Mad Sad Glad – A Reflection Report

Introduction

In this survey Shropshire Parents Carers tell us what makes them Mad, Sad, and Glad about their lives caring for children with disabilities and additional needs. PACC have carried out this same survey in 2011, 2015 and 2016, creating a picture of how parent carers feel about their lives and shining a light on the key issues that make them mad, sad, or glad.

The families who responded to the most recent survey had a range of different experiences and knowledge of many disabilities, including autism, learning disabilities and medical needs. Despite this range of experience, some clear themes emerged in the responses as they also did in previous years.

The reports from previous surveys are published and presented to PACC's professional contacts and are available on the PACC website.

Due to the COVID-19 pandemic, the 2021 survey was carried out virtually and participants communicated their concerns and feelings via a Microsoft Office form survey in the categories of Mad, Sad, and Glad.

The comments which resulted were snapshots of family's lives and the issues they face, as in previous years the resulting comments are spontaneous and heart-felt.

Key issues in the 2021 Report are parent carers reflecting the difficulty accessing appropriate timely services, concerns about the quality of communication with families and a lack of understanding of their lives. This feedback highlights the effect of this on parent carers, in particular the significant impact upon their mental health and that of their children.

What follows are parent carer comments grouped into similar themes under the Mad, Sad, and Glad headings. 90 parent carers responded. Their comments have not been edited to retain authenticity. The number of respondents give an insight into the current situation across the parent carer community in Shropshire. Comments express disappointment and frustration about services and service delivery and as in previous surveys some parent carers class this frustration under mad and others class this in the sad category, once again similar points are made as has been the case in previous surveys. We cannot tell if this is because each individual reacts in a different way or whether it is down to the length of time they have felt this way (which comes first – mad or sad?) We have used similar themes as the 2016 Mad, Sad Glad report to summarise the responses, however there are some new themes due to the pandemic and the effects of this on parent carers and also their children and young people.

Issues with service delivery are common and the length of time waiting for services is prominent in the responses received *'Took 11 years and finally have autism diagnosis for my son.'* In particular, mental health services are reported as being inadequate *'Support services are pitifully inadequate. CAMHS actively operates a blame culture and employs delaying tactics at every step, in the hope that people will give up trying to get help. To be told "Unless they're self-harming there's not a lot we can do." Is utterly sickening.'*

Parent carers tell us of the impact of caring on their work *'have had to reduce my working hours'*; lack of wraparound care for young people with SEND which impacts parent carer work *'Lack of access to childcare, so i can't go back to work!'*; also carer allowance being less than the rate a PA would be paid to support their young person.

Parent carers report of the exhaustion they feel; lack of support services and that *'Accessing help is a constant battle !'* and '*How difficult services are to navigate and how hard it is to get support we are entitled to. And even when it's recognised, delivering of support takes an incredibly long time.'* Additionally, feelings of loneliness and isolation are felt by parent carers *'Being lonely, if not for groups would see no one.'*

Concern over the future and equality for children and young people with SEND are again, as in previous reports highlighted by parent carers *'When I take his siblings somewhere and there isn't place for him to be as well.'*, and *'Fighting for clubs which are available to kids without disabilities',*

However, there are many positive examples of services and service providers who are getting things right and making a difference. The overwhelming response from the survey is that the child/young person in a parent carer's life is what makes them feel glad '*My child is awesome'*, *'My daughter is exceptional. She's an incredibly talented musician. She will change the world for the better if only people let her.'* People who understand are an important part of a parent carer's support network *'Having a great community of parent carers who always have each other's backs and support one another in times of need'.* Parent carers also recognise successful provision and the value it brings for their children *'That the provision we can access is excellent and has enabled my child to successfully access mainstream provision too.'*

There are a number of parent carers who find that there is nothing that would make them feel glad about being a parent carer of a child with a disability or additional need in Shropshire *'Nothing! Everything is underfunded, lack of support, the time and effort of continuous fighting for the basic needs of my child to be met. The worry and effect it has on my own mental health as you can't get an answer from anyone.'*

The impact of the pandemic is highlighted where parent carers tell us this has made waiting lists longer and support more difficult to access *'Covid has delayed vital medical care.'*

We want to thank all the parent carers who took the time to respond to the survey.

