



# Learning to Change III

## Conference Report

Devised by Parents for Parents  
with disabled children

Monday 19<sup>th</sup> April 2010  
North Lakes Hotel



## Contents

Introduction .....	3
The National Picture .....	3
The Cumbria Model .....	4
Local Groups Feedback.....	4
Carlisle .....	4
Eden.....	5
Furness .....	5
South Lakes .....	6
West.....	6
Aiming High in Cumbria .....	8
Information and Communication.....	8
Proposals for Next Steps.....	9
National Indicator 54 .....	9
Short Breaks.....	9
What's Changed For You?.....	12
Give Us a Break.....	15
Aiming High Parent Participation Funding .....	15
Parking Lot Questions and Answers .....	18
What Next? .....	23
Evaluation Comments.....	24
Next Steps .....	24
Appendix One – The Cumbria Model.....	26
Appendix Two – Full List of What Next Ideas .....	27
Carlisle .....	27
Eden.....	27
Furness .....	27
South Lakes .....	28
West.....	28
Appendix Three – Full List of comments from Evaluation Sheets .....	29

## **Introduction**

Kelly Monks, a parent member of the steering group, chaired the event and began by welcoming everyone to the third 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 parent/carers and professionals who had been invited through the steering group.

Through effective partnership working between parents and professionals, some changes are already being made and the aim of this conference was to share information about what has been happening locally and to look at the next steps of the Learning to Change process.

Kelly also fed back briefly on how, along with fellow parent steering group member Rachael Davies and Jon Parnaby from Cumbria County Council, she had recently attended the National Parent Participation Conference held in London in March 2010. This had given Cumbrian parents and professionals the opportunity to hear about what has been happening across the country and to share good practice with others.

## **The National Picture**

Kathy Rist, Regional Manager Contact a Family North East & Cumbria

Aiming High for Disabled Children (AHDC) is a long and sometimes slow transformation process but changes *are* being made. Because of the current situation with regards to an imminent General Election, it is also a time of uncertainty, even though there have been verbal promises of cross party support for this agenda.

## **Partnership Working**

### Parent/carers

- Have to navigate a number of systems
- Try to find out what information is available to them
- Constantly have to try to find the person that is going to make a difference to them

### Professionals

- Have to know how to tell parents about the services available to them
- Often don't have the resources available to provide families with what they need

Frustration and stress can be felt by everybody but links between them are what can bring everyone together; what makes us all strong and what can make a real difference.

This is the essence of effective partnership working and the aim of days like today, the third Learning to Change Conference in Cumbria.

## **The Cumbria Model**

The local model of parent participation that is being implemented in Cumbria had been devised from information gathered by parent/carers at the first two Learning to Change conferences.

A copy of the model is attached to this report as Appendix One.

## **Local Groups Feedback**

Joanne Cooper-Holmes and Dawn Raynor, Parent Steering Group Members

Joanne and Dawn gave short presentations on what has been achieved so far in each of the 5 local groups in Cumbria. Below each presentation is the name(s) of the parent lead for the groups and their contact number as each has now been given a mobile telephone through the Learning to Change process to make it easier for parents to access them and to ensure no personal numbers are shared.

### **Carlisle**

Parent Leads – Kelly Monks & Joanne Cooper-Holmes  
Contact Number - 07824 838 498

The group has now met three times in the community rooms at Carlisle Fire Station. At their first meeting, parents got to know each other and get a few things off their chest and then set to work on information sharing and short breaks.

In the second meeting, the group collated all the information they knew about and how parents had actually accessed that information. They also identified gaps they felt Carlisle had.

From that, they invited a sports development officer from the City Council to discuss leisure activities and they also met with their disability champion.

Where the group is now:

- SAS Club in Carlisle for older children has now been re-established
- Information is starting to flow and is being shared
- Signposts and networks are being created and change is beginning to happen

The group would welcome new parents to the meetings.

## **Eden**

Parent Lead – Hazel Hanley & Sandra Taylor  
Contact number - 07824 838 505

The Eden group meets at Kirkby Thore Children's Centre. They have established a forum for parents and others. It has been particularly useful to have Jennie Taylor, Information Officer from Cumbria County Council, Debbie Armstrong, Family Support Worker from Contact a Family and Mark McKay from Eden District Council along to have a communication flow now going both ways.

Issues the group have looked at include:

- Short breaks
- Information and how to build up a useful network for parents
- Transport
- Very useful information sharing on a local level and troubleshooting e.g. sorting out issues with access to local facilities

Remember, hope doesn't trickle down from above, it bubbles up from below – that's us!

## **Furness**

Parent Lead – Jackie Bell  
Contact number - 07825 125 657

In Furness, there was already the established Furness Parents/Carers of Disabled Children Forum and several existing parent support groups that were represented at Forum meetings. Rather than develop a new Aiming High Group, they decided to work with the existing Forum and groups. Through previous consultation events they had already identified short breaks and information sharing as priorities in the area and had started to make changes.

Most of the Furness groups meet on a monthly basis and information from the Forum is passed on and comments and views are fed back.

In the past 15 months, they have established links with the local Community Development and Sports Equality Officers and the local Leisure Centre and they have several representatives that attend the Transforming Short Breaks Stakeholder meetings. Through these links, they have begun to transform the short break opportunities in the area.

They now have a regular programme of activities for each holiday that includes swimming, climbing, safe cycling, trampolining, horse riding, football, canoeing, cinema visits and music sessions. They are constantly reviewing these activities and consulting with children and families in order to develop and improve them.

