

NORTH YORKSHIRE CHILDREN'S TRUST BOARD

20 July 2009

Strategy for Children and Young people with Learning Difficulties and Disabilities (LDD)

LDD Parent Participation: Report on the development of North Yorkshire's LDD Parent Participation Forum and an update on progress in the involvement of parent/carers in shaping services for disabled children and young people.

1.0 Key Points

- 1.1 The report updates the Board on developments in the participation of families caring for a child with learning difficulties and/or disabilities in planning health, education, leisure and social care services to effectively meet their needs and aspirations.
- 1.2 A copy of the Summary of the Parent Participation Event at Ripon is attached at appendix 1.
- 1.3 A copy of the first LDD Parent Participation Forum Newsletter May 2009 is attached at appendix 2.

2.0 Recommendations

- 2.1 The Board requests representation from the LDD Parent Participation Forum on the Children's Trust.
- 2.2 The Board recommends that the Parenting Support Working Group, chaired by the Assistant Director of Learning, Youth & Skills, has two representatives from the LDD Parent Participation Forum to feed back key issues at each meeting in order that a route for addressing the issues can be agreed.

3.0 Background

- 3.1 [Aiming High for Disabled Children \(AHDC\)](#), launched in May 2007, is the government's transformation programme for disabled children's services, jointly delivered by the Department for Children, Schools and Families (DCSF) and the Department of Health (DH).
- 3.2 The AHDC programme aims to deliver:
 - service improvement – commitment of substantial sums to improve specific / priority services, including additional funding in PCT baselines;

- system change – whole system improvements through national expectation setting, performance management and user involvement;
- 3.3 All services for disabled children should be delivered to the core offer standards set by the government.
- 3.4 The disabled children's services indicator – National Indicator (NI) 54 specifically measures parental experiences of services for disabled children and young people aged 0 -19.
- 3.5 The indicator is mirrored by an NHS Tier 3 Vital Sign on parents' experiences of services for disabled children.
- 3.6 The five elements of the core offer for disabled children are:
- good provision of information;
 - transparency in how the levels of support are determined;
 - integrated assessment;
 - participation of disabled children and their families in local services; and
 - accessible feedback and complaints procedure.
- 3.7 The government has contracted a research company (BMRB) to carry out a survey with around 200 parents of disabled children in each local authority. This information will then be used to measure parental experience of the core offer in local health, education and social care services.
- 3.8 The government has also initiated the parent participation programme as part of AHDC and aims to help groups develop parent participation activities in each local authority area across England.
- 3.9 This report focuses on the work taking place in North Yorkshire to develop an LDD Parent Participation Forum.
- 4.0 North Yorkshire Parent Participation Forum
- 4.1 The Together for Disabled Children partnership has been selected by the Department for Children, Schools and Families (DCSF) to support the Aiming High for Disabled Children short breaks and parent participation programmes. Together for Disabled Children is a partnership between Serco and Contact a Family, working closely with the Council for Disabled Children.
- 4.2 Over the period 2008 to 2010 £3 million has been made available for parent participation through a programme of grants and support from Together for Disabled Children.
- Phase 1 of the grant programme was open during the period September to November 2008. Grants of up to £3,330 were available for each local authority area to be spent by March 2009.

Phase 2 (2009 -10): Working together, parents' forums, parents' groups, voluntary organisations and services (including parent partnership services) can apply for £10,000 for each local authority area in England. The funding is for the period April 2009 - March 2010.