Section One: MAD

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

Parent Carer Comments

Service Provision Comments

- Using GP services … poorly educated GP's
- Covid has delayed vital medical care,
- Support during COVID-19 pandemic
- Lack of services, lack of staff,
- Accessing help is a constant battle !
- Also it takes so long to get the help support when it comes available.
- Been told that services and support are there but accessing them is a red tape nightmare
- Took 11 years and finally have autism diagnosis for my son
- The fact nobody really listens and everything takes so long! Years for an assessment.
- That there is limited provision in North Shropshire
- There is nothing provided for people who live in the south of the county and are rural, the emphasis on facilities and support tends to be in Shrewsbury only. There are people who need the support who don't live in or near Shrewsbury, but still in Shropshire.
- The lack of services and help for parents with a child who has special needs
- Lack of support. Professionals also fobbing people off. No support in schools for people on the pathway!!
- The constant struggle for support. Constant struggle to get support for child, the hoops you have to jump through for referrals to then be declined.
- Everything is so slow and under staffed
- Lack of any help for my son
- Little respite.
- The length of time to get a diagnosis and for appointments. I appreciate that their are a lot of people waiting but more funding is needed so it doesn't take as long. Also the fight a lot of parents have just to be heard, being dismissed by GPS and schools and really having to battle to be heard.
- We were lucky that once my son finally got to the diagnosis stage it was all very straightforward and we suddenly had a huge amount of advice and support offered, but that really isn't the case for most people.
- Lack of support as my child went through school and received no help she is an adult now
- The complete lack of support available for my child. It's so difficult to find out what is available and to get to. Professional
- The many years it has taken to obtain a diagnosis for our child and the dis-jointed infrastructure that forces parents to fight for every scrap for their child.
- Not being able to get my child the support they need

- The waiting times for my child to get an assessment he so desperately needs. The negative attitude when your chasing constantly from the staff at the services. The amount of children who are struggling and don't have an answer.
- Not being listened too and understood.
- Lack of support during covid
- That there is such limited support
- How slow everything takes to get sorted. Or equipment and health waiting lists.
- Not being able to get support you need. Having to constantly fight for everything and still get no help. Not being able to get any resources for your child, and can't afford to buy them
- Lack of funding to support them in their childcare placement
- Length of time taken for applying for anything (at present EHCP which is 11 weeks over the deadline and still no answer)
- Lack of services, having to fight constantly for their rights and equal access to things, from what's written in their ehcp, to the right to be able to be changed in a clean environment when out and about, and to still have to continue to fight and fight.
- Having to fight to get any form of support.
- How difficult it is to get any help. I'm truly sick of hearing "does not meet the criteria"
- Fighting to get the support our children so desperately need
- The constant struggle to see or speak to anyone from majority of services across the board, and then when you do speak to someone, the further battle required to get support/ appointments/ appropriate action. As a parent carer it is exhausting trying to constantly fight for the help you know your child critically needs, and is entitled to.
- How difficult services are to navigate and how hard it is to get support we are entitled to. And even when it's recognised, delivering of support takes an incredibly long time.
- The struggle to get educational help for them
- Start to finish it took 8 months following receipt of the application to complete a process that should by law take 20 weeks.
- They failed us massively during that initial period.
- Poor communication between services eg (1) consultant teams (often the Bee U admin teams, not consultants themselves) not communicating well with parents and GPs/pharmacists. Admin team told us GP had taken responsibility for repeat prescriptions. Ordered prescription from prescription ordering service- wrong dosage. Phoned GP, told not their problem and to phone consultant! Took 5 calls to sort out. Not the first time I have to do chasing. (2) EHCP - often individuals are invited but don't attend - only because I chased up individuals do we get input - again, a huge amount of effort for something that is supposed to happen automatically!
- The amount of follow ups you have to do yourself to see where things are going. Things being very repetitive but not really moving forward with diagnosing and support.
- Lack of help and support despite been told the council has lots of services and support available
- Having to negotiate the SEND system and fight for everything I feel my young person is entitled to have.
- Services are not signposted in time - often informed from other parent carers rather than professionals and often too late; waiting times are very long for assessments due to lack of staff, meantime our child misses out on developmental

support; always having to fight for what our child needs and limited choice of a specialist school in Shropshire.

Support for parent/carer health & mental health/stress

- My own health has suffered significantly as a result of constant battling.
- As a parent carer it is exhausting trying to constantly fight for the help you know your child critically needs and is entitled to.
- They refused to asses him at first for an EHCNA, then when they did asses him they failed to do the learning & cognition assessments , then the response to my complaint failed to take into account the EP findings. It was just a mess and so stressful.
- How much harder you have to fight for everything they are entitled to, some of which you aren't aware of until you speak to other parents with children with additional needs.
- Shropshire council blamed me and my divorce situation as the reason for my sons behaviour despite having a private EP report stating he needed assessing for autism. I had to spend over 100 hours fighting his case to get him a place at a special school. This process made me very unwell and put a strain on my relationship with my child.
- I feel strongly that I want to formally complain but lack the emotional and physical resources to do so at the moment without it being further harmful to my mental health.

