



SHROPSHIRE Parent
And
Carer
Council

Mad, Sad, Glad 2016



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Mad, Sad and Glad 2016

Shropshire Parents and Carers tell us what makes them Mad, Sad and Glad about their lives caring for children with disabilities and additional needs.

In 2011 and 2015 PACC carried out surveys asking members what made them “Mad, Sad and Glad” about being the parent/carer of a child with a disability or additional need. 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. The reports were published and presented to PACC’s professional contacts and continue to be available on the PACC website.

We repeated the activity at our June 2016 Conference. All those who attended were asked to write their concerns and feelings on slips of paper and to categorise them as Mad, Sad or Glad. The resulting comments were spontaneous and heart-felt and we believe that they give a very effective snap-shot of family lives and family issues.

Entailed in this spontaneity are some honest appraisals of what has been disappointing and frustrating about services and service delivery. Interestingly some parent carers classed these as making them mad, others sad, even though similar points were being made. It is impossible to know whether this is due to how each individual reacts or to the length of time that they have been feeling this way (which comes first – feeling mad or feeling sad?). However, there are also sound and optimistic examples given of person centred services which parent/carers are keen to acknowledge, and we are very pleased that the number of these (in the Glad section) have greatly increased since last year.

We have used the same themes as in our 2015 Mad, Sad, Glad report to summarise the responses. Concern for the future continues to dominate the thinking of many parent carers, and this is evident in the final comment of the Glad section, where a parent wrote:

Can’t be really ever truly happy – always negative clouds (transition, what will happen as we age).

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

Poor Communication and a Lack of Information

- Trying to use the Local Offer website
- Lack of a clear pathway through transition to adult services – gaps in professionals' knowledge

Lack of Respect and Understanding

- People who are rude to us regarding my daughter's disabilities
- Professionals who are patronising to me

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

- Not being able to get DENTAL TREATMENT
- Waiting time for referrals
- Children still fall through gaps
- Poor system design
- Lack of sufficient capacity in services
- No ME/CFS support for children
- Uncertain future adult social care package (and therefore where my son lives) is only agreed on a year by year basis
- Being told there is NO FUNDING
- Lack of service-user focus
- I feel frustrated by services not listening and not being child-centred
- Social services
- Length of time it can take to get access to respite and then how difficult it is if you need to amend it.
- Lack of holiday activity provision
- Inequitable services – some get lots, others get nothing.
- No diagnosis – and having to pay for services that NHS locally do not provide
- Lack of services from adult services between 2010 and 2016 – we have had no useful help or support!
- Still wheelchair clinic!
- Frustration – fulfilling their regulations/protocol is more important than needs of child – cannot be creative or flexible.
- Not receiving the support my child needs
- Inflexibility in provision – short breaks and support for personalisation / independent payments

Life feels like a Constant Battle

- Feeling judged when people don't take the time to find out the truth.
- Constant fighting for services and chasing up of appointments/services

- Having to fight for basic services and having to place my child out of county when he should be home with his family
- Trying to get help and support
- Having to be very assertive to get what I need
- The system – why do we have to keep pestering!

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

Fear of the future

- I worry about his future and what can be offered
- Feeling that expectations of the future quality of his life are so low amongst professionals
- Unsure funding for future causes anxiety
- Not knowing what the future holds, and having no control over it!
- As gets older might decrease in community acceptance of “quirks” and odd actions.

Lost opportunities for the parent, child or family

- Family – my son being in a 52 week residential placement has affected his relationship with his brothers
- Not being able to be with her all the time
- That my son has limited opportunities to access clubs etc out of school time without me due to needing 1:1 care
- Low expectations in behaviour in school and academies, wrote her name when she joined school 6 years ago but can no longer to so.
- Feel guilty that my eldest son’s needs get relegated/forgotten about, as his younger sibling is disabled.
- Opportunities for my child shut down due to funding cuts.

Isolation

- Isolated
- Being isolated – my son having no friends
- Lonely
- Siblings constantly arguing/conflict/exhaustion
- Son is unable to keep up with his friends. He feels excluded and I don’t know how to help him through this.
- Watching othe children the same age going to town with their friends, or going down to the park together – but my daughter can’t do that without me.
- My son doesn’t want to go to school because he doesn’t have any friends.

Constant responsibility

- Feeling frustrated with the amount of people who want me to fill in forms.
- The difficulties communicating with her which means she can't understand why, so often keeps asking WHY?

Lack of understanding

- Having to fight for diagnosis.
- Lack of understanding of Aspergers in young adult – can walk and talk so he must be "rude".
- Poorly trained professionals.

Concern for other families

- That many people do not know what support is available. Only get information from other parents.

Service provision

- That services aren't currently joined up – leaving families desperate
- Prescriptions not being ready at the chemist (or orders getting lost)
- When applying for respite for our 17 year old was "interviewed" by a young person on the phone and denied a place "as we didn't need it."
- Poorly designed support system.

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

My child

- She's (mostly) gorgeous and a delight to share my life with
- Time at home – whilst out of school allowed me to get to know my child really well
- My son has Aspergers and has got himself paid work with no support from any services.
- I am made happy by small achievements of my son.
- All three of my children
- Having my daughter! Being in 'Narnia' (it's a wonderful place).
- The joy of living with him – and the feedback from professionals as to how delightful he can be.
- I've spent lots of good quality time with my son since he's been ill. We have a strong relationship as he's seen me care for him and fight for what's best for him.

- The person my daughter is – fun to be with. Doing things together. Having lot of mum – daughter time, shopping, trips, make up, hair days.
- I know what unconditional love is. Love doesn't need language.

People who understand

- Friends who I've met through my son's disability
- Great friends I have made through support groups
- The group I have set up with fantastic families
- Friends
- The friends I have made
- Having a great network of people to talk to who understand!
- Empathy/understanding of other parents
- Supportive friends.

Any progress - big or small

- Services that respond to individual need
- Professionals who know their job and do it well.
- Young person has left home and carers in residential home very caring and supportive
- Good support from residential school
- The Saturday clubs, All in Wednesdays, trampolining club, Friday club at The Grange, good visits from social worker.
- New school has been very supportive. They are very skilled at pastoral care and include my son in all meetings and ask him what he wants and what will help him.
- Some really great quality, positive support – some great workers.
- Very happy with teaching staff at Severdale. They (in my experience) are child centred, caring and supportive.

Family resilience and fun

- Fun, love, strong relationships with many individuals, strength, community

PACC would welcome the opportunity to discuss issues that arise from this report and to suggest positive responses that could be made.

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