



# Making Changes Together IV

## Conference Report

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

Thursday 12<sup>th</sup> November 2009  
Ramside Hall, County Durham



**contact** a family  
for families with disabled children

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## **Introduction**

Lileen Cuthbertson, parent member of the Making Changes Together Steering Group welcomed everyone to the Making Changes Together conference, the fourth that has been organised **by** parents **for** parents of children with disabilities and additional needs in County Durham.

The aim of this conference is to share the progress that has been made through the Making Changes Together Steering Group and Focus Groups and gather parent and professional views on work already undertaken and future Making Changes Together developments.

## **National Update**

Kathy Rist, Regional Manager, Contact a Family North East & Cumbria and Regional Advisor for Together for Disabled Children

Kathy introduced herself and her Together for Disabled Children colleague Jane Harrison, who is working with the Local Authority around Aiming High for Disabled Children (AHDC).

Kathy told the conference that at a recent event hosted by Contact a Family at the House of Lords, Ed Balls the Secretary of State for Children Families and Schools had expressed his commitment to the Aiming High Agenda and commented that the job of including children into mainstream society and services was only just beginning and that he was impressed with the work that was being carried out nationally by parents, carers and staff who wanted to make a difference.

While his comments were exciting and very welcome, we have to be cautious not to rest on our laurels. These are tough financial times when we all have to start to think smarter around different ways of providing services that are timely and meet local need. Good solid partnership working where people are listening to each other and finding new ways of working together will help change happen.

Kathy encouraged parents to join the Focus Groups to support that change.

## **Lead Professional Update**

Lesley Moore, parent member of the Making Changes Together Steering Group

Given the information provided with regards to current funding situations it is important to stress that a lot of the work undertaken by the Lead Professional Focus Group will not require extra funding as it is about changes in practice rather than introducing new staff or activities.

At the beginning of this process, one of the main reasons for developing a Lead Professional Role was to create more co-ordinated working between different services and professionals and that requires a change in ways of working and expectations rather than funding to achieve it.

In order to illustrate the challenges faced, attendees took part in an exercise which involved each person being given one of 8 roles including Educational Psychologist, Health Visitor, Connexions Worker etc. Everyone was then asked to move about the room to find one of each role to then form a "Team around the Child" This proved no easy task as many people could not get a complete team together!

This exercise highlights the difficulties faced in co-ordinating teams that include so many individuals all involved in a child and family's life.

The introduction to this way of working is going to be a gradual process to ensure everyone is on board and understanding the requirements of a Lead Professional and a fully co-ordinated "Team around the Child" way of working.

At the last conference, attendees were asked what they thought of the Lead Professional role as it was seen at this time. People were nearly unanimous in wanting the Lead Professional role to be available to ALL children with an additional need. If it had been solely for children with complex needs, then the Lead Professional role could have been launched at this conference. However, after listening to everyone's views from the last conference and now developing the role for any child/family with an additional need, the Focus Group has realised how many more teams and people will be involved and the level of training and awareness that this now requires.

Commissioners have decided, after looking closely at the Lead Professional Passport, that they would like every child with additional needs undertaking a Common Assessment Framework to have one. The Focus Group therefore needs to inform and update many further professionals and teams.

As a reminder, 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 health visitors, teachers, nurses, Children's Centre Worker, and anyone else who works with a child/young person with additional needs.

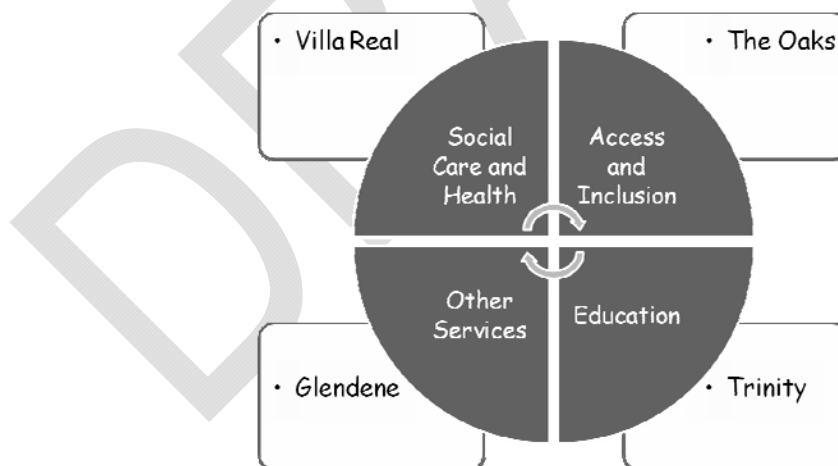
The CAF will provide a more effective way of assessing a child/young person's needs. It will take into account the child/young person's strengths and needs and also the parent/carer's strengths and the effect the child/young person's environment has on their development.

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.

