the role and involvement of each lead professional and that the process should be organic.

The Lead Professional follows these key areas of effective service delivery:

- The voice of children, young people and families must be actively sought and heard
- Services must be child centred and needs led
- Services must be coherent and accessible
- Service provision must be fully informed about choices they are able to make regarding their care

- Services must be equally offered and available regardless of gender, age or ethnicity
- Services must be monitored and evaluated



It was agreed that the discovery route would focus on parent and young people's expectations and what they would mean for the lead professional.

- The family will have a name and number of someone they can contact about their child and this person contacts the family regularly to see how they are. Regularly may be weekly, fortnightly to six monthly depending on what the family need
- The Lead Professional will know the family and their history and will have an understanding of the child's disability/diagnosis and has a responsibility within their role to provide the child, young person and family with relevant information when it is required
- The Lead Professional be available to provide support for the child, young person and family upon diagnosis or when required. They will put the family in contact with support groups and give information relevant to the child's disability/diagnosis (including lists of relevant contacts such as Contact a Family)
- Responsibilities of the Lead Professional will include being able to signpost the child, young person and family to relevant benefit information and support them in obtaining benefits. This may require additional time for training and research
- The Lead Professional will be in contact with the "Team around the child" and is responsible for the relevant sharing of information with the family's permission. The "Team around the Child" will recognise and value the role of the Lead Professional and will support them in their role
- The role of the Lead Professional is not dependent on professional background and thus the lead professional will be afforded the assistance that such a role requires. This may include training and the opportunity to attend meetings and offer support when required by the child, young person and family

- The Lead Professional may change according to the development of a family and at key transitions with the family's agreement. Any change will be planned and organised to provide a continuity of the plan for that child, young person and family. Within this context the role of the Lead Professional will be respected and valued by all parties involved with the child, family and young person
- The "Team around the family's Child" will give the family as much information as they want and/or need and share good practice, information and research developments with the family to empower them to enable informed decisions to be made about the family

The pilot will be reviewed in October where further families will be included. Numbers are limited and restricted at first to specific groups to assist the discovery route.

## **Early Years**

Michelle Cook, Shirley Wilson and Caroline Richardson

The Early Years Focus Group has met on three occasions and its membership consists of parents and professionals.

The group is tasked with looking at Early Years provision across the county and to look at ways that service provision can be improved for children, young people and families with complex needs.

As a result, the group has developed a mission statement and this will be worked upon to make things better:

### **Services should be inclusive to *all* families and meet individual needs**

High quality services should be fully integrated and delivered according to need and not to age and service approach should be informed by service users through a consultation and evaluation process.

With parents, professionals and young people, the group will work together to get a shared understanding of what this means for all Early Years provision. County Durham has a fantastic amount of resources, enthusiasm and trained staff who will all work together to make provisions inclusive to every family.

So far, the group has looked at Children's Centres in County Durham to see what there is available for families. The next steps are to work together to *use* what there is to benefit every family.

The group wants Early Years to be the focal point of service delivery and information for parents. The group have discussed parents' experiences with Early Years provision in County Durham and Sure Start County Durham are working with Together 4 Children to tackle the accessibility of Early Years and the information about services available for families of children with additional needs.

The group have made links with Contact a Family and are looking to:

- Improve training for staff
- Empower parents
- Raise the profile of Early Years provision
- Offer support to parents groups

The group want more parents to assist them – they need parents help to shape where they are going and work on how to work together as a team. To further this aim, within conference packs, parents were asked to complete a form to take part in discussion groups with Sure Start County Durham's Cluster Managers.

This is a unique opportunity for everyone in partnership to make things better; to make services inclusive and to let families be involved and at the centre of future developments.

Early Years are the first experiences that parents get out of services that are provided so there is a real need to make sure they are integrated and informative.

The group realise that these changes will take time but with the commitment to change and the momentum to make things better, they are confident that they will deliver a real change to Early Years provision in County Durham.

## Information

Chris Shield and Elaine Chandler

The information focus group has met twice since the parent's conference in May and its membership consists of parents and professionals. The group are tasked with reviewing the current way information is presented and looking at new, creative and innovative ways to get information to parents, young people and professionals.

The group have discussed the current information available across all areas for children and young people with complex needs and found that in some cases the information is difficult to access and not as friendly as it could be. These sentiments were echoed by the work compiled by Investing in Children who have provided each focus group with information from a child and young person's perspective.



The group thought that using new technology would be a good idea to get bullet points to parents and young people and have arranged through Elaine Wilson to use a mass texting service. (Elaine Wilson is the Children's Network and Information Officer for County Durham). This will allow snippets of information or routes to larger pieces of information to be sent to individual's telephones.

Within the conference pack, an Information questionnaire was distributed to attendees to help the group to decide on how often messages should be sent and what information they should contain.

Elsewhere the new look Children's Network information has been created and the new FIND IT EXTRA will be scrutinised by the group. The new FIND IT EXTRA is the new and improved directory for children, young people and families with complex needs and has information from children's centres opening times to facilities at Alton Towers. The group have decided to leave some blank pages at the back of the book so if children, young people and parents find a worthy addition they can send it into the communications team and it will feature in the next edition.

The group have also looked at the current internet pages and where they are accessible they are perhaps not very easy to access and need updating. With this in mind the group are looking at the possibility of using existing talent to design a website which could either be stand alone or linked to the existing "Every Child Matters" pages. The group are considering approaching the excellent technology schools in County Durham to utilise that talent and have their input into to site.

The group are clear that any site would need to have three portals, one written by parents for parents, one for professionals written by professionals and one for children and young people by children and young people. Investing in Children has agreed to assist the group when the pages are ready to be produced.

