



Learning to Change II

Conference Report

Devised by Parents for Parents
with disabled children

Monday 19th October 2009
North Lakes Hotel



contact a family
for families with disabled children

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Introduction

Rachael Davies, a parent member of the steering group, chaired the event and began by welcoming everyone to the second Learning to Change conference. The parent steering group had organised and arranged the conference with the assistance of Contact a Family and staff from Cumbria County Council. In attendance were parents and a number of professionals who had been invited through the steering group.

The aims of the day were to share information and gather parent views on local parental engagement and involvement, based on the outcomes from the first parents' conference held in July 2009.

Rachael stressed how Aiming High for Disabled Children is a transformation programme to improve services for disabled children across England. Those improvements can only be achieved by parents and professionals working together, and the Learning to Change conferences give everyone a platform to do this.

Setting the Scene

Kathy Rist, Regional Manager Contact a Family North East & Cumbria
Jon Parnaby, Strategic Officer – Inclusive Services, Cumbria County Council

Current Developments

In response to information gathered from the first Learning to Change conference, there have already been developments in local Short Break services for families with disabled children.

An additional 700 hours of short break care were available over the summer holidays alongside more activities for children and young people.

The medium term goal is to expand after school and weekend services and long term, there will be a large commissioning procurement programme for short break services across the whole county.

Aiming High for Disabled Children: Communications Survey

To address some of the issues that had been raised around how information is shared with families, a survey was distributed at the conference to gather parents' views on communication.

The results of this survey are attached to this report as Appendix One

Proposed Parent Participation Model

At the first conference held in July 2009, parents heard from a County Durham parent about the model of participation that had been adapted there and were asked to design a suitable model for Cumbria.

The purpose of a participation model is to engage effectively with as many parent/carers as possible to influence change and the improvement of services for families with disabled children.

Some of the issues affecting local parental engagement in Cumbria include:

- Huge rural county
- Spread out population
- Lots of local Initiatives
- No central point of contact
- Informal information exchange
- Cut off coastal area
- Too many lakes, mountains and sheep!

At the first conference, parents identified the following issues that were important to them:

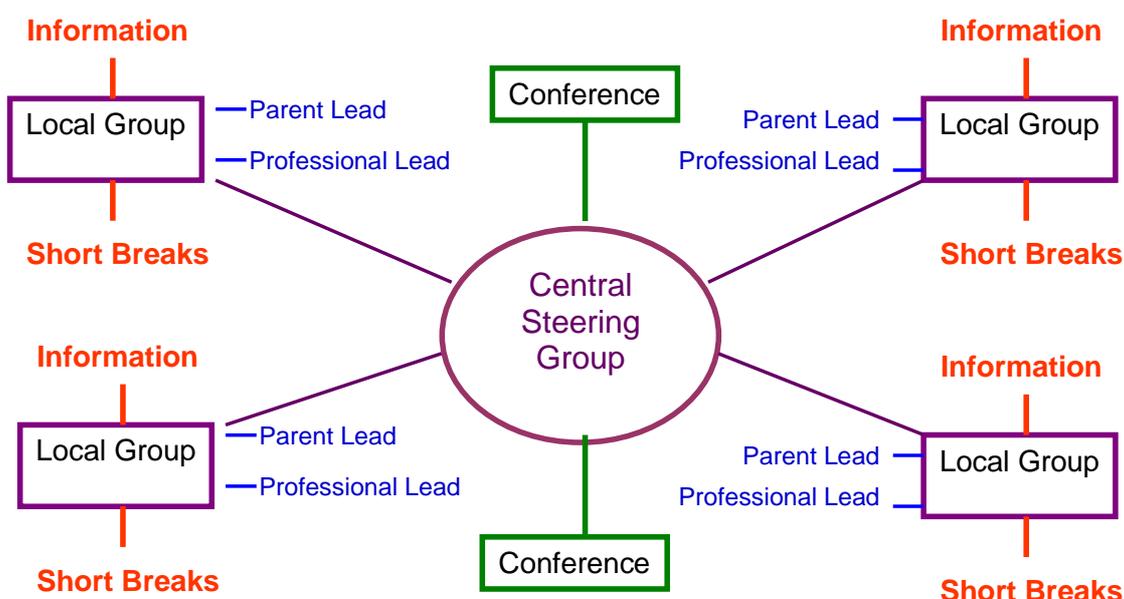
- Central point of contact (could be virtual e.g. a website or a text service)
- Good Information sharing
- Key worker system
- Parental involvement
- Professionals listening
- Working together
- Ask us

Whilst working through this agenda, it is important remember the Five Fs for Success:

- Focus
- Flexibility
- Fun
- Food
- Feedback

Out of the suggestions from the first conference, the following participation model has been designed.


