



Report on Parent Carer Forum 2007

Thursday 11 October 2007

The vision for Children's Services:

“Working together to improve life chances and aspirations for each child and young person in Sunderland”

Introduction

This is the report of our eighth Parent Carer Forum in Sunderland. This annual event enables parent, carers and family members of disabled children and those with additional needs to meet with professionals who support these families to share information and contribute to the planning of services.

The focus of the Forum this year was “Listening to families” and therefore focused on how we can better encourage and support the participation of parents, carers and young disabled people in the development of services within Sunderland. A presentation was given by Katie Clark, a parent carer from Calderdale Parent and Carer Council and in the afternoon a theatre presentation on Individual Budgets was given by the Lawnmowers Theatre Company from Gateshead. Workshops were held during the morning and afternoon on a range of key topics.

Chair's opening remarks

Michele Carr and Dawn Kelly who are both parent carers, chaired the forum and gave a brief presentation outlining the scale of the task ahead for disabled children and their families.

Nationally 1 in 20 children are disabled and the overall numbers of disabled children have increased by over 60% in the last 25 years. Whilst the overwhelming majority of these children live at home, over half of the families are at the margins of poverty and excluded from participation in a society that most take for granted. Within Sunderland, almost 10,000 children have been identified as having a learning difficulty or disability. We need to explore new ways of involving parents in developing services to meet the needs of their child and family so that parent participation is active and meaningful. The time is right to make this change.

Achievements over the last year and plans for the future

Steve Fletcher, Services for Disabled Children, gave a summary of the City's achievements over the last year.

Sunderland has signed up to the "Every Disabled Child Matters" charter, which is an important commitment to improving services for disabled children.

Significant progress has been made over the last year in joining up and integrating services. This has included enabling very young disabled children to access Children's Centres across Sunderland and ensuring that the Early Support programme is fully implemented. With older children, Sunderland has been successful in obtaining funding through the Learning Skills Council and the European Social Fund to undertake some innovative work around helping students with learning difficulties and disabilities into employment or further training. A professional's guide to transitional planning has also been produced.

The termly "Real Issues" newsletter has been replaced by a monthly information mailing as a result of the partnership between Sunderland Carers' Centre and the Council.

Looking forward to the next year, the Government has produced a report "Aiming High for Disabled Children: better support for families", and as part of the Government's comprehensive spending review, £340million has been committed nationally to support disabled children over the next three years. This will result in increased support for young people in transition to adulthood, improved child care, a review of community equipment and wheelchair provision, workforce development, improved parent participation and improved short breaks. Significant funding, which is likely to exceed a million pounds in Sunderland, will be available to ensure that short break services are transformed. This includes overnight short breaks, sitting schemes, befriending schemes and residential services. This additional support must reach children with the most complex needs and must build and support a diverse and high quality market.

Parent participation

Katie Clark, a parent who is part of the Parent Carer Council in Calderdale gave an overview of what a parent carer council is and how she was involved in setting one up.

The Calderdale Parent Carer Council has been established for over 5 years

with a growing membership of active parents. It has developed successful ways of working in partnership with service providers and has made a real difference in a number of ways, including:

- an award winning playground project
- partnership working on the disabled children's strategy
- promoting inclusion through courses for parents and professionals
- information and training sessions
- parent focus groups working with professionals
- transitional projects – person centred planning
- setting up a young disabled children's forum.
- family activities
- peer support
- representation at strategic level both locally and regionally
- assisting other groups to set up.

Some of the challenges ahead are how to motivate parents when they are busy with enough to do already. This means that there needs to be a good balance between targeting families and listening to what people are saying so that families can see the difference that their participation has made. All of this costs money and so the funding needs to be available for participation.

The establishment of creative ways of engaging with parents so that they can become more active in their communities involves thinking more broadly about how, where and when parents can be engaged and listened to. The benefits of working equally together - parents and professionals - means that both sides can see that this is the way forward and that it really works, and that by putting the needs of the child first there are better outcomes for everyone.

“Heroic feats”

The Lawnmowers Theatre Group gave a presentation on Individual Budgets. The Lawnmowers is a company of people with learning difficulties based in Gateshead.