One of the ideas is to have a blog space with a fictional family passing information. This will be interactive and children, young people and families will be able to contribute so that information and support groups can be published.

However, the group are acutely aware that not everyone has the time or access to the internet and that we should not assume anything!

With this in mind the group want to use the 43 children's centres as points of information and have information available for children, young people and families to access when they need it.

To help reach all areas of the community it was agreed to hold road shows in each of the Local Children's Board areas, Easington, Durham and Chester Le Street, Sedgefield, Derwentside and Durham Dales where information sessions would be held at community venues and professionals would be on hand to answer questions. The role-out of the Lead Professional may be the first event of this kind in the New Year.

Parents have also told the group that in some cases the best source of information is local support groups and so the focus group will raise the profile and available information around these support groups to both families and professionals.

The Information Focus Group is committed to listening to parents, children and young people and improving the quality and variety of the information that is provided.

The group feel that many of the opportunities that are available for children, young people and families with complex needs are just not promoted enough and the group's role is to sell the information and promote what is being developed.

## **Transport**

Julie Killeen and Allen Hazlett

The transport focus group comprises of parents and professionals and has had the benefit of information from Investing in Children; the group have now met three times.

Transport is a key issue that has a daily impact on Children, Young People and Families with Complex needs in County Durham. County Durham, due to its sheer size and structure, is a huge challenge to provide transport for. A vast amount of money is spent each on transport and yet this is still one the major issues parents and young people highlighted as a concern.

The group have focussed on the key issues that parents and young people have raised around transport issues for Children, Young People and Families with Complex Needs in County Durham.

Some of the issues raised were around information and criteria. The decisions made for young people. Why was there a need for a medical opinion when discussing transport? This turned out to be a preventative measure against fraudulent claims.

Some of the questions the group had were, "What are the pathways for agreeing transport?" Why are working transport arrangements and contracts changed? Could parents be consulted around this?

The group have also discussed the information that drivers are provided with and whether relevant information always gets to those providing transport? One key query was around an independent appeals process.

Maureen Clare, Head of the Access and Inclusion Service provided a detailed report of all the information available around transport for the groups to consider. Maureen then agreed to attend the following meeting to discuss with the group the points raised from the information provided and other issues.

The meeting was very informative and clear priorities were recognised including the need for communication to explain why processes are in place. It was agreed to work in partnership to take forward some of the issues raised.

This is very much a shared agenda between, parents, young people, providers, the Local Authority and other agencies. We need to have a system that lets parents share good and bad experiences so that when we discuss renewing contracts, which legally has to happen every three years, we can look at who is providing the best service with actual evidence provided by service users.

This partnership will actively seek to promote the health and happiness of Children, Young People and Families. This partnership will recognise that the needs of learners with Learning Difficulties and/or disabilities are significantly different from the needs of their non-disabled peers.

We, as a group, feel that dialogue and involvement with those people charged with making the difficult decisions around transport is the way to progress and improve outcomes so that we can understand each others roles and position.

One of our priorities is to make information accessible, interactive and hold regular events to inform parents and professionals alike about transport.

We will continue to work in partnership with parents very much at the heart of the process to celebrate good practice and to improve areas where genuine concerns are raised.

The transport group has come a very long way in a short period of time. They are determined to continue to move forward in partnership to improve outcomes for families and ensure that existing arrangements are reviewed and new options explored.

A snapshot transport survey was included within Conference Packs to gather parent views.

#### Evaluation Quotes

What was the best thing about the conference?

**“Getting feedback from parents on the Focus Groups. We trust them and stuff is getting done”**

**“So much to single one thing out but they include emboldened parents; professionals listening and seeing signs of progress”**

## **Question and Answer Session**

There followed a short question and answer session where a number of issues were raised from the floor.

Q – Where are the communication needs of children included within these focus groups, especially for those who use communication aids?

A – The Information Focus Group will be the one to address such issues and Investing in Children are involved with each group to ensure that young people and children's views are included.

Q – At the point of diagnosis, some sort of counselling service would be helpful?

A – The Lead Professional Group will make a note of this within the work they are undertaking

Q – During the Lead Professional Group feedback, the term “where possible” is used and parents may feel that this is too vague and will mean services etc are not provided as a result

A – There has been a commitment from service managers to prioritise a Lead Professional services, it will be highly valued and made a priority but the wording is difficult as there will be times when a professional may not be available at given time

Q – There has been much talk of services joining up together but just what are these services that have been mentioned?

A – Lynne Gregory's presentation later in the morning will address these issues

Q – As parents, we have been promised therapy services and they have never happened?

A – A new focus group has been established to look at Therapies and address issues such as these

Q – What do we do when schools do not act on what is in a child's statement

A – Elaine Chandler's Parent Partnership Service should be contacted for advice and support around these issues (telephone number is 0191 5873541

## Charter Signing Session

A major part of the Every Disabled Child Matters (EDCM) Campaign is to get Local Authorities and Primary Care Trusts to sign up to the EDCM charters (full copies on pages 14 and 15) and at the first Making Changes Together Conference, participants were advised that Durham would be doing this.

Durham Local Authority and the Primary Care Trust have devised a joint action plan to ensure they can meet all requirements of the charters.

To demonstrate their commitment to delivering better services to disabled children; the charters were signed on the day.