Numbers of children accessing these activities are increasing as they establish more effective methods of advertising and establish better links with local schools and groups.

One of the most exciting results of the collaboration between parents and professionals and local providers is the proposed soft play and sensory area that will be suitable for disabled children of all ages. The Council has recently agreed to allow it to be built within the local Leisure Centre and the group hope that structural work will begin within the next few months. Consultation with families will continue throughout this project.

### **South Lakes**

Parent Leads – Glynis & Steve Pepperell and Joanna Cartwright  
Contact number – 07825 112 548

The group meets bi-monthly on the second Monday in the month and has now met three times. They have also held a meeting on a Saturday at Sandgate School, Kendal with Karen Hull (South Lakes Disability Champion) and Debbie Armstrong (Contact a Family) which was very well attended and is going to be repeated.

The group have collected a lot of information from families and the main issues arising are short breaks, information, transition and inclusion in mainstream activities.

- Information is reaching more parents
- More inclusive activities are becoming available
- Parents are having a say in how the Aiming High funding can be best spent

There are many issues still to address but it is early days yet. The group are working more closely with professionals. The professionals are also listening and together, everyone is beginning to work in partnership. Things are moving forward and parents together can achieve great things.

### **West**

Parent Leads - Dawn Raynor and Rachael Davies  
Contact number - 07825 099 480

Dawn and Rachael have been running the focus group in the West now since last September. They have managed to get quite a lot of parents to join their email list but due to the lack of bridges and the large area they cover, the groups are still in their infancy.

Their main focus in the West not only covered short breaks, but was also to keep their overnight respite care centre up and running.

What they managed to do, with a bit of persuasion, was to achieve good participation and negotiation with the NHS and PCT to help relocate the service to Workington. Seacroft 2 is now up and running successfully after they all managed to work together pooling ideas and keeping all professionals/parents/carers concerned informed at all times.

They still believe however that there is a great need for a new disability centre where all services work together, with parents, carers and professionals to achieve good working practice and better outcomes for their children and those that follow.

Their next focus will be about information sharing. Firstly though, they are concentrating on getting parents on board. They do not know how long this will take as some/most parents appear to just function each day and are happy just to let things go by because they are tired and sick of fighting but if we work together we can prevent this from happening.

Other focus areas will be transition, equipment etc and whatever issues are not apparent to us at this time. They have decided to have meetings across Copeland and Allerdale.

The West group wanted to express a big thank you to the Children's Centres who allow them to have a room free of charge.

The group also wanted to thank the professionals for now treating parents as equals and listening to what they have to say. They are also looking forward to seeing and working with all the parents in attendance to make services better.

## **Aiming High in Cumbria**

Jon Parnaby, Strategic Officer for Inclusive Services, Maria Kielty, Strategic Officer for Short Breaks, Cumbria County Council

The Cumbria Model is really helping to move the process of change along in the right direction and its effectiveness can be highlighted by the fact that other areas of Cumbria County Council want to engage with local parents through this process. For example Connexions are doing some work around transition and will be attending the forthcoming South Lakes Local Group meeting to consult with local parents.

Jon wanted to therefore pass on his appreciation to all the parents who have been involved so far within conferences, the steering group and at local group meetings for helping to drive this participation model forward.

### **What has happened so far?**

#### **Information and Communication**

At the first and second Learning to Change conferences, parents identified Information and Communication as a priority area that they wanted addressing.

Aiming High 4 Us Magazine – parents wanted more parent stories and input and these are now included in each edition

Texting Service – parents wanted this to be introduced to help keep them informed of local events, activities etc. Cumbria County Council think this is such a good idea, they want to adopt it for other groups (such as young carers) and not just families with disabled children. This is excellent but has meant that the implementation of the service has been held up as a result.

Cumbria County Council Website - the Aiming High pages have been redeveloped and will be launched as soon as possible incorporating the whole of the Aiming High agenda in Cumbria as well as a library of useful documents and minutes as well as further links to other web sites.

Record 4u Database – parents said that they did not know enough about this database and others said it was too complicated to join. The process has therefore been made easier and is being re-launched as the Aiming High Network

Sharing information about Short Breaks – a supplement to the regular Aiming High 4 Us Magazine will be issued shortly which will give details of all providers that have been commissioned to offer short breaks to families with disabled children in Cumbria

## **Proposals for Next Steps**

What does transition mean to families? Transition can mean different things depending on a child's age, education and circumstances.

Initially, Cumbria will be looking at making improvements for older children who are moving from child to adult services and will focus on issues such as further education, work, adult social care health and housing. Parents are involved through the transition sub-group developing a new protocol to be signed up to by all partners as well as identifying pathways through services

## **National Indicator 54**

The Disabled Children's National Service Indicator is a survey undertaken by the Department of Children schools and Family that has been sent out to some families to ask them their experience of service change resulting from the Aiming High Core Offer. 200 families in Cumbria were approached to take part in this survey.

The views of these families are being used to measure how the Local Authority is currently performing.

The national average score was 61 out of 100, Cumbria scored 62 out of 100.

The council have plans to increase this score as they are fully aware that although above the national average, the score is still not good enough.

## **Short Breaks**

Maria Kielty gave an update on the work that has been undertaken on improving and developing local short break services for families.

As of 1<sup>st</sup> April 2010, new providers will have started to plan delivery of short breaks services around Cumbria. The providers will be working closely with Learning Disability teams, parents, carers, children and young people within locality stakeholder groups to discuss and agree what type of group activities can be delivered up until March 2011 and within the funding they have been given. The council also needs to ensure that they can reach all children and young people eligible to access Short Breaks and that any services provided are sustainable.

