



Learning to Change

Conference Report

Devised by Parents for Parents
with disabled children

Monday 13th July 2009
North Lakes Hotel



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Introduction

Don Sillars, a parent member of the steering group welcomed everyone to the conference. The steering group had organised and arranged the conference with the assistance of Contact a Family and staff from Cumbria County Council.

In attendance at the conference were parents/carers, representatives from Cumbria County Council and Cumbria Primary Care Trust.

This is the first parent's conference to be held in Cumbria. Don emphasised how today was the start of a process for parents to contribute to service development and influence change. This is an opportunity to focus on the future rather than dwell on the past and ensure that parent views are listened to and acted on to improve the lives of disabled children and their families in Cumbria.

Background

Kathy Rist, Regional Manager for Contact a Family North East and Cumbria gave a brief background to the Learning to Change Conference.

Contact a Family is the leading UK charity working with all families with disabled children. They provide advice and information and bring families together so they can support each other. They also campaign for rights and justice for families with disabled children and have been involved in many consultation exercises with parents over a number of years. .

What parents tell us they want

- Support
- Information
- Help

Big Change: Why Now!

Every Child Matters (ECM)

ECM was set up as the Government's aim is for every child, whatever their background or their circumstances, to have the support they need to:

- Be healthy
- Stay safe
- Enjoy and achieve
- Make a positive contribution
- Achieve economic well-being

Every Disabled Child Matters (EDCM)

To meet the challenges faced by disabled children to achieve these outcomes, a consortium of organisations made up of Contact a Family, Mencap, the Council for Disabled Children and the Special Educational Consortium set up the Every Disabled Child Matters Campaign.

This campaign is driven by the views of parent/carers and children and young people. The campaign asked parent/carers the question; “If you could change on thing, what would it be?” Out of this request came the following key suggestions:

- Good quality **Short Breaks**. To be flexible to include babysitting services, short breaks for a few hours at a time not necessarily overnight or weekend stays, someone to spend time in the family home so that parent/carers can, for example, spend time with other children, have a bath or do the ironing.
- Improve the **Transition** from child to adult services
- If you want to change and improve services **Ask and Include Us** as parents!

This last suggestion is why this event is being held, to gather the views of parents in Cumbria to help to improve the services provided for disabled children.

The Cumbrian Perspective

Michael Watmough, Head of Commissioning & Management Support spoke about the Cumbrian Perspective. Michael’s roles within Cumbria County Council give him the opportunity to work across a shared agenda as they include:

- Strategic Lead for the Aiming High agenda
- Member of Cumbria Children Trust Board and NHS Commissioning Board
- Directly accountable to the Head of Children’s Services

With the emergence of the Learning to Change agenda, Cumbria County Council recognises that they need to do just this and are committed to improving services for local families and their disabled children.

They welcome the opportunities this new way of working will give them to work alongside parents to effect real change. They acknowledge the support of central Government in making funds available but are also aware that the money is not sufficient to meet everyone’s needs. It is therefore important to now work on how best to maximise these funds and in order to do this successfully, the Council needs the help and support of local parents.

The Council knows that new structures, a new focus and a new status are all necessary to bring about real change in Cumbria. Constructive relationships between parents and the Local Authority are needed so that both parents and professionals feel they can support and challenge each other appropriately.

Only though working together can we make a real difference and today's conference is welcomed as the first opportunity to start off on a positive platform and for professionals to really *listen* to what parents have to say.

Wish List Exercise

Don Sillars introduced the next session where parent/carers were asked to brainstorm to produce a wish list where no wish was too grand. In tables, parents were asked to think about what could be done to improve life for their family? What impact better services could have on their lives?

Parents and professionals were also asked to share good practice and information so that things that work can be replicated across the whole region.