Cumbria – Parent Participation Model

NB:

- Co-ordination & Administration
- Capacity
- Ground Rules & Vision
- Disability Representation

Key Points about the Proposed Model

- The model needs to be one that suits local parents, not the Local Authority
- The proposal is to hold two conferences per year, one in Spring and one in Autumn
- Information gathered at these conferences will feed into the main steering group and drive the agenda forward
- Information and Short Breaks were identified by parents as priority areas at the first Learning to Change conference which is why they are included as the focus areas for local groups
- Within the central steering group, it is important to have representation from a range of disabilities, children’s ages and geographical areas
- Parents can choose which local group they want to feed into, this could be based on where they live or where they primarily receive services, the important point is that it is a choice
- Each local group will have a parent and professional lead, to facilitate effective partnership working

Timescales

The model may look daunting to parents who would like to be involved, but who may worry about the time and commitment they would be expected to give. To address this issue, the model can be broken down into sessions of time (rather than thinking of whole days)

- 2 sessions per year – for those parents who would like to attend the Learning to Change Conferences only
- 8-10 sessions per year – to attend the Conferences and local group meetings
- 15-17 sessions per year – to attend the Conferences, local group meetings and steering group meetings

Local Authority Information

Cumbria County Council work in four localities, each having their own devolved money and devolved power:

- West
- South Lakes and Eden
- Carlisle
- Furness

It is proposed that a Disability Champion will be appointed in each locality; this champion could be the professional lead within the Cumbria Parent Participation model.

Is This Workable? - Table Discussions

In tables, parents and professionals were asked to discuss the proposed model, focusing on the following issues:

- Is this workable?
- What happens in each area?
- Where would you meet?
- Does the amount of time asked of you seem reasonable?
- Could you trust other parents to represent you?
- Disability Representation
- Administration & Planning
- Ground Rules and vision

The majority of attendees agreed that they could see the proposed model working in Cumbria. Key issues identified through the discussions were:

- Parents felt that the South Lakes and Eden group would be too large and should be split into separate local groups
- There would be a repetition of parent views through each local group but this would not be a negative as it would reinforce the priority areas identified by parents
- There are lots of local parent support groups already running throughout Cumbria so it is important that parents within these groups have the opportunity to feed into this process and that existing initiatives are supported to take part in local engagement and participation
- There is a need to ensure parents of children with a broad range of disabilities are included in the process
- There should be more than one parent from each Local Group on the main Steering Group. This will help cope when there are illnesses, when parents have to be at appointments with their children etc
- The timing of meetings and issues such as a group's ground rules should be decided by each Local Group and not imposed by the main Steering Group
- To ensure parents do not become bored or disillusioned, it is vital that changes actually happen as a result of their involvement in this engagement process
- There are concerns about populating the groups and ensuring a fair representation of all disabilities
- Meetings need to be planned in advance, for example a year's worth of meetings need to be organised so that parents can plan their attendance
- Any professionals who are involved need to have experience of working with families with disabled children
- Parents will be spread out, even within a local group area so there needs to be other methods of gathering views rather than just meetings. Suggestions included having email addresses and contact through text messages (being aware that there can be local signal problems with mobile telephones)
- Learning to Change needs to be advertised widely through the Aiming High 4 Us newsletter and other agencies communication methods
- Within a local area, rotate where meetings are held to make it easier for parents to attend
- Administration should not be problematic but parents who are involved will need to receive any out of pocket expenses incurred or a voucher to say thank you for their time
- Ensure that discussion areas (currently Information and Short Breaks) do not remain static but change to reflect the priorities identified by local parents
- Parents who are involved in the participation process will need to be aware they are representing others and working to a wider agenda than their own families needs

Locality Area Discussions

Following lunch, parents were asked to “Choose Your Area” and sit with others on tables from the **5 local groups** that had now been proposed. In each local group, participants were asked to think about what could be achieved, the quick wins, between now and the next Learning to Change Conference which will be held in April 2010.

