



Report on Parent Carer Forum 2008

Thursday 9 October 2008

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 the ninth Parent Carer Forum to be held in Sunderland. Over the past year two major Government initiatives have been launched, “Aiming High for Disabled Children” and “Carers at the Heart of 21st Century Families and Communities. The focus of this Forum was consultation concerning the implementation of these initiatives. The Strategic Partnership for Disabled Children and Young People and those with Complex Health Needs, which organised the Forum, is committed to ensuring that this consultation exercise influences the Carers Strategy and the Implementation Strategy for Aiming High and any services that are subsequently developed.

Chair's opening remarks

Maureen Morris, Lisa Amos and Joanne Fenwick, parents from the Sunderland Washington and Coalfields Parent Carer Council opened the Forum for 2008. Maureen, along with Lisa and Jo, was very happy to welcome everyone to this year's Forum. She gave a brief history of how the Parent Carer Council came into being and how they were now becoming a voice for parents and carers of children and young people with disabilities in Sunderland. She spoke of how they were starting to work together with Sunderland City Council to provide a broader involvement of parents at all levels of decision making and how, most importantly they were all in this together: parents, carers, and council officers alike committed to making the experiences of children and young people with disabilities in Sunderland the best that they could be.

Carers at the Heart of 21st Century Families and Communities

Professor Sue Yeandle from the Centre for International Research on Care, Labour and Equalities, at the University of Leeds gave an overview of the issues facing parent carers both nationally and more specifically in Sunderland.

National Issues

The role of carers is receiving more prominence in national policy with a public consultation, The case for change: ***why England needs a new care and support system***, in May 2008. This covered three key themes;

- **Rights, recognition and respect for carers** to remain in work; to be dual partners in care; and to be valued by employers, health services, schools, care providers, wider community
- **Support and services for carers** which is flexible, reliable, affordable, sensitive
- **Financial security for carers** including support in sustaining paid work, fair benefits, recognition of the costs of caring

In June 2008 the UK government launched ***Carers at the heart of 21st century families and communities***, which is a 10 year strategic vision, covering health and social care, employment, income and equalities.

Research findings

The University of Leeds has undertaken research and has also analysed the 2001 Census. This has highlighted a number of issues.

- **Combining work and care**

In Sunderland there are 31,274 carers of disabled adults or children of whom 24,696 (78%) are people of working age. However, only 60% of those of working age are in employment, and only 22% of those providing high levels of care (more than 50 hours per week) are in employment. Those providing high levels of care are much more likely to be in poor health or disabled themselves.

There are over 700 households in Sunderland with a parent carer of a sick or disabled child aged under 16. These were slightly less likely to be 'two-carer' households than in England as a whole. One parent-carer households in Sunderland are split fairly evenly between those outside the labour market and those with a paid job.

Fathers in households with a sick/disabled child sustain high levels of paid work even when they are carers, whereas mothers are much less likely to be in paid work if they live in a household with a sick/disabled child.

• **Support and services**

Recent research has found that whilst most 'working carers' felt supported by their family, friends and neighbours, only about half felt supported by a 'carer friendly' employer (this was slightly higher if employed in the public sector). Only 1 in 4, working in both public and private sectors, felt services were adequate to enable them to combine work and care.

Parent carers in this study reported a higher level of negative findings about services than most other carers, with 58% saying that services were not flexible enough; 50% saying that services were not sensitive to their family's needs; 47% saying that there were no suitable services in their area and with 41% saying that they did not know what services were available locally. The vast majority were women; over half had left work to care and were much more likely to be struggling financially. Over 75% had been caring for more than five years and provided care for more than 50 hours per week.

In the same study of parent carers, two-thirds wanted at least one service they were not currently getting; a large minority wanted respite, breaks or sitting services. A third were getting no services at all, yet only 14% of parent carers said they did not want any services

The Future

Professor Yeandle concluded that as we enter the 21st Century the role of caring needs to be further acknowledged. Unpaid care is pivotal to the health and social care system, but carers currently pay an unfair financial penalty for caring. In the future, there will be more disabled children living at home requiring higher levels of support. Adults will have longer working lives, combining work and care. Pressures on carers will be too great unless we transform local support so that parent carers receive:

- Help to maintain/access paid work, as this is the best protection against financial hardship
- A system which does not add stress by inflexibility, poor communications, or slow response
- Flexible breaks from caring
- Access to training/support
- Ready access to occasional /emergency services at times of crisis

The full presentation and references to research and Government publications are available at www.sncwd.org.uk.