Following some very enthusiastic discussions, tables were then asked to agree on just one priority wish from their table. A full list of wishes is attached as Appendix One but the key points identified were:

- Keyworker – one person to co-ordinate a family's needs and the services that they should be receiving. The current Common Assessment Framework (CAF) system is not working
- Information – one place where families can get all the information they need
- One single budget across disabled children's services – so that there is an end of arguments across agencies about whose responsibility it is to provide a service and to help the co-ordination of joined-up services
- Two way communication - openness in reaching decisions together and a needs-led togetherness is required
- Comprehensive, individualised family support plans for the **whole** family – taking account of a family's expectations, we are "Aiming High" after all!
- Listening and Learning - training for parents and professionals to help them to achieve this effectively
- One stop shop in each locality – 4 needed to provide a place for all information and resources for families

The Durham Parent's Perspective – The Durham Model

Lesley Moore, a member of the Durham Parent Steering Group shared her experiences of parental engagement in County Durham.

Background

Lesley has a son Cameron who is 10 years old. Cameron has very complex cerebral palsy and learning difficulties and has great difficulties with seating and sleeping. In Lesley's working life, she has worked with children with special needs since she was 18 but nothing could have prepared her for the day in, day out, reality of having a child with a disability.

Involvement with Durham

Lesley attended Every Disabled Child Matters Campaign (EDCM) and Aiming High for Disabled Children (AHDC) Conferences in the North East. At the second EDCM event held in Durham, parents and professionals were asked to spend time together looking at how parents could become involved.

The overall message seemed to be that professionals were not interested so Lesley emailed one of the professionals and then contacted Kathy Rist from Contact a Family. Following meetings with other parents and the Head of Specialist Services, it was decided to set up a parent steering group and organise a conference **by** parents **for** parents.

Initial meetings of the steering group were difficult with lots of, on Lesley's part, frustrations and cynicism, but once everyone had got past the initial setting of unspoken boundaries and ways of interacting and working, it became much easier and Lesley now feels very able to and allowed to challenge what is being suggested or what is taking place.

Making Changes Together

The first Making Changes Together Conference was arranged and took place in May 2008. Feedback from the conference was very positive and a report was compiled that included a wealth of information from parents in attendance. After the conference, the steering group met with the County Durham implementation group which is made up of senior professionals from a range of services. Parents and professionals were coming through the door as equals. There was obvious respect for each other and a visual changing of opinions and expectations before everyone's eyes.

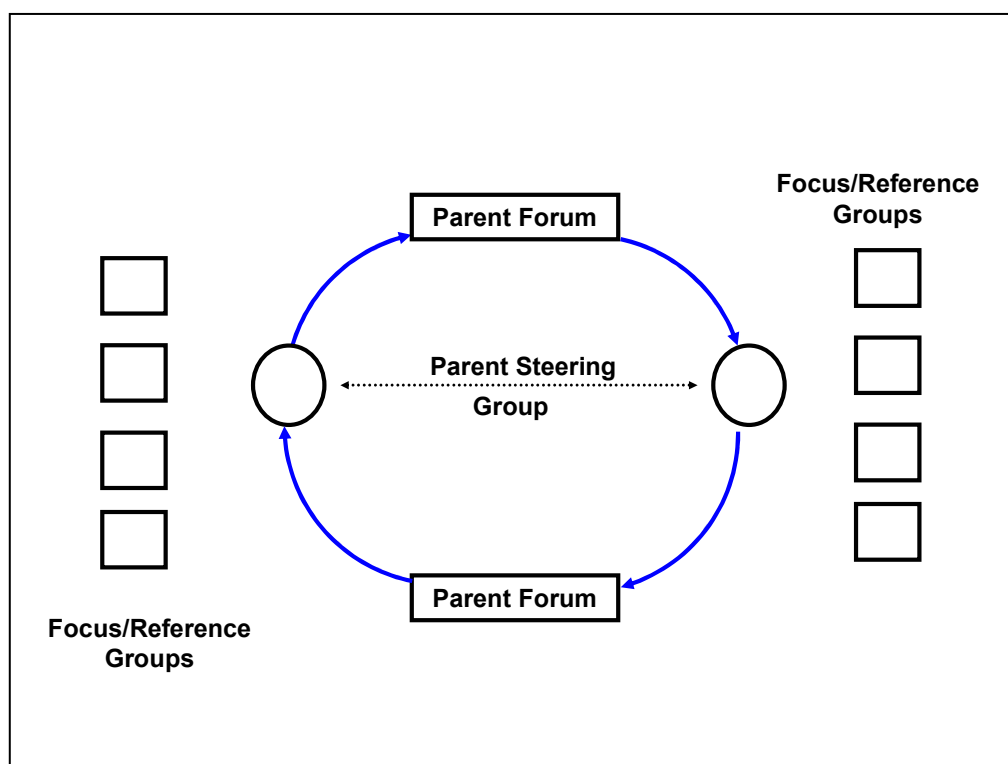
The steering group asked these professionals to sign up to the groups that the parents had suggested at the conference as those they wanted to focus on and those that parents had already signed up to themselves.