- 4.3 In October 2008 a multi-agency AHDC Parent Participation steering group was established comprising parents, voluntary organisations, parent partnership coordinators and senior officers from the North Yorkshire and York PCT and Children and Young People's Services.
- 4.4 One of the aims of the steering group was to agree a Parent Participation Strategy for North Yorkshire which has the sign up and commitment of all key partner agencies and parent carers.
- 4.5 To move forward the strategy, an event was held in Thirsk on Friday 23 January involving the Steering Group and some additional interested parents and professionals. The event was facilitated by Kathy Rist from Contact a Family who presented a model of parent participation which has worked well in Durham and other northern local authorities.
- 4.6 The Durham model is parent-led and involves two conferences each year the priorities of which are determined by parent carers themselves. Although financial and facilitation support is made available, the conferences are organised and chaired by parents through a Parent Steering Group. Parents therefore have control over the content and format of the conferences.
- 4.7 A bid was made on behalf of parents by the North Yorkshire Forum for Voluntary Organisations for the Phase 1 grant of £3,300. The bid was endorsed by the Director of CYPS and commitment given by the steering group members on behalf of their agencies.
- 4.8 Following the successful bid parents and carers of disabled children and young people across North Yorkshire were invited to an event on 18 March 2009 at Ripon Racecourse called "Improving Services for Disabled Children".
- 4.9 The event had 82 attendees of which 68 were parents or representatives from Voluntary organisations in North Yorkshire. (Report: Appendix 2). All six Integrated Service Areas of the county were represented.
- 4.10 On 6 May a further event was held at Thirsk Racecourse which was facilitated and chaired by parents themselves. It was agreed that the LDD Parent Participation Forum would have three sub-divisions, west, central and east, to enable more parents from all areas of the county to attend. Each area would hold meetings in a range of towns

rural locations each would nominate up to five representatives to attend to the county forum.

- 4.11 The LDD Parent Forum produced its first newsletter in May 2009 which was disseminated through schools, services and children's centres.
- 4.12 Any parent involved in the local or main county forum will have the opportunity to take part in focus groups relating to an issue of specific interest, such as childcare, short breaks, transition.
- 4.13 The LDD Parent Forum will invite representatives from relevant statutory agencies to the focus groups to receive up-to-date information and share views.
- 4.14 Similarly, key working groups and strategic boards may wish to invite the LDD Parent Forum to nominate a parent carer to participate in their meetings so that the parental perspective and insight will influence the planning of services from the outset.
- 4.15 The LDD Parent Participation Forum has been successful in its bid for Phase 2 of the AHDC grant which will provide £10,000 for the current year until April 2010. The LDD Parent Forum aims to become an independently constituted group although currently the group does not exist in a capacity where it can hold funds.
- 4.16 The parents have asked the North Yorkshire Forum for Voluntary Organisations to care take the grant and to provide training, advice, support, both administrative and practical, to develop the LDD Parent Forum so it widens and strengthens its membership to be a representative and influential voice for parents and carers of disabled children and their families.
- 5.0 Other developments in LDD parent participation.
- 5.1 As well as the development of the LDD Parent Forum, there are a number of other initiatives to promote and increase the involvement of parents in shaping the future services their families may use.
- 5.2 Many of these initiatives reflect the elements of the core offer referred to in 3.6. These are information, transparency, assessment, participation and feedback.
- 5.3 Multi-agency events including parents are taking place on a regular basis across the county. There is a growing awareness that parents and young people, who use services, are an essential ingredient of the planning process.
- 5.4 Many parents have asked to be consulted through surveys and to be kept informed via newsletters and websites.

- 5.5 Many of those parents attending the LDD Parent Forum had already expressed a wish to be more involved in shaping future services when they responded to the “Short breaks” parental questionnaire in the autumn of 2008.
- 5.6 Some of the grant funding has been used by North Yorkshire Forum for Voluntary Organisations (NYFVO) to establish an LDD Parent Participation page on their CYP website www.cypechange.org.uk which will be developed to include an e-forum for parents to exchange information and ideas. The recent annual CYP Voice, Influence and Participation Conference hosted by the NYFVO, included a workshop on the involvement of parent/carers in improving services for disabled children.
- 5.7 The Families Information Service (FIS) has an important role in providing information to parents and collecting new information from parent groups in the community.
- 5.8 The Parent Partnership Service also has a sub-site which can also be used to give information and feedback to families and to seek their views about a range of issues and services.
- 6.0 Aiming High for Disabled Children – Participation Strategy
- 6.1 The participation of parents, carers and young people in planning services is a theme which runs through all the work streams within the Aiming High programme.
- 6.2 The identification and promotion of good practice in participation is the responsibility of all practitioners and managers and has implications for all services and children’s workforce development. Parent/carer involvement on recruitment and selection panels is an example of how service users can have an influence on the ethos and delivery of services to vulnerable children and young people.
- 6.3 To this end, where parent/carers give freely of their own time it is important for them to feel valued and respected by professional colleagues. It is also important that parents are not left out of pocket because of travel or childcare expenses incurred in their voluntary work.
- 6.4 For some parents, training and support will be needed to build up their confidence and to help them to recognise the difference between advocating for their own child and representing parents interests as a body.
- 6.5 Services will need to be sensitive to the additional demands in caring for a disabled child and arrange meetings and events which parents can fit around the school day. Without this understanding,

participation will not be effective or inclusive, and resentment and division may arise which will be counter-productive.