Heroic Feets follows three young people as they wake up to the possibility of taking control of their lives. They explore how to turn a dream into a plan which will work, how to get support and how to get started. They face obstacles, fears and questions on their journey to discover their inner strengths and a new beginning. Ultimately success is within their grasp.

Parent carer participation

Led by Katie Clarke and Dawn Kelly, who are both parents.

The purpose of the workshop

To ask parents for their views on how they would like to be involved and have a say in the development of services for disabled children including health, education and social care.

The key points and priorities that were raised at the workshop

1. To share information

- Parents currently get information and support from:
 - Children's Services
 - Parent Partnership - quite a few parents had never heard of Parent Partnership which is a service offering support and information to families with a child with special educational needs
 - Carers' Centre
 - support groups
- Parents were asked if they used the Children's Information Service but most said that the information the CIS provides is not particularly useful for disabled children and their families. The

information that is available gives no indication of how accessible the schemes and events are, both in terms of disability and physical access

- Parents want to be able to get information over the phone and to have a named person to contact for information.

2. Opportunities to share ideas and support

- To gain support from and give support to other parents – it was acknowledged that there are already some good support groups, particularly around ASD
- To be part of a larger group of parents
- Mailing list/newsletter
- To meet regularly.

3. Parents want to see better levels of support and assistance at leisure facilities, events and youth clubs and more leisure opportunities

4. Parents want more opportunities for their children to enhance life and/or independence skills

5. Parents were asked how they feed their views to service providers

- A very small number of parents gather the views of parents from

either their child's school or support group and feed this back through the Carers' Centre or sometimes school

- 3 parents are now representatives on the Strategic Partnership for Disabled Children.

The group acknowledged that most parents do not have the energy, time and commitment to sustain a Parent Carer Council and therefore viewed a paid worker as vital. There was a very strong view that there needs to be a commitment from the Local Authority in terms of support and funding a parent council, to give independence and a meaningful voice to parents.

By the end of the first meeting some parents had decided to get together to set up a parent group/forum/council. They talked about what they would need, such as:

- designing and printing flyers to go out to as many parents as possible
- a database
- a meeting place.

The group arranged a meeting for 2 November 2007 at Columbia Grange School.

Aiming high – Overnight short breaks

Led by Steve Fletcher, Services for Disabled Children

The purpose of the workshop

The "Aiming High for Disabled Children" programme will provide significant additional funding for overnight and daytime short breaks. The workshop gave an opportunity for parents and professionals to consider priorities for the development of additional short breaks in Sunderland.

The key points and priorities that were raised at the workshop

1. Parents need to have information about what is available. This must include universal and specialist provision

What parents would like professionals to do:

- improve Children's Information Service
- have all relevant information to pass to parents
- use "Every School Day Counts" newsletter
- create more individualised search facility on website
- create a dedicated short break information officer.

2. Parents need to be involved in setting priorities for service development

What parents would like professionals to do:

- ensure the process is inclusive of parents not currently using services (must be broad-based and using a variety of approaches)
- send newsletter and questionnaire to all on current Children's Services databases
- run a range of consultation events
- use existing parent groups wherever possible.

3. Help must be available quickly and easily; it must be flexible and include choice. Parents are often at breaking point before they ask for help

What parents would like professionals to do:

- review existing processes within Services for Disabled Children to ensure that help is available quickly and easily
- ensure parents are able to access a range of short break services without the need for an assessment
- establish an independent fund for complex needs and emergencies
- establish a dedicated short break team.

4. Initial thoughts on priorities for expanded services.

What parents would like professionals to provide:

- more activities for high functioning children
- more overnight short breaks
- more day time short breaks throughout the year
- improve and expand existing services such as leisure link and youth clubs.

Communication passports for children and young people in transition

Led by Lucy Shouksmith, Speech and Language Therapy Assistant

The purpose of the workshop

This workshop gave an overview of what passports are, discussed different types of passport and what purposes they can serve, how passports can be used to aid transition and how passports are produced in paediatric and adult LD SALT services (Learning Disability Speech and Language Therapy).

The workshop also focused on important issues and things to consider when making passports and also address further training options open to those who wish to start

making passports for their child/or for those in their service.