The specialist services that have been commissioned with the help of 4 parents from around Cumbria include:

**Element 1:** Specialist group holiday and weekend activities for children and young people aged 8-13 with severe and complex needs particularly children and young people with severe learning disabilities and/or autism AND challenging behaviour, children and young people with profound and multiple disabilities, children and young people with complex physical disabilities (including children and young people who used assisted or augmented communication).

Funding of £125,000 will provide 12,500 additional hours.

West	£41,500
Furness	£22,500
Carlisle	£25,000
East	£35,500

**Element 2:** Specialist age appropriate group activities – holidays, weekend and after school/ evening for young people 14 -19 with severe and complex needs -particularly children and young people with severe learning disabilities and/or autism AND challenging behaviour, children and young people with profound and multiple disabilities, children and young people with complex physical disabilities (including children and young people who used assisted or augmented communication)

Funding of £125,000 will provide additional 12,500 hours

West	£41,500
Furness	£22,500
Carlisle	£25,000
East	£35,500

**Element 3:** Individual sitting service/ community support  
Sitting service/ support to access community activities – up to 4 hours a week - for children and young people 0-8 with children and young people with severe learning disabilities and/or autism AND challenging behaviour; children and young people with profound and multiple disabilities, children and young people with complex physical disabilities.

Funding of £150,000 will provide 12,500 hours

West	£50,000
Furness	£27,000
Carlisle	£30,000
East	£43,000

## **Commissioned Providers**

After a rigorous tendering process which was supported by the Short Break Stakeholder Groups including parents and partners, the following providers were chosen;

- **Oaklea Trust** have been commissioned to deliver all 3 elements across both Furness & the East locality
- **Carlisle Mencap** will deliver all 3 elements across the Carlisle locality
- **Action for Children** will deliver element 1 & 2 in the West locality, working closely with partners. We are in discussion with a provider in West Cumbria to deliver element 3 and support to Action for Children to deliver element 2
- **Actionnaires (Action for Blind)** will deliver group activities across Cumbria to sight impaired children and young people

Oaklea Trust, Carlisle Mencap and Action for Children will be delivering presentations at the locality stakeholder groups shortly. Actionnaires are delivering presentations at Carlisle and West Cumbria at the April meetings and at Furness and East meetings in June.

## **Inclusion Workers**

In recognition that some children with disabilities may not want to access specialist activities and considering the sustainability of all activities after the Aiming High funding finishes; 4 Inclusion Workers have been appointed around Cumbria to work with locality stakeholder groups, workforce development, existing providers, local extended services coordinators and youth work development workers, to help speed up change and ensure that by the end of March 2011 at least 500 additional disabled children and young people will be able to access universal activities, including uniformed organisations, such as cubs, scouts etc. Inclusion workers will ensure that systems are in place to provide accurate and up to date information about activities available. The aim is for Inclusion Workers to reach an additional 500 children and young people to access universal services for at least 2 hours a week, 40 weeks a year.

Two full time workers in the West and East localities and two 20 hour posts in Carlisle and Furness and will all be working flexible hours.

## **Childminders**

Cumbria County Council are now identifying childminders who can provide services for disabled children. This work is currently at the very first stages of development.

## **Children's Centres**

Children's Centre providers have received funding through Aiming High to provide additional services for families with disabled children.

## **Extended Services**

The Extended Services Access Fund is for children aged 5 to 18 who fall into a range of categories, one of which is Children with an Additional Need. The fund amounts to up to £300 per child per year to enable them to access Extended Services activities.

Parents in attendance at the conference were all given information about the fund and encouraged to contact their child's school, as the funding will be distributed through them. Every school has an Extended Services Advisor who works with a cluster of schools, who can also be approached to support their application. .

## **What's Changed For You?**

In tables, parents were asked to share information and identify the changes they feel they have seen already as a result of the Learning to Change process, however small these might be.

There is an acknowledgement that there are still many areas of work that need to be improved and there is still a lot to do but within this exercise, parents were asked to try and focus on the positives.

Each table then gave feedback on the changes they had seen:

### **Table One**

- Not alone
- Knowledge of structure
- Networking, meeting more people
- More information available about activities
- Personal recommendations of what works – positive feedback
- Direct Payments – having the confidence to apply and receiving “me time”

### **Table Two**

- Lot more information being shared (Shirley Gilpin from Kendal Drop in Centre is a good source)
- More activities for children with additional needs and more information about these making it easier for children to access them
- Hearing about the Learning to Change conference and the locality meetings
- The chance to meet other parents and realise that you are not on your own
- More confident about “harassing professionals” due to shared knowledge

### **Table Three**

- Receiving more information
- Less activities so parents are awaiting plans
- Local Eden Support Group has realised that they need to organise their own activities
- What has not changed – information is still sporadic, funding is available but still not always advertised and parents have to access it most times and schools are still taking challenges personally

### **Table Four**

- During the Easter holidays, in Carlisle, Barnardos provided activities for children aged up to 8 with profound difficulties. These included musical picnic, swimming.
- In Shap, parents have to travel to get anywhere
- Actionnaires was running until Christmas but has now stopped
- Information not reaching all parents, don't get information from schools until the last day of term
- Penrith Leisure Centre did not have a sports instructor to work with children and young people with disabilities to access activities.
- No Occupational Therapist in Penrith, they are coming from Carlisle
- In Millom there is a multi-sensory facility that is fantastic. During the Easter Holidays, there were extra activities and one day to book on activities for children with additional needs, horse riding in smaller groups
- In the West there have been respite care developments