### **Integrated Working Team Developments**

Because of the difficulties of physically getting co-coordinated working across disciplines, County Durham have also decided to introduce 'Integrated Working Teams', though these **will be** for the children with the most complex needs. There are about 450 children with complex needs in County Durham, for example severe autism, life limiting conditions, complex cerebral palsy, etc.

There will be four locality teams across County Durham:



There are currently four initial functions of the Integrated Service teams:

- Assessment
- Developing ability and skills
- Support and care
- Statutory Responsibility

Each team will be based **around** four special schools (not necessarily within them). These are Villa Real, Glendene, Trinity and The Oaks. A child does not have to attend these schools and a family may want to attend the team which is nearest to their home but it does give families the opportunity to choose which is the most accessible to them.

This model is very new in thought and parents' views are being requested to help with the further development.

Briefing sessions about the model have already taken place across the county. There will be further information available soon on the Making Changes Together website and through the Children's Network magazine.

None of this can be looked at in isolation from everything else that is beginning to develop in County Durham. Each focus group development and new initiative blends and interacts with the next and really we are only just beginning to get a picture of what future services and ways of working will look like in County Durham.

## **The Lead Professional Passport**

Attendees were given draft copies of the new Lead Professional Passport.

In tables, attendees were asked to familiarise themselves with the passport and then discuss specific issues:

**Which mainstream teams/professionals should be added to the list of people who require information on the Lead Professional role and passport to enable it to be successful?**

### **Suggestions made:**

- Teachers, particularly those in mainstream schools
- Learning Support Assistants
- Outreach Workers
- Community Paediatricians
- Nursery Nurses
- Community Nurses
- GPs
- Specialist Health Visitors
- Homecare Teams
- Therapists
- Parent Support Advisors
- Heads of Services
- Opticians

- Podiatrists
- Direct Payment Workers
- Frontline staff who work with families
- Support Carers and Respite/Short Break Workers
- Social Workers – split into Children with Disabilities Teams and Children in Need teams
- Portage
- Residential and private schools
- Housing associations
- Connexions
- Voluntary Sector
- CAMHS (Child & Adolescent Mental Health Teams) – staff within Learning Difficulties Teams
- Dietician
- Wheelchair Services
- Religious leaders
- Befriending schemes
- Taxi escorts
- Speech and Language assistants
- Anybody involved with child
- Audiologists

**What other ways are there of getting the message about the Lead Professional Passport out to parents and professionals alike, particularly to universal services?**

**Key Points:**

- Launch the passport first to professionals before it is given to families
- Support groups could act in a “semi-professional” capacity to help share information about the passport to relevant families and professionals
- Through the Parent Partnership Service
- Use Support staff in schools
- Sensory loss peripatetic teams
- Children’s Centre Family Support Workers
- School Governors
- Leisure groups
- Develop the passports in languages other than English
- Ensure information about the passports reaches families whose children are home educated

## General points made

- It would be helpful to get professionals together so that everyone is working together on this
- Rather than make it complex, have an additional glossary so that families know what terms/acronyms mean
- Develop a virtual passport, this would help ensure information was never lost, even if the physical passport was
- Include a profile of the child including their likes & dislikes
- Add space for emergency next of kin details
- Attendees felt that more blank pages in the back would be helpful - loose or spare sheets for changes of details (in a pocket at the back that could also be used for business cards etc)
- Include numbers of local hospitals
- Needs to be clear who is responsible for updating the passport when information changes
- How will parents know who to contact to obtain a passport?
- Possibly look at having a loose leaf version to help with incorporate updates
- Maybe link to a website where parents can download updates and newly designed content

## Information Update

Marsha Dolan, Parent Steering Group Member

The Making Changes Together steering group have set up a group email address so that parents and professionals can contact them to share information, find out what is happening and give their views.

The email address is [steeringgroup@mctdurham.co.uk](mailto:steeringgroup@mctdurham.co.uk)

Making Changes Together also now has administrative support provided by Ann Connor from County Durham's Parent Partnership Service.

## Making Changes Together Website

[www.mctdurham.co.uk](http://www.mctdurham.co.uk)

This website has been set up by the steering group but currently has little content because the Information Focus Group wanted to ask parents what they think should be included before going ahead and adding lots of information. In tables, attendees were therefore asked to discuss what *they* would like to see on the MCT website.