It was decided to focus on Early Years and Children's' Centres, Lead Professional, Transport and Information.

These groups have now been running since May 2008 and have made significant achievements already. For example the Information group has developed text messaging as a way of informing parents what is happening and is holding a number of information days in 2009.

It has become obvious that a number of the groups won't be short fixes but will need to run for at least a year to 18 months to consolidate change and set up future ways of working. Each Focus Group runs very differently; the groups will be constantly evolving and it has been recognised that this way of working; parents and professionals working closely and in partnership together, is very new to everyone involved.

The Durham Model



The Parent Steering Group organise regular conferences (parent forums). From these events, priority areas are identified by parents and focus/reference groups are then established based on these issues. These groups meet regularly between conferences and then the idea is to feed back what has been worked on and achieved at the next parent conference.

At the second Making Changes Together conference, Focus Group Members (both parents and professionals) fed back to attendees and then gave parents the opportunity to add their views and suggestions to what is happening so far and to make suggestions to what they wanted to develop in the future. The EDCM Charter was also signed by both parents and professionals from County Durham; highlighting their commitment to families with disabled children.

Following this second conference, new focus groups were established on Therapies, Transition and Short Breaks and new parents were again given the opportunity to join the present steering group. This has allowed for parents to drop out or to attend when they can, but there are always parents at the focus groups.

At the third conference held in April 2009, the steering group invited equal numbers of parents and professionals as now it was no longer “them and us” but just us. Also, professionals were now *asking* to come to the conferences. During this conference, parents and professionals again fed back the focus and steering group achievements and as a large group, they all decided to concentrate on the seven already established areas in the near future as significant progress was already being made.

It had also become obvious that many parents were now more in the loop than many frontline professionals. The steering group has therefore decided to hold a conference for professionals to get them up to speed.

Essential to County Durham’s Success

- A few key senior personnel absolutely committed to working in partnership with parents/carers
- Utilising the skills of Contact a Family and their independent status as a ‘critical friend’
- Power sharing; A willingness to foster a new way of working, to trust each other and to embrace the forthcoming changes

Summary

Evidence provided within the Making Changes Together Conference Reports has helped to drive forward changes in County Durham including a significant amount of extra funding that the Primary Care Trust has now made available to increase therapies available in the region.

Over a period of 18 months, a number of considerable changes and developments have been achieved. This parental involvement will last longer than the EDCM charter and Aiming High campaigns and is beginning to be embedded in attitudes and practice within County Durham.

The Durham Experience shows that real change is achievable. Lesley encouraged Cumbrian parents to sign up and get involved to help effect real change in this region too.