The following people were joined by three parents from the audience to sign the charters:

- Claire Vasey, Councillor & Cabinet Head for Children and Young People
- Gail Hopper, Head of Safeguarding and Specialist Services & Chair, Disability Joint Commissioning Group
- Cameron Ward, PCT Director of Systems and Administration



It is recognised that the measures outlined within the charter are not currently being met, but this signing is a significant moment as it demonstrates that County Durham are committed to:

- Being held to account
- Being able to deliver
- Making progress in partnership with parents

**“Excellent to have the charter signed”“**

**The day was very uplifting and positive. Hope for the future and for change”**

Quotes from Participant

## Local Authority Charter

### We will ensure that in our authority...

- We know how many disabled children live in our area and that all agencies in our area are planning services on the basis of this knowledge.
- There is a key worker service in our authority providing support to families who are accessing more than one specialist service.
- Our parent partnership service is sufficiently resourced to provide advice, information and support to parents of disabled children and young people who have been excluded from school.
- Parents and carers in our area are getting accurate and timely information and advice on the full range of services available to them and their families.
- All staff have received both disability equality training and training to ensure that they have core competencies to work with disabled children; relevant staff have received specialist training and other staff know how to contact them for information.
- Disabled children are involved in drawing up our Disability Equality Scheme and also in monitoring its effectiveness in eliminating discrimination.
- Our Children and Young People's 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.
- Our Local Area Agreement includes targets for the level of service to be delivered to families with a disabled child.
- Disabled children and families are involved in the planning, commissioning and monitoring of services in our area, including both specialist and universal services.

## Primary Care Trust Charter

### We will ensure that in our PCT...

- We know how many disabled children live in our area and that we are planning future services on the basis of this knowledge.
- We have an identified children's lead with specific responsibility for services for disabled children and families.
- We can demonstrate that we work closely with our local authority partners and have had an input into all the Children and Young People's Plans in our area and are members of all relevant Strategic Partnership Boards.
- All staff have received disability equality training and training to ensure that they have core competencies to work with disabled children; relevant staff have received specialist training and other staff know how to contact them
- Parents, young people and carers in our area are getting accurate and timely information and advice on the services available to them.
- Disabled children are involved in drawing up our Disability Equality Scheme and monitoring its effectiveness in eliminating discrimination, including involvement in the planning, commissioning and monitoring of health services in our area.
- We are working to reform our community equipment and wheelchair service to improve the quality of the equipment available, and to address the holistic and changing needs of children and young people in a timely way
- 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 wider children's services.
- 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.

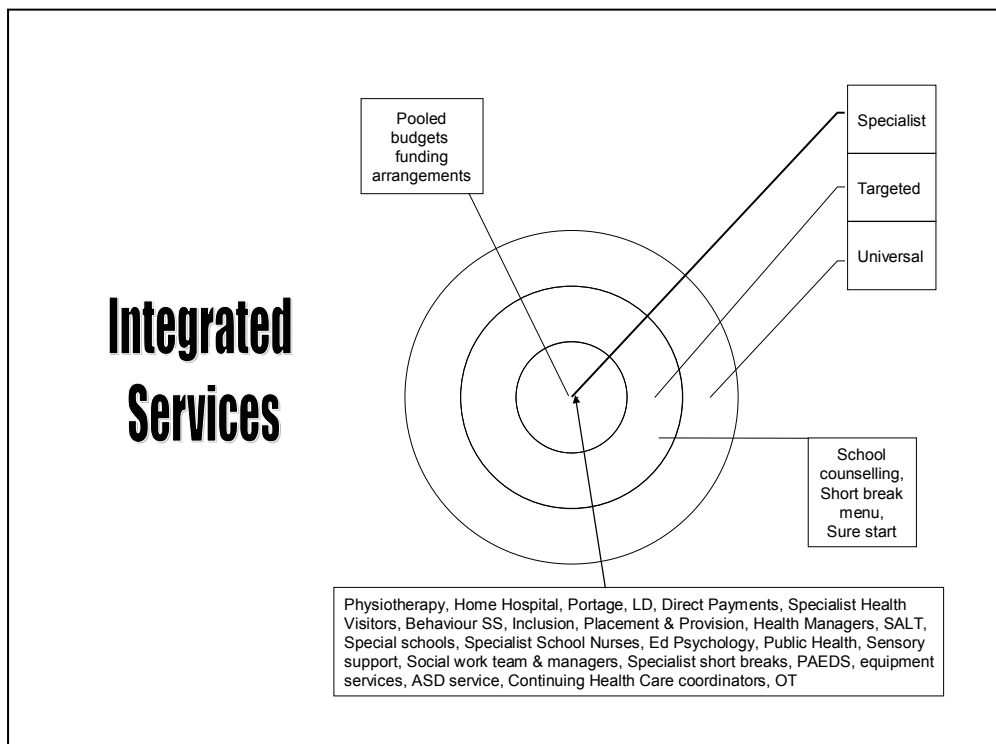
## Work Stream Updates

### Integrated Services

Lynne Gregory, Special Educational Needs Strategic Lead

This work stream has been looking at cross agency working on a strategic level to move integrated services forward. The work recognises that the important issue for families is that they receive the right services; it does not matter *where* they receive these services from. There have been major developments already in that professionals from Education, from Social Care and from Health are already talking to each other and working together in a way that has not been done before.

The diagram demonstrates how integrated services work and where each of the three outlined services (Universal, Targeted and Specialist) is situated.



The real test for Integrated Services is that they must lead to real improvements for families as there is no need to make unnecessary changes for the sake of it.

Although there is currently no parent's focus group attached to the integrated work stream, County Durham do need parents to identify where things are working well, where they are not working so well and where the gaps are.

Within the Focus Group sign up sheets in the conference packs, parents were asked to identify if they would be interested in feeding into these processes.