Impact on family

- Not being able to go and do what the family wants when they want.
- Shropshire council blamed me and my divorce situation as the reason for my sons behaviour despite having a private EP report stating he needed assessing for autism. I had to spend over 100 hours fighting his case to get him a place at a special school. This process made me very unwell and put a strain on my relationship with my child.

Impact on work:

- Lack of support from agencies that you need help from and everything is a battle and takes months to try and get sorted. Not enough support given to Grandparents that have become legal guardian which I have 5 years ago and have had to reduce my working hours in order to give my grandchild the support needed on a daily basis

Carer's Allowance

- Carers allowance being £67.60 per week for over 35hrs and a P.A. Who doesn't know your child being paid a decent wage

Specific provision problems

- You can't get a blue badge. Referral for the right help takes a very long time. Not being able to back date his 15hr funding to the date of his successful PIP and no one informing us we could get both PIP and 15hrs when he first was diagnosed (9 months earlier).

- It would be nice if Portage could be extended until children start school. Portage has been a fantastic support for us but it stopped when my child went to nursery. Portage should continue to support the transition into school.
- The SEND Team
- I'm mad that despite more children having Fetal Alcohol Syndrome that Cerebral Palsy, Down Syndrome, ASD and ADHD COMBINED that there are no services in Shropshire for this. I was told to go to Alcoholics Anonymous with my 6yr old. We get nothing not even recognised by Community Paediatrics
- SEND team regarding GSP's - Shropshire council. Waiting time and manner of employees involved in ASD assessments
- The constant struggle to see or speak to anyone from majority of services across the board, and then when you do speak to someone, the further battle required to get support/ appointments/ appropriate action. As a parent carer it is exhausting trying to constantly fight for the help you know your child critically needs, and is entitled to. This said Community paeds team are generally very responsive and quick to act; however OT, physio, house adaptations and other such services are horrendous and add such an emotional/ mental strain to an already often difficult situation.
- Trying to get hold of someone at the disabled children’s team, when you’re child doesn’t have a social worker.
- Lack of help and support despite been told the council has lots of services and support available

Mental health services for children and young people

- Cbt therapy with a specialist who is also a neurodevelopment practitioner (trained) should be widely available.
- The inadequate services provided by CAMHS. My daughter was referred well over 2 years ago and we began her ASD assessment only 3months ago following MP involvement. We have only completed the first stage of assessment (parental interview) and awaiting the second stage (classroom observation) 4months later and no indication of when this will be.
  I feel now that not only are the services inadequate, they are detrimental to my daughter and our family and I am considering trying to find the funds to pay privately for an assessment so that we can move on with our lives.
- I am incredibly angry at how her CAMHS referral has been dealt with. The communication is disgusting. To be placed on the ADHD pathway, discussed and discharged to the ASD pathway with no communication to the parents is completely unacceptable, no explanation or discussion of results from XXXXX questionnaire. I have received no written communication from CAMHS regarding my daughter or the assessment process. *(XXXXX indicates name removed).*
- The lack of appropriate mental health support offers for cyp with SEND.
- Sheer lack of service for children's / teen's mental health, far too much reliance on online service and expecting young people to engage when they are already dis-engaged. My daughter still has no support other than medication 6 months on from crisis team input for suicide attempts, still waiting for therapy. We had to fight for medication for nearly 3 years and were stuck in-between GP and CAMHS.
- Constant referral to BEAM, which cannot provide anything extra that we don't already have. BEAM is not set up to operate in an ASD way- different person each time, not same slot each time, no face to face meetings, provides counselling service which my daughter already accesses face to face with same person every

week in school. So frustrating that we have to prove we need an alternative service by subjecting daughter to service we know won't add anything to her support.

- No real support, passed around from agency to agency. Told we don't meet criteria. Very little mental health support in schools. CAMHS are a complete waste of time, even when presented with a suicidal child, we get no support at all.
- Having to fight to get the support they need especially from CAMHS and local authority special educational needs team. The long waiting times to be seen by services.
- No suitable CAMHS mental health support for children with suspected ASD until they have completed ASD assessment (in our case 4 years and waiting) - this makes me furious!
- Support services are pitifully inadequate. CAMHS actively operates a blame culture and employs delaying tactics at every step, in the hope that people will give up trying to get help. To be told "Unless they're self harming there's not a lot we can do." Is utterly sickening.
- The lack of support services within BeeU for mental health problems. My daughter tried CBT and because she struggled to engage with its format was told that was it, nothing else available. Kids with autism can't always engage in direct therapy and need other means eg play or art therapy. It's maddening that even BeeU therapies are designed around what works for neurotypical kids.
- How difficult it is to access help. I have had to fight for referral to CAMHS, fight for ASD referral, fight for help in school. It is exhausting and I feel for those families who for whatever reason can't fight for their child's needs to be met.