The Durham Parents’ Perspective and Model was the best part of the day – it illustrated that it can be achieved

Lesley Moore speaking – what we are aiming for

Parent Quotes

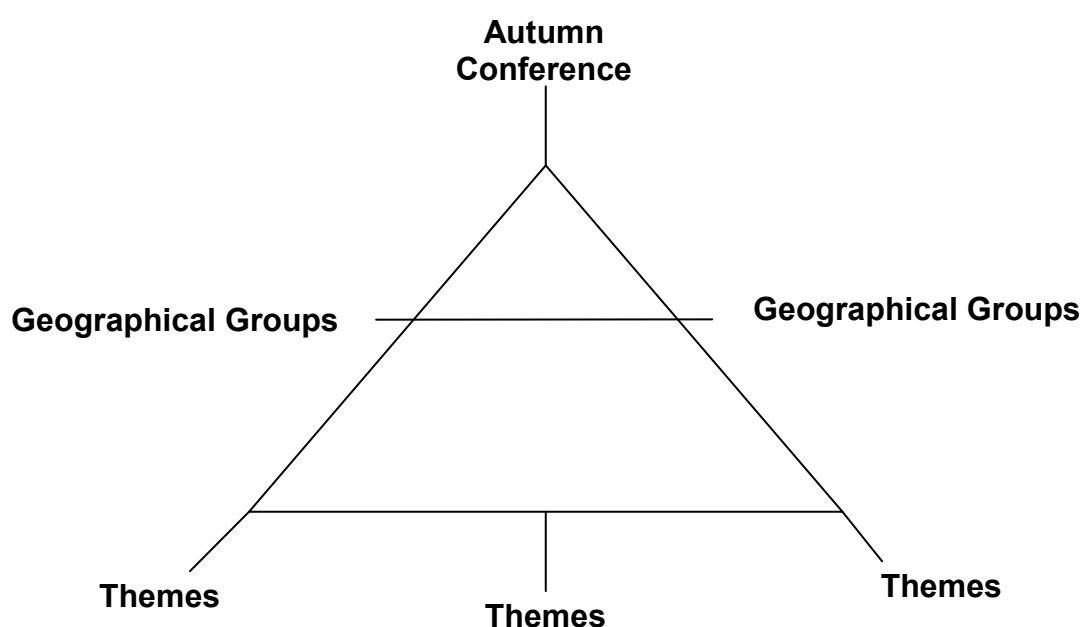
Cumbria's Direction

From the morning Wish List sessions, parents have already identified some priority areas that they would like to focus on. The challenge now is to work out how Cumbria can move forward with this agenda and how good quality parental participation can be achieved in Cumbria.

In tables, parents and professionals were asked to think creatively and collectively about these issues and how Cumbria can make it work.

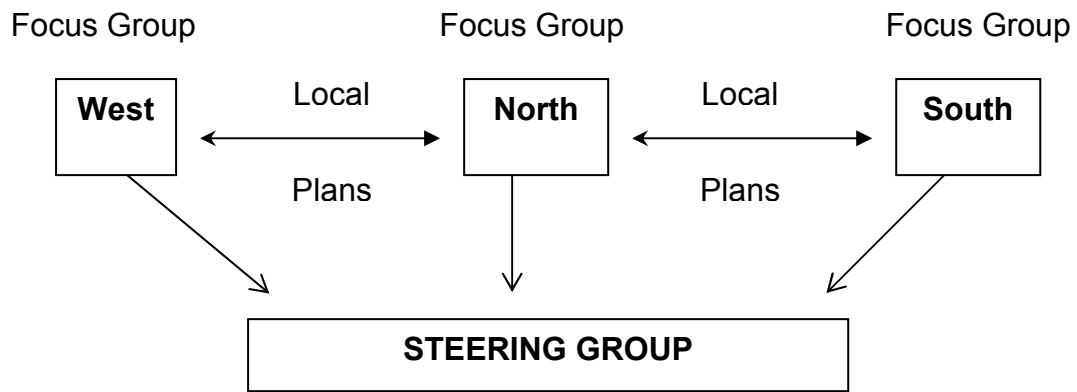
Ideas that were generated from these discussions:

- Have Focus Groups in every area (each area has different issues)
- Run splinter Groups like a pyramid system:



- This would enable hard to reach parents to attend groups
- Have sub groups (but not too many)
- Establish a database/network for parents to contact each other

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- 6 district councils
 - 4 children's service areas (Carlisle, Furness, West, East)
 - Steering Group – have a geographical split as follows:



- More people are needed to sign up for the steering group
 - Where are people coming from? Make the focus groups around them?
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- Stay as one focus group per topic, county wide
- Rotate them around the county
- Use car sharing to help ensure people can travel around the county
- Ensure the Steering Group and Focus Groups are representative of all disabilities/needs and regions/localities
- Reimburse travel costs

Next Steps

Within conference packs, parents were given a sign up sheet to complete if they would like to join the steering group.