## Key Points

- Rather than replicate other websites with lots of information, add clear links to other relevant sites (e.g. County Durham's Children's Network, Contact a Family, Sure Start, local Carer's Centres and Parent Support Groups, School Sites) but make sure the link takes you to the relevant page, not just the home page of another website
- Need to make sure other organisation's websites have links to the Making Changes Together website too
- Add a useful telephone numbers page
- Ensure navigation of the site is simple by using headings so that families can find out very quickly, the information they are looking for
- Have sections on each of the Making Changes Together Focus Groups that could include regular updates, meeting minutes, a place for parents to input their views etc
- Possibly have an informal chat room so that parents can easily share information on what's available, what works and what doesn't etc This could also have a "ratings" system linked to it that services and places could aspire to (e.g. if a family has a good experience they can give this a 5 star rating)
- Give people details of local training opportunities
- Have a glossary of terms, jargon busters section that could include explanations e.g. Common Assessment Framework, Eligibility Criteria , SENCO practice guidelines – shortened to be parent friendly
- Ensure there is an automated response to emails which explains to people that their email has been received and will be replied to as soon as possible
- Also include an explanation on the website about what would happen when an email feeds into a Focus Group
- Include humour to keep the website user friendly and less formal
- Include information for families about children who are undiagnosed, getting diagnosed, and what happens when you get a diagnosis or don't get a diagnosis
- Include a weekly updated news section
- Look at getting professional assistance for the website to help with maintenance, updating, systems for reporting abuse of the website etc
- Have a calendar of events section which could give details of both Making Changes Together Meetings and Conferences, Activities for Children and other events organised by other agencies
- Suggestion of including a blog for parents' own individual stories
- The website will be as useful for professionals as it will be for parents to inform and share
- Possibly also include helpful information to include directions to places (e.g. hospitals and GP surgeries)
- Important to ensure the website is used as a two way communication tool – sharing information and obtaining information are equally significant

- Don't rely too heavily on the website as there will always be families who do have internet access
- Any information on the website must be accurate and kept updated

## **Summary**

**Don't duplicate information already out there but make it far easier for families to access the information they need to find.**

## **Afternoon Sessions**

Chaired by Teresa Crich, parent member of the Making Changes Together Steering Group

## **Lamb Inquiry and Education Update**

Lynne Gregory, Head of Learning Support Service  
 Mick Watson, parent/carer member of Lamb Project Steering Group  
 Helen Sutherland, Inclusion Management Adviser, Learning Support Service

## **Background to the Lamb Inquiry**

- Was set up to investigate a range of ways to improve parental confidence in the Special Educational Needs (SEN) system through research and innovative projects.
- Interim recommendations have been made including review of the inspection framework and SEN, developing parental rights of appeal and improving the quality of Statements of SEN
- The final Lamb Inquiry report is due at the end of November 2009

## **Durham Innovative Project**

### **Set Up**

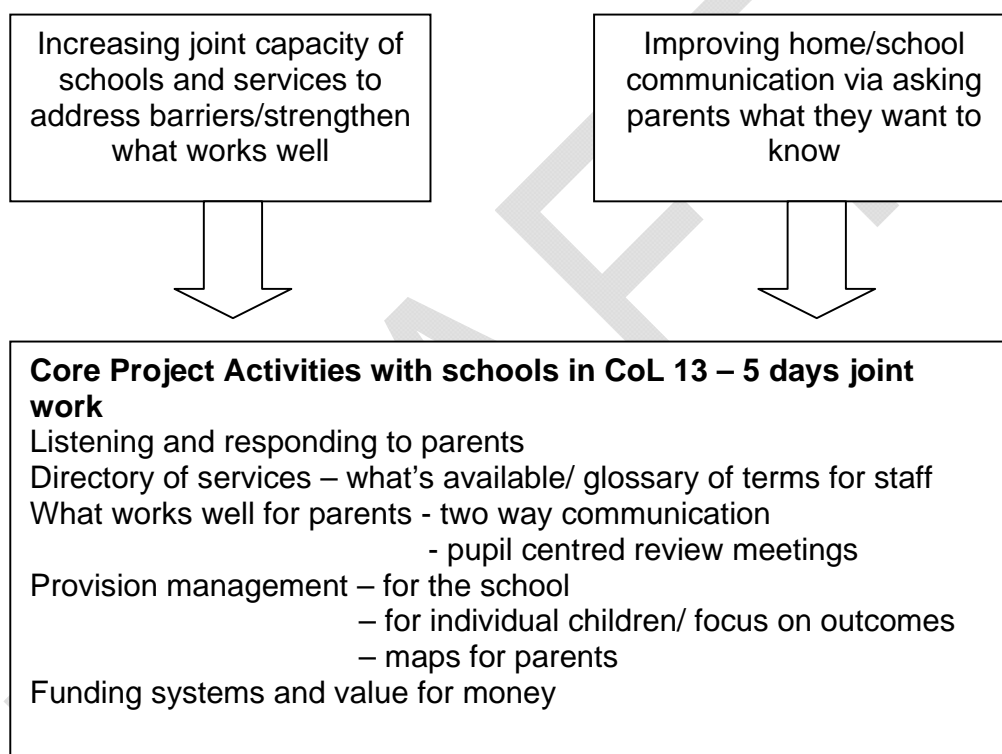
- Focused on increasing parental confidence in School Action/School Action Plus
- Acknowledged issues are complex and require intensive collaboration between Local Authority, schools, parents and health to find joint solutions
- Build on Community of Learning (CoL) developments to date
- Started from where Durham currently are – ask schools, parents and health what they think will help
- Committed to practical, useful and sustainable outcomes

## Hypothesis

Confident and knowledgeable schools are better able to communicate confidently and effectively with parents of children and young people at School Action (SA) and School Action Plus (SA+)

A pre-project evaluation of parent and staff views was undertaken to provide a baseline of information.