School issues

- Schools have very little training so they do not spot the signs that a child may be struggling or the reasons why this could be . Especially in my case, a shy child who didn't speak much in class , with excellent behaviour, who was doing her work . They said my child was fine at school when she wasn't. She had a breakdown and suffered Trauma because I was sending her to somewhere she wasn't ok with. All schools staff need to have training even dinner ladies, on comprehension learning difficulties, sensory issues , autism, adhd and many more .. this will create better understanding and help these children and I believe improve behaviour and have less School Trauma.
- Also Smaller quieter working areas in all schools would make a big difference.
- My daughter was failed by the Sen team whilst at preschool 5years ago, she was only seen once and had barely any support in place before she started school. Every bit of support she has received has been down to me as her mother chasing people, meetings, phone calls, emails, fighting, providing evidence and making sure it is provided within a timely manner. This has hugely taken its toll on my mental health. Once starting school with her ehcp in place her educational support has been good, although getting her into the appropriate specialist provision at the appropriate time was much more complicated than it needed to be.
- You are always pushing, for help. How long it takes to get help and school really do not understand
- Disconnect between schools and activities for SEND cyp.
- The school seems totally unaware of.the needs of a dyslexic child. There is no written plan in place and you almost have to shout to get any answers or get told to do it at home!
- Lack of communication from school. their obsession with unimportant issues such as wearing a tie but losing sight of my sons sense of failure and diminished self esteem due to unrealistic expectations and going against the EHCP.
- Lack of SEN school provision

- The struggle to get educational help for them
- They don't get to meet their potential in mainstream school.

Lack of wrap around childcare for children with SEND

- Lack of access to childcare , so i can't go back to work! I have 2 degrees and due to their being no childcare options for children with significant needs it isn't possible.
- Fighting to find after school care post the age of 12.
- In addition the lack of provision for breakfast & after school clubs for children with SEN
- I have asked for more support and have had a Social Work assessment suggesting I need after school care to source myself after waiting 3 calendar months for the outcome.

Understanding

- Limited understanding or care for our children's needs
- lack of listening to parents, excessive parent blaming
- Professionals seem dismissive of parent's views and concerns. Some can be condescending and patronising. Seems a daily struggle to get what's needed and even if you succeed, the execution of needs seems hit and miss. School staff are ill-informed and seem to lack SEN knowledge.
- Not listening to us as parents
- Some people who are judgemental
- Having to constantly defend his diagnosis and remember examples of his autism to give to people.
- Having to fight for support from the LA. The LA managers telling professionals not to write that children need additional support (e.g. GSP or EHCP) in their reports. Unqualified, unexperienced people in charge of SEN in LA. The expectation for schools to refer to Early Help even when this is not relevant. The incompetency of SEN managers and health services which means that children are not getting onto diagnosis pathways.
- Having to fight endlessly to get heard
- As a parent you are forced into situations where you are expected to know absolutely everything one day and then your opinion is not even acknowledged another. The lack of real support is shocking and we only ever ask for help with things that we have no choice but to...and our requests are ignored, not listened to and rejected without discussion. Shropshire services are often shockingly lacking in common sense and human approach.
- time wasted on factitious safeguarding, defamation and harassment of parents and data breaches, false documentation, false representation and inaccuracy of reports,
- lack of awareness and understanding of their needs shown by the social services team at Shropshire Council
- Not being able to figure out the problem because they can't say what it is that's making them mad
- Belittled by professionals, not listened to and being dismissed as just being "mum"
- Outdated and old fashioned concepts of autism and other neuro-divergences in our daughters school (even at SENDCO and Head level) and as a result of this a total lack of awareness of the complexities of autism and how multifaceted it is (especially sensory needs) lead to lack of empathy and failure to understand our

child, their needs and thus our needs as a family. This contributes to ableist and discriminatory views which we find undermining, disrespectful and totally frustrating.

- Nobody seems to listen
- The people that take advantage or don't understand
- When your asking for help and no one seems to listen

Continuity issues and Transition

- The discharging of patients from therapies in transition years (whole drama unfolding about how that happened).
- For it being a role of the dice each year if my child will get a team that work to really help him progress or if its his job to teach them how to understand children with special needs. Not matter how much I personally put in place some years his team don't get him and he doesn't relax and so the whole year is pretty much a pause until he gets a team that connect with him so he can progress again.
- There is no single place and proactive approach to help you find what is best for your child at each new stage.