### **Table Five**

- More information from other parents
- Opened a new respite centre in Workington
- Access to Aiming High activities through Mencap
- Carlisle wheelchair supporters club through the university
- Funding to subsidise activities for disabled children at school
- New parents becoming involved
- What hasn't changed – not a lot of things for siblings to access; respite centre grounds are not accessible to all children. work is on-going but need better communication about the adaptations

### **Table Six**

- Support - Parents don't feel isolated; wider support networks are developing, more use of carers' funds
- Participation - There are more meetings between parents and professionals and parents are being listened to – “power to the parents”
- Information - Courses/workshops for parents and hearing more about training opportunities for parents; parents are receiving more information (mostly by email) and have easier access to information

- Activities - There are more activities for children with disabilities and some for siblings but often these are over-subscribed

### **Table Seven**

- More activities – weekends, holidays, day trips and leisure centre involvement; activities are more inclusive
- Sharing of information – parents, groups, information is more accessible and improving; more networking between parents, groups and services
- Special Schools – activities after schools and more socialisation
- Parents - becoming more active and empowered as they have support and backing; feeling less isolated and receiving mutual support
- Funding – information is being shared
- On-going process – areas of change are being highlighted

### **Table Eight**

- No apparent changes yet but there is hope for the future
- Need more information about activities – who does what, who they are
- Parents are getting more relevant/clearer information and receiving information in different formats/mediums
- Professionals are more responsive to parents' concerns and worries and are more accessible than before
- Sometimes professionals will not deal with a parent if they are referred out of county but this is slowly changing
- Since the last conference, one parent said they had now got the professional involved that they needed
- Different departments and services are starting to talk to each other
- Negative information sharing – sometimes professionals will tell you about something new but don't have the details (i.e. saying one thing will stop but there is nothing to replace it)

### **Table Nine**

- There have been more short breaks available at Bendrigg
- Parents are more aware of things like youth clubs
- Better information
- In the process of discussions with local swimming club
- Communication is better
- Sense of isolation has diminished
- There are better chances to discuss problems with other people

### **Table Ten**

- Parents get a lot more information than they used to but still want better information that should be provided for parents, shouldn't have to go out and find it themselves
- Small groups are forming but growing

- Divided opinions about whether parents feel their voices are being listened to and valued

## **Give Us a Break**

Following lunch, a short DVD was shown. There had been an acknowledgement that the voice of the disabled child/young person had been missing within the current participation and engagement process. To address this, a DVD had been made by children attending Mayfield School with the assistance of Cumbria based Prism Arts and the Haltwhistle Film Project.

Give us a Break gives disabled children and young people a chance to have their say about what they want to do in their spare time and the sort of short breaks they would like to access.

Showing the DVD at the conference is a reminder of why everyone is here today – to meet the needs of local children and families.

The DVD will feature on the new Aiming High web pages to be launched shortly by Cumbria County Council.

## **Aiming High Parent Participation Funding**

Karen Hull, Senior Parent Partnership Officer

Unfortunately, due to illness, Karen Hull was unable to attend the conference but has provided the following information about the Parent Participation Grant, overleaf.

### Costs and Expenditure to date – March 2010

Event name	Event purpose	Admin. Support costs	Venue & refreshment costs	Expenses claimed by parents/carers	Total cost of event(s)
Planning /information meeting 13/3/2009	Held initially to advertise and promote the Ah – PP agenda in Cumbria.	Provided by CCC Childrens' Services LDD & PPS	Venue - £74.25 Refreshments £55.20	£159.80	<b>£289.25</b>
Steering group meeting 9/6/2009 8/7/2009 23/11/2009 8/2/2010 1/3/2010	A county wide group to co-ordinate and inform the work of the local parent/carers forums and to plan and arrange the bi-annual conferences	Provided by CCC Childrens' Services LDD & PPS	Venue - £140.00  £140.00  £80.00 Refreshments - £87.40 £87.40	£90.71 £23.50	<b>£649.01</b>
Local parents/carers forum meeting	Local groups – agenda recommendations from central steering group and local need	Provided by local parent lead – keeping costs to minimum. Purchase phones for lead parent in each area and arrange set up and distribution. (Estimated costs per phone per year £40/45)	Hire of venue  Refreshments		
Learning to Change Conferences 13/7/2009 19/10/2009	County wide - Information exchange events – an opportunity for all members of local groups to meet with other parents/carers from around the county.	Provided by CCC Childrens' Services and Contact a Family	Venue and refreshments £1,608.26 £2,412.39	£427.89 £537.64	<b>£2,036.15</b> <b>£2,950.03</b>

From the above figures – average costs for each type of event can be calculated:

- The average cost of an Ah – PP planning meeting is £289.25
- The average cost of an Ah – PP Steering Group meeting is £216.00
- The average cost of an Ah – PP local parents/carers forum meeting is £10 – refreshment charges + free venue
- The average cost of a Learning to Change conference is £2,493.09

The local meetings need to be multiplied by 5 as there are 5 areas.

2009/2010 funding allocated to Cumbria for Aiming High - Parent Participation was £7,764.

Total information, production and communication costs - £1,183.97 Total meetings costs – £5,924.44

Expenditure to date - £7,108.41, still not showing some parent/carers expenses forms and mobile phone costs.

