



Making Changes Together

Conference Report

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

Tuesday 20th May 2008
Seaham Hall, County Durham

Contents

Introduction	3
Aims of the Day.....	3
The National Picture	4
“The Perfect Service” Poster Design.....	7
County Durham Perspective	9
Parental Involvement – Making it work	11
Next Steps	13
Ideas for Future.....	14
Summary	14
Appendix One – Full Details of “The Perfect Service” Poster Design	15
Appendix Two – Full Details of Parental Involvement; Making it Work	20
Appendix Three - Evaluations	24

Introduction

Lesley Moore and Chris Shield, Co-Chairs for the day

Both Lesley and Chris are parents of children with disabilities and had attended the first Every Disabled Child Matters (EDCM) Conference in Durham last October which is where the idea for this conference originated. An important part of the campaign is encouraging each Local Authority and every Primary Care Trust to sign up to the EDCM charter which is a list of best possible practice. Both Durham Local Authority and Durham Primary Care Trust are signing up to the charter and will be using this to inform their practice and services.

A steering group of parents from all over County Durham was formed and met on a number of occasions along with Kathy Rist from Contact a Family and Elaine Chandler from Parent Partnership. The conference has been organised by PARENTS for PARENTS and we are hopeful and positive about the outcome.

Holding the conference at Seaham Hall highlights Durham's commitment to valuing parent's contributions; many people had asked why such a luxurious venue but why not – parents are worth it!

Aims of the Day

The EDCM campaign really emphasises parent involvement and today is the start; we would like to see this as an opportunity to really get involved with the planning and implementation of the services that are involved with our children and the children of the future. This is Durham's opportunity to get to know everybody's views.

Already, the preparation for this conference, has led to the involvement of parents in looking at the Lead Professional Role and parents at this conference will to be asked become involved in a number of initiatives including the development of Children's' Centres.

Changes that have already been seen over recent years were highlighted; for example the development of wheelchair services which has increased the choices available to families. There are also more opportunities for activities such as those organised by the Durham Area Disability Leisure Group and there seems to be more acceptance and understanding of the high expectations that parents have for their children.

Key issues raised:

- Durham to really listen to parent/carers and involve them from the start
- Positive attitudes, especially within Education Departments
- Trained staff working with parent/carers and valuing and respecting their input
- Today as a definite way forward

The National Picture

Helen Wheatley, Principal Officer for the Council for Disabled Children

Council for Disabled Children

- Raise awareness of the needs of disabled children, young people and their families
- Promote the participation of disabled children and their families in all decision making about their lives
- Contribute to the development of policy and practice in central and local government
- Provide an independent forum for the discussion and resolution of issues relating to children and disability
- Sits within the National Children's Bureau

Which children?

- Around 770,000 children and young people of 16 and under are regarded as disabled under the Disability Discrimination Act
- Population of disabled children is changing, with a growing number of children with very complex disabilities or health needs now growing up. Also, unexplained increase in number of children with autism.

These growing numbers places greater expectations on both parent/carers and services. For parent/carers these centre on managing children's health and behavioural needs and for services, on providing services that they haven't been asked to provide before.

Disabled children: some facts

- Only a small minority of disabled children receive social care support
- Prevalence of severe disability increasing
- Families with disabled children more likely to live in poverty
- Lower educational attainment for disabled children, with and without Special Educational Needs

What do disabled children & young people want?

- To have fun
- To have friends
- Adults who understand
- Support to join in at activities and other places
- Being able to get in places without a fuss
- No bullying
- Access to all places

A Changing Picture – Parents

- Increasing expectation on parents in relation to care and therapy needs
- Increasing expectation on services
- ‘If I could change one thing...’ – a piece of work conducted by the Council for Disabled Children to gather parent/carer views

‘If I could change one thing...’ was a piece of work conducted by the Council for Disabled Children to gather parent/carer views and helped to inform the Aiming High for Disabled Children agenda which will include work on measuring parent/carers’ satisfaction with services.