- 6.6 The LDD Parent Forum is in its infancy. Parents themselves will drive it forward and determine its course and its priorities.
- 6.7 There may not be any additional grant funding from the DCSF beyond April 2010. However, there is already a commitment from the voluntary sector, parent partnership and parents themselves to ensure that the LDD Parent Participation Forum continues to thrive into the future.
- 6.8 This commitment along with the LDD Participation Strategy is an encouraging sign that families will have a real say in the development of services which really meet their needs and aspirations.

References:

Aiming high for disabled children – better support for families. DfES /HM Treasury May 2007. Available on www.hm-treasury.gov.uk

Aiming high for disabled children -Delivering the core offer standards
Available on www.dcsf.gov.uk/everychildmatters

National planning guidance and ‘vital signs’ - Department of Health February 2008
Available on www.dh.gov.uk/en/Publicationsandstatistics

Healthy Lives, brighter futures – The strategy for children and young people’s health: DCSF/DH, February 2009
To obtain a copy visit: www.orderline.dh.gov.uk and quote 285374

Report prepared by Helen Forshaw, Senior Parent Partnership Coordinator, Learning, Youth & Skills, CYPS.

APPENDIX 1**Report on the Parent Participation Event March 18th 2009**

The event had 82 attendees of which 68 were parents or representatives from Voluntary organisations in North Yorkshire. A list of attendees is shown in Appendix 1.

The event was opened by Sheila Constable, a parent, who introduced the context of the event and explained that the aim was to develop the voice of the parents of disabled children. She was followed by Miranda Parrot, regional adviser for Together for Children. Miranda explained the context of the Aiming High grant that was supporting the event. Miranda's presentation is attached in Appendix 2.

This was followed by a presentation from 2 parents from Durham Parents' Forum, Elaine Chandler and Chris Shields, together with a commissioner for LDD services from Durham County Council, Paul McGinty. Their presentation is attached in Appendix 3. The key message was that the development of the forums for the Parent Voice in Durham had developed over 2 years. It had been a demanding journey but had been rewarding and through perseverance and building effective relations with key advocates within the statutory sector they had seen changes and constructive progress in translating their voice into action. They showed a directory of services that they had developed and this was well received.

This was then followed by group discussions. There were 8 tables which discussed three questions:

- what areas work well;
- what areas need to be improved;
- what needs to be done now.

The details of the outcomes from the groups are detailed in Appendix 4. The key outcomes are summarised as:

What areas work well?

- There has been an improvement in early years support in recent years; information and guidance is well received, although some groups described the support as patchy.
- Local voluntary sector support was effective and highly valued
- Health Visitors are valued but need more support.

What needs to be improved?

Information lacks coordination, places great demands on parents having to seek advice

- From multiple sources and there needs to be a 'one stop shop' service;
- health visitors provide a valuable service but seem to lack support and have become increasingly restricted in what they can do;
- transition is confusing as both adult services and children and young people's services' work in different are set ups;
- there is a need for better emotional support for parents e.g. counselling;
- There needs to be feedback when questionnaires are sent out to parents.

What next?

- Develop and support local voluntary networks;
- establish local district organisations to develop the voice of parents, with a whole area or two area groups (East and West) to interface with the statutory sector;
- parents need to be involved in work with statutory groups on developing transition and information.

Course Evaluation

How did you learn about the event?

Contacted by email	13
Contacted through VCO	27
Contacted via SENCo	9
Other parents	4
Other	8

Conclusions is that all sources worked but the voluntary sector contacts and email are the primary form of information

Facilities

Pre event Information -25 found it to be good, 17 satisfactory and 4 felt it to be poor.

Venue

26 said it was good, 1 satisfactory. There were several requests to ensure there are crèches facilities at the next meeting or to have the meeting closer to their base, especially Whitby. Two suggestions sought weekend or evening meetings.