#### **Future anticipated costs:**

- Funding of local meetings – administrative costs, venue and refreshments, expenses claimed by parents/carers attending meetings. What about stationary costs – paper, ink cartridges, envelopes, stamps, telephone calls, emails/internet costs?

Would £50 per year cover this? x 5 = £250 per year = refreshments and venue costs if necessary.

- What about purchasing and paying yearly rental for a mobile phone for the lead parent in each area?

These have been purchased – with £2 month line rental and approx £12.50 per month top up for 5 phones = £870 per year

- Funding of conferences – as more parents/carers attend the costs increase – also need to include compilation, production and distribution of conference reports

Business support, organising and co-ordinating, advertising and publication costs to be met by Contact a Family PP fund –approx £300 per conference. Approx cost of actual conference and parents/carers claims - £2,493

- Training for parents – if requested, to achieve participation

Costs from business support for arranging and co-ordinating training sessions, stationery, vouchers, refreshments and refunding expenses. Use Children's Centres for free venues.

## Parking Lot Questions and Answers

Throughout the conference, parent/carers were encouraged to add any questions, burning issues or individual concerns they may have to a Parking Lot area. The questions follow along with responses from the relevant agency and individuals.

### Health

Q Children with Autism/Asperger Syndrome with an IQ over 70 cannot access social care teams and Direct Payments

**Eligibility decisions are being made on the basis of the eligibility criteria which is under review. We understand that only those children and families with severe and complex needs are eligible for support from the disabilities teams but we are not aware that this decision is based on IQ. Further information and clarification is being sought from the social care teams**

Q Could the PCT let us know how they have spent the budget allocated to them from the Aiming High budget?

**The Department of Health does not break down primary care trust allocations or 'ring fence' funding. Instead, decisions about funding for health services are taken locally by leading GPs representing each part of Cumbria. It is therefore not possible to disaggregate NHS Cumbria investment in a way which apportions a specific monetary benefit to the range of health services which support children with disabilities.**

**However NHS Cumbria fully supports the Aiming high agenda and invests in a range of services for children with disabilities including MENCAP, community children's nursing teams, residential respite, hospice services and improved health services closer to home which benefit all families.**

Q PCT Short Breaks Aiming High for Disabled Children money – how was it spent?

### See Above

Q Frustrations with OTs in the East (Penrith) area

**There has been a lack of OTs in the East locality due to staff leave and illness. OTs from other areas are offering to support the East in the interim until a more permanent solution can be found. This comment has been passed on to the OT team leader for information/action**

Q Community Paediatrician needed NOW please

**We currently have a locum community paediatrician doing some sessions for Eden (Elaine Service who has undertaken this role previously for the PCT). We have advertised for a full time locum unfortunately without success. The PCT is currently in the process of redesigning how all the children's health services are delivered across the County and resolving the Paediatric medical provision in the community is the top priority for action.**

Q Information from health visitors

**Information and communication is one of the priorities of the whole Aiming High Agenda. We are working with parents and many partners to ensure that accurate and up to date information is available in a timely manner through a variety of mediums. This will include a revision of information available to Health Visitors**

Q No diagnosis of conditions such as Autism, ADHD etc. No diagnosis means no access to correct social worker and no access to correct support

**There is currently no clear diagnostic pathway in Carlisle and Eden localities, however, pathways are in existence in all other areas of the county. When there is the likelihood that a child may have an ASD, in the absence of confirmation, all professionals should be responding to presenting need rather than waiting for a diagnosis**

### **Short Breaks**

Q If a person is chosen to accompany a child to allow them to access extended services does the "carer" have to meet certain criteria i.e. CRB checks etc?

**If a family is using their Access monies to pay for a "carer" to accompany their child on an Extended Service activity it is the family who must ensure they are happy with the "carer" they have chosen. CRB checks will not be a necessity for the Local Authority however depending on the activity, the provider may request one.**

Q Actionnaires Carlisle has been cancelled from the beginning of this year. When is this going to start back up and is there going to be a closer group set up in Penrith area?

**Actionnaires has since started in Carlisle having been commissioned by the Local Authority to provide services across Cumbria. In doing this work they will be looking at settings in other areas including Penrith.**

Q There is still confusion with professionals and with parents as to what “short breaks” are

**Short Breaks were identified by parents as their number one priority this being regular and reliable short breaks from caring. Children and young people also told us that they wanted more things to do and more places to go.**

**Further promotion and ongoing information in a variety of formats will continue to educate everyone as to what short breaks are and how to access them**

Q By the time I get around to booking anything the places are all filled

**Some short break activities do prove very popular. The newly commissioned providers of short breaks across the county have been tasked with reaching a wide a range of children and young people as possible. This will be monitored by the Local Authority and at feedback at the Short Break Locality Stakeholder groups.**

Q No information about holiday activities in Eden during Easter – were there any put on?

**There were very limited holiday activities in Eden over Easter compared to other areas of the County. The reasoning for this is unclear but will be monitored to ensure there is an equitable split across the county with the newly commissioned providers.**

Q Information about holiday activities coming out too late for parents to book places

**This will be rectified with the commissioning of new providers across the County as well as being monitored by the Short Break Locality Stakeholder groups**

## **Finance**

Q Is there help getting a private car or transport if you are not on high rate?

**If this transport is needed to access what can be termed as an extended service activity then you would be able to apply through your school for up to £300 per child through the newly launched Access fund.**

Q Having to use Direct Payments to use activities; some parents cannot access this

**There are no activities I am aware of which specifies that payment must be done through the Direct Payment system. If the person who raised this would like to get in touch with Jon Parnaby (01228 221156) to discuss which activity this refers too.**

## **Education**

Q On OFSTED panels, could there be a parent with a special needs child on them?