They can also be accessed via the University of Leeds, together with other research led by Sue Yeandle and colleagues at: <http://www.sociology.leeds.ac.uk/research/care-employment/care-labour-equalities/> .

Aiming High for Disabled Children

Steve Fletcher, Strategic Manager for Disabled Children in Children's Services gave a presentation on the Government Programme, "Aiming High for Disabled Children" and how this is being implemented in Sunderland, which is a Pathfinder authority.

The programme has three strands:

Access and empowerment

This strand puts families in control of the care packages that they receive and also involves parents, children and young people in designing and developing services. The key aspects are identified as

- Families need information as to what is available and eligibility criteria and decision making processes must be transparent
- The assessment process needs to be clear and brings together existing assessments and does not repeat them
- People who have participated in developing services must be given feedback as to the impact of their involvement.

Responsive services and timely support

This strand is about providing support before a family is in crisis and ensuring that the support is well coordinated across all agencies. There needs to be a better understanding of disabled

children's needs and better systems for ensuring that services provided do help disabled children and their families in the way that was intended. Support for families as young people become adults is particularly important.

Improving service quality and capacity

Four areas have been identified as priority for development

- The provision of short breaks, which can be in the day, evening, at weekends or overnight, and can be in the child's or carer's home, or in a residential or community setting. The purpose is to provide children with a positive experience and their families with a break from caring. Five priority groups of children and young people have been identified to receive additional short breaks, those with autistic spectrum disorder (ASD) with challenging behaviour or SLD; those with complex health needs; those aged 11+ with moving and handling needs requiring equipment and adaptations; severely disabled young people aged 14+ and those with severe learning disability and challenging behaviour
- The provision of childcare to enable parents of disabled children to continue or resume work

- A review of the equipment and wheelchairs that are provided
- The development of a workforce with the skills necessary to work with disabled children in universal and specialist settings.

Funding

The Government is expecting aspects of this programme to be delivered through other funding streams, but has committed significant additional funding to Aiming High as follows

- Parent participation grants £5m nationally; Sunderland is submitting a bid
- Child care £35m nationally; first wave of pilots announced
- Transition to adulthood £19m nationally; details to be announced; tender out for support agency
- Short breaks programme; £280m nationally to Local Authorities and a further £280m to Primary Care Trusts; pathfinders announced Sunderland has been successful and will receive:

Revenue Funding

2008-9	£292,900
2009-10	£944,700
2010-11	£944,700

Capital Funding

2008-9	£147,300
2009-10	£343,700

- PCT funding for short breaks is matched to Local Authority funding. Priorities are to be decided locally.

Progress so far in Sunderland

- A Project Team has been established and will be fully operational from 1 November
- A Programme Board has been established with broad representation to make decisions on implementing the programme. The Parent Carer Council is represented on the board
- An expanded range of youth and play schemes has been provided during the summer holiday period and will continue during half term holidays
- Overnight breaks for children with severe learning disability and severely challenging behaviour have been provided in a holiday cottage during the summer holidays
- Plans are being drawn up to expand facilities at Sea View Road West and to offer some day and evening care
- A young person's participation officer will be appointed to ensure that disabled children and young people are fully able to contribute to developments
- A consultation event with deaf children and young people and their parents is planned for the New Year
- A Participation Fund is being set up to provide funding to overcome the barriers that often prevent disabled children and young people from participating in universal services

- The recruitment of foster carers has been increased in order to provide more overnight and day short breaks in family based settings
- The creation of a parent involvement officer is being considered to ensure that parents have the opportunity to be fully involved in the programme
- More families are now receiving Direct Payments in order to arrange their own support and many of these families are receiving larger amounts of money
- Sunderland has also been awarded Play Pathfinder status and is developing an inclusive play centre at Silksworth. This will include a sensory room funded by the Aiming High programme
- A number of additional staff training courses have been run
- Sunderland TPCT is considering how best to use the additional funding available, options currently under consideration include providing increased community nursing at weekends and in the evening; improved palliative care facilities; increased funding for specialist equipment; increased availability of therapies; improved provision for children with ASD; and increased provision for families of children with sleep problems.