They were also asked to think about the practical arrangements for their local groups e.g. meetings, venues and timings etc and discuss how they would see the vision of each group developing.

West

- Half-termly meetings organised a year in advance
- If professionals are not able to attend meetings, there should be an opportunity to email them with information to ensure continuity of communication
- Need to be aware that from a service perspective, children cross over into different areas (e.g. for speech and language therapy, health services etc)
- Meeting group minutes from each local group meeting should be shared with other areas
- Would be good to have an independent Learning to Change website which would give parents another option for feeding in their views if they are unable to attend meetings

Furness

- Important to build on and improve communication with existing groups
- Ulverston was suggested as a suitable place for a venue for meetings
- Alternate times of meetings and plan them well in advance
- There is already a parent/carer forum in Furness. This group was established through concerns that the local leisure centre was not inclusive. Through the involvement of this forum, in 6 months the leisure centre has turned around and now offers holiday activities for disabled children, they are looking to use Aiming High funds to build a soft play sensory area and music is turned down for part of activity times to meet the needs of children with Autistic Spectrum Disorders. This is an example of how parental involvement can influence real change
- Essential to have good communication between all local groups

Carlisle

- Hold a midday meeting to raise awareness of the Learning to Change agenda
- Share information far and wide to reach more parents, including through local schools
- Possibly use a local Children’s Centre as a venue

Eden

- Look at meeting once every half term within a local Children's Centre, possibly in Kirkby Thore
- Hold meetings from 10.00 a.m. to 12.00 p.m. to make them manageable for parents
- Concerns were raised around who the local Lead Professional would be as this is not currently clear to the group

South Lakes

- Use Kendal Children's Centre as a venue for meetings
- Alternate meetings between weekdays and weekends
- Will hold a first meeting with just parents and then invite professionals after this first meeting
- Hold meetings bi-monthly
- Have a collated list of everyone's email addresses so that it is easy to communicate and keep everyone updated with what is happening

During these discussions, parents were asked to complete Sign Up Sheets to highlight which group they would like to be a part of. A total of 43 forms were completed, illustrating the fact that parents are welcoming the opportunities to have their say and influence change in Cumbria.

Each group will be contacted through the current parent steering members to set up initial local meetings.

Parking Lot Questions and Answers

Throughout the Learning to Change II Conference, parents were encouraged to add any questions they may have to a Parking Lot area. The questions follow along with responses from the relevant agency and individuals (Cumbria County Council in Bold, Kathy Rist in Italics):

1. Relationship duplication – Parent Partnership and Parent Participation

Parent Partnership is the name of a service to support parents of children with special educational needs by providing advice and information about matter relating to those needs. They are mainly involved in advising and supporting with educational needs, including statutory assessment and the statementing process. However, they may also be involved in parents support groups. All Local Authorities must provide this service.

Parent Participation is about parents being involved in their own child's assessment and care planning, as well as being involved in the design and development of services that would best meet their needs.

It would be a first task of all of the locality parent forums to find out exactly what parent groups are already established in their areas and how they can link in with them to avoid any duplication of effort.

2. Personally, I would think 5 areas would work better than 4 for local groups. South and Eden needs 2 groups, splitting Eden into Carlisle/South would mean that professionals would have to go to two meetings

5 groups are now agreed upon with Eden and South Lakes each having their own locality parent forum.

3. Concerns whether Eden/South Lakes should be together?

See 2 above

4. We need to consider how to link with Aiming High

Jon Parnaby, Strategic Officer for Inclusion (Aiming High) for Cumbria County Council will continue to support the work of the Parent Steering group as well as attending as many locality meeting as he can. This will feed into the overall plan for Aiming High in Cumbria. In addition a parent representative from the steering group may be asked to attend the Aiming High Partnership meetings which report directly into the Children's Trust Board.

The Parent Steering Group will have a direct link to Aiming High through Kathy Rist from Contact a Family who is the Parent Participation lead for Aiming High in Cumbria & NE England.

5. Potential to use video conferencing available in some Cumbria County Council offices and schools. Build up talking with small support groups

Video conferencing can be used from Cumbria County Council premises however room availability where this facility is available cannot always be guaranteed. Talking with small support groups; see 1 above

6. Two trusts? Parents need to know where it is going to. Do we need to link with Aiming High?

If the 2 trusts refer to the Primary Care Trusts; we are all awaiting the results of the PCT commissioning and reorganisation process and will look to the NHS in keeping everyone updated. For link to Aiming High see 4 above.