Equality

- When I take his siblings somewhere and there isn't place for him to be as well.
- Any SEN child is set up to fail, until things are sorted.
- Support being allocated according to educational ability and gender - there is NO support in Shropshire for an exceptionally bright girl who also has moderate autism. If she was a boy of below average ability with mild autism, she'd get help. If she was a boy of low ability without a diagnosis she'd get help. Girls go under the radar because they tend to internalise rather than act out. Self-harm rather than violence to others. Give equal support to all based on actual diagnosis. We have an NHS diagnosis of significant difficulties and yet not a single minute's support given in school. Give support based on need not educational ability. You wouldn't award help for a physical disability based on IQ level but that's exactly what happens with neurodisability
- Lack of understanding from mainstream parents and their children, education system fails to teach capable and able children to be tolerant of disabilities/additional needs.
- The lack of awareness and way other families can treat you on days out / parks / soft plays.
- Fighting for clubs which are available to kids without disabilities
- Disabled children don’t get enough time to socialise with their peers, as a family we are prevented from doing normal things because of disability and everything you have to fight for
- The inequalities in services

Facilities; changing places

- Having to locate toilets more frequently than usual families, having a hidden condition & growing too old to join me in the ladies, my son is misunderstood and urgency not always believed.

Section Two: SAD

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

Parent Carer Comments

Service provision
• Children left with no help and constantly failed. • Lack of support groups for the same condition. Lack of awareness and understanding of the condition. • Young children are being let down by the system. Children that need help and families that need support. • That promotion of the offer is not wider. I only found out about it by accident and have been trying to get out school to promote it ever since • The fact we always seem to be at the back of the queue for any help or get told help isn’t available due to lack of funding. • The future as a young adult and lack of support • Children are let down. School staff are caught in the middle when they're trying their best with limited resources. • That so many parents are suffering through lack of support • Watching them suffer and you cant do anything about it. • That I paid private and he was assessed and diagnosed in 3 weeks. • The system letting children down makes me so sad. Borrowing money to pay for assessments makes me sad. • Ex we couldn’t leave the house because we didn’t have a wheelchair and she was to poorly to walk. • The years my child had very little or no support, due to being dismissed by professionals, the implications of that will have adverse effects on my child's education for years to come • Nobody seems to want to help • Having speech therapy on his ehcp and being told the needs are met in school yet knowing there not! Any sort of therapy would be amazing! • SALT is not provided enough for a non verbal child and other siblings can not enjoy normal days out because the disabled child cannot manage it, also however ill or in pain or bad health you are in you still have to carry on caring their is no one else to do it social workers don’t care • Lack of support for the child when they need it the most • Not enough activities • Everyone blames each other - it would be so much better if everyone worked together to make things easier but it feels like some want to be heroes and blame other organisations. Individually everyone is good. • That my child misses out on key things because of their postcode! • Do not seem to be many opportunities in Bridgnorth for children or carers • Lack of social provision activity opportunities near Bridgnorth • Lack of empathy from some staff (some BUT CLEARLY NOT ALL) - it’s simply a job to them and don’t want to actively engage children or help them progress / they look for easy option (eg watching TV)

- seeing my son struggle day to day whilst being aware of the importance of getting the correct diagnosis and how this can help with additional support
- SALT is not provided enough for a non verbal child and other siblings can not enjoy normal days out because the disabled child cannot manage it, also however ill or in pain or bad health you are in you still have to carry on caring their is no one else to do it social workers don't care

Loneliness and isolation

- Loneliness of being a sen parent
- Being on my own with an SEN child and having no one to talk to - have a break (other than when he's in school)
- Being lonely, if not for groups would see no one.
- The loneliness. And the constant chasing of professionals

Impact on family

- Neglecting other children as send child has priority
- SALT is not provided enough for a non verbal child and other siblings can not enjoy normal days out because the disabled child cannot manage it, also however ill or in pain or bad health you are in you still have to carry on caring their is no one else to do it social workers don't care

Understanding, listening, empathy, professional knowledge, frustration

- The so called professionals refuse to listen to you as the parent
- The biggest cause of sadness is the constant fight to get any help or even a little understanding from the people who are paid to help and understand!
- That professionals seem driven by funding and not by the child. Longlasting views of needs are made at a snapshot in time, often discounting parents views.
- feeling no one is listening or helping
- The fact children aren't diagnosed for the pure fact they don't meet a certain criteria. Every child is different and handles things differently. Eg, my son masks at school and is like a bomb going off at home.
- That have to fight do hard for something that your children should be able to access (EHCP).
- Nobody listens
- Exhaustion. Battling the system. Battling prejudice and inbuilt gender disparity. Having my career destroyed due to caring responsibilities when if there had been quicker diagnosis, more willingness to believe us rather than blame our child's obvious difficulties on being a middle class child in a working class/deprived area there would have been no need. Lack of early intervention. Lack of any post diagnosis support whatsoever.
- I've spent the whole of my adopted daughter's life fighting for her instead of loving her. My heart breaks for her.
- That you have to play a political game to get what you need even though by choice you would need absolutely nothing! We didn't choose our situation.
- That to get any help we have to keep banging on to the power that be.
- We do not always feel listened to by professionals and that there can be a lack of empathy when you are an exhausted worn out parent carer desperate for support. Feel that you have to be at crisis/breaking point before professionals allow you to get help. Sometimes the professionals do not know themselves where to access a budget so the system isn't even easily signposted for them.