The next steps

A needs analysis will be undertaken to draw together information that we already hold and to consult with children and parents to better understand the needs of priority groups.

Decisions will be made on how to spend the additional money next year and the year after.

Embedding Parental Involvement

Kathy Rist, Regional Co-ordinator for Contact a Family gave a presentation on the issues facing parents and professionals working together to plan services for disabled children and their families.

As parents first come into contact with systems which provide support to disabled children and their families, they are confronted by complex systems which they often find threatening, not helpful. This is a stressful time as parents are often in crisis and suffering from lack of sleep. The task of finding out who does what and how they do it is shrouded in jargon, and there is a real need for reliable information which gives power and control to parents. Parents and professionals often seem to be living in separate worlds as characterised in the following table.

Two Worlds

Parents

- Full time commitment and full time involvement, very intense
- Low power
- Apparent acceptance of professional worker as all-knowing
- Knowledge through experience
- No control of flow of information
- Dependence on professionals for information on diagnosis, treatment and services
- Isolation
- Everyday language
- Loss of confidence
- Loss of finance

Professionals

- Involved with many families
- High power
- Power to grant or deny a service, or give global information
- Knowledge through theory
- Control of flow of information
- Some professionals may choose what to tell parents!

- Colleague support
- Jargon
- Growth in confidence
- Paid for working

Parents develop strategies to cope with this new world and professionals develop strategies to cope with families. Parents are often seen to be managing, but then they can become invisible and their needs can be ignored by professionals. Other parents appear to be in control, but in reality they are “squeaky wheels” who can easily lose control, and whose needs may or may not be met by the professional system. Parents often are sliding along this continuum, so that at some times they are coping and their needs are being met, and at other times their needs are not being met.

It is hard for parents to know how best to approach professionals. Partners in Policymaking suggested the following often happens:

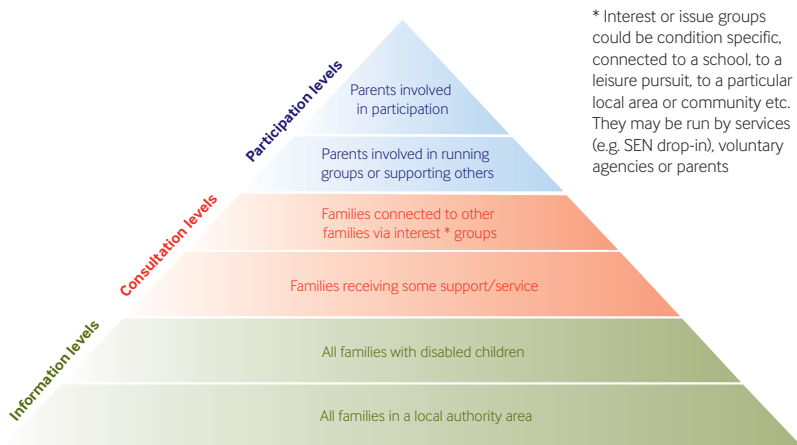
The Expert (Parent)

There is something I don't know that I am supposed to know.

I don't know what it is I don't know and yet am supposed to know.

And I feel I look stupid if I seem both not to know it and not know what it is I don't know. Therefore I pretend I know it. This is nerve wracking since I don't know what I must pretend to know. Therefore I pretend to know everything.

Parents need to be engaged at a number of different levels, and in a number of different ways. Parents are not all the same and need to be able to choose how they are engaged. The following diagram shows how this can work.



At the base of the pyramid are all families who need information about all the services and facilities that are available to them in their locality. When a family has a disabled child they need additional information about services and facilities specific to the needs of a disabled child.

The next level involves consulting with families by asking them for their views on what they need and how services could be developed, and asking for their opinion on plans prior to implementation. This consultation can take place either individually or in groups.

At the top of the pyramid, parents are involved in running groups for themselves and other parents. Parents are also involved in planning the development of new services and in the decisions which are subsequently made.