7. Concerns over representation of children in wheelchairs with physical disabilities in Eden

Each locality parent forum would be self monitoring and would look to ensure that all age ranges and disabilities are represented in their group where possible.

8. Access to Children's Centres? Some areas don't have one

Children Centre development is now in Phase 3 and it is hoped all communities would have some access to Children's Centre services and facilities shortly

9. Difficult to populate local group. Parents need to be encouraged, supported to join local groups

Cumbria County Council and Contact A Family will support the locality parent forums in the promotion of their existence through its website and magazines.

10. Source meeting places – suitable places for parents

As previously mentioned the groups are self monitoring and as such it is the groups decision as to where and what time to meet. Venues need to be free for parents to access such as at Cumbria County Council offices, Children's Centres and other local free venues.

Local pubs

11. Need good representation of all special needs – is important

See 7 above

12. Could access 2 focus groups if living in the boundaries of 2 areas

Parents are free to choose which locality parent forum they wish to access. There has already been examples of parents accessing forums in the area they access services rather than in their home area.

13. Need to ensure all groups of disabilities are represented

See 7 above

14. Any expenses for attending courses/meetings may be an incentive and even necessary

A system is to be introduced for any parent attending a forum or meeting on behalf of Cumbria County Council to be able to reclaim out of pocket expenses such as mileage and childcare

- 15.5 local Disability Champions - local champions not all professionals

The local champions are members of the Local Planning Group who have been identified as having experience of or an interest in the needs of disabled children. The local disability champion may change depending on the needs of the locality.

16. Professional Lead needs to have experience with disabled children

The professional lead for the local forums would ideally have experience with disabled children but may also be someone with influence in the locality.

17. Alternative meeting places to suit parents

See 10 above

18. Inclusion of LEAs and other agencies for children with learning difficulties

The LEA is now part of Children's Services. If the local parent's forum feels it would be helpful to have different professionals representing different sections of Children's services, e.g. Child care, SEN, then this can be arranged. Any agency can be invited to a parent locality forum to support a locality moving forward on their agenda (currently limited to Information and Short Breaks). If a number of localities are facing the same issues and these are being brought to the parent steering group; a representative of an agency, or a service could be invited to attend the Parents Conferences for the same message to reach a wider audience at the same time.

19. Information - text messages, email via schools and via NHS website

Information is one of the key areas each locality parent's forum will be looking at. Texts and emails are proving popular and a system may be introduced depending on the needs fed back from each locality forum.

20. Website – forum for parent/carers and parent/carers answering questions

The Cumbria County Council website is being updated more regularly and will shortly have an overhaul in response to comments and suggestions from parents. If an online forum is required parents could set one up independently of the Council website. However they would need to introduce moderation of the forum.

21. How do we get information out at the point of diagnosis?

The whole arena of information is one of the areas each locality parent's forum will look at and feed into a plan for both Cumbria County Council and the Primary Care Trusts to improve their information quality, method and timing.

22. Information packages for SEN/Additional Needs in NHS

See 21 above

23. Restraint training for behaviour for parents

This is a very specialist area and is usually specific to individual children. The need for this training has been identified and will be discussed with specialist providers. However, Cumbria County Council is currently investigating the possibility of widening access to some of its training opportunities to include schools, carers and parents of children with learning difficulties and disabilities. This may include general behaviour management. Any opportunities once agreed will be notified to the locality parents' forum, steering group and conference.

24. Any training on lifting and handling for parents

See 23 above

While we know this issue (and the difficulty raised above) is a problem for some parents we must be aware that this is a very specialist service and may need a small select focus group of parents who can move help it forward in the future.

25. Speech and Language Therapy

Query as to what the issue/question is here. If this was raised by you please contact Jon Parnaby/Kathy Rist

26. Low income families – school needs, books, trips (food tech materials)

All schools have an obligation to ensure that any child is not excluded from an activity due to financial hardship. In the first instance the schools inclusion policy should be referred too.

For some parents who feel awkward approaching the school please contact Karen Hull the Parent Partnership officer who may be able to help.

27. Siblings coping with brothers/sisters with disabilities and the emotional impact on a family

More inclusive activities are planned under the improving short break offer thereby enabling siblings and whole families to have access to short breaks together. More and a better quality of short breaks will reduce the emotional impact and effect a child with disabilities has on a family and the need for emergency respite care.