Part of a mainstream agenda

- Aiming High for Disabled Children (AHDC)
 - Supporting Families
 - Better Support for Families
 - For Young People: A ten year strategy for positive activities

AHDC core themes

- Parents at the centre
- Access and empowerment
(core offer, parents’ forums, Individual Budgets)
- Responsive services and timely support
(Indicator, data, Transition Support Programme, rollout of Early Support, early intervention)
- Improving quality and capacity
(short breaks, childcare, community equipment and wheelchair services, workforce issues)

The funding commitments

- Short breaks- £370 m
 - £280 m revenue
 - £90 m capital
- Childcare - £35 m
- Transition Support Programme - £19 m
- Parent Forums - £5 m
- Individual Budgets

The National Commitment

- Recent national conference
- Parent and young person chaired
- 3 Ministers in attendance
- Also in attendance; lead members and senior managers
- Range of materials launched

'Good practice into common practice'

Ed Balls, Secretary of State

Local action

- Local Authority charter – targeted at Lead Members
- Almost half of Local Authorities now signed up
- Primary Care Trust (PCT) charter also available

There has never been a better time for parent/carers of disabled children to influence service delivery and development. It is now really important that we use this time to establish sustainable and effective support for disabled children and their families.

“The Perfect Service” Poster Design

Within tables, parent/carers were asked to collaborate to design a poster showing what a “perfect service” should look like.

A full list of design contents is included as Appendix One.

Key elements identified:

- Invest in and respect parents
- Plan and Deliver – “A little less conversation, a little more action”
- Parents are the professionals
- Child and family to be part of society
- Parents deserve the best

Communication

- Parents are passionate. They want to be listened to; they want messages and telephone calls returned and they want professionals who will get back to them with information when they say they will
- Parents want respect and don’t want to be judged
- Clarity from professionals; no more jargon

“We need people who do what they say or will explain to us why they can’t”

Quote from parent/carers

Support

- Parents want to have a key worker to help them to access information and support and to act as an advocate for them
- Parents need appropriate support including emotional support and counselling

Practical Issues

- Equipment should be put in place in education settings prior to a child attending
- Equipment and adaptations should be in homes too; not just in schools

Services

- Parents want to be involved in setting criteria for services
- Services should be based on needs and not on protocols or finances
- Services are often provided for intense periods only when they should be on-going
- There should be an end to a postcode lottery so services are available to all

Staff Training

- Parents want to be involved in staff training
- Staff should have an understanding of different disabilities
- All staff in education settings to be appropriately trained; not just teachers and learning support assistants

Information

- A one stop shop where families can obtain advice, support and access to professionals
- Information needs to be more accessible so that families who don't know how to access services are given the help to do so

“Why is the range of resources available not recommended by professionals?”

Quote from parent/carer

Respite/Short Break Services

- Respite needs to be child-friendly
- Hospice provision needs to be more affordable and not means-tested

Transport

- Parents want to know who is responsible for transport
- Should be made widely available across all areas
- There needs to be continuity; problems of short term contracts when there are always changes to who children travel with
- Training is needed for escorts and taxi drivers

Leisure Activities

- There needs to be more social activities available for children including after school clubs
- Parents need appropriate support to enable their children to travel to and access leisure services

Needs of the whole family

- The needs of the whole family should be taken into account, especially siblings

“Look at the child and the whole family; not the disability”

Quote from parent/carer

“We know it's not going to be perfect but please try. We are willing to help, give our opinions and listen to you!”

Quote from parent/carer

County Durham Perspective

Gail Hopper, Head of Safeguarding and Specialist Services, Chair Disability Joint Commissioning Group

Also in attendance at the conference were Maureen Clare, Head of Access and Inclusion and Anthony Prudhoe, Associate Direct Joint Commissioning, Primary Care Trust

Where have we been?

- Early 2005 – Disability Pathfinder
- Chance to think about doing things differently – to get better results
- Aims
 - Reduce duplication
 - Make better use of resources
 - Stop need to jump through hoops
 - Learn from what works and do it
 - Engage parents and young people

What have we done?

- Number of work streams: community equipment, therapies, high cost placements, lead professional, Autistic Spectrum Disorder (ASD)
- May 07 – Children’s Trust decision
- August 07 – Joint commissioning –NHS and council
- Changing way therapy services across Co Durham are delivered
- Specialist community equipment - children
- April 08 – Integrated Occupational Therapy service – reduced waiting times

Current Priorities

- Single service (integrated)
- Better co-ordination for complex needs
- Wider range of short breaks for those in greatest need
- Better range of services in early years
- Transport
- Value of parents as experts

Where are we going?