How to engage

There are some key issues for professionals to consider when engaging parents

- There needs to be clarity as to what the purpose is and who the different people are
- When providing services, parents need to know what the eligibility criteria are, and how the assessment will be undertaken
- Meetings and visits need to be arranged at a time that is convenient for parents, for some this will be during the school day, but for others it will be in the evenings
- Professionals need to use language that is understandable and jargon free
- Parents need to be acknowledged as experts in their child's needs
- Permission must be sought from parents before information is shared

- When parents are involved in developing services, they need to be clear whether they are giving a personal view, or representing a wider group of parents
- Parents need to have reliable and accurate information
- Child care and other expenses may need to be covered in order for parents to attend meetings
- It is important that meetings are also fun and that refreshments are provided. Quality chocolate biscuits are essential!
- It is essential that feedback is given so that people know that their views have made an impact.

Kathy Rist concluded that effective engagement with parents results in a Win:Win situation where the needs of families with a disabled child and those of the agencies and professionals working with them are met in better ways than could be achieved without such collaboration.

The full presentation is available at www.sncwd.org.uk

Workshops

Developing a Local Carers Strategy

Led by Graeme Burt – Strategic Commissioning Officer Planning

Development and Joanne Thynne – Policy and Improvement Officer

Key Points

1. Parent carers want to be able to access the same opportunities as other parents. They want to be able to have quality time with their other children, their partner or friends. This can be difficult because of the sometimes complex nature of their child's disabilities or health needs and the difficulties that parent carers experience in finding someone that they trust and have the confidence in to look after their child whilst they have that quality time away from their caring role.
2. Parent carers would like to have a single route into services to enable easier and quicker access into services. In addition to this, parent carers need access to comprehensive information, as many people are not aware of the services available to support them.
3. Recognition and respect of the specific role of parent carers is crucial. Recognition by parent carers themselves so that they see themselves as a carer, but also recognition by professionals across organisations such as education, health and social care that parent

carers are experts in the care of their children so that they receive the support that they need.

4. How developed are services particularly within the voluntary and community sector, eg. scouts or brownies, to support a child with disabilities. These services should be accessible.
5. Carers in the workshop queried whether 'an ordinary life' was a realistic ambition for the strategy and discussed whether 'a normal life' would be more achievable.
6. Psychological support is crucial for parent carers, particularly to help them to come to terms with their child's disabilities.
7. More flexibility around direct payments is needed.
8. Often the services that are offered are often not what parent carers need.

Opportunities for Employment – returning to work and staying in employment

Led by Gill Charman – People into Employment

Key Points

1. Finding someone that the carers can trust to provide care to their child with disabilities. It would be helpful if special schools could provide holiday and after school clubs.
2. Parents/carers need access to adequate transport to after school clubs or doctors, hospitals or dentists. The times of these types of appointments are a big problem.
3. The rate for the carers allowance needs to be raised. Carers allowance is not payable if you are in full time learning.
4. Money is needed to help support carers wishing to study.

Finance for carers

Led by Sue Yeandle – Centre for International Research on Care, Labour and Equalities, University of Leeds

Key Points

1. The complex administration of child to adult financial affairs process.
 - System complex and costly. Places barriers to disabled people
 - Regulations are complicated and discriminate against disabled people to access banking services without paying a large fee
 - Hidden cost to carers – time/stressful
2. Hidden costs of using direct payments
 - When personal assistant accessed through a direct payment supports users to go on an outing or activity, the hidden costs of them needing to fund that extra person can be quite costly to the carer
3. Inconsistent information
 - Information to parents/carers on financial support/practical support needs a more consistent method
 - Suggest triggers from Social Care at critical and timely intervals, also Benefits Agency

- Suggest health visitors as sign posters
- Signposting from self help groups
- Information at point of diagnosis.