The steering group will be following principles of participation to ensure that although individual stories can be told, they will be used to share **common goals** and influence change for **all** children.

The vast amount of information, views and ideas provided by parents and professionals at this first Learning to Change conference will be used to drive the agenda forward.

Parents were asked to spread the word about the next conference that will be held during the Autumn and were also asked to try and bring along just one more parents each.

From completed evaluations, it is very clear that parents welcomed the opportunity to come together, share information and be part of a process for change.

The conference was enjoyable and uplifting. I was left with optimism that something would happen

Very informative, can see a vision of better services in the future

Parent Quotes

There is a wealth of enthusiasm amongst parents in Cumbria to contribute to the Learning to Change agenda. Both parents and professionals from Cumbria County Council now need to build on this enthusiasm and develop parental involvement options to ensure that the momentum and opportunities are not lost.

From the full list of comments made during the wish list exercise, there is obviously a lot of work that needs to be done to help meet the needs of families in Cumbria, but the more parents that become involved, the more influence parents will have and TOGETHER, we can Aim High and make a real difference to the lives of local disabled children and families.

Appendix One – Full List of Wish List Comments

- Information is needed on DLA (Disability Living Allowance)
- Need more social activities, after school clubs etc. A group of parents took their kids bowling but I couldn't go as I need help
- Improved transition process
- Parents need to know *how* to get services
- Children and young people need to have carers from their peer group to help them to access social activities – perhaps Health and Social Care students on work placements?
- Information
- Peer group social activities
- Work experience and how young people can get work?
- Help for university
- Doing things with your peer group
- How do you get a Social Worker?
- Need to get pass disability and get to ability
- Doing things after school when you have to get on school transport is a problem
- The same escort every day and someone wearing a badge
- Emergency care for a child with a disability
- Importance of continuity of carers
- Young People First – said it was stopping because there was no more money but in Carlisle, only 5 people were going
- Need a central information point where someone won't pass you on and on and on
- Need help with DLA forms
- Need a keyworker per family
- One budget
- Work strategically, act strategically
- Need one parent and professional forum for Cumbria, giving a voice for young people with disabilities
- Need a comprehensive individualised family support plan with identified key worker which takes into account a family's expectations (Aiming High!)

Need ONE budget for disabled children of all ages combining Health, Social Care, Education, Voluntary Agencies and Local Councils

- Use the limited amount of money effectively
- Stop professionals arguing over whose budget services/equipment should come from

Needs to have flexible, accessible in county short breaks and respite care

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- Hospice for children with medical needs. Chorley is the nearest and we need local provision. Could be mobile for a start?
 - Respite care – that you can book in advance, responding to family need and during school holidays