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- I get sad at having to be a speech therapist, occupational therapist , mummy, teqcher and carer, sometimes I just want to be a mummy.
- The ongoing risks and never being able to fully relax and chill - always waiting for the next frustration.
- Seeing mum's struggle with their children
- Many people do not get to see the kind and generous boy that my son is as they do not see past his initial difficulties
- Lack of understanding coming from teachers/headteachers. The terminology used to describe my child in a school setting. Out of date views on children with disabilities.
- That thay get picked on and others don't understand
- Being excluded and avoided.
- More understanding needed and more time for groups to meet
- That schools could do more to teach children about differences, understanding and inclusion of children with disabilities and additional needs.
- The knock on effect from question 1's answer is that our daughter is:
  A) misunderstood
  B) isolated as a result of A
  C) not believed in her difficulties
  D) not getting the support she needs as a result of C (and because she's "achieving" academically)
  E) lack of family support due to them living a long way away and this our resulting exhaustion
- Having to explain why your child is the way they are to people and people lacking understanding.
- The ignorance some people still have of special needs, the stares we can get and the one time someone called the police on me because my child had a melt down and they assumed it was me in the wrong, instead of approaching me and offering help or seeing g if everything was okay!
- That neurotypicals don't give neurodiverses the chances and understanding they deserve.
- Facing struggles with every day tasks, facing being misunderstood when going out in public - shopping, for a meal, for appointments, for activities- challenging behaviours putting us in the spotlight embarrasses myself and my daughter.
- Feeling guilty not being able to support my son as I don't feel like I have the guidance needed.

Mental Health Services for children and young people

- I am incredibly sad that no-one, specifically mental health services, seems to be interested and no one seems to care about my daughter. Every step of our journey has been about providing evidence and proof, proving the difficulties that my daughter has, constant reports, fighting for her to be seen, chasing appointments etc. I can't understand how we have got this far with CAMHS and no-one has properly met her. The system appears to be about jumping through hoops, ticking the right boxes, pushing to be taken seriously rather than professionals wanting to help my daughter who has quite obvious significant needs/behaviour. I work in a caring profession within the NHS and if I made any of my patients feel as insignificant as our family has been made to feel I would be devastated. This makes me incredibly sad.

- Sad that my daughter struggles and is being let down by mental health services
- I get sad when people don't want to listen and the referral to beeu got declined
- The difficulty of contacting and seeing CAMHS in the north of the county.
- That so few people (hardly anyone) understands her needs. It took a complete mental health crisis lasting 12 months, threating suicide, unable to access school, refusal from TMBSS application, and discharge from CAMHS before someone happened to mention Life Shed and she finally has a mentor who completely understands her. It shouldn't be that hard to find!!!
- It breaks my heart that my child has had to wait so long to get the right support and help and understanding. We have had very little parent support or advice and I know I’m not the only parent but I feel like I have had to fight (still fighting) to get my child the correct support.. 4 years on when she couldn’t go to school. Everyone has a right to a fair education that doesn't effect there mental health.

Equality

- That may child feels different
- How many opportunities they miss just by being different.
- The lack of inclusion still in society and the recognition that it is important that society as as a whole needs to value those with SEND
- No real options in terms of education. Very few options available.
- That the opportunities for him are not the same as a neurotypical kid.
- That my child doesn’t get what she needs to live life to her full ability.
- I'm sad that my 2 boys can't go out with their friends like most 12 and 9 year olds and sad that their being failed by the system. I fear for they're futures.
- My child doesn't have the same opportunity as others
- The lack of inclusivity for our children, there are so many areas/ places our children with physical disabilities can not visit within the local area due to poor accessibility. For example we struggle to go for a family walk in our local area, other than around the housing estate because pathways are in terrible condition and too narrow for a wheelchair/ walking frame due to overgrown bushes. Yet when we visit other parts of the country we find an abundance of accessible pathways and inclusive playground/ parks, something our LA appears not to be concerned with!
- That there is such a focus on ‘normal’ and a failure to recognise that diversity makes our society richer. Also not knowing how my boys will make their way in the world
- Seeing my son suffer at people's arrogance and ignorance
- The faillings in Q1 mean that my child and the rest of the family do not get support that could help.