- Commitment to EDCM charter – joint plan
- Commitment to further improving how therapies are delivered
- Pilot the lead professional approach – single point of contact for families
- April 09 – Integrated community service – working as one service

What part can you play?

- Use your expertise as parents
- Opportunities to take part and influence work described
- Advise us of your priorities
- Hold us to account
- Tell us if we are getting it right and wrong
- Take part in follow up conference

Parental Involvement – Making it work

In tables, parent/carers were asked to look at the different issues around their involvement on a local level, focussing on four areas:

- 1. Quick Wins – what has to happen next?**
- 2. Long Term – what happens in the future?**
- 3. How can you get involved?**
- 4. What are the barriers to parental involvement?**

A full list of responses is included as Appendix Two

The main points identified were:

1. Quick Wins – what has to happen next?

- Listen and respect parents
- Information needs to be accessible and available in a range of formats; a website would be a great way of communicating information but should not be relied upon as the only source, given that some families either don't have access to or are not comfortable using a computer
- Offer parent/carers different ways to give their views, e.g. surveys, questionnaires, websites, forums, post and telephone
- Use clear language and communication
- Durham County Council to provide clear action plans
- Link into existing networks such as Local Area Agreements and the Children and Young People's Strategic Partnership Board

2. Long Term – what happens in the future?

- Make transport safer and more effective by offering training to all staff, involving parent/carers on interview panels and ensuring equal access for all across the whole county
- Set up sustainable, commissioned services that do not end after initial three year funding periods
- Make the transition to adulthood easier for young people and their families
- Ensure a Parents Forum is well funded, supported appropriately and operates at a strategic level at all times, not just when money is being made available to develop services
- Timely information for parents made available when needed

3. How can you get involved?

- Focus Groups on particular issues – this would help parent/carers become involved if they could choose to take part in groups on issues that they are particularly interested in.
- Make it easier for parents to become involved e.g. offer crèche, transport
- Share information between parent networks and use networks that work across the whole of County Durham

- Pass information on to all – use parents' knowledge

“Our knowledge makes us involved”

Quote from parent/carer

4. What are the barriers to parental involvement?

- No appropriate support or childcare in place for children so that parents can become involved
- Lack of energy; lack of sleep
- Parents feeling disenfranchised; the feeling of “What difference will my opinions make?” or “Will there really be any positive changes if I get involved?”
- Feelings of complacency which are replicated in the whole community, not just in families with disabled children
- Not knowing where to go or who to ask. Information one stop shops would help to address these issues
- Living in a large rural county which makes transport difficult and complicated for many families
- Lack of confidence and knowledge about what you are getting involved in

Next Steps

Frank Whitelock, Strategic Manager for Specialist Services

Acknowledgements

The work undertaken by the parents on the steering group for their enthusiasm and organisational skills in putting this conference together.

Lesley Moore and Chris Shield for chairing the event and the powerful messages they delivered at the start of the day.

The support, involvement and commitment received by Kathy Rist at Contact a Family and Elaine Chandler from Parent Partnership.

All parents/carers in attendance for giving up their time

So what really will happen next?

A further conference is planned to take place in the autumn at Beamish Hall Hotel.

The aims of this next conference are:

- To report on progress made so far
- To hold services and professionals to account
- To re-set the agenda and re-new ideas
- To involve new parents

Conference packs included a sheet asking those parents who would like to be more involved to sign up to look at specific issues within County Durham.

These issues were:

- Transport
- Information sharing
- Children's Centres/Early Years
- Steering Group for next conference
- Key worker/Lead Professional

Those who sign up will be contacted about future involvement in each of these groups.

Confirmation that this report will be circulated widely across the whole of County Durham and the contents will be used to determine where we go from here.

Ideas for Future

Parents were asked for any burning issues that they wanted to raise for possible inclusion in the next conference.