- Better communication – being told and supported. Pack for parents that includes information on people, policies, procedures and funding and to include distribution to mainstream schools
 - Need more experienced, qualified children's services staff across all agencies
 - "Team around the family" is working well but families need support to make it happen. Parents need to be in control with laptops, admin assistance etc
 - Everyone to know basic communication needs e.g. makaton, picture exchange and sign language
 - Everyone to have basic disability discrimination awareness including children in schools, all staff and siblings too
 - Carers allowance for working parents
 - Someone to help parents/carers with everyday jobs e.g. gardening, ironing, cleaning so they have time to enjoy their children
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- Drop Ins
- Talk to other parents in social settings
- Evening opportunities to meet
- Groups open to all children with disabilities not just specific disabilities
- One stop shop for all services – Speech, OT, Physio etc
- Choice on appointments and more co-ordination of appointments
- Alan Shearer Centre model
- More hydrotherapy pool access
- Children's emergency plan
- Statement process – more support needed from school
- Why is Cumbria so different to other regions with regards to the statement process?
- Why do parents need to go through a tribunal process to get services?
- Mentor – another parent with a child with disabilities
- Parents as key workers (choice) and reimbursed and recognised for providing this role
- Training in key worker role for parents
- More training and education for all school staff in child's needs including dinner ladies, play workers etc
- Information is hit and miss – parents need a consistent flow
- One portal that all information feed through from all services
- More support and information at early stage (dismissal from hospital) - something in bounty pack or at diagnosis to include signposting, contact numbers, easy read information and details of Contact a Family
- Cumbria social networking forum
- Equal access to all charities, opportunities and money
- Support for managing behaviour
- More widespread understanding of other communication methods
- More disabled play park equipment

One stop shop in each locality for a purpose built all service, respite delivery, social and information centre and training/conference venue open 7 days a week

- Easier way to find help – resources are the best kept secrets
 - More social inclusion
 - I want to feel confident that my son will get support he need from the Learning and Skills Council
 - A friend for Suzie
 - Professionals that know how to really listen to parents
 - More help for child in transition from class to class, school to school i.e. special needs teacher to be able to go into transition with child
 - Statements for pre-schoolers
 - Specialist training for carers
 - Long term information/advice and support from a friendly advocate
 - Carer support for going on holiday with family
 - Access to outside school activities with trained staff
 - Consultant community paediatrician for North Cumbria
 - Specialist advice more easily available in schools
 - Transferable CRB (Criminal Records Bureau) checks
 - A school in North Cumbria for children who do not need Jamen Rennie or fit into mainstream
 - Change to transport regulations
 - Easier access to professionals who are making decisions about our children – it is not acceptable that officers are too busy to meet with parents
 - Parent involvement in training of Education Officers
 - Positive feedback between agencies
 - Parental advisors
 - Parents know the children but the people who are making the decisions about the support our children will or will not receive do not know our children. It is professional arrogance plus cost cutting which interfere with listening to people who live and will always live with the child
 - Information database
 - Kids on Children's Trust – not purely as a token gesture
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- Timely information
- Commitment to inclusion but acceptance of the needs for special provision if that is necessary
- Training for staff and for parents
- Shared inclusive services e.g. play and transport
- Education do listen
- Local parent links
- Training to be parent directed

- Regular visits to Bendrigg Lodge for child/family accessible and inclusive breaks with experienced staff
- Ewan McGregor's motorbike
- Respect
- Acknowledgement of skills
- Regular training on disability issues
- Partners in policymaking in Cumbria
- A bank of qualified staff
- Information/action about inclusive services including transport
- Parents paid as consultants
- Holidays, outings, shopping
- Residential short breaks
- Readily available respite or short breaks
- Funded night time cover

For professionals to Listen and Hear – training, education, parents, empathy and ideas

- Where do I go? Need and area issues hotline or a one stop shop – an independent person who can signpost you to services
- PECS system to be mandatory
- Getting children to join in anywhere is a real problem – need a support network and strategies, communication with all agencies – the “team around the child” and “common assessment framework” really working
- Places to take her to that cater for special needs
- Having someone to talk to who understands and who can put you in touch with the right agency
- Carer to come with me so they can care for my daughter so all of us can go on holiday together
- People to start understanding child's needs
- My child has a diagnosis so stop questioning and just act!
- Consistent respite from the same provider with the same staff
- Structured events with facilities fully appropriate for each child's needs
- Pool of trained direct payments professional support
- Support in understanding behaviours and help to cope with them
- Having a safe place to send children that they enjoy
- Mainstream education as inclusive is not true
- Key professional with time allocated to undertake the role
- Support for taking whole family to inclusive events
- More support during school holiday periods
- Being able to have a break without worrying about children
- Good quality family events
- Networking and social friendships
- Appropriate transfer to adult services
- Good quality, need centred services not fitting into current services available
- More respite during the school holidays