The key points and priorities that were raised at the workshop

1. Training

Training specifically for parents and carers, and support available to those who want to make passports for their own children - producing a passport would be a slightly daunting task for a parent if there was no support from a professional

2. Referral pathways

Clearer referral pathways for people whose children would benefit from a passport but are in a mainstream school placements

3. Transport

Another issue that was raised was about the cost and time public transport can take, depending where any training sessions are held. This was especially a concern when parents have to get back home for their children.

Direct payments

Led by Philip Snowball, Direct Payments Manager and Michele Carr, a parent who receives direct payments for her son

The purpose of the workshop

Direct payments are one way of arranging support for a disabled child and their parents. The workshop provided information covering what direct payments are, who can receive them, examples of what they can be spent on, the type and nature of support provided by the Council, and a question and answer session.

There was also the opportunity for attendees to hear first hand the experience of Michele Carr, a parent who receives direct payments for her son.

The key points and priorities that were raised at the workshop

- The scheme is flexible, fits into the lives of parents/carers and offers more choice suited to an individual
- The scheme can revolutionise parents lives – gives them a break
- Services in Sunderland do not always fit in with the needs of the child/parent; therefore the flexibility of direct payments helps overcome this

- Accessible information about the scheme
- Need to carry out more promotional work, especially in 'Special Schools', insert in 'Early Support Pack', Council's Sunrise Article
- Services for Disabled Children should ensure all families are offered the option of direct payments
- The child wherever possible needs to be involved in determining what he/she wants to do via short breaks, e.g. travelling to where and how by train
- On direct payments you decide what, where and when your child goes/does - flexibility
- At the assessment stage it is important for parents/carers to determine the needs of their child, the difference between these and those of non-disabled children and the parents needs
- Parents will need to be clear what their needs are as well as their child's –this is key in the assessment process and will help in compiling Care Plan
- Assessment – is it really equitable – groups are available to support/help parents with this e.g. Sunderland Carers' Centre, Contact a Family
- No two children are the same; each child has their own needs
- Good timing, from a parent/young person agreeing to direct payments and subsequently being paid
- If services are no longer commissioned or services are not needed anymore the money should be re-directed into the Direct Payments Scheme
- Personal Assistants – making the right choice to work with the child
- Important to get the Contract right for the Personal Assistant – Go Direct, Direct Payments Support Service will help with this
- Support is available from the Direct Payments Section and Go Direct, Direct payments Support Service
- The development of a User Group/Peer Support Group would be beneficial
- Important to listen to users of direct payments in the development of the scheme
- Participation by parents on the Services for Disabled Children Direct Payments Steering Group has been a positive experience
- It is important to have an accessible and a well-developed Direct Payments scheme, as it is the Government's direction of travel in relation to social care.

Circle of friends

Led by Dawn Kelly, parent

The purpose of the workshop

To explain to parents what a circle of friends is and how you can create a 'circle of friends' for a child. Anyone can use the circle to help them achieve their goals regardless of the child's difficulties or disability.

The key points and priorities that were raised at the workshop

Everyone was given a handout which explained that Circles of Friends originated in Canada and used throughout North America as one of a range of strategies to encourage the inclusion of children and adults with disabilities into mainstream settings. Circles have been used to support children with a wide range of disabilities and have also been used in the community.

Dawn explained for some children making and keeping friends is very difficult. Sometimes this is because the child has difficulties with getting about or sometimes this is because they are seen as different. In the absence of a naturally formed circle of friends, parents and teachers can facilitate a circle process which can be used to enlist the involvement

and commitment of peers around your child. Circles of Support are a relatively simple concept that can lead to very powerful changes in somebody's life.

During the workshop everyone looked at their own network of friends and support and talked about the importance of friendship. These circles were then compared to that of a vulnerable child who often has very few friends around them. The group then looked at how a 'circle of friends' could be created for their child and Dawn talked about some of her daughter's achievements since creating her 'circle of friends'.

Useful websites that can be used to find out more are:
www.inclusive-solutions.com
www.circlesnetwork.org.uk

Burning issues

Led by Ros Watt, Parent Partnership Officer and Susan Mustoe, Specialist Health Visitor

The purpose of the workshop

To enable parents and carers to discuss any issues that were not covered by the other workshops.