- Need to make sure people know about the communication aids that are available for children
- At a future conference it would be good to have a disabled adult talking about what made a real difference to their life
- We need to raise the expectations of disabled children
- Need to address the fact that the equipment and support in schools is not replicated in the home
- Need to look at getting a comprehensive database of families within County Durham; how to combine data from different organisations within one directory of services and activities that needs to be in different formats to make it more accessible to a wider range of families and kept updated
- There are currently gaps in service for young people aged 16 to 18. **(Aiming High for Disabled Children should address this as there is a financial commitment for a transition support programme).**
- County Durham to make “new schools” for disabled children who are in the middle as they do not always fit into the two broad categories that are currently in place. Inclusion does not always work, there needs to be more specialist units and parents should have a choice of schools with a robust transportation system in place
- Eligibility criteria for respite and short break services is often too limiting and means that many children cannot access the service for example those with Attention Deficit Hyperactivity Disorder (ADHD)

Summary

There is now a real opportunity to move forward in County Durham with the wealth of information and ideas that have been shared at this conference. It has been evident from the passion and energy of parent/carers in attendance, and from the majority of comments received in evaluation forms, that there is a real sense of enthusiasm to become involved.

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

Durham County Council now needs to build on this enthusiasm and develop a range of parental involvement options to ensure that the momentum and opportunities arising from this conference are not lost.

Making Changes Together – we can all now make a genuine difference to the lives of disabled children, young people and their families across the whole of County Durham. The following comment about the day from a completed evaluation form sums up the importance of ensuing change happens

“It’s been excellentif something comes out of our input “

Appendix One – Full Details of “The Perfect Service” Poster Design

Table One

Invest in and Respect Parents

Parents want:

- Clarity from professionals
- To be listened to and to have choices
- Information

“There are parents on our table who are accessing services that others don’t even know about”

Quote from parent/carer

- Transport – of any kind!!
- Facilities
- How can we go out and work? There is not support to enable us to do this
- Proper care and training
- Look at the child and the whole family; not the disability
- Realistic help

“What can two hours help really do?”

Quote from parent/carer

Table Two

Plan and Deliver

“It’s time to start getting on with it now, not just planning”

Quote from parent/carer

“Stop getting ready to get ready!”

Quote from parent/carer

- People who plan should also be accountable
- Don’t let protocol hinder what we need
- Be clear about the money available; how much is being spent now? Is this enough?
- Don’t take finances as the most important factor in getting services

“Where do boundaries lie between provision by health and by social services?”

Quote from parent/carer

- Respect the parent and the child
- Be aware that parents have knowledge
- Offer appropriate support, including counselling

“I want someone to talk things through with who is not going to judge”

Quote from parent/carer

- Answer our messages and pass on messages we leave
- Listen to us

“We need people who do what they say they will or explain to us why they can’t”

Quote from parent/carer

- More activities for our children
- Transport ; need to know who is responsible for this, there needs to be continuity across all areas and it needs to be available to all
- Information

“Why is the range of resources available not recommended by professionals?”

Quote from parent/carer

- Details of benefits that you can get
- Training for Staff we need early years support in nurseries and early in school; we need people who understand difference and pre-school understanding of different disabilities; staff who have the right attitude to achieve
- Equipment to be put in place and checked prior to child starting at nursery/school/college
- Listen to us; answer the telephone and get back to us with information when you say you will

Table Three

It’s all about me; we deserve the best

A little less conversation, a little more action!

- Address housing needs
- Equipment facilities and adaptations need to be in homes, not just in schools

- There needs to be a good diagnostic procedure for assessments e.g. care of the parent
- Respite needs to be child friendly; we need befrienders for our children
- Sibling support and extended family support
- We need mainstream schools that understand and training for all (not just teachers and Learning Support Assistants)
- More affordable, not means-tested hospice provision
- We need a trained key worker; an advocate

“All staff in public services should be trained and given advice on the needs of disabled children and their families”

Quote from parent/carer

- Therapy
- Communication – no more jargon
- Transport

“Transport; not changing who our children travel with constantly, contract lengths are no good; no training is given to escorts/drivers apart from wheelchair users but it’s not just about wheelchairs”

Quote from parent/carer

“We need accessibility to life and play opportunities for the most complex disabled children”

Quote from parent/carer

“Find those parents who don’t know how to access services and help them to access them”

Quote from parent/carer

- Shouldn’t just be charities that supply services

“If it is just charities that can deliver services then fund them and give them the resources”

Quote from parent/carer

- Need non-judgemental accessible health services including CAMHS (Child and Adolescent Mental Health) teams
- There should be a one stop shop for advice, support and to access professionals

“Everyone should talk to each other and share information, advice and work together”

Quote from parent/carer

“It should not be a postcode lottery; there are varied services across the county, not just nationally”

Quote from parent/carer

- There needs to be statutory commissioned services for holistic needs

“Every therapy should be based on need not on money or diagnosis”

Quote from parent/carer

- Information; information; information!