**It is unclear here as to what is meant by OFSTED panels. If this refers to OFSTED inspections of settings or schools; every parent has the right at an inspection to make their views heard. Dependant on the number of parents that may be wanting to do this they can either be interviewed by inspection team/officer or submit comments to them in writing.**

Q There is no information from education about the options in Year 9 going into Year 10

**This information is with schools and is readily available through the SENCO, headteacher or school office**

**If parents feel that they are not getting enough information, they should contact their Area Assessment Officer or the Parent Partnership Service for further advice.**

Q Transport and information from Shap. Information through schools is lacking and late

**Transport is an issue for all services across large swathes of Cumbria. The newly launched Access fund from the Extended Services team can be used for transport costs for children with an additional need. Information through school portals is overwhelming school admin staff. Discussions are underway to try and get this information direct to the SENCO network rather than using the school portal**

Q Negotiating Education and getting support, therapy etc

**The Parent Partnership Service is available to support families through the special educational needs process and to support families whose children have a disability which affects the way they can access education and the options available. Supporting parents to make informed decisions about their child's education.**

## **Learning to Change Conference**

Q Amplification at next conference is needed (hearing difficulties)

Q Loop system, struggled to hear planning for next conference

**These issues will be addressed at future conferences to ensure the right sound systems are available so that everyone can hear fully what is being said**

## Other

Q Keyworkers are needed

**The role of Key Worker, Lead professional and Team around the Family/child is an area Cumbria County Council are keen to support and are currently undertaking a whole workforce review which will lead to training opportunities for everyone to take forward these roles.**

Q We need adequate parking at meetings

**Unusually for the North Lakes Hotel they were hosting 2 separate conferences which did cause an issue for some when parking. There should be ample parking at the next venue on 11<sup>th</sup> October at The Castle Green hotel, Kendal**

Q Individual practical family support

**See answer re Key worker**

Q Practical help needed for families. Parents should not have to hunt it down; GPs, Social Services should signpost

**This again highlights the importance to parents and carers of relevant information at the right time and will be incorporated into the work already underway regarding a review of information and communication.**

## Other comments posted

National multi-carers card which can be used by all carers for access to various things i.e. travel, theatre etc so that we can show this to access discounts secretly along the lines of the cinema card (CEA) or impaired/partially sighted cards given by local councils

**Any national card would have to be led by a national organisation rather than a Local Authority to have any affect. If there was such a scheme I would be happy to support it within Cumbria.**

Carers Card implementation

**Money has now been allocated in the current financial year's budget to progress this piece of work. This will be along the lines of the Adult Carers card where the carer carries a card with 1 contact number on it which is rung if the carer has an emergency (accident etc). The contact number is for a call centre in Carlisle which holds a contingency plan for the carer which is then put into action.**

**This may be a list of who to call, what the carers caring responsibilities are (including medication) who has keys to the house, domestic routine etc If you are interested in helping the County develop a similar system for parents or carers with children with disabilities please contact Jon Parnaby (01228 221156). Due to the nature of the work and the location of the service provider, most meetings will be in Carlisle.**

## **What Next?**

Steve Pepprell, Parent Steering Group Member

In locality areas, parents were asked to think about the areas they want to focus on in the forthcoming months. This opportunity to identify priority areas is one of the most important aspects of the Learning to Change conferences as it helps to shape future work around service developments.

Steve reiterated that all ideas parents/carers come up with will be taken to forthcoming locality and steering group meetings to drive forward the Learning to Change process.

A full list of the ideas from each Locality can be found as Appendix Two to this report but on the day, each gave feedback on the one great idea they had:

### **Carlisle**

- Support in mainstream schools including activities and parent support

### **East**

- Well organised activities for children and families

### **Furness**

- Better transition planning into adult services

### **South Lakes**

- A local guide to schools, to help families pick out their strengths and make choices

### **West**

- Professionals to listen, hear, acknowledge and respect parents

## **Evaluation Comments**

There had been a real buzz at the conference, particularly in break times and during lunch where attendees were able to network with each other and share information. This is one of the major aims of Learning to Change, to ensure that more and more parents become involved and hear about what is happening in their local area.

From evaluation comments (a full list of these can be found as Appendix Three to this report), the opportunity to meet others is obviously valued by a number of parents who attended on the day:

What have you felt/experienced today?

**“The feeling that we all want the same thing and I am no longer alone”**

**“Meeting other people who are also passionate about positive change”**

From other comments, it is clear that many parents feel change is really happening but there is an acknowledgement that there is still a way to go:

**“Change is happening but still needs to progress”**

**“Even if no changes have been seen, there is hope that things will improve”**

There is also a very real sense from many parents that they are being listened to and valued in the participation process.

**“Parent power is increasing”**

**“As parents we’re listened to more than I had previously thought”**

Another major success of the Learning to Change process is in information sharing which was made very evident by the fact that so many parent/carers commented that they had learnt a lot on the day, especially around the Extended Services Access Fund which the majority had not heard about before the event.

## **Next Steps**

Kelly Monks closed the conference by thanking everyone for giving up their time to attend and participate.