Including Carers

Led by Ailsa Martin – Senior Manager, Sunderland Carers Centre

Key Points

1. Need services to be better. Sometimes easier for parents to “opt out” of seeking services.
 - Services need to be of good quality to enable carer inclusion (e.g. returning/continuing to work, accessing leisure activities)
 - Professionals need to listen to carers to enable personalised outcomes, e.g. care services adequate and carers feel comfortable in seeking a life outside caring
2. Information for carers needs to be available as soon as possible
 - Important for signposting at an early stage as possible in the caring process – signposting to other professionals/agencies should be appropriate and not just a ‘ticking box’ exercise

3. Child does not have a diagnosis/eligibility criteria which leads to parents being confused about where to go for help/advice
 - Where does guidance/advice for these carers come from?
 - Without a diagnosis carers are confused about the services they can/can't access and end up going round in circles
4. Parents of disabled children knowing what is available to them.
 - Parents still don't know how to get a voice.
 - There should be at least a starting point where carers can go to get key information. Where necessary signposting will happen and be appropriate to the caring situation
5. Disability affects whole family life.
 - The whole family needs should be considered in delivery of services and information given
 - Role of grandparents, other family members important in delivery of care. Also important for family to have quality time together and other children in family are not excluded.

Parent Power

Led by Kathy Rist – Contact a Family and Ailsa Martin – Sunderland Carers Centre

Key Points

1. Information
 - Parents cannot have power without information
 - Parents need the right information at the right time. Everyone, including schools, must take responsibility for sharing information e.g. at annual reviews. Staff must listen to parents so that they know what information is needed
 - Ensuring that good quality information is up to date and accurate should be a priority and funded accordingly. Provide links to parent carer groups so that parents can learn from each other, ensure health visitors etc, have information and provide links to web sites, telephone links etc
 - Follow up after diagnosis
At diagnosis parents may receive too much information or be unable to take it all in. A follow up about 2 weeks later would be valuable and ensure all relevant information had been made available.
 - As parents learn a lot from each other, explore establishing a "buddy" scheme
 - Ensuring families with disabled children are included
 - Use public information sources to ensure people are aware of

disabled facilities in public settings, e.g. Metro Centre, so that whole family outings/activities are possible

2. Short Breaks

- Exhausted parents cannot be powerful
- Regular breaks should be available – not just in an emergency, to prevent parents becoming exhausted and enabled them to give time to non-disabled family members etc.
- Definition of short breaks must not just be of overnight and away from home opportunities but should include day time/evenings, a break at home etc.

3. Collaborative working

- Demonstrate parent power is valued
- Collaborative working needs to be valued. Parents need feedback to demonstrate that something is happening as a result of collaboration.

Connexions role in transition

Led by Liv Slingsby – Lead Personal Advisor for Learning Disabilities and Difficulties Team, Connexions

Key Points

1. Transition planning meetings

- Parents not recognising or having knowledge of having had a transition meeting
- Transition plans should be more person centered
- There appears to be an assumption at the special schools the child will remain there until 19. Therefore funding for an alternative not sought
- Not enough detail in plans to meet requirements of special needs children.

2. Loss of daytime activities after 18

- Day time activities are lost during the summer break. No equivalent during this time in adult services
- Local authority day time services not available for short term use.

3. Person centred plans

- Excellent when done properly
- Lengthy process problematic
- Much more focused on the person – (good)
- Parents feel more involved
- Seems a more positive approach
- Needs a key person to oversee plan – implemented.

Aiming High and Health

Led by Janette Sherratt – Health Improvement Lead Sunderland Teaching Primary Care Trust and Diane Watson – Specialist Health Visitor

Key Points

(Note: this workshop was mainly attended by health professionals)

1. Additional Aiming High funding – Health. What are the priorities?
 - Community Nursing
 - Palliative Care
 - Equipment
 - Therapies
 - ASD provision
 - Sleep

With the above in mind the following points were considered critical to the success of the project:

- Professionals and parent carers should look across boundaries of all professionals – health/education/voluntary etc. to access support services
 - These agencies and professionals should ensure parent carers are listened to and their views are central when planning any care packages.
2. Early intervention to involve parents. This does not always happen. There is a gap in this service on neo-natal wards.
 - Pre-diagnosis – time of uncertainty for parents. If parents are included in information/decisions at the earliest stage possible this reduces problems later.
 - When parents are given information they say this is the turning point for them so the earlier the better
 - Important to empower parents at an early stage and to tell them they are doing the right things – builds a trusting relationship between carer and professional
 3. Sleep deprivation – what would make a difference? How can parents get advice/support if they suffer from sleep deprivation?
 - Provide respite care in the home so parents can get uninterrupted sleep
 - More trained practitioners to help disabled children get into a sleep routine – intensive, ongoing support as sleep patterns may change
 - Knowledge of illness/disability and how this can affect sleep
 - Training for teachers to understand sleep deprivation of the children
 4. Barriers facing parents from coming into contact with health professionals. Parents may not

have confidence to approach health professionals

- Working class families – less informed about services
- The way 'parenting' skills is 'sold' to parents – often negative
- Parents should have a healthy relationship with health professionals to build trust
- Important for professionals to have real listening skills – parents do not always know what they want but it is brilliant when professionals can pick up on chance remarks and act.