Young carers' schemes provided by the carers' organisations also offer support to siblings – Carers Organisations can be contacted directly

28. Left on own to cope with transitions

Transition is huge topic within the Aiming High agenda. Cumbria County Council has already hosted a transition conference for professionals and created a steering group to look at Transition across a number of services (social care, health, transport, leisure, education, work etc) and update and improve the Transition protocol. There will be an opportunity for parents and children's views to be considered in the revised protocol

29. 16 – 18 years – no help, even in crisis. Not in children's services, not in adults services

Cumbria Youth Support Services (CYSS) develop services for young people aged 13-19 according to their needs. This includes access to positive activities and personal development opportunities, impartial information, advice and guidance, and targeted youth support for vulnerable young people at risk of poor outcomes. Key people involved and working together are Youth Workers; Connexions Workers; Drug, Alcohol and Sexual Health Workers; Leaving Care Workers, Young Carers Workers, PAYP Workers, and Youth Offending Service Workers.

CYSS aims are to:

- **Reduce the number of first time entrants into the criminal justice system aged 10-17**
- **Reduce the number of 16-18 year olds who are not in education, employment or training (NEET)**
- **Reduce young people's substance misuse**
- **Reduce under 18 conception rates**
- **Increase young people's participation in positive activities**

30. Mental Health – CAMHS to Adult services not smooth and little to no communication

See 28 above re transition

31. How come there are various activities planned for half term (next week) but no-one on our table had heard about them!

Information and communication is an area we are hoping to improve upon (see previous answers). Details of the half term activities had just been finalised at the time of the conference. The timescale is not satisfactory (just 1 week before activities) and we are looking to improve this for activities for both the medium and long term

32. Mainstream schools need more training for kids with ADD. Need ADHD, ASD, Dyspraxia and Behaviour training

See 23 above

Absolutely agree – the separate Lamb Enquiry is looking into school access for all disabled children but particularly those with behaviour difficulties. We already know that this Enquiry will lead to staff training in schools and will hopefully be able to tell you more at next Conference.

33. Where did Early Support go? Are the Early Support boxes still available?

Early Support is still available and training is ongoing to engage more professional in this process. A database of all trained staff and those families accessing this service is being created which will highlight areas of the county where further training support is needed. The Early support boxes are still available and should be on offer to parents of children who require the service.

Next Steps

Rachael Davies thanked everyone for giving up their time to attend the conference and thanked all members of the Learning to Change steering group for organising the event.

The fact that at the first Learning to Change conference, only half of the room used for this event was needed, highlights how local parents and professionals welcome the opportunity to get involved and effect real change for local families with disabled children.

This is just the beginning of local parental engagement and participation. The process is evolving and is a learning curve for all involved. Most important is the fact that the process is PARENT LED. Only parents' knowledge, experience and expertise can influence real change working in partnership with local professionals throughout the county.

From completed evaluation forms, those in attendance had again welcomed the opportunity to network and share information as well as share their views and thoughts on how local parental engagement moves forward in Cumbria. (A full list of evaluation comments is attached as Appendix Two)

It is important to now build upon the enthusiasm and positivity from this event to ensure the development and improvement of local services for families with disabled children.

Parents who have signed up to be further involved will be contacted through the main Learning to Change Steering Group with details of the first Local Group meetings in their chosen area.

Appendix One - Aiming High for Disabled Children: Communications Survey and Results

Responses received at Learning to Change II: 19 October 2009

Number present	66
Number of responses received	36

Nb not everyone answered every question

Firstly, please tell us what you think of our current means of communicating with you

1. **Our website:** www.cumbria.gov.uk/aimhigh

Are you aware of the website www.cumbria.gov.uk/aimhigh ?

Yes	No
10	26

Of those who answered 'yes':

Do you find the website www.cumbria.gov.uk/aimhigh a useful source of information?

Yes	No	Fairly
5	-	4

Please tell us how we can improve the website www.cumbria.gov.uk/aimhigh

- More up to date info about activities
- Local links
- Email alerts to new material
- Break down into geographical areas
- Hyperlinks to national websites
- More user friendly / pleasant to look at
- More info

2. Our dedicated magazine for families of disabled children: Aiming High 4Us

Are you aware of the magazine *Aiming High 4Us*?

Yes	No
23	11

Of those who answered 'yes':

Do you find the magazine *Aiming High 4Us* a useful source of information?