## Implementation



## Key Outcomes

- Powerful opportunities for shared learning,
  - Listening to parents challenged current practice,
  - Collaborative working generated practical approaches and useful resources.
  - Increased confidence in SA and SA+

Outcomes will be shared and built upon during 2010 through the new Confident Schools – Confident Parents programme.

## Confident Schools – Confident Parents

- Roll out to all Communities of Learning during 2010
- Continuing Professional Development and pack of resources
- Enabling the Local Authority and school to securely meet responsibilities and better engage with parents of children with SEN

### Parent's Perspective

Mick Watson is a parent and foster carer whose foster-daughter has Special Educational Needs. He has been involved with parent participation forums in Community of Learning (CoL) 13 and is also a member of the Lamb Project Steering Group for County Durham.

Mick feels that the Lamb Project has been worthwhile, so far in that the Government, via Brian Lamb and the professionals involved, are listening to parents' views, highlighted by the new SEN Information pack for Schools which has been developed through the Confident Schools, Confident Parents programme. The pack is a parent friendly resource that can be printed off in segments so parents are only given the relevant pieces of information and not a huge amount of information all at one time.

Key issues that have been raised include:

- Children with SEN currently often receive support only through Learning Support Assistants (LSA) who are not trained in SEN. From report recommendations, it is hoped that, in future, children will receive support from appropriately trained class teachers and LSAs
- Parents currently do not receive enough **information** about SEN and about their statutory rights. Examples include basic information about SEN processes, who professionals are and their roles in this process
- Statements usually have the same wording for a number of years, despite the needs of the child changing
- Ofsted inspectors need to receive SEN and disability training and there needs to be greater accountability in schools for any SEN discrepancies in support or any other issues
- Parents should have greater rights of appeal if they are unhappy with their child's statement
- Schools seem to receive most of the criticism from parents but any improvements made to the SEN system must apply to *every* professional involved

## **Schools SEN Information Pack**

Information within the newly developed school information pack came out of the views collated within meetings with local parents.

Schools will receive their pack on an editable CD-ROM so that these can be personalised, for example at the very beginning, the name and a photograph of both the Head Teacher and the School Special Educational Needs Co-ordinator (SENCO) of the school should be included so that parents know who they are.

Contents of the Pack Include:

- What are Special Educational Needs?
- How are they identified?
- Who is a SENCO?
- Who is the SEN Governor?
- What are School Action, School Action Plus and Statements?
- What does an Individual Education Plan (IEP) or a Provision Map include?

There are nine resources within the pack, including a Glossary and Terms section that was asked for, not only by parents, but by teachers too!

The pack will now be rolled out to more schools throughout County Durham with continued parental input. Schools will not only receive packs with clear instructions and training on its use.

Other materials that have been developed include large scale resources to be used in pupil centred planning at review meetings. These place the focus primarily on the needs of the child and the family and not on the professionals “around the table”

## **Further Focus Group Updates**

### **Early Years**

Michelle Cook, Shirley Wilson & Caroline Richardson

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

- **Portage Pilot – Home Based Service**  
Parents and children who were accessing Portage came together at local children’s centres to undertake group activities and to develop skills needed for being in a group and moving on to nurseries/pre-schools. This was very successful and highlighted how parents need to be in a small group first before moving into more inclusive groups

- **Training for Parents**

At the previous Making Changes Together conference, parents identified a list of training that they would like to access. At present, Children's centres are beginning to deliver training in Autism Spectrum Disorder and Behaviour Management.

- **Communication Pathway**

To be completed

### What Next?

- **Two Year Pilot**
- **Early Support Pilot**
- **Further Training**

To be completed

Within conference packs, attendees were given an Early Years Training Needs Analysis questionnaire where they were asked to vote on the one area of training they felt was most important out of the following that had been identified by the previous conferences and the work of the Early Year's Focus Group:

- Autism Awareness
- Communication Issues – PECS (Picture Exchange Communication System), Makaton, Sign Language, AAC (Alternative Augmentative Communication)
- Epilepsy Awareness
- First Aid
- General Public, Raising Awareness
- Moving and Handling
- Nutrition
- Sensory Difficulties

Training will therefore be arranged based on the results of this questionnaire.

It was also confirmed that Sign Language training is available for families through the Teacher for the Deaf, part of County Durham's Sensory Support Team.