5. Role of Health Visitors (HV)/School Nurses (SN) and health services being joined up. Parents are often confused about the health professionals they can turn to for help.

- A lot of parents don't know who their HV is. (there was acknowledgement the case loads of HV's has been a problem but this is being addressed)
- A lot of parents think they are unable to access SN services if child is off school ill. It was confirmed parents can access the SN service if the child is off school ill. Services need to be joined up to help parents.

6. Equipment.

Turnaround times for equipment was too long, early intervention important.

- Equipment should be supplied as quickly as possible and be specific to the needs of the child
- Early intervention – aids/equipment available to children as early as possible so they get used to them (e.g. in preparation for school)
- One piece of equipment preferable if it can handle multiple functions
- Social inclusion – equipment training for all professionals/parents supporting the child.

Aiming High for Disabled Children

Led by Steve Fletcher, Strategic Manager, Services for Disabled Children and Karen Parry, Aiming High Programme Manager

Key Points

1. Build on existing activities that are already there
 - make sure new services compliment these rather than compete with them
 - use AHDC to safeguard services that families value, that may be at risk due to being run on short term funding.
 - use AHDC to do more of what is working well.

2. More choice and provision for people.
 - make sure existing provision is utilised more fully
 - inform families about what is available
 - could funding be put in to enable provision to be open at the weekend? Can different budgets be pooled/combined/merged/shared to enable simple things to happen that would tick lots of people's boxes.

3. The potential of the Aiming High participation fund.
 - need to be careful it doesn't clash with other funds e.g. Family Fund
 - families don't care where money comes from as long as their child gets a service.

4. Information & networking
 - people keen to have more than one Forum per year.
 - need to increase the number of parent carers to come along. Could smaller sessions be held to discuss the needs to different groups of children e.g. different age ranges, with different types of disability- parents could attend the session most relevant to them e.g. those with a physically disabled child may have different ideas than those whose child has autism. May

make more parents come along if the session seems directly relevant to them.

5. Plans for capital money
 - Thompson Park Nursery is an accessible building; are there any options around acquiring it and using it with Aiming High money.

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 39 completed forms in total: 26 from parent carers; and 13 from those that work in Children's Services, health and the voluntary and community sector.

Responses:

What people hoped to get from the day?

- Find out more about services (x29)
- Meet staff (x11)
- Have a chance to express their views (x21)
- Find out more about Aiming High (x2)
- Listen to parents' views (x2)

100% said the event met expectations
100% said the Forum was good-excellent

87% felt they had enough of an opportunity through to every opportunity to express their views
54% felt their views had been listened to and 33% felt these would be taken seriously

The following ideas were suggested for the forum next year:

- Repeat the workshop on Finance for Carers
- Need to hear about any success from last years forum (2007)
- Build on information gathered this year
- More parent involvement
- Wrap around clubs for disabled children
- Help and support for siblings of disabled children
- More activities and more time needed
- Venue was ideal and worth the money
- Longer forum needed, still within school time
- Difficult to see overhead slides
- Forum to be held more than once a year

The following ideas were suggested to improve parent participation:

- Make services more transparent
- Invite parents to speak to everyone
- Hold forum twice per year
- Wider marketing in public places, radio etc
- More information leaflets
- More events like the forum to promote awareness
- Survey sheets
- Contact Parent Carer Council
- Target individual parents more systematically (email, text etc)
- More meetings
- Need to get information out to more people
- Invite more people and promote, make sure parents are informed
- Encourage all parents/carers to come together to express their views and opinions
- Go to small venues, like schools
- Transport – i.e. put in place via Children’s Centres

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