One interesting proposal was to split the county into east and west areas and to have local meetings in these areas.

Catering

Was well rated with 46 'good' and 4'satisfactory'.

Clarity of the Event

How clear were you regarding the purposed of the event?

34 recorded being clear and 13 were not clear. Therefore future events need to have more information concerning purpose and outcomes.

Did the event meet its objectives?

43 said 'Yes' , one said 'no' and one said '50/50'

Was meeting parents/organisations useful?

All 48 evaluations stated it was

What would you like to happen next?

The key responses were:

- parent participation at all levels, particularly information groups
- feedback on the event and future developments;
- action to take place and to see greater interaction at both local and county level;
- better interface with key professionals from education, social services and health at the future activities.

Parental Response to requests for further involvement

Parents were asked if they would be willing to participate in any future events. 42 parents indicated they would be willing to participate. These were broken down as:

Craven	3
Harrogate	13
Selby	3
Richmondshire	1
Hambleton	9
Ryedale	8
Scarborough	3 (Whitby)
Unknown	3

That 43 volunteers came forward was excellent. However there may be others as those districts with low scores are those located furthest away from the venue.

This would suggest that there may be merit in having local meetings to generate further interest.

18 March 2008
R K Curry

Parent Participation event Ripon

3

Parent Participation Event Group discussion feedback FEEDBACK from group sessions

What went well?

- professionals following procedures and protocols
- local initiatives e.g. TAS
- parent network support
- early years network well managed, patchy but improving
- difficulty in answering as statutory services involving parents is poor; social care has very limited opportunity for involvement
- voluntary sector involvement is better
- occasional questionnaires – no feedback but better than nothing
- Education – annual review asks for our opinions
- home school link experience when encountered is very good – had access to information and guidelines
- v. negative, lack of information available
- parents should not have to fight for things and should receive a more [positive response
- portage works really well, regular, helpful
- early years workshops for parents of disabled children
- some grass roots work e.g. extended schools
- statutory sector does nothing re full participation
- voluntary sector feeds into statutory sector locally. works well.
- giving diagnosis is better, more support than in the past. Now there is more information
- support groups are helpful if parents have access to an appropriate group
- be ok if parents linked to support groups
- v limited consultation. questionnaires on education, short breaks BUT no feedback
- poor patchy, tokenistic
- early years can be good but still patchy
- voluntary sector has worked well
- parent partnership

What needs to improve?

- one point of contact
- no fragmentation of services
- joining of networks
- health visitors role needs to be reinforced and better supported
- need to know where to go for services
- communication, designated key links
- need to deliver what it agrees to – need progress
- better information re opportunities to be involved, future events, groups
- reputation and credibility of parental involvement activities
- approach/ attitude to parent carers - appreciation
- resourcing and support timings to enable parental involvement

- initial/general information re what to expect, time frames, contacts, signposting
- access to information at all stages – directory
- awareness and education of all practitioners to be ready with help, support etc for parent/carers
- need support to groups to help, support and advise parents including emotional impact
- listening and acting upon what families actually need
- improve developments in communication – website
- more information needed
- no information if child not statemented
- more information about family information service
- listening and capturing needs
- accessing all parents
- knowing who is who
- extended schools
- communication between services

What needs to be done next?

- locality support
- representatives from localities to meet and network
- counselling support
- one stop shop for information
- locality structures with a representative body
- adult services and children services must be aligned at points of transition and beyond
- coordination of helpful information
- information booklet sound a good thing – one place with everything
- local support groups
- identify a 'champion w' within children and young people's services
- invite key people to next event
- be more accountable
- steering group for North Yorkshire, subgroups to be area based and to identify issues
- no more than ¾ focus groups
- develop alternative communication systems
- identify existing mechanisms and forums to start parental involvement both at practitioner level and into the more focus groups / event type of activity
- find efficient ways to reach parents to enable them to voice opinions
- build on existing support groups to channel their experiences. Strengthen their ability to sign post and work in true partnership
- develop parent groups for support and information
- parent groups established in schools
- local parent forums with links
- audit what is already available for parents and families

18 March 2008
R K Curry

Parent Participation event Ripon

The North Yorkshire AHDC Parent Participation Initiative

Newsletter

Parents Together Aiming High for Disabled Children
May 2009

PARENTS MEET AT THIRSK

Following the parents' conference held at Ripon Racecourse in March parents who attended and said they wanted to be involved in the next stage met at Thirsk Racecourse on 6th May. Over twenty parents attended the meeting along with representatives from the voluntary sector, which came along to support parents in planning the delivery of Parent Participation in North Yorkshire. There was parent representation from across the county and this will ensure all parents are kept up-to-date as the initiative rolls out while also providing ample opportunities for involvement.