## Therapy

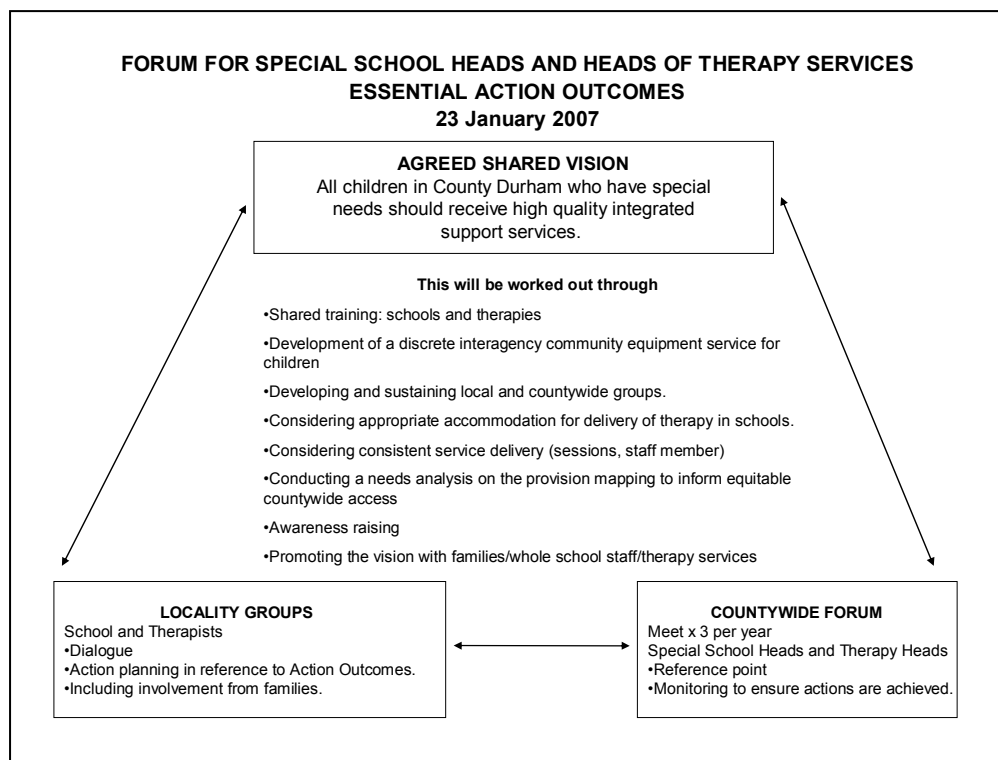
Sue Hood, Children & Young People's Health Lead/Professional Lead for Children's Therapy Services

Anne Morrell, Senior Manager Learning Support Service

To help to set the work stream update in context, Sue presented background information about an evaluation of therapy services in County Durham that was undertaken in October 2005 by Dr Aiden O'Hora. Results of this evaluation included:

- Therapy Services are not consistent and are not equitable
- Therapy Services cannot demonstrate effective or efficient practice
- Children, young people, their families and representatives are not proactively engaged in the design and delivery of services they access
- Services are struggling to take account of recent Health, Education and Social Care initiatives

A forum had been held in January 2007 which outlined the following outcomes:



### **Improvements seen so far have included:**

- Special Schools Forum
- A dedicated Children's Home Equipment Loan Service (HELS)
- Increased Funding:
  - Physiotherapy
  - Occupational Therapy
  - Speech and Language Therapy
  - Multi Therapy Assistant Practitioners

### **Next Steps include:**

- Measure progress
- Plot current levels of therapy available
- Look at evidence base
- Collect opinions and patient stories
- Draw up next steps improvement plan
- Redesign where needed
- Produce future investment plan

### **The therapy work stream would like parents help to:**

- Help us to establish parent focus groups
- Tell us your own stories
- Let us know how you think we can improve services to your children

### **Short Breaks**

Frank Whitelock, Strategic Manager for Specialist Services

Following pressure from the EDCM campaign, in 2007 the government announced a major funding package for families with disabled children entitled Aiming High for Disabled Children (AHDC)<sup>1</sup>. Included within this package is specific funding to develop short break care.

In County Durham a needs assessment has been completed and SERCO, the organisation responsible for this element of AHDC, have given some very good feedback following this. The draft specification will be distributed to parents and young people for consultation.

Running parallel to this, expressions of interest from prospective service providers are being received.

This increased funding should enable more families to receive flexible short break care which meets their needs.

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<sup>1</sup> For full information of AHDC please see the EDCM website at [www.edcm.org.uk](http://www.edcm.org.uk)

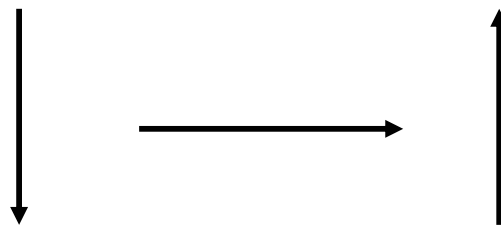
## What's it got to do with me?

Srabani Sen, Chief Executive Contact a Family

### Aiming High for Disabled Children (AHDC)...We all have a role in making it work

County Durham is further forward than many other Local Authorities. This is not to say that things are fine, but there is a commitment to change. It is vital that *everyone* involved works together to ensure the changes that are proposed materialise and work effectively for families with disabled children.

### How Decisions Are Made



In the past, decision making was top down but changes are now being made with more and more parents and service users being involved in decision making and change.