Employment/the future for children and young people

- The lack of opportunities for them to progress into sustainable employment. I can't see an easy future for my child in Shropshire.
- The future as a young adult and lack of support
- Worry about the future for my son and me as a carer, as I grow older.

- The realisation that your child will always have limited options & opportunities.
- Knowing he will need support long after I am gone
- The guilt of constantly wondering if I'm doing it right! Worrying about the future for my child if resources remain so poorly funded.
- That there isn't enough investment in the services and staff so we are left vulnerable and fighting for support - so shortsighted. Help now could mean our children could thrive and live independent lives as adults.
- not knowing how my boys will make their way in the world

Education and schools

- I feel my daughter is left behind and lost because of a lack of education for the teachers about dyslexia.
- That my fantastic primary school has bent over backwards to support my daughter (year5) with her needs, without having EHCP etc as yet, but I have not heard positive comments about the SEND provision at secondary level and am sad that she might not get a placement that suits her needs nearby.
- Children are let down. School staff are caught in the middle when they're trying their best with limited resources.
- That the schools do not receive enough funding to effectively support children who need it. Especially children who may be undiagnosed and need extra support in the classroom but the school can't afford it so the children are not supported enough.
- That my son has daily challenges both at school and in everyday life.

- My child receives no support in education amd this would benefit him massively to allow him to be able to get the most from his time in school and allow him to get the best grades and a better chance at going to college and gain employment
- That some times his team in school don't see how wonderful and beautiful he is and don't put the effort into connect and help him. You have tk really care to work with kids with special needs and I think it should be a necessity.
- That money is clearly more or a priority than the education of these children.
- Lack of appropriate SEN places suitable for autistic kids small classes and so on
- I felt sad when our son left primary school. He had been in a mainstream setting all the way through and whilst he was very happy throughout, I never really felt the school were very bothered with him. Whilst I did not expect any special treatment, it would be nice to feel they had got something from the experience.

Professional knowledge and understanding

- The fact children aren't diagnosed for the pure fact they don't meet a certain criteria. Every child is different and handles things differently. Eg, my son masks at school and is like a bomb going off at home.

Effects of the COVID-19 pandemic

- During Covid I feel that parent carers and children with disabilities were very much forgotten about. Especially during the first lockdown. Everything just stopped and support services that were vital to some were gone over night. We are very fortunate to have a really good support network around us but a lot of people don't and I watched a lot of parent carers really struggle.

Behaviour support

- Not being able to help my daughter understand what is appropriate behaviour and what is not
- When he hurts another child due to not processing his feelings, and even though yes it's awful for that child...my child didn't premeditate it. He was having trouble handling his emotions and something silly would have made him react, and then he gets the same punishment as a neurotypical child. Which I know he needs to understand its not acceptable to hurt someone, but at the same time I'm not sure it's the right process or not and this is why
- you hear about so many autistic children being put in isolation/suspended/expelled and given the label of naughty.
- When child is having a meltdown and you can't help

After school/wraparound care; lack of respite; SEN leisure activities at antisocial times

- That there are not enough after school or holiday activities opportunities
- Being on my own with an SEN child and having no one to talk to, have a break (other than when he's in school)
- That sen sessions at leisure activities are always at quite antisocial times , like an after thought, why can't they access activities at normal times of day.
- Lack of opportunities for my child to meet other kids like him, there's no after school clubs and stuff that he could attend whilst I'm at work. There not clear information from short breaks how to access the horse riding or things like that

Changing places; facilties

- Changing my child on a dirty bathroom floor because that's the only option.

Section Three: GLAD

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

Parent Carer Comments

My Child

- The pride I have in my child
- That I have a special child , he may challenge me everyday but he is a wonderful human being .
- That he has progressed a bit at nursery
- I'm glad my daughter has such a strong ethic of right and wrong and she has just the most wonderful sense of humour! Her giggle is infectious!
- Because my child shows so much strength and makes sure people know what extra he needs
- My daughter is fantastic but I feel her needs are sorely missed in Shropshire.
- The child is special in their own way and i would not change them for anything
- Nothing, apart from love for my child
- Our unique daughter, she's amazing!
- How special and individual my.child.is
- My daughter is exceptional. She's an incredibly talented musician. She will change the world for the better if only people let her.
- Although being a parent/carer can be exhausting the rewards of seeing your child is worth it all
- every time i see my babies it cheers my heart
- My daughter is extra special to me and her quirkiness makes me.smile
- He is such an amazing child, whatever his make up I am glad for both of my children.
- I'm glad I know my daughter and her needs
- Glad that i have a special child who is full of love and there disabilities dont stop them with what they want to do.
- I am glad I get to share a different world through my child's eyes. He teaches me so much and brings so much laughter with his truthful literal honesty. I am glad I have him to give me the strength to battle for him.
- My son is so special, he is funny, intelligent and really good to be around.
- That thay have us to talk to when thay need to and I can help
- She's been a complete gift to our family. We get so much from her. We are lucky to have her.
- He is so inquisitive, he has a genuine thirst to know all about the world, some of his everyday questions are when did humans first appear, how is fog made, how do helicopters stay in the sky, how does the heart work.....
- That my child is wonderful
- My child is awesome, some local charities are fantastic and have supported us greatly.