### Further Developments

Because of the ages of their children, both Michelle and Shirley will now be leaving the Early Years Focus Group so more parents were encouraged to sign up and get involved.

To reflect the needs of families, the **Transition** focus group will now be split in to two; one for parents who have children aged 14 and under and one for those with children over 14.

The under 14 group will look at a range of transition issues such as home to nursery, nursery to school, hospital to home, etc.

The 14 plus group will look at transition into adulthood and adult services.

## **Therapies**

Sue Hood, Janet Cummings, Anne Morrell and Denice Fairfield

### **Children's Therapies Work Stream**

#### **"Next steps" that were identified from October 2008**

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

#### **The Good News**

- All planned next steps set in October 2008 have been achieved, some are on going
- Service delivery within the current resources available has been improved, based on what you have told us
- Further improvements are planned within the next six months

#### **The Bad News**

- Extra funding temporarily frozen
- Budget savings are required for next 2 years
- Community Equipment Budget overspent

#### **Moving Forward in 2010**

- Planned increased provision will be implemented as soon as funding released
- These plans will be discussed and agreed with the Parents Focus Group
- The Parents Focus Group will help us to collate parent views on current and planned service delivery

## **Physiotherapy Service**

Orthotics are now running extra clinics with only Physiotherapy input and utilising the time of the orthotist for more specialised assessments and equipment, as waiting times for clinics and issues were becoming too long. There are no automatic review appointments offered for footwear, insoles etc, parents are responsible for telephoning in for review appointments and a jogging list runs to ensure no child goes longer than a year

Musculoskeletal clinics are run more frequently using hydrotherapy sessions to deliver some of the more intensive treatments. Hydro sessions have been increased using assistants as well as qualified staff

Group sessions for pre-school children are truly multi-disciplinary i.e. the current one at Chester-le-Street has planning and regular input from Physiotherapy, Occupational Therapy, Speech & Language Therapy, Sensory Support and the Conductor/Teacher from Villa Real School. This means the group can be led from any discipline and if one therapist cannot attend, it can still continue. Parents do not then require home visits as well as group input

There has been a re-organisation of clerical staff and where there is a shortfall; staff have been employed through an agency. This means qualified staff can use all their time more effectively by not having to type up their own reports, letters etc or do their own filing.

There is also now dedicated clerical time for clinics, not only for appointments but also for costing clinics, data input, sorting out orthotics as they come in and prioritising appointments based on need.

## **Speech and Language Therapy**

Children's Speech and Language Therapy is currently split into two separate services, north and south of the county. The methods of service delivery are different, the waiting times to be seen are different, and the level of therapy a child gets is different.

Over the past four months a small project team has been working with Oaklands quality improvement team to improve the waiting times for children to access assessment, so that all children can be seen within 18 weeks from referral.

Data information has been examined in great details to identify a better way to offer appointments to families, which allows for fairer access wherever the family lives, with one contact number for any queries, so that families will be contacted direct to arrange a suitable appointment over the telephone.

This should cut down on the number of "did not attend" appointments wasted, ensure therapists are assessing children and not spending so much time on administrative work, and provide a more accessible service to families who can find getting into clinics for appointments really difficult, by seeing more children in schools, nurseries and children's centres.

## **Occupational Therapy**

- Integration of Social Care Occupational Therapy provision with Primary Care Trust provision
- Development of a new countywide process for application for Disabled Facilities Grant and access to funding for minor adaptations.
- Development of Home Equipment Loans to offer a countywide service and establish processes and waiting times for equipment with designated children's funding.
- Occupational Therapy for Special Needs - designated Occupational Therapy staff have sessional input across all special schools. Additional staff being appointed for Easington locality
- Developing an equitable approach across County for screening, treatment and waiting times.

## **Transport**

Lileen Cuthbertson and Elaine Chandler

Transport was one of the four original areas of concern, identified by parents and carers at the first Making Changes Together conference held in April 2008.

Several focus group meetings have taken place since then, highlighting a wide range of issues that include;

- The overall transport policy addressing general issues, rather than those around children and young people with additional needs
- Transport appearing to be an 'add on' rather than part of an integrated care package. Sometimes resulting in care packages failing, or breaking down
- There was confusion over the appeals process and what was meant by the phrase 'exceptional circumstances'
- There was some concern over how effective the cascading of information was, between departments and between transport companies and drivers

These issues lead to the group debating the following questions:

- Could the policy on how transport is agreed and provided be simplified?
- Could we make services 'needs led' for disabled children and young people?
- What are the access criteria for transport within social care and education?

- Were parents involved in agreeing the criteria and can they be involved in the future?