### What the Government is doing

- With the introduction of AHDC, the Government is acknowledging that services are currently not right for disabled children and their families
- They will be introducing a new National Indicator to measure if services are getting better. (Parent/carers will be providing this information)
- Government departments are working together which offers a clear message to local decision makers
- Providing money! £430 million across the country has been given to ensure services are improved

### What parents together can do

- Get involved
- Tell service planners what you want
- Come together with other parents
- Be brave – challenge people who make the decisions
- Tell Contact a Family what is and isn't working
- Say well done when things go right

### What parents individually can do

- Find out what you are entitled to (Contact a Family can help)
- Ask for what you are entitled to (NB Core offer)

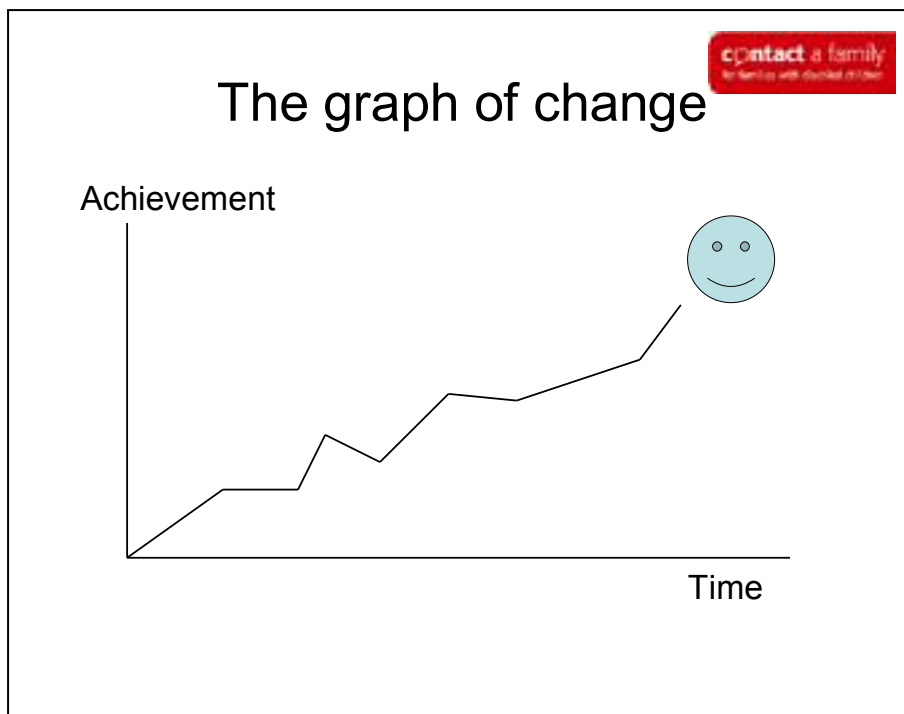
- Tell Contact a Family if it is not happening – we might be able to help
- Support each other – share the knowledge

The Core Offer sets out that each family will be entitled to:

- Information
- Transparency – any decisions made need to be fully explained to families
- Participation
- Knowing How to Complain

### What service planners can do

- Understand the needs of your local communities
- Work collaboratively across sectors/organisations
- Be brave – take some risks/ be creative
- Listen to parents and disabled children
- Act on what you hear
- Be honest – but be prepared to be challenged
- Value what parents and disabled children tell you



As the diagram demonstrates, the journey will involve many ups and downs; at times it will go slowly, at others it will quicken, it will go backwards as well as forwards, but ultimately, if we all work together and take responsibility, the journey will result in better services for disabled children and their families.

## Focus Group Table Discussions

Parents divided into groups after being asked to choose which of the four established focus groups they were particularly interested in to share views and look at future developments.

### Evaluation Quote

What was the best thing about the day?

**“Discussion and information gathered which is great because you learn from other parents”**

### Feedback

Key Points were identified by each table and feedback was given to the wider conference audience.

### Lead Professional

- Firstly, questions were raised about whether the term Lead Professional was the most appropriate title. Key worker and coordinator were offered as alternative suggestions
- Parents felt that they needed much more information about the role of the Lead Professional to be able to effectively give their opinions and views. It was agreed that the proposed methods of sharing information discussed during the morning session by the Information Focus Group would be a good way of telling people about the role and what it would involve
- Parents also felt that they would need more information to make sure they knew *which* professionals would be best equipped for the role based on the skills required
- Some parents raised concerns about being able to identify an individual who could act as their Lead Professional, given the present minimal input from services for their child
- There is a need to ensure parents are aware they do not have to have a Lead Professional or that they may just want a Lead Professional for a specific period of time e.g. throughout the transition process
- Some parents would prefer a buddy system to link parent/carers with other parent/carers rather than have an appointed Lead Professional. Parents asked if any local support groups were providing this kind of system already or whether they could in future.
- Concerns were raised as to *which* families would qualify for a Lead Professional. Parents also felt that more families are needed to take part in the current discovery route to road test the system and identify any barriers
- The Lead Professional role needs to be flexible to meet a families needs. If the role is not working then both sides; parents and professionals, must feel comfortable to request a change of person
- Parents identified a number of key elements that they felt would be vital as part of the role of the Lead Professional

- They will need to know how to access therapy services and ensure the child is receiving all that they are entitled to
- They could take on advocacy roles as they would have an understanding of a family without being emotionally involved
- There is a need for a complete cultural change so that the role of the Lead Professional
  - is appropriately supported by managers in order to allow them the time to both undertake the role and also appropriate training to support them in their role
  - has appropriate powers to co-ordinate meetings and pull everything together
  - is suitably recognised by other professionals in order for them to best support a family
  - is prioritised by local authorities
- Concerns were raised where a child may receive services out of the area, for example if a child attends a school out of Durham, could the SENCO (Special Educational Needs Co-ordinator) be the Lead Professional if the family wanted them to be? Would they be equally valued and supported in undertaking this role?