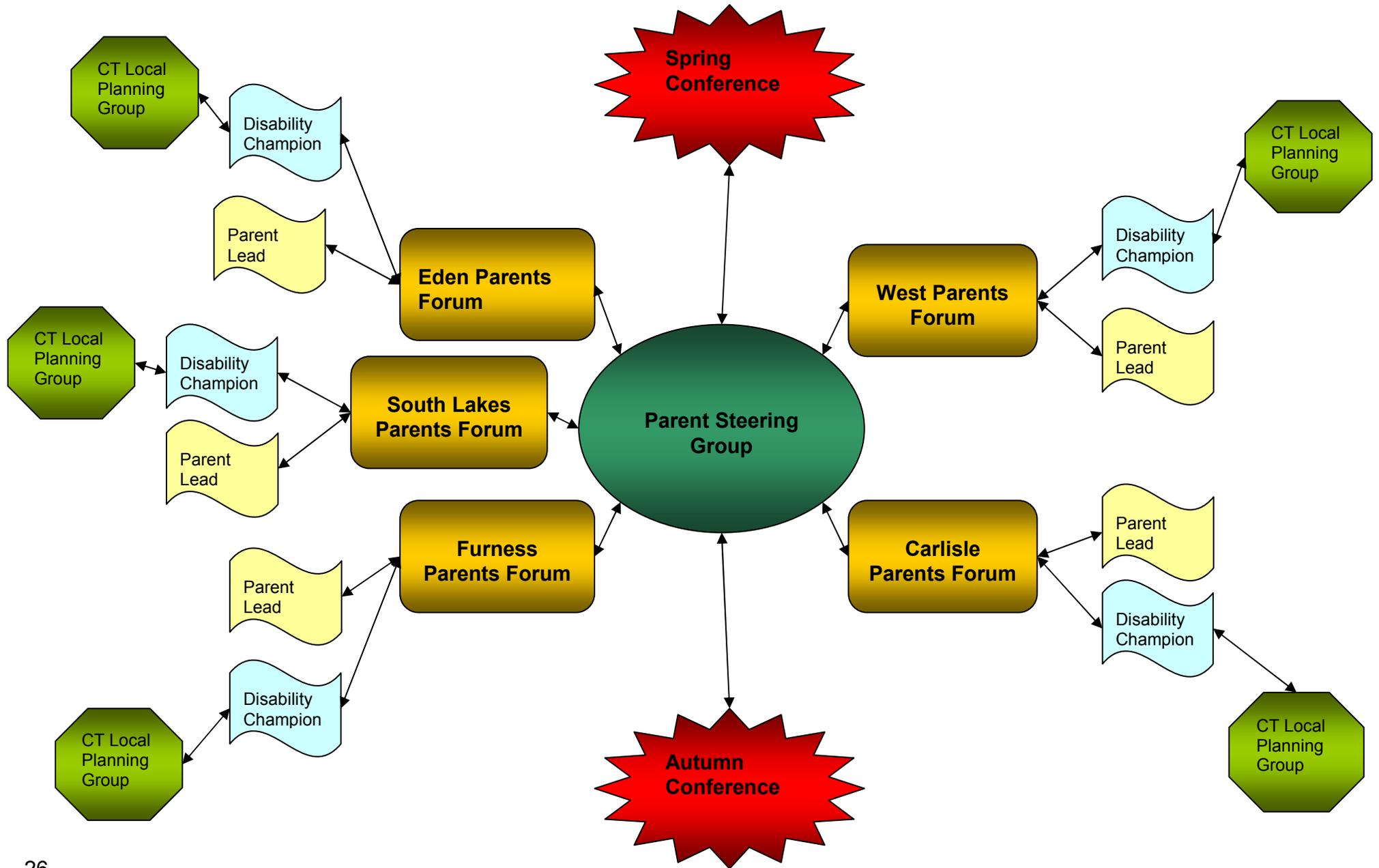
The views and opinions expressed on the day and included within this report will now be used to take the work of the Learning to Change groups forward within Cumbria.

Parent/carers are encouraged to sign up and become involved with their locality area groups.

Kathy Rist extended the Learning to Change Steering Group's thanks to Jon Parnaby and the role he is playing within this process to ensure that parent's views are listened to and heard by his colleagues throughout Cumbria County Council and also to Kelly for doing a fantastic job of chairing the conference.

To ensure the momentum is not lost and to keep the process moving forward, the next conference date and venue has already been arranged. This will take place at the **Castle Green Hotel in Kendal on Monday 11<sup>th</sup> October 2010**. Parents were encouraged to put the date in their diaries and also spread the word so that more parents can become involved.

# Appendix One – The Cumbria Model



## **Appendix Two – Full List of What Next Ideas**

### **Carlisle**

- More activities for 9 to 12 year olds
- Better information to parents
- Use Jennie – Cumbria's Disability Information Officer
- Sports and Leisure activities (Playground to Podium by Nicola Cartwright)
- Support in mainstream schools without having to fight for it (education and inclusive activities)
- Transition workshops (children to adult, primary to secondary schools)
- Money
- Carlisle parents to be consulted
- Information at a more applicable time (i.e. now for Summer) not one week before an event and all different providers to liaise so activities are not on the same day
- Texting service
- Barrow activities and sensory at the leisure centre
- Information on how to claim Direct Payments possibly a workshop

### **Eden**

- Fulfilled and fun-filled summer holidays – better and earlier communication from all relevant providers
- Swimming pools etc to be ready for disabled young people to access sessions
- Penrith Leisure Centre to provide specific sessions for young people with disabilities
- Linking up of inclusion worker and local parents group to discuss activities
- Calvert Trust to re-prioritise their horse riding provision
- Clarify and use access fund to extended services
- All take advantage of cinema card that means a carer goes free
- Focus of short breaks to be access to leisure activities
- Improved access to one to one support e.g. via Direct Payments
- On line information from Eden Forum group