The group then made the following recommendations to Durham County Council:

1. Regular parental engagement should take place regarding service development The need for an effective reporting system regarding transport
2. The need for a review of the system by which information is passed on to taxi services and drivers
3. The need to move towards a system where transport is considered an integral part of overall care packages
4. Information on transport should be designed and developed relating to the requirements of children and young people with additional needs
5. The need for a review of services for older young people
6. Where transport providers are likely to change (via the legally required tendering process) as much notice as possible should be given, so families can prepare children and young people for such change
7. Discussion should take place between Durham County Council and the National Health Service regarding the possibility of a shared transport list

During the past year the group have met with Maureen Clare, Head of Access and Inclusion and with Richard Startup, Head of the Integrated Transport Unit (known as the ITU) which is responsible for all of the Council's transport arrangements. Both senior officers gave a firm commitment to working in partnership with parents and carers to seek solutions to the issues we raise regarding transport.

During the time we have been meeting as a focus group our remit has had three strands:

- Identifying issues
- Engaging with transport systems
- Suggesting solutions to identified problems

The Transport Focus Group agrees with Maureen and Richard that the continued engagement of parents is required to highlight issues in a joint approach to finding solutions and designing future services. Therefore the group will continue its work as a commissioning reference group, working together with transport services.

## **Short Breaks**

Paul McGinnety

### **What Has Been Done**

- Key question – what have we changed?
- Look at two specific areas
- Short breaks
- Integrated Service
- Consolidation
- Next Steps

### **Short Breaks**

- Six months on....
- We asked the conference for ideas
- We were supported by Contact a Family & Together for Disabled Children
- We worked with Families
- Voluntary Providers
- Schools
- Private Sector

### **We did what we said we would do!**

- A target of 10,000 additional short break hours was set for the year
- So far we have delivered over 24,000 hours
- Universal, Targeted & Specialist
- Free to access – including transport
- Evaluation - nationally recognised
- Evaluation is our blueprint for the future
- There was a reduction in crisis
- Children and Young People with complex needs could do what all children should be doing ..... Having fun!

### **Quotes from Families**

Feedback from families has been phenomenal.

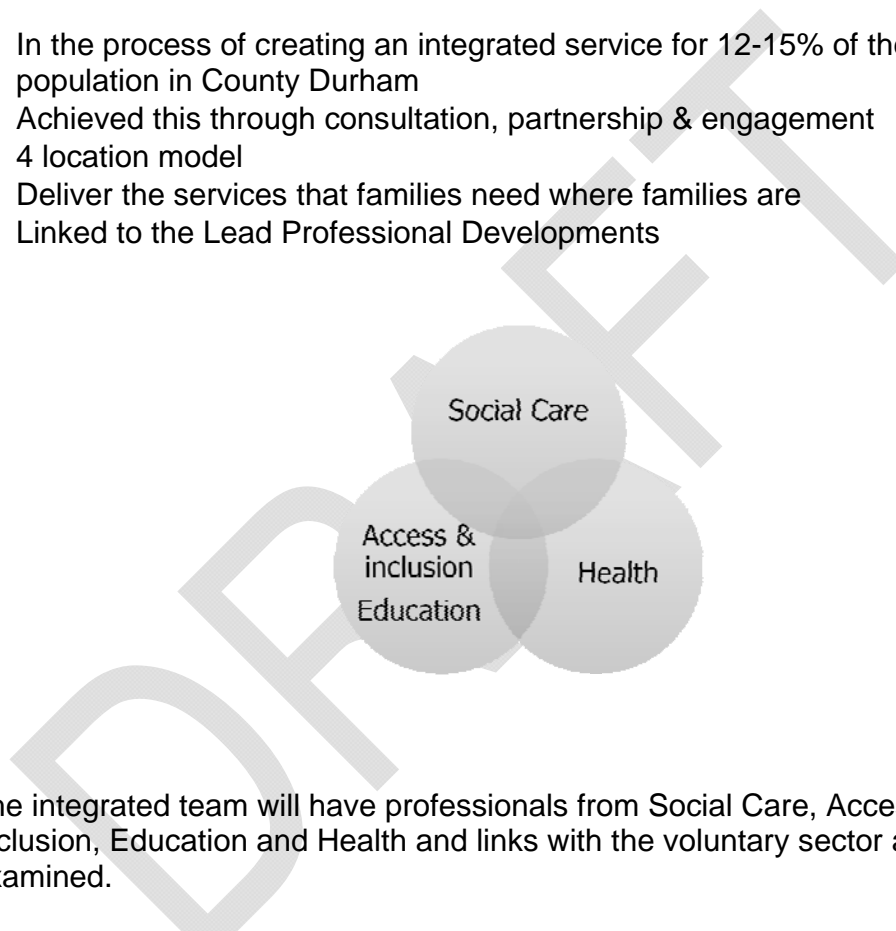
- “It was the first time we have been on holiday as a family”
- “This was a god send”
- “Thank you it was a lovely break and lots of fun & laughter”
- “We enjoyed picking fruit & baking muffins on our return”
- We had a lovely day out which we could never normally afford”

## Next Steps

- Use data and families experience to re-commission
- 1,518 children benefited –who did we miss?
- Get universal & targeted services to deliver
- Use every penny wisely - ask parents, ask children & young people and deliver what people need when they need it

## Integrated Service

- In the process of creating an integrated service for 12-15% of the disabled population in County Durham
- Achieved this through consultation, partnership & engagement
- 4 location model
- Deliver the services that families need where families are
- Linked to the Lead Professional Developments



The integrated team will have professionals from Social Care, Access and Inclusion, Education and Health and links with the voluntary sector are also being examined.