- There were a number of issues raised around how we seek the views of parents who work who would not be available to attend day time meetings and support groups
- Questions were asked about how the role of the Lead Professional would fit in with Common Assessment Frameworks (CAF) as these are being increasingly implemented across the area. A Lead Professional is identified within this process and it was unclear to parents where these discussions fit with CAF

## Early Years

- The importance of a positive Early Years experience was highlighted by families. An example given was a family who had a poor Health Visitor from Sure Start. As a result, their two year old child with Autism, as they got older, did not mix because of missed early years socialisation
- Concerns were raised by parents around restrictive age criteria within some Early Years settings. For example, in some areas, children are not allowed to attend groups such as messy play at Sure Starts because they are over one year old
- There needs to be more training and awareness raising for Early Years development workers on a wider range of rare conditions and on inclusion issues
- Within Early Years provision there needs to be more inclusion, acceptance and diversity
- There needs to be greater promotion of local Children's Centres and the services they can offer families (ideas on how to raise the profile included using adverts on milk cartons)
- Children's Centres are willing to provide allocated places but need direction from parents about what they and the children need. One suggestion was for parents to be on management boards to feedback on what parents and children want
- Children's Centres should be used for families to access other services e.g. therapies and parent support groups

## Information

- In the first instance, parents need to know *what* information is available and *how* to access it
- The procedures need to be in place from all the other Focus Groups around Early Years, Transport and Lead Professional to ensure that Information provision is right too
- Lead Professionals, as a main source of contact, could help with ensuring consistency of sources and within information produced around their role, it would be helpful for them to have a tick box form so they can ensure they share all the information they need to with a family they are working with (have we told the family about this, have we told them about that etc)
- Concerns were raised about current practices where families rely on professionals who can have different attitudes and do not share information with parents as readily as they should and equally where some professionals get frustrated at not being able to come out of their "box"
- Ideas to assist with the improvement of information sharing included
  - A pack of information given to families from a paediatrician
  - The production of a communication passport about a child, what interests they have, what communication aides they use (words and pictures, electronic)
  - A possible database that needs to be regularly updated. It should use a keyword system to make it easy for families to search for the information they need

- Small booklets which cover Durham
- Continuation of Newsletters
- Text messages should be sent to landline numbers as well as mobiles
- Continue to hold meetings and conferences
- Information needs to be:
  - Jargon free
  - Clear , consistent and relevant to a family's particular needs
  - Focussed and compact – parents do not want to be overloaded with information
  - Equally available to everyone across County Durham
  - Accessible – so would need to provide in various formats including Braille, internet etc and also ensure the needs of parents who do not read or write are met
  - Regularly reviewed, updated and evaluated
- Information on language, literacy and alternative communication solutions for all children needs to be shared with families
- Parents need to understand *why* they are receiving the information
- Ideas to increase the distribution of information included
  - Using Children's Centres to disseminate information to families
  - Local parent support groups can share information and more professionals should be invited along to groups to listen to parents and share experiences
- Confidentiality issues may need to be addressed with regards to sharing certain kinds of information
- There was acknowledgement that with any ideas for improving Information sharing throughout County Durham, the cost of things and budget restrictions may need to be taken into consideration

## **Transport**

- Parents need clear information around transport policies and procedures including:
  - details of the medications that taxis can carry and those that they and aren't allowed to.
  - clear guidelines on who parents can take complaints to
  - information on who can access transport services
- Where services are working well we need to share the good practice so that this can be replicated with other families
- Staff within the transport department need to be able to answer parent's questions no matter how simple or complex, for example, one parent requested information about an appropriate harness for a child but staff did not know what the parent was talking about. This may require training for staff within these areas
- Safety issues need to be addressed; some vehicles have seat belts and others don't; some school buses should have more adults on them
- There are major issues around current poor communication
  - between home-taxi-school-taxi-home

- with escorts who do not communicate when handing over children. Some children are not escorted all the way into the home, the bus just drops them off which can cause huge safety issues around children's safety
- sometimes taxis do not show up and parents don't know the reason why
- Training for escorts needs to be vastly improved. They need training in disability issues, particularly around "hidden disabilities" such as Autistic Spectrum Disorder
- Consistency is vital as sometimes escorts and drivers change without any warning to families
- Some children with special needs are expected to use mainstream transport which can cause particular problems including those children who cannot socially interact, those who cannot cope with crowded transport and bullying issues
- There needs to be clearer, more straightforward planning for special transport arrangements when pupils transfer from school to college
- There is no appropriate transport available for out of school or leisure activities

### **General Issues Raised**

- Work on transitions and clarity needed
- Major lack of leisure activities and out of school life skills building for disabled children
- Even if you can find something (leisure activities) you can't get them there – back to transport issues!
- Children with special needs should be afforded equality of access to services regardless of their education setting
- Schools should have "registers" of young carers so that they can offer the support they need

## Next Steps

Frank Whitelock, Strategic Manager for Specialist Services

## Acknowledgements

Those who have organised the conference, particularly the parents on the steering group for giving up so much of their time and for their enthusiasm and drive and to Lesley Moore and Janet Cummings for chairing the event

The support received from both Contact a Family and the Parent Partnership Service and everyone in attendance for contributing and helping to make a real difference to families with disabled children in County Durham.

## What will happen next

- Current Focus Groups to continue and grow with any new parents who would like to sign up to be involved
- New Focus Groups being established to look at Therapies and Short Break Care
- Another parent/carer conference will be held in Spring 2009

## Evaluation quotes

What was the best thing about the day?

**“Presentations and seeing the changes from the last conference. Excellent to see changes as a result of consultation through focus groups and conferences”**

**“First time coming to this conference and found the whole thing very interesting, dynamic and enthusiastic”**

## Summary

We are now seeing an increasing momentum for change from both parents and professionals within County Durham. From presentations at the conference, we have seen the positive benefits of partnership working and now need to build on these relationships, involve more parents and drive through real change for children and families.