“We know it’s not going to be perfect but please try. We are willing to help, give our opinions and listen to you!”

Quote from parent/carer

Table Four

<p>Parents <u>are</u> the Professionals</p>
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- Parents should get respect from professionals at all levels
- We want to have fun!
- We need easy access to a one stop shop for information
- Respite services need to accept all disabilities as worthy; they need to work with parents to set criteria
- Access to funding, support and transition of services especially occupational therapy

“We need to have information on every worker right up to the big boss so we know who is responsible and accountable”

Quote from parent/carer

- Enforcement of laws for disabled facilities
- Transport; try and keep some taxi and drivers for ease; integrate taxis
- All professionals have information to pass on
- Leisure – parents need information on what’s available and support to access leisure – to, from and during
- Education – parents need to be involved in setting the criteria for statements
- We need to take into account sibling’s views as these are very important
- Easington Young Carers. 18+ years and to be brought into working with the children. Get up and about get jobs
- Parents have loads of passion
- Allocation of services is often for intense periods only when really they need to be on-going

Table Five

Child and Family to be part of society

- Formalise a plan of action with health, education and social service professionals in conjunction with parents
- Set targets in health
- Information resources
- Appropriately trained staff
- Communication – needs everybody to know how to listen and hear; believe in child and be able to facilitate child's communication
- Access to social activities – transport to respite
- Enjoyment – after school clubs; adequate to needs; inclusion
- Transport needs to be suitable – problem of contracts changing; why do you put financial remits before child's needs?
- Education; staff need training and knowledge of specific disabilities
- Available resources specific to needs assessment to produce outcomes that meet needs
- Key worker
- Changes can be made without impacting on the family
- Integrated
- Improper assessments; parents are left to fend for themselves
- All services need to work together

Appendix Two – Full Details of Parental Involvement; Making it Work

Table One

1. Quick Wins – what has to happen next?

Not token involvement
Simplify – no jargon i.e. in statements
Information
Hold schools to account

2. Long Term – what happens in the future?

Bring County Durham into the twenty first century with regards to equipment provision
Sort out Transport
Avoid need for social workers
Make it easier to access a GP and other services e.g. childcare
Make disabled children and their families one of the priorities of the Local Area Agreements
Recruitment and training (appropriate use of funds)

3. How can you get involved?

Create focus groups on issues such as transport, therapies and equipment

4. What are the barriers to parental involvement?

Autistics children
Energy
Appointments
Lack of information

Table Two

1. Quick Wins – what has to happen next?

Create parent focus groups and use interviews and questionnaires to identify needs
Bring all parents together from all areas and backgrounds
Offer different mediums for communication e.g. internet, newsletters, formal and informal meetings

2. Long Term – what happens in the future?

Specialist knowledge of different conditions to inform decision making
Information on all sources available to all parents at the right time e.g. pack or directory

3. How can you get involved?

Parent Groups

Passing information on to other parents and to professionals

Involvement in joint planning and attending relevant meetings etc

4. What are the barriers to parental involvement?

Time

Confidence

Getting the information

Letting other people "do it"

Transport

Table Three

1. Quick Wins – what has to happen next?

Every parent aware of information – what, why and when?

Make information accessible; use the voluntary services network and carers centres

Get information on the Children's Network and how to join

Special needs health visitors in Easington – use them to do a mailshot

Set up parents forum and other ways of contacting and communication

No jargon

Ask children!

2. Long Term – what happens in the future?

Commissioned services not just voluntary

Don't just focus on disabled children and families for the next three years but continue to establish a good process to help to continue the good work we have already achieved

Parents be involved in everything

Motivational support

Training for all involved (especially transport escorts)

3. How can you get involved?

Needs to know what is happening

What's new e.g. making involvement more accessible

Various methods of communication delivery e.g. newsletters, e-mail, website and telephone etc.