This will be the basis of the integrated teams for a small amount of children and young people but elsewhere, the integration agenda across the county has already started.

## Team around the Child



This agenda will see the integration of ALL children and young peoples services into hubs across the county and there is now an opportunity to shape these services from being involved at the very start.

### Next Steps

- For the many not the few
- Opportunity to create work streams to deliver the integrated service
- Influence the wider agenda
- Take on new issues

However, we have to get the balance right and to do this; more people are needed to be involved.

### Key Points

- Isolation will not deliver
- Partnership will
- Fantastic model in Durham
- Please get involved
- Shape the future

## **Thought for the Day**

**“Do not go where the path may lead, go instead where there is no path and leave a trail”**

Ralph Waldo Emerson

## **Summary**

From the range of comments made on completed evaluation forms (a full list can be found as Appendix One to this report), it is evident that parent/carers and professionals continue to welcome the opportunity to come together at these conferences to share information, learn about what is happening and give their views on future developments.

However, some evaluation comments show how poor communication can still be significant as many parents highlighted the fact that they heard about services and support that they had not realised was available before.

**“Again what I am missing out on, I am struggling in areas I don’t need to”**

**“Missed out on short breaks; poor communication”**

A number of comments were received around the challenges faced by ensuring that parents and professionals who are new to the engagement and involvement process do not feel overwhelmed by information. These will be addressed at future conferences by distributing more information from previous events to those who are attending for the first time and by summarising the whole process at the beginning of each conference.

Overall, attendees are very encouraged by the successes and developments achieved so far so it is vital that Making Changes Together continues to build upon these to maintain enthusiasm and momentum and ensure that services for disabled children and families continue to increase and improve.

**“I am proud at how far we have come and the progress we have made”**

**“I want to get more involved in Making Changes Together because it is worthwhile and it’s close to my heart. Changes are going to be good too”**

**“Things discussed at previous conferences are actually being done. Huge steps have been taken; well done. We need to continue”**

## Appendix – Full List of Evaluation Comments

A total of 38 evaluation forms were completed by attendees at the conference.

### Something I've learnt today ....

- More names of useful people and contacts
- We need an ASD working party looking at the specific needs of ASD. 1 in 100 children are diagnosed with an ASD related condition
- Updates
- Information – how many parent groups there are
- Many other organisations in County Durham that help children with additional needs
- Lead Professional Passport
- Things are moving in the right direction
- I think we need an Autism group to discuss the need for a specific service as the increase in Autism continues
- There is help if you ask
- I am missing out on a lot of services that are out there. Communication is poor
- The new passports
- Integrated teams – some information given
- Introduction of pupil centered reviews is being rolled out.
- Website
- Lead person for each family and the lead person passports
- Lead Professional Passport
- Everyone has the same problem of waiting for things for their child
- Sharing information with others. Knowing there's services out there I didn't know about. Not feeling so isolated
- That there's going to be good changes in Education etc – Lamb Inquiry and pack
- More about Lead Professional Passport
- Information on the Lamb Inquiry Project and resource packs
- Information on how all Focus Groups are working together with parents
- I've learned about the Lamb Project
- Presentation, professionalism and venue. So important in delivering the message
- Future ideas and forecasts
- Passports, short breaks
- There is a need for an ASD working party as so many kids in Durham are diagnosed with Autism
- Autism Alert Card
- The good things that are happening

- The success of short breaks. Not everyone is good at delivering to an audience
- How wide we need to think about services and how so many services are needed for disabled children
- That changes are happening
- How much work has been going on in the Focus Groups etc. Better understanding of what groups are trying to do
- I had never heard of a Specialist Health Visitor before!
- Things discussed at previous conferences are actually being done. Huge steps have been taken; well done. We need to continue
- There is help out there
- Training available for parents and Early Years work
- Developments in therapy services
- About the CAF (Common Assessment Framework)
- Lots! How hard the parent steering group work! I learnt more about difficulties with spreading the word, getting messages to all the people who need to hear about them. I also learnt a lot from the Focus Group updates