**“We are all valuable and can learn from each other, no matter who we are”**

The wider commitment is highlighted within a letter received by Lesley Moore from Kevan Jones, MP, a copy of which is attached at the back of this report to highlight his support for the Every Disabled Child Matters Campaign.

Overall, the commitment from everyone involved will help County Durham meet the measures outlined within the EDCM charters and will benefit the lives of disabled children by making *real* changes to the services and support they and their families receive.

## **Appendix One – Local Parent Support Groups**

Below is a list of local parent support groups covering the County Durham area:

### **Bishop Auckland Parent Carer Support Group**

The Group meets once a month on a Wednesday morning at Durham Dale Action for Carers, 30 Edgar Grove, Bishop Auckland. They offer mutual support and information sharing plus guest speakers, training events and social activities. New members are very welcome.

Contact Pauline Lanagan on 01388 451 400

### **Cerebral Palsy Group**

Group for parents/carers of children and adults with Cerebral Palsy who aim to share information and experience, reduce isolation and create opportunities for socialising and leisure activities and help improve services for people with Cerebral Palsy and their families in Gateshead and surrounding areas. The group meets monthly, please call or e-mail for meeting dates and times.

Contact - Joanne Watson on 0191 4100 412 or by e-mail at [gatesheadcerebralpalsygroup@yahoo.co.uk](mailto:gatesheadcerebralpalsygroup@yahoo.co.uk)

### **County Durham Autistic Support Group**

Parent run charity providing advice, information and support for families. They run an informal advice line available to anyone. Meetings held monthly at Darlington, Bishop Auckland & Stanley. Children are welcome. They also run regular group activities, conferences and workshops for parents and

Contact Helen Geldard on 01388 819 880 or by e-mail at [helen.geldard@cdasg.org.uk](mailto:helen.geldard@cdasg.org.uk) or visit the website at <http://www.cdasg.org.uk>

### **Derwentside Carers Parent Carer Group**

Parent Carer Group meets on the first Monday of each month from 10 to 12 at Catchgate Children's Centre. Contact Dawn Mallows on 01207 502688 or by e-mail at [carerscenter@aol.com](mailto:carerscenter@aol.com)

### **Down's Syndrome North East**

Offers support and information for families who have someone with Down's Syndrome in their family.

Tel 0870 7652 121 or e-mail: [Contact@DownsSyndromeNorthEast.org.uk](mailto:Contact@DownsSyndromeNorthEast.org.uk) or visit the website at <http://www.downssyndromenortheast.org.uk>

### **Durham & Chester-le-Street Carers Support**

Helping Hands – this is run in partnership with Sure Start. It is at Grange Villa, near Chester-le-Street on the last Wednesday of the month between 1.30 and 3pm. There is a crèche for under 5's and older children are welcome e.g. in school holidays (crèche must be booked a week in advance!).

Laurel Avenue – this group meets on the 2nd Thursday of the month between 10 and 12 at Laurel Avenue Children's Centre, Sherburn Road Estate, Durham (next to Laurel Avenue Primary School). Transport is available from central points in Chester-le-Street and Durham.

Although they are held in Sure Start Centres, parents of children of all ages are very welcome! To book a crèche place, transport or just to find out more, please call Susan Doyle at Durham & Chester-le-Street Carer Support on 0191 387 1991.

### **Dyslexia Support**

For group details, contact Joan Temple or Elaine Chandler from the Parent Partnership Service on 0191 5873541

### **Dyspraxia Foundation County Durham**

Holds monthly Saturday Kids' Club, run a regular parents' room support group, produce monthly member's newsletter, offers telephone befriending/support line and holds social events in the school holidays and day trips.

Contact Tina Wilson on 0191 3848 283 or by email at [dfcd@btinternet.com](mailto:dfcd@btinternet.com) or visit the website at <http://www.durhamdyspraxia.org.uk>

### **Dyspraxia Foundation – Stanley**

Derwentside Group meets on the second Thursday of each month, 6.30-8.30pm at the Activity Den in Stanley

Contact Lynn Lumley on 01207 290 550

### **Easington District Carers Support Parent Carer Group**

The group meets on the third Monday of each month from 10 to 12 at Easington Carers, Peterlee. Contact Janette Browell on 0191 5869134 or by e-mail at [janette@easington-carers.co.uk](mailto:janette@easington-carers.co.uk)

### **Murton Parent Support Group**

Offers support to families in Easington with children with any disability. The group meets Wednesdays, 9.30 to 11.30

Contact Chris Shield by e-mail at [chrisbooby38@aol.com](mailto:chrisbooby38@aol.com)

### **Sedgefield Carers Centre Parent Carer Group**

Group meets on the last Thursday of every month at Oaks School from 10 to 12. Contact Joanne Lancaster on 01325 313123 or by e-mail at [joanne.lancaster@sedgefieldcarers.org.uk](mailto:joanne.lancaster@sedgefieldcarers.org.uk)

### **Teesdale Autism Group**

Support group for parents who have children with an Autistic Spectrum Disorder. Meet on the first Monday of every month.

Contact Lindsey Starborn on 01833 630 202 or by e-mail at [lstarborn@durhamdalescarers.org.uk](mailto:lstarborn@durhamdalescarers.org.uk)

### **WECAN Group**

Support group for parents/carers who have children with ADHD/Behavioural Difficulties/Autistic Spectrum Disorders/Dyslexia and Dyspraxia. For details contact Gill Burdis on 01325 300598

## Appendix Two – Evaluations

A total of 43 evaluation forms were completed by parent/carers attending the Making Changes Together II Conference.