PARENTS DECIDE!

One important aim of the meeting was to discuss and agree the most effective way of dividing the county into parent friendly areas. The aim was to generate positive parent involvement by making access to meetings and information as 'local' as possible. After discussion parents felt that dividing the county into three locality groups was the best option. The three localities identified were;

- **Craven/Harrogate/Richmondshire**
- **Whitby/Scarborough/Coast/Ryedale**
- **Stokesley/Hambleton/Selby**

Hopefully, each area will offer a convenient central meeting point for parents. Meetings in the three localities are planned to take place in June - details are on page 2. As it's essential that information from the localities is shared at a county wide level the plan is to have a couple of parent rep's from each locality area to form a county wide steering group.

There will also be a need to establish parent focus groups. These will meet with service providers over the coming months to take forward the main issues raised by parents.

TOGETHER FOR DISABLED CHILDREN
- £10,000 GRANT

The next round of funding for Parent Participation is underway. The grant of £10,000 will be used to develop parent participation in North Yorkshire to March 2010. The grant will be used to cover parent travel costs, training for parents, admin, a parents' conference, developing a parents website and childcare for parents attending meetings. As parents haven't yet formed a formal constituted group with a Chairperson, Treasurer and Secretary, parents at the Thirsk meeting agreed that when the grant is awarded it will be held and administered by the North Yorkshire Forum for Voluntary Organisations on behalf of parents. This should be a great help and means its one less thing for parents to worry about and do!

GET INVOLVED!

Although we've made a good start the success of parent involvement obviously depends on as many parents as possible getting involved. All you need is determination and a little patience. You can help as much or as little that suits your individual circumstances. We all want to see improvements in services for our disabled children and this is where it starts. As the Chinese proverb states, '*A journey of a thousand miles begins with a single step*'. So, find the details for your locality meeting on page 2 and be sure to go along - have a cuppa and chat and take the opportunity to say what the important issues are for you and the type of improvements you would like to see for your child/children.

KEEPING IN TOUCH

Enclosure 4

This newsletter was produced by parents for parents. Our aim is to keep parents fully informed of developments as they happen. Watch out for further news coming your way. A website is also underway where parents can 'talk' to each other, share ideas or post comments. Details will follow shortly. If you need printed versions of this newsletter or would like to be placed on the Forum mailing list to receive information by post or email please contact Tracy Bingley on 01609 536210 or email: tracy.bingley@northyorks.gov.uk

Craven/ Harrogate/Richmond

Locality meeting for parents to be held on:

Date: Wednesday June 10 2009

Time: 10.00 – 12.00

Place: Barnardos, Grove Road Project, 37A Grove Road, Harrogate, HG1 5EW

Directions: no map link either access via a route finder or contact Tracy Bingley

Further details and to confirm attendance email tracy.bingley@northyorks.gov.uk
or telephone 01609 536210

If you can offer a lift or require transport please contact Tracy Bingley

Whitby/Scarborough/ Coast/Ryedale

Locality meeting for parents to be held on:

Date: Wednesday 17th June 2009

Time: 10.00 – 12.00

Place: Pickering Memorial Hall, Potter Hill, Pickering, YO18 8AA

Directions: no map link - either access via a route finder or contact Tracy Bingley

Further details and to confirm attendance email tracy.bingley@northyorks.gov.uk
or telephone 01609 536210

If you can offer a lift or require transport please contact Tracy Bingley

Stokesley/Northallerton/Selby

Locality meeting for parents to be held on:

Date: Wednesday 17 June

Time: 10.00 – 12.30

Place: Golden Fleece, Market Place Thirsk, YO7 1L4

Directions: www.goldenfleecehotel.com

Further details and to confirm attendance email tracy.bingley@northyorks.gov.uk
or telephone 01609 536210

If you can offer a lift or require transport please contact Tracy Bingley