- That as a family we fully embrace the concept of neurodiversity and celebrate all of our quirks together - that we talk openly and honestly about neurodiversity to share this pride with others in the hope that we can dispel myths and shout about the many positives and strengths that come with neurodiversity. That our daughter is loved and accepted just as she is and that every day she teaches us something valuable and new about herself and also about ourselves - subsequently supporting us all to grow stronger and better connected.
- Having an SEN child is amazing, yes there are more down days than good, but when they come in and have had a good day and give you a hug it makes me so glad.
- Getting smiles and doing things you know they love.
- Life is never boring.
- My beautiful boys smile and cuddles. The incredible mums I've met fighting the same battles that I am.
- My son.
- That my daughter hasn't developed the extreme food seeking or hunger that other Pws children have yet and she is always smiling also the amazing activities we enjoyed as a family with actio and all in
- The joys of achievements other parents deem mundane or routine.
- Each time he achieved something new
- Every Good day makes.me glad has child.happy
- The connection I have with my daughter from being through some really tough times together because of her condition.
- My children help me to reach to be the best parent I can be. Make me appreciate every win. Not take ANYTHING for granted. To be kind.
- I value every smile, I feel proud at every milestone, I know how much effort is made (whether successful or not) and celebrate. Hurdles are so much bigger but the rewards are so much bigger too.
- That they bring so much to the world inspite of my first two answers.
- That I still have a happy child regardless
- The live and joy I gain from my young person. The support and friendship from other parent/carers.

People who understand

- We all stick together
- A pro active nursery who helped me get 15hrs when he qualified for PIP and have got funding to buy things to help him in their care.
- We have leant so much as a family and are stronger for it. Finding a head teacher who understands and who referred my child (this was the 2nd time) this was the only reason my child is in a better place right now. Understanding yourself what ever age is the key to helping manage anxiety and helps you have a good life .
- Having a great community of parent carers who always have each other's backs and support one another in times of need.
- Support groups I've found on Facebook with children like my sons.
- Excellent, quick use of ELSA trained TA to support, plus councillor support also provided over holidays for daughter. Amazing use of school dog to inspire and help daughter. Empathetic staff and well led school (X Primary School).
- Excellent provision, understanding and support from his teacher X, at X School; consistent and sensibile advice from X, psychologist at CAMHS LD Team.

- The support we have received from various places, SLT, OT, physio, Portage, the NHS, the incontinence team, etc.
- That there are things happening and parents voices are being listened to.
- The many kind and considerate people we have encountered that have gone out of their way to help our child.
- That there is some support
- Additional support/opportunities
- We are also glad for our friends 😊
- That people ate growing a bit more awareness.
- The friends I have made with other parent carers.
- Connecting with other parents on similar situations
- That I've met some fantastic other parents that I would not normally have met.
- That I am not alone and the parent network is strong and supportive.

Success of the provision

- That the provision we can access is excellent and has enabled my child to successfully access mainstream provision too
- That the majority of the teaching staff who have worked closely with my daughter have been wonderful.
- School support and school staff willing to fight for my child until she receives the support he needs.
- full NHS funding for out of county assessment and treatment
- X! This is where my little boy goes, they are amazing, the support we have received from them has been fantastic. They deserve so much credit for how hard they work and how committed to the children they are. The thing that makes me the gladdest about being a parent carer though is my beautiful little boy, he has severe learning disabilities and ASD but he is an absolute joy and makes the world a much brighter place.
- We have a fantastic GP surgery who are always supportive and there for us as a family. That once support service are in pace the help they offer is great especially the early help team.
- X is a good school and the staff are very helpful. Transport staff are good and many of the activity groups are great. It is a shame it is disjointed.
- AFC
- Authority figures are approachable.
- Finally getting my child into the right school, it’s an independent school but the provision seems really good , being able to get a blue badge too
- The range of Sen sessions through out venues in Shropshire.
- X school
- Help and support from school
- His current school, X. The exact opposite of his primary school.
- Any progress big or small

Family

- We see life in a totally different