Communication between parents

4. What are the barriers to parental involvement?

Local meetings

Employment – getting time off

Money – transport, childcare

Apathy – parents are fed up
Family commitments
Shy, withdrawn, quiet people
Being intimidated or feeling intimidated
Parents not accepting or classifying their children as disabled
Lack of information
What difference will my appearance or opinion really make?
Health Issues
Lack of support
Marriage breakdown

Table Four

1. Quick Wins – what has to happen next?

Listen and respect parent/carers
Someone to be a first point of call for information
Local Area Agreement; parents are already involved

2. Long Term – what happens in the future?

Parents' Forum (at all levels, individual, operational and strategic)
Sure Start/Children's Centres to come on board
All information from all points of contact

3. How can you get involved?

Parents' forum – all on table four want to be involved!!

4. What are the barriers to parental involvement?

Childcare – both the cost and the lack of availability
Transport to and from events, meetings etc

Table Five

1. Quick Wins – what has to happen next?

Build on child's strengths rather than weaknesses
Information backed up by written providing action plans, targets and timescales
Language and communication via alternative technology – meet a proficient AAC user who can't use their hands, is blind etc who has a successful life which would mean instant realisation that others with same needs could achieve the same

2. Long Term – what happens in the future?

Transition from childhood to adulthood to be easier and more help is needed throughout the process

More transport needed and about the needs of the child, not the money available

All staff, Speech and Language Therapists and carers need AAC and language training. The UN Convention now states that a child now has a legal right to facilitation of AAC and equal education

3. How can you get involved?

My 18 year old son could give talks on using his communication aid

Come to meetings like this

Make moves, websites and books about language and literacy for disabled children and young people

Talk to other parents and get information

Bring my son and his friends out of school for story writing and movie making and literacy teaching and to use our AAC technology with us

4. What are the barriers to parental involvement?

Don't know where to go or who to ask

Low expectations of professionals towards our children which means they don't think there is anything they should do or learn

73% of professionals are under trained e.g. AAC is not part of Speech and Language Training

Feeling that we are just the parents and no-one really listens to parents; we are not important

Appendix Three - Evaluations

A total of 32 evaluation forms were completed by parent/carers at the conference.

All but one parent/carer said they were happy with the venue. Comments added included very nice and posh; interesting, fabulous and wonderful.

The issue of transport and accessibility were raised and one parent/carer did say that they felt the venue was not okay because of these issues.

What do you think was the best part of the day and why?

- Hearing parents talking positively and passionately about what matters
- Meeting other passionate parents because they are what matters
- Work groups were very animated and had lots of good ideas
- Everyone has new ideas and it was a great learning experience
- Listening to everyone and everyone singing from the same hymn sheet
- Being with so many pro-active, passionate people who all want to affect positive change
- Meeting parents and professionals; getting opportunities to talk to people (oh, the chocolate biscuits were good too!)
- Ideas and the venue. Having the opportunity to talk and give input and ideas
- The chance to exchange ideas, thoughts and niggles with other parents
- Parent participation
- Meeting other parents; talking to them and finding out what they are going through
- Informal times; good discussion and good sharing of information
- Identifying themes; sharing ideas and information
- Listening to parents' views that will inform my practice as a carer support worker; the sense of positiveness and enthusiasm from the parents I hope that this can be carried forward into change – all too often we focus on the negatives today hasn't been about that
- All of it was great because it raised issues to be taken seriously
- It was well organised and informal; it was great to meet other people in similar circumstances
- Heads of service being present; actually listening to parents, taking on board people's opinions
- Involvement from parents to expect changes from professionals
- Seeing parents do things for themselves; hearing parents get totally involved and knowing people/professionals were listening; the day left me feeling enthused and wanting to do more
- Meeting new people; have not been to event like this before so it was great to meet professionals and parents that can help an to know how we all feel

- Meeting people who are wanting to make changes and discussing what we need for our children and for ourselves
- Getting together with others to share information and ideas and talk about the future
- Getting all views across
- Meeting new people; the day was great
- Meeting people who are in the same state and have the same worries that I do
- Meeting other parents; sharing experiences, ideas and ways to move services forward

What was the worst part of the day and why?