- More training for support workers, teachers etc
 - Activities appropriate to the needs of each child
 - Signposting, knowing who to ask about strategies and ways of coping
 - Acceptance of child's condition
 - Please put people "in charge" who know what they are talking about
 - Key worker
 - Educational Psychologists think they know it all
 - Flexibility around Disabled Facilities Grants and consideration for the wider family
 - Consistency throughout Cumbria – not just for those who shout the loudest
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- Transparency
- Evidence
- Consistency – of areas, of workers and of approaches
- Team, teachers, training for parents
- Belief and trust
- Believe in parents
- Record unmet need
- Social worker and key worker
- Access to right information
- Listen to me – staff from education and the NHS
- Out reach –stop centralising services
- Requests go in to a void – who we chase up and what are the timeframes?
- Point of contact – who are you?
- Bridge the gap when there are staff taking sick leave
- Be pro active and representative
- Blame culture but in future let's be solution focussed
- Choice and options – services are limited
- Complaint, compliance policy
- Family support plan
- Finance, in control
- Support to complete paperwork
- Access to expertise. Therapists receiving the correct training
- Positive attitudes – from parents and professionals
- Residential medical services etc versus independence
- Sibling support
- Transport versus venue
- Flexibility
- To be taken seriously
- Equity of services
- Emergency support – who can support me at short notice, crisis intervention point?

Appendix Two – Full List of comments from Evaluation Sheets

A total of 17 evaluation forms were completed and all said they thought the venue was okay for the day. The following comments were added:

- Very central, parking and access, good food and pleasant surroundings
- Directions taken from the hotel website were incorrect – takes you to a no through road

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

- Discussion with Durham presentation – beginning to move forward and Durham showing how it can be done
- Meeting people and sharing a range of relevant experiences. Plus a large degree of optimism
- Meeting other parent/carers – listening and sharing and listening to Lesley was inspiring
- Positive aspect of the day – moving forwards
- The brainstorming session because it made me think about what does and does not work
- The Durham Parents' Perspective and Model – it illustrated that it can be achieved
- Discussing the wish list and listening to other people's views and opinions
- All of it – something that looks like it has a "light at the end of the tunnel"
- Sharing information with other parents
- Opportunity to network and very interesting topics of discussion
- The whole conference – that something positive will come from this meeting and it will move forward
- Thinking that we could make a change
- Lesley Moore speaking – what we are aiming for!
- Lunch – needed sometime to reflect on the morning session
- Having my concerns listened to
- Learning a bit about what things are out there; meeting more people, where to get more information from - to the point of maybe thinking of joining a group (even though I am very quiet)
- Discussion with other parents over their major problems and some answers to these problems

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

- Nothing really. Perhaps the ending was a little uncontrolled and less certain as people drifted away
- None – all pleasant
- Didn't understand some of the jargon used but that is just my own ignorance

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

- More information about Aiming High in Cumbria

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

- Very positive, well planned
- Enjoyable and uplifting. I was left with optimism that something would happen
- Fun, refreshing - a brilliant start
- Looking forward to sharing and bringing about positive change – not sure how but I am interested in working with the folks with the cash!
- Thought provoking and positive
- Short and sharp, very enjoyable and empowering
- The whole day was informative and worthwhile. Looking forward to the next one
- Excellent, seeing as I just turned up unannounced! Plus, good food – for a fussy eater who had brought a packed lunch
- Very informative, can see a vision of better services in the future
- Excellent, so refreshing to hear parents are empowered. Keep up the good work and I'm with you!
- Brill
- I thought the day was good – was good to meet other parents. Looking forward to the steering group
- Very well organised, great facilities and good to spend time with like minded parents/carers. Well done
- Lots of lively comments, positive attitudes and enthusiasm from all concerned
- I thought the day was very good. It was good to meet people who had the same problems as me
- Next time I will bring more people
- Very logical, well planned day