### **Furness**

- Transition into Adult Services
- Holiday activities specific to Autism
- Weekend/after school clubs
- Child sitting service
- Flexibility within services
- Training for all professionals e.g. fire service
- Constant consultation with parents
- Education for all e.g. child, siblings
- More support for siblings and inclusion including family days

- Personalised service for individual
- More transparent criteria
- Bespoke activities according to needs and disability
- Suitable, available, affordable transport
- Access to healthcare, e.g. speech therapist
- A key worker to co-ordinate all service providers
- Early support – family support plan and information packs when needed

### **South Lakes**

- Activities – are centre workers trained? If not who will do the training? How will they access the training, what will the costs be? If they are trained are they confident that they are able to provide the support needed?
- Parenting courses need to be adapted or changed for parents of children with additional needs
- Information needs to be sent out with more notice as often parents need to make a lot of arrangements to attend events
- To have events organisers get together and try not to organise events that then clash
- Make mainstream activities open to those with physical disabilities by having access to equipment
- Social activities for teenagers
- Support to access life skills training for teenagers
- Specialist consultation with our children to find out what they want to do
- Local guide of schools in the area to pick out the strength of different schools
- Less jargon!

### **West**

- Professionals listening, hearing, acknowledging and respecting parents
- Formal structure to the support for children and less bumbling by professionals
- A lead professional who can do the above as there needs to be a more focussed, concise service; co-ordinated effective use of resources
- Stop taking families off the disability service/list
- Professionals to make sure information is accurate
- Professionals need to accept that it is okay to make mistakes as long as these mistakes are used to improve services
- Attitudes and cultures on the ground need changing
- Need to drop egos and be more focussed on the child and family
- More parental control, facilitator as opposed to key worker
- Carers Cards Schemes – a passport that is positive detailing needs (especially for leisure centres)
- More training for parents including challenging behaviour and epilepsy training

## **Appendix Three – Full List of comments from Evaluation Sheets**

A total of 30 evaluation forms were completed. Comments made were:

### **Something I've learnt from today**

- Change is happening but still needs to progress
- Parent power is increasing
- That there are avenues to go down that are able to help
- Names to network – Brilliant! Provision is still a postcode lottery even within Cumbria. I'll be finding out about Access Fund and Extended Services Advisor. Communication is always a major issue, it's getting better but is still not good enough
- As parents we're listened to more than I had previously thought
- I'm not alone! Funding and benefits from other parents
- Information about funding for activities for my local area
- That there is hope
- Parents really want to get information easily for their children and all want to be listened to too
- Not everyone has seen changes and improvement
- Things are improving slowly
- The process of Learning to Change is working and from the first conference to this one, changes have happened
- Talking helps to find out lots of new things that help
- What's available (i.e. funding)
- Disabled area for fire show – take blue badge

Another 14 comments were made about attendees finding our about the Extended Services Access Fund.

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

- Not alone
- Sense of belonging and not along in my life with what I have to deal with
- Positivity
- There is hope
- A real sense of parent power working
- Experiences of other parents
- Humbled by the dedication of parents
- Not alone
- I felt included and experienced a wealth of knowledge
- It has been interesting to meet other parents and find out what is available in their areas
- Meeting other people who are also passionate about positive change
- Relieved that finally school holidays will no longer be long hours of nothingness
- We are not alone

- The feeling that we all want the same thing and I am no longer alone
- Parents are passionate for their kids
- I'm very lucky
- Even if no changes have been seen, there is hope that things will improve
- Peer support
- Enthusiasm is bubbling away, lots of conversation
- Supported and understood
- Positive
- Understanding
- Loads of networking, groups seem to be growing
- Shared feeling of both helplessness but also of empowerment
- Parents are being listened to and changes are being made
- A lot of positive conversations with other parents
- Positive
- More positive about future service provision

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

- Feeling that progress is being made
- Things are beginning to change
- More information about what's happening in the (hopefully) not too distant future
- How things are changing for the better in Cumbria
- More email addresses to share information
- Positive attitude
- Support
- Hope of change for the future
- Some more email addresses
- Parents do have a voice
- Encouragement
- Tasks to do before next meeting
- Information
- Positive that things will change
- Some new friends
- Friends and contacts I've made and information to take back to local support group and Children's Centre
- Lots of contacts
- More information about the forum in my local area
- The ability to access more information
- Lots going on
- Need to continue to promote parental views
- Information about the access fund and a lot more friends
- A lot of information to help for the future
- Information. There is hope for the future for disabled kids; it'll be better than when I needed help now my daughter is at transition. Good food, much appreciated
- That we are heard as parents and carers
- Funding, benefits and confidence

A further 4 attendees said the Extended Services Access Fund.

### **Something what was not so good about today**

- Acoustics in the room
- Went too quickly
- It was all good
- Nothing – it was all superb
- Not enough time
- No water glasses after lunch (only minor irritation)
- Negative comments
- Bring speakers so we can hear audio on the film please
- Sometimes feel a bit isolated among others that know each other
- Acoustics
- Cumbria County Council – Short Breaks a visual powerpoint would have simplified information they were trying to get across. It needs to be more parent friendly
- Ran out of time
- Went too quickly, a lot of information to take in
- Hard to hear people speaking at times, need a microphone/sound system
- Nothing it was all excellent
- Time it takes to make things happen
- Realising still a very long way to go