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

- Increased empathy with parents of children with SEN. I also felt very sad about some of the experiences/battles parents have had when seeking support for their children
- Very positive about the way things are moving forward
- Listening to parents views and experiences and listening to the enthusiasm of parents and professionals about today
- How hard everyone has worked to achieve all they have done. Networking always good
- That the parent forum can/is making a difference for our children
- We're all at different stages; I've a lot of other parent/carer friends I've made through this
- Slightly overwhelmed. A lot of people knew each other and made bee-lines for each other and for people who were here on their own it was slightly intimidating
- Power of being organised and getting things done
- Always feel so enthused meeting parents – they have so much energy for having such a tough job
- That I'm not alone but that you need to be "in the know" in order to access what is required
- Affinity with other parents, shared our experiences
- That I'm not alone in my frustration at not getting help
- Reassurance that I am not alone. People out there to offer help and other people/families going through the same
- Therapies. Talking to other parents about their child/children and their disabilities

- Knowledge
- Disappointment
- Anger and sorrow about the way a family are left feeling when their needs are not being met. I'm determined to try and help ensure that people get services when they need them
- I've experienced a real closeness to all who attended
- Pride at how far we have come and the progress we have made
- I want to get more involved in Making Changes Together because it is worthwhile and it's close to my heart. Changes which are going to be good too
- Meeting new people and also people I haven't seen for a long time and generally feeling part of something. The meal was lovely as well
- That I am not on my own
- Puts into perspective what we're working towards
- Sad to hear about frozen money for therapies
- Enjoyed talking to a variety of interested parents and to remember that parents can be passionate about their children's needs
- Meeting old and new faces
- Again what I am missing out on, I am struggling in areas I don't need to
- Missed out on short breaks; poor communication
- Sorrow that some parents still continue to have a nightmare accessing support/services; it's a disgrace. That changes is happening – that's fantastic
- Others are not getting as good as we did at first with our son
- That everyone at the conference has the same aim and are all working together to achieve and support each other in doing so and how empowered parents are to achieving this for their children
- The commitment from parents/professionals to SEN children and the parents' participation
- Very caring people, excellent venue and food
- How everyone wants to achieve the same thing, the best for our children and how we need the help and support for us parents
- Experience from other parents
- Discussion with a parent about her child – very moving

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

- Transport is heading in the right direction. Passport is looking good and should be of great benefit for newly or not yet diagnosed kids/parents
- Extra weight around the tummy!
- More help via websites will be made available. Knowing people in the groups working hard to help parents and make help available to us to support us
- Passport
- Confidence that parents are capable to voice their opinions. Fabulous conference run by parents
- That changes have happened and will continue

- Information about what's happening in SEN in schools
- Parents can help facilitate change
- BSL Sign Language contacts
- Phone numbers, information on how to access services
- Knowledge
- Lots of information to pass on to parents
- Hopefully help
- A lot of information
- There's always someone to help you and there is improvements being made to the systems
- Information
- Lead Professional Passport
- Knowing that changes in County Durham and Darlington are happening
- My determination to help ensure people get the services they need; to become part of a truly integrated team
- Information
- Friendship
- Shared experiences
- Hopefully, successfully joining the Children's Network as I will now complete my second form (the first I completed several weeks ago and have received nothing. I also requested written information on half term activities for children but this didn't arrive)
- How we need to take this model and expand it to other areas
- Positive feelings; value of working together; information and feedback to others
- Feeling my opinions are valued
- To put time in to help things move forward
- Knowledge that Making Changes is making a difference
- Website access etc. Passport; short break improvements – well done
- Passionate parents opinions; that parents want to join an Autism Focus Group
- New information and ideas, some from informal chats and some from presentations
- Listening to parents' experiences

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

- To feed back about where we meet now and catering by Mencap
- Better microphone!
- I had a toothache – yuk!
- The projector/slide show wasn't easy to see from the back of the room
- A smaller group would have been more personal
- Not long enough
- Food

- Still some talking in circles because people don't know what's already happened/happening
- Not enough time
- Sat on a table with too many professionals when we moved. Did not feel comfortable with only 2 parents
- Information given about progress regarding therapies – only related to services in the North
- Moving tables because too many professionals were on my table
- Lamb Inquiry – very interesting but too long
- So much information that it's difficult for me to take it all in
- Nothing, everything was good it was a valuable conference
- Not enough puddings (me being greedy really)
- I'm left feeling a bit powerless again; how can I affect change?
- Clearly defined aims
- Focus Feedbacks and small screen
- Cakes/desserts were too nice not to eat!
- The first half of the morning was too rushed and confusing. I did not know what was happening and when. I did not fully understand initially what was expected of me. Deliverance was too fast
- Thought that the food was very poor; cheap dishes and poorly presented. Also bringing hot food through the conference room – no!
- The food
- First half of conference felt rushed
- We already have the Moving On file, the early support pack – the passport replicates some of this. However the size and format is very good
- Hotel staff going through where presenters were before lunch and waiting for them to finish afterwards. The NHS/PCT promised money not coming through. Microphones provided were useless
- The broccoli was undercooked
- Nothing – I really enjoyed it all. Thank you to everyone who organised the day