Yes	No	Fairly
14	1	5

Please tell us how we can improve the magazine *Aiming High 4Us*

- | |
|---|
| <ul style="list-style-type: none"> • Increase publicity / awareness! • Info on transition • More for young adults (15+) • More info on local disability-specific support groups • More info from CFIS • More info about social events • More individual stories, celebrating success, inspiring CYP & their families |
|---|

3. Direct mail – using our dedicated voluntary database for families with disabled children, record4u

Are you aware of the record4u database?

Yes	No
7	24

Are you registered on the record4u database?

<i>Of those who were aware</i>		<i>Of all respondents</i>
Yes	No	Not sure
5	2	3

4. Dedicated conferences and events organised by Cumbria County Council – e.g. short break stakeholder forums, steering groups, Learning to Change conferences

Are you aware of our dedicated conferences and events?

Yes	No
21	12

Have you attended any of our dedicated conferences and events prior to this one?

Yes	No
12	20

If yes, please say which
<ul style="list-style-type: none"> • Short breaks x 2 • Learning to Change I x 8 • Contact a Parent, Lakes College Workington

If you have attended a dedicated conference or event, please tell us how we could have improved it

<ul style="list-style-type: none"> • Less costly venues – nice to be spoilt but not when services for our children are threatened by cuts • Venue & agenda all good – speakers informative & representative of specific subjects (<i>learning to change I</i>) • More parental involvement • First time attender: v good clear messages

Please tell us what issues you would like future events to cover

<ul style="list-style-type: none"> • Respite care • 15 years + • ADMD • General autism awareness & funding • Activities for wheelchair children who are alert & aware • Getting the right help for kids & parents • Anything involving the input of parents & carers • Transition • Transport • Statementing process – help for parents through this difficult time (LA officers seem hard to contact and not really interested) • Family support – real support for the family, not just a paper filling exercise for an employee

- Health
- Schools – sharing information about Learning to Change

Second, please tell us what other sources of information on issues to do with disabled children you find useful (e.g. national or local media, dedicated publications, websites, meetings etc)

- Cumbria Cerebral Palsy website
- Sport England website
- Autistic help group, Brewery, Kendal
- Parenting Asperger website
- Local ASD groups
- Contact-a-Family website & magazines x 2
- DCSF website
- Parent Know How – direct.gov
- NONE!
- National Autistic Society
- Publications: NAS, Look, RNIB
- National charities
- NAS website
- Special kids website
- Kendal Family Drop In Centre
- Health visitor

Lastly, please tell us how you would like us to communicate with you in future

The website www.cumbria.gov.uk/aimhigh	21
The magazine <i>Aiming High 4Us</i>	25
Direct mail – letter	18
Direct mail – email	25
Conferences & events	26
Text	12
Social Networks (e.g. Facebook, Twitter etc)	2 pro 1 anti: Don't have time!
Other (<i>please specify</i>)	
<ul style="list-style-type: none"> • Letters would be nice (but expensive) • Focus groups 	

Appendix Two – Full List of comments from Evaluation Sheets

A total of 9 evaluation forms were completed. Comments made were:

Something I've learnt from today

- Families are struggling to be heard
- That Contact a Family are in the centre of change
- How we can work together and influence changes
- That most parents are very keen to get things moving forward
- People are keen to move forward and improve services
- The implementation of the parent partnership model
- That I am not alone in being dissatisfied with the services we are currently receiving
- That things are moving forward in a positive way
- Website exists

Something I've felt/experienced today

- Friendliness
- Encouraged that change is possible and that people will listen
- That there are many parents who feel that it is the right time to make changes
- That all parents want the best for their children
- Parents feel the same way
- That the lack of communication and information sharing is very poor
- Less isolated; that the problems we are experiencing are not unique
- An understanding of problems encountered by other parents of children with special needs
- Hope

Something I'll take away from today

- To put families in touch with Contact a Family
- Good to meet more parents and feel mutual understanding and possibility of future contact and support
- Enthusiasm to encourage other parents to join local groups
- Experience of other parents and how they cope
- A way forward
- Too much to name – vast amounts of information
- Hope that things can improve
- Knowing that things are changing in a good way and hopefully soon
- Positive planning

Something what was not so good about today

- Slightly confused about groups which already exist e.g. steering group/strategic group for short breaks
- Having to travel so far
- Could have done with more time for discussion
- Just getting here