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All respondents said they were happy with the venue for the day. The only extra comments received were a couple that said “**excellent**” and “**just the right size room**”. One parent/carer did feel that some parents may feel intimidated by such a venue.

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

Many respondents simply replied “**all of it**”

A summary of other key elements identified were:

- The positive atmosphere
- Receiving feedback on the changes that are taking place and the work that is being done
  - Feedback from parents on the Focus Groups. We trust them and stuff is getting done
  - Enthusiasm from professionals
  - Finding that some strategies talked about at the Seaham Hall Conference have started to change
  - Focus Group Work as you feel closer to management
- Signing charter. County Durham to be more accountable
- Listening to what has been achieved so far and what is planned for the future within County Durham, sharing the “real” development to enhance provision and care for our children
- Lesley Moore – she is fab!
- Meeting others in the same position as I am in and people listening to one another
- Talk from Contact a Family. It inspired positive thinking, not emphasising the negative
- All the day was useful once I took in what I’d missed from the first Making Changes Together conference
- Helping parents feel less isolated
  - Learning that there are more children with similar problems as my child
  - Becoming more involved and being able to offer my views
  - Being listened to. Sometimes I feel invisible and alone. It is very useful to be reminded that many others have similar sets of problems
  - Meeting like-minded people. Learning from others the positive changes and what parents can do together
- First time coming to this conference and found the whole thing very interesting, dynamic and enthusiastic

- Putting faces to names and seeing commitment from strategic professionals
- Having both professionals and parents together
- So much to single one thing out but they include emboldened parents; professionals listening and seeing signs of progress
- Presentations and seeing the changes from the last conference. Excellent to see changes as a result of consultation through focus groups and conferences
- Receiving information relevant to my situation. Having the information can help to find out further questions I need answering and how to do this
- All of it was interesting. Would have been useful to have background information on the whole thing

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

Many parents mentioned the problem of not having enough time for all the presentations etc which resulted in parts of the day feeling a little rushed

Other key elements included:

- Not knowing at the beginning what was going on. I was baffled by all the information about how the groups were formed (didn't relate to real life)
- Information/language shared and used. Parents/carers are all at different levels of understanding/knowledge re these changes. Some parts generated negativity as a result of this
- No role models. We need to see role models i.e. disabled kids and adults demonstrating their skills in particular use of VOCA machines
- Bit of parent negativity
  - Listening to parents with "axe to grind" It's not the place or time for personal problems
  - Feeling of antipathy when service professionals were talking
- Being sat at tables with no one you know, but a good thing about this is that you talk to others on the table
- No childcare or transport. Arranged as voluntary through Durham Carers' Centre.
- Speeches – but they were short and sweet!
- No mobile signal
- Being given job of facilitator and not knowing what I was supposed to do!

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

As well as more time, practical matters mentioned included a P.A system as some parents found it difficult to hear.

Other gaps identified were:

- Perhaps a child/young person to come and give a talk

- Role models. A disabled kid or adult to give a talk/presentation to show what they can do given access to equipment and VOCA (AAC Communication Aids)
- More about education as this area is a big part of my child's life
- More professionals to explain exactly what is provided by their department
- Longer time to discuss and feedback. Time credited for Local Authority workers
- Children's rights, their perspective/testimony. We don't know what it is like to be disabled
- More information on benefits, therapies, support groups, education etc
- A location where my mobile could get a reception
- More time to have questions and answers and share information. Possibly "It's a Knockout" style

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

To highlight the feelings of everyone in attendance, below is the full list of comments made by parents/carers:

- I have to believe there is something better and I want to shape what that will look like
- Excellent day, thoroughly enjoyed
- Very uplifting and positive. Hope for the future and for change
- Excellent
- Very good, informative day
- Brilliant day, excellent venue, felt equal to professionals being a parent myself
- Fantastic day
- Brilliant day. Venue was great, people were friendly and having an input
- Parents should be made aware that the day is not for bringing individual cases to professionals
- Fantastic
- Amazing, Thank you Kathy and Sarah; you are the wind beneath our wings
- Excellent
- Nice to meet parents and professionals and see them working together for a better future for children and schools
- Very useful information. Found out a lot more that I never knew about
- I thought it was interesting to learn that me and my partner are not alone
- Useful day. Hopefully we will be able to build upon this
- Very good; more please. We covered a lot of stuff and difficult to decide which focus group to join
- I enjoyed the day very much. Just hope everything that was said they will do does happen
- Very useful. Always find out something new at an event like today. Keep up the good work
- Excellent
- Day was great and can't wait to see the changes happen

- Brilliant – some progress
- Informative
- Rather too much “management speak” and jargon for parents
- Brilliant; very effective – hope it continues
- Excellent, professional – a relaxed atmosphere
- Excellent - well done to all
- Very good
- Interesting and informative. More conferences and meetings please! And thank you
- Excellent day. Well done parents and Contact a Family
- Really informative, inspirational and fun
- Very enjoyable and a lot of hard work done in getting speakers together. Excellent to hear other parent’s experiences
- Excellent, really useful
- Very informative day
- Excellent to have the charter signed. Overall a good update on progress, we need to be careful not to isolate parent/carers with information/language used. The focus tables need to have trained/support facilitators to lead discussions
- Very informative but overwhelming at the same time
- Too good to be true! Why has it taken so long?
- Very interesting and very informative
- Generally uplifting. Feeling that we’re doing something
- Interesting, informative. Opened up opportunities
- Wow – so much! Definitely want to be more involved to better the future for our young people and families and professionals