Face 2 Face
Parents supporting parents
of disabled children

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A day in the Life of a Parent Carer of a Child with a Disability or Additional Need in Shropshire

Between December 2011 and February 2012 the Shropshire Parent and Carer Council (PACC) asked parent carers what made them mad, sad and glad about being a parent of a child with a disability or additional need. Responses were collected at the PACC AGM, PACC OASIS meetings , via e-mail request to PACC members and at the Shropshire Annual Information Day for Families of Children with Disabilities. The families who responded had a range of experience and knowledge of many disabilities; including Learning disabilities, Autistic Spectrum Disorders, challenging behaviours and medical needs. Despite this range of experience some clear themes emerged in the responses.

All the response recorded in this documents are direct quotes from Shropshire parent carers and inevitably reflect individual experience. PACC is aware that in Shropshire there is some extremely good service delivery and many families feel well supported by individuals. This project asked parent carers to focus on what worked and what didn't work in their lives and as such provides a snap shot of how in general, Shropshire parent carers feel about being a parent of a child with a disability or additional needs.

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What makes you MAD about being a parent of a child with a disability or additional need?

This was the question to which we received the most responses. The themes that emerged were;

- Poor Communication and a Lack of Information
- Lack of Respect and Understanding
- Problems with Service Delivery; waiting times, bureaucracy, lack of provision, not person centred, lack of accountability
- Life feels like a Constant Battle

The comments made by parent carers are listed under each theme heading below.

Poor Communication and availability of information

- That vital information which I provided about my child to the transport department was not passed to drivers/escorts who have day to day contact with my child.
  Mad - poor communication and information
- Not being informed about changes to transport until they don't turn up
  Mad - poor communication and information
- I received a letter one Saturday, telling me my child had an 8 week session of therapy starting the following Thursday – a 45 minute drive away starting at 9.15pm. We were going on a an overseas holiday 1 day later. The letter stated if we didn't respond that week we would go to the bottom of the waiting list. Pure chance we received the letter in time, there was also an expectation that I could take time off work at short notice. There was a total lack of communication
  Mad - poor communication and information
- Child signing toilet but escorts / drivers not understanding sign language
  Mad - poor communication and information
- No understanding of the fact that a person may have more than I child – appointments given at school drop off time when other child needs to be dropped off
  Mad - poor communication and information

- You have to search for information yourself and professionals do not pass information on
  Mad - poor communication and information
- You have to find out information; there is not always the help and support that you need
  Mad - poor communication and information
- Some healthcare professionals giving wrong advice regarding disabilities they know very little about
  Mad - poor communication and information
- Lack of knowledge of disability and education law among professionals
  Mad - poor communication and information

Lack of Respect or Understanding

- Everyone having a view about my child – my family feels like it is public property
  Mad - lack of respect or understanding
- Being called Mum by someone who isn’t my child
  Mad - lack of respect or understanding
- My child being expected to improve in something that they have no control over i.e not be distracted
  Mad - lack of respect or understanding
- Comments like;
  “…a child like that’
  “I’ll pray for you”
  “How do you manage?”
  Mad - lack of respect or understanding
- School (mainstream) seem to constantly try to do their best to make things difficult
  Mad - lack of respect or understanding
- Lack of respect for me as an individual
  Mad - lack of respect or understanding
- Not being listened to
  Mad - lack of respect or understanding
- Not having a voice – opinion not listened to
  Mad - lack of respect or understanding
- The assumption that as a parent I am getting it wrong
  Mad - lack of respect or understanding
- Being told – “I don’t have a magic wand you know” – when I was complaining about the appalling service that their therapy service provided. I know they don’t have a magic wand I just want them to do their job.
  Mad - lack of respect or understanding
- People making decisions about my child or family without really knowing them. In some cases they have never even met them!
  Mad - lack of respect or understanding
- I have sometimes experienced negative reactions from people at my child’s behaviour when out in public. Ranging from disgusted looks to actual comments! – A unkind comments from adults or other children.
  Mad - lack of respect or understanding

- People without Blue Badges who park in disabled spaces.
  Especially police cars!

  Mad - lack of respect or understanding
- Uneducated ignorant people who just stare when you walk past

  Mad - lack of respect or understanding
- When people stare and point
  Mad - lack of respect or understanding
- Medical staff who do not take our problems seriously or blame the parents
  Mad - lack of respect or understanding
- People assuming that I am coping when I am not and even when I ask for help they are stuck for answers
  Mad - lack of respect or understanding

...OH YES, DOES MUM HAVE ANYTHING TO ADD?