The key points and priorities that were raised at the workshop

1. Further Education

- We want the same as Tyne Metropolitan College. South of Tyne there is nothing post 16/18 years for young people with physical difficulties
- No reasonable adjustments in LA college in Sunderland
- No personalised integration plans for young people with sensory issues
- More training for mainstream staff
- To send young people to Tyne Metropolitan transport is £48 per day per person
- Costs to LA for tuition fees
- A need to compare costs against developing local FE colleges
- Young people contribute to their fees from their own independent living fund. They attend 38 weeks per year but have to pay for 52 weeks of year, at £46.00. Is there no funding from social care? LSC? Transition? Adult services?

2. Social care

Children with ASD and ADHD do not have access to “children with disabilities” services as they do not meet the criteria. Why are children with ASD and ADHD sent to “Initial Response Team”? Does the IRT have training to respond to their needs?

3. Housing issues

- Need equitable services; same diagnosis not able to access “disability facilities grant” WHY?

4. Schools

- Schools seem not to take on training needs
- NEED whole school training
- STOP teachers diagnosing or questioning diagnosis
- STOP illegal exclusions
- MAKE schools pick-up & recognise student stress related to diagnosis and act upon behaviours appropriately
- There is a need for 3 or 4 Columbia Grange Type Schools
- PCT funding OT but this is not available in mainstream, WHY?

Overview of issues raised

The Strategic Partnership for Disabled Children and those with Complex Health Needs will consider the issues that have been raised and look at how best they can be taken forward.

The key issues that the Partnership will look at are:

1. Ensuring that services provide help quickly, easily and flexibly and enhance the child’s life and independence skills.

2. Involving parents and carers in the development of services, using a variety of approaches including supporting the development of a parent carer council
3. Improving information available to parent carers through the Children's Information service and the website www.sncwd.org.uk
4. Improving leisure provision by expanding leisure opportunities and providing a better level of support and assistance at leisure facilities, events and youth clubs
5. Improving Direct Payments by promoting the scheme and providing more accessible information so that everyone who might be eligible is aware of the scheme; by improving the process of receiving a direct payment and by developing a user group/peer support group
6. Improving the use and understanding of communication passports by ensuring that there is a clear referral route to getting one and providing parents and carers with information and support so that they can produce a communication passport for their own child
7. Improving short breaks by creating a dedicated short break information officer and/or a dedicated short break team; establishing an independent fund for complex needs and emergencies; making available more short breaks and offering more day time short breaks
8. Ensuring that appropriate further education facilities are available in Sunderland and that transport costs for students to attend regional colleges are addressed
9. Ensuring that appropriate support is available for children with ADHD (attention deficit and hyperactivity disorder) and ASD (autistic spectrum disorder).

Evaluation

We asked participants to complete an evaluation form to give us their views on the day and to help plan for next year's event.

We received 49 completed forms in total; 32 from parent carers; and 17 from those that work in Children's Services, health and the voluntary and community sector.

Responses

Responses included:

- find out more about services (x40)
- have a chance to express your views (x20)
- meet staff (x13)
- meet, listen to and talk with other parents and carers.

Responses to the Forum included:

- 98% said the event met expectations
- 100% said the Forum was good-excellent
- 92% felt they had enough of an opportunity through to every opportunity to express their views
- 65% felt their views and recommendations had been listened to and 30% felt these would be taken seriously.

The following ideas were suggested for the Forum next year:

- Keep bringing speakers who can give us lots of information and advice to improve Sunderland services
- I would like to hear some good things that have happened and maybe the Director of Children's Services should come back
- More parent participation
- More time in discussion groups

- More centralised location, better facilities for groups and better publicity
- Twice a year perhaps having the 'afternoon' session later (6 months). The morning session is too short, and should roll over into the afternoon
- More events like the Forum and possibly ones where disabled children can attend as well.

The following ideas were suggested to improve parent participation

- Encourage parents to get more involved in meetings and sharing problems with other carers and professionals
- Set up a parent council to represent parents views and to inform and influence services in Sunderland
- Involve parent carers through Schools and support groups.
- Try an article in the local press
- Make sure information is simple and sent out individually to parents.
- Utilising all services – use the children's centres and other organisations who work with families
- Encourage meetings in non-threatening places, ie cafes.

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