- Not enough time; not much can be done apart from a week long conference – which would still probably over-run!
- Local Authority presentation as they didn't really understand parent participation
- Lack of time; we all have so much to say and it is difficult to see the main points
- Groups were too close together to be able to hear ourselves properly; noisy room and we needed more time for group sessions
- Realising communication and literacy are not at the forefront or knowledge of everyone or at the forefront of what everyone wants for their kids – we have a long way to go yet.
- Returning to the real world; realising how let down we all feel and hearing stories that back that feeling up. Lack of support, information and really useful help
- Too short
- Steering group; confusing jargon re inclusion; I left with unanswered questions
- Formal presentation; said questions would be answered but we ere stopped and told they would be answered at the end but they weren't!
- Time went too quickly; it felt rushed and there was more concern over time rather than importance of information being shared
- Questions with the heads of service didn't happen we moved on
- Too short
- The ending; because there is so much needs to be said and done to make any difference
- Not enough time to discuss the issues; wanted more time to hear everyone's views
- Hearing some voices (the loudest). It can be difficult to get views across when the same voices are talking about their own priorities; when you are new to this arena it can be difficult to express your views; my concern is it will be the same in smaller focus groups
- It ending and going home
- Not long enough; so much to discuss
- Not letting people talk; getting cut off from what you are talking about
- Not getting to speak too much e.g. putting points across
- Leaving

- Not long enough

Was there anything you would have liked to have seen included in the day that wasn't?

- Childcare support for those who need it; transport services for those who need it
- Could have been longer
- One of the heads of service should have been sitting at each table talking to parents
- More time to discuss issues
- Guest speaker who is severely disabled and uses Augmentative and Alternative Communication (AAC). This person could have a particular interest, job, achievement that matches the theme of the conference (e.g. Stephen Hawking if the conference is on Black Holes!) or they could just be there to BE THERE, a positive role model for achievement of disabled people. Someone who has experienced and overcome the difficulties faced by our kids now
- Small/brief biography of everyone attending; two lines with who, why and where from with email addresses for networking attached to the table plan
- More time to question the representatives from the Council, both questions asked were deflected well
- Explanations for next conference to set the tone for future debate and action
- For the parents to have more of a voice
- Real life experiences; SNUG would have been great
- Durham's plans for implementing this agenda; what is happening with today's information
- Guest speakers more associated with disability
- More time for questions, not specific to individual cases
- Children and families that miss out on services that are needed
- More people to help you
- Maybe more opportunity to speak to other people and learn from each other; make better relationship. A longer day would maybe have been better
- More information on how to access services
- Role models to come to the day and show use of AAC aids or other skills they have
- More time for questions

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

- Need to think about parents who do not have transport. One central group/forum for county will exclude lots of others who would get involved locally. Also need to look at what voluntary organisations are supporting families and all work together
- Brilliant; see you at the next one
- Energy and passion off all was very evident; well done all
- It was one of the most positive experiences I have been to and I felt spoilt in such a nice hotel
- Inspiring, powerful, proactive and not just the chairs. Thanks to Durham County Council for making us feel important and worthy enough to be at Seaham Hall
- Inspiring
- Very good; a little more time would have been good; lots of questions by parents went unanswered due to the time issue
- Excellent if something comes out of our input
- Constructive, informative and useful
- Good debate which was well facilitated; gave lots of constructive ways forward which are parent led
- Was a good day; each individual parent has different issues about their child; more time to be spent with individuals
- Good; lots of discussions a bit of a worry that people highlighted individual issues but not sure if these will be answered or addressed
- The day was excellent
- The support from statutory services was positive. I feel that they listened and this was due to the skill and honesty of the parents in expressing their views. I truly hope that the listening turns into positive action and am sure that differences can be made that result in parents not having to “fight” for services for their children
- Interesting, fun and packed full of information
- Excellent arena for parents
- The place was nice and everything ran as planned and there was a lot of good speakers
- It was very interesting, fund and full if information
- Excellent, full of information; our voices were actually heard. The venue was excellent and the food superb
- Excellent, well organised and great venue. Good to see senior people from health and social care being so receptive and willing to take on parent’s views and involvement
- Excellent thanks to everyone who organised it
- Really enjoyable and useful
- It was a very good day, I enjoyed it all and the meal was fantastic
- It was a really great day
- Good day; just hope changes do happen
- Longer talks and question time. Very good informative day
- Met great people, made friends and picked up useful information