Problems With Service Delivery; waiting times, bureaucracy, lack of provision, not person centred, lack of accountability

- That respite that has been commissioned and assessed as needed is not being provided to me
  Mad - Problems with service delivery
- No childcare post 14
  Mad - Problems with service delivery
- Poor reliability of transport – sometimes children not picked up from here, sometime not dropped back off (respite carer)
  Mad - Problems with service delivery
- No one answering questions or taking responsibility for resolving issues
  Mad - Problems with service delivery
- Everything takes a long time
  Mad - Problems with service delivery
- Services provided not according to need but to how determined the parent is.
  Mad - Problems with service delivery
- Decisions made on text box scenarios rather than individual sessions
  Mad - Problems with service delivery
- Assessment that are done for the benefit of the support services not the child or family – their assessments not ours
  Mad - Problems with service delivery
- People not doing what they are supposed to do even when required by law – e.g not implementing statements
  Mad - Problems with service delivery
- Professional incompetence – resulting in extending waiting times (example given of a 5mth wait for shoes)
  Mad - Problems with service delivery
- Not planning ahead
  Mad - Problems with service delivery
- TRANSPORT - not understanding just how important it is because includes
  Relationships
  Trust
  Reliability
  Knowledge of the child
  Security

This impacts negatively on initial implementing transport, changing transport or getting transport wrong is huge for families. The system seems to focus on logistics only and doesn't see the individual.
Mad - Problems with service delivery

- Lack of understanding and co-operation from medical, educational and benefits bodies.
  Mad - Problems with service delivery
- Lack of treatment.
  Mad - Problems with service delivery
- Having to fill in countless forms to access local services
  Mad - Problems with service delivery
- Having to fill out countless pages of the DLA form to get the support that should be yours from the day of diagnosis. Having to justify everything on paper and being forced you to look at the extent of your child's disability.
  Mad - Problems with service delivery
- Having to fight for funding for higher education when others who leave school can have the choice of which university/college they want
  Mad - Problems with service delivery
- The in-balance between the public voice of those with physical disabilities and those with special/additional needs.
  Mad - Problems with service delivery
- Waiting ages for appointments, being put on a waiting list and not being given a time or date for the actual appointment
  Mad - Problems with service delivery

DELIVERY DAY AGAIN. WHICH ROOM SHALL WE DO WITHOUT THIS MONTH?

Life Feels like a Constant Battle

- Feeling that we have 'to fight' for services – I just want the same for my child as any other child would have, I don't want more, I just don't want less
  Mad - Life feels like a constant battle
- Constantly having to chase things and find out yourself
  Mad - Life feels like a constant battle
- Having to constantly push
  Mad - Life feels like a constant battle
- Everything is a battle
  Mad - Life feels like a constant battle
- It makes me mad that absolutely everything is a constant battle, you practically need to jump through hoops to get any help. I'm made to feel like a paranoid mother, or that I'm over reacting or even in fact lying about my son's inability to cope as a lot of his behaviour is bottled up while at school or at a function, then released when in the safety of our home.

  Mad - Life feels like a constant battle
- All the brick walls you have to break down
  Mad - Life feels like a constant battle

What makes you SAD about being a parent of a child with a disability or additional need?

The themes that emerged in response to this question were;

- Fear of the future
- Lost opportunities for the parent, child or family
- Isolation
- Constant responsibility
- Lack of understanding

The comments made by parent carers are listed under each theme heading below;

Fear of the Future:

- That there is a very little by the way of services out there for my child to enjoy when she becomes an adult
  Sad – fear of the future
- A future where my son will always need support
  Sad – fear of the future
- Not knowing if my child will ever be independent, but even if she is knowing that she will not have the life that most of us take for granted
  Sad – fear of the future
- Fear of the future when my husband and I are no longer alive
- Sad – fear of the future
- I worry about my child's future
  Sad – fear of the future

Lost Opportunities - for Parent, Child or Family

- That I had to give up work due to lack of available / affordable childcare
  Sad – lost opportunities - parents
- Seeing other children enjoying being with one another (which is some thing my son misses out on)
  Sad – lost opportunities - child

- My son’s fear of change and that we can never be spontaneous
  Sad – lost opportunities - child
- That there are so many places that we cannot access as a family because of my child’s needs
  Sad – lost opportunities - family
- That my other child must feel like he is in a one parent family eventhough he lives with both parents as we often have to split the family down the middle
  Sad – lost opportunities - family
- Not knowing if my child will ever be independent, but even if she is knowing that she will not have the life that most of us take for granted
- The loss of a sibling that my other child has experienced
  Sad – lost opportunities - family
- My child wanting to be able to do the things that his peers do but not being able to
  Sad – lost opportunities - child
- Not being able to do things that other take for granted, holidays, parties, Christmas disco’s
  Sad - Lost opportunities - family
- Siblings growing up too quick.
  Sad – lost opportunities - family
- Missed life experiences. E.g. school trips, sports or music activities Involving large numbers of kids.
  Sad – lost opportunities - family
- Missed opportunities and the all or nothing approach. It makes me very sad that school experiences that are offered to able children routinely, such as looking down a microscope or watching a visiting theatre group can’t be also offered to my sick child.
  Sad – lost opportunities
- My child cannot communicate with others whilst desperately trying to
  Sad – lost opportunities - child
- My son seems to be on the outside in a group of children
  Sad – lost opportunities - child
- Access to buildings is restricted (to wheelchairs)
  Sad – lost opportunities - family
- When your child suffers due to not getting the right support
  Sad – lost opportunities - child
- My child is unhappy!
  Sad – lost opportunities - child

Constant Responsibility:

- Never being able to switch off / always being responsible
  Sad – constant responsibility
- Having to be the ‘naggy’ parent
  Sad – constant responsibility
- My child and family are suffering and I can’t help them
  Sad – constant responsibility

Isolation:

- Feeling different
  Sad - isolation
- Having to make it ok for society that my son has a disability, having to overcoming other people’s fears and ignorance rather than it being my son’s right to belong
  Sad - isolation
- People not listening to me
  Sad - isolation
- People not understanding that sometimes things are just too stressful or emotional
  Sad - isolation
- The feelings of isolation that I often get, the fact that we don’t get invited to usual social events and we do go out for the day it is generally very difficult
  Sad – isolation
- Isolation. The lack of anyone who takes an interest in my child.
  Sad – isolation

What makes you GLAD about being a parent of a child with a disability or additional need?

The themes that emerged in response to this question were;

- Having a different view on life
- My child
- People who understand
- Any progress - big or small
- Services that respond to individual need

The comments made by parent carers are listed under each theme heading below;

Having a Different View on Life:

- My daughter has a fantastic sense of humour. When I am feeling low she can always cheer me up with a quip (apparently teachers must all be daft because they need to go to school when they are grown up too!)
  Glad – a different view on life
- How my child notices the small things in life, going for a walk in the forest and being fascinated by cobwebs, insects, the wind etc
  Glad – a different view on life
- Has increased my understanding of and willingness to explore why things happen rather than just reacting to them
  Glad – a different view on life
- Increased humanity and awareness of the needs of others – life doesn't always go to plan
  Glad – a different view on life
- Everything that I have learnt and experienced that I would not have done otherwise.
  Glad – a different view on life

My Child;

- My son's innocence and trust that all people are good
  Glad – my child
- Having fun with my child – their innocent enjoyment of things
  Glad – my child
- He loves life.
  Glad – my child
- The sun, swimming, animals, his sister & extended family, school. He sees no difference in himself and enjoys everything
  Glad – my child
- The disability makes our children who they are - their disability is not the problem it is societies reaction to it
  Glad – my child
- My connection with my child: it may be different but it is there.
  Glad – my child
- I get to spend loads of time with my child.
  Glad – my child
- My son is unique and tells it how it is, the things he comes out with are way beyond me and if channelled in the right direction I have no doubt he'll achieve magnificent things. Life is never dull with my son and if I could change just one thing it would be to educate people on the difficulties he and many like him face in almost everything they do.
  Glad – my child
- When my daughter smiles
  Glad – my child
- When we get a good hour and there is fun and laughter instead
  Glad – my child

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People who Understand;

- That having a disabled child has enabled me to meet so many wonderful people whom I would otherwise not have met
  Glad – people who understand
- When you meet people who listen to your point of view
  Glad – people who understand
- Meeting other parents
  Glad – people who understand
- Most individuals I meet are lovely and care for my child on a 1:1 basis
  Glad – people who understand
- When people are willing to make changes to accommodate my son or family
  Glad – people who understand
- The feeling of being part of a community from being with like minded people
  Glad – people who understand
- Family time
  Glad – people who understand
- When things are provided for my child that show people have understood their needs
  Glad – people who understand
- Proud of siblings awareness
  Glad - people who understand
- Meeting amazing people
  Glad – people who understand
- When you find someone to help who get's it!
  Glad – people who understand
- When people see beyond their disabilities to who they really are.
  Glad – people who understand
- When I meet people who understand
  Glad – people who understand

- When I see all children integrating and playing happily
  Glad – people who understand

- The help and support through CAMHs, PACC and Spectrum.
  Glad – people who understand

Any Progress - Big or Small;

- The small steps that feel like huge achievements
  Glad – any progress
- Seeing my son perform in the nativity play with the other children
  Glad – any progress
- When we see them doing something for the first time
  Glad – any progress

- When they reach a goal
  Glad – any progress

- My child started walking
  Glad – any progress

- I finally got a diagnosis and was able to get on with life
  Glad – any progress

Services that Respond to Individual Need;

- We had an opportunity to design our own completely unique, completely 'suitable' education.
  Glad – services that respond to individual need

- Specialist youth services that allow my child to integrate with his peers on an equal footing rather than having to keep up (or not) in a mainstream club
  Glad – services that respond to individual need

Summary

There are some clear messages from the comments provided by parent carers for this report;

- While the level of service available is obviously important it is just as important to consider how a service is delivered . For example is it person centred and does it meet the need of the family concerned?
- The individuals delivering a service need to understand the full impact of a child disability or additional need on parent carers. This includes the emotional as well as practical impact.
- It is essential that parent carers are seen as part of the team and as such have a mechanism for input into a shared decision making process.
- Transparency and good communication is essential
- Families really value contact with other families who share similar experiences.
- It is not, in most circumstances, the disability itself that causes the major distress for families it is societies reaction to it.

PACC would like to extend our thanks to all the families who contributed to this report

If you would like further information about the work of PACC please contact Sarah Thomas or Jill Cleveley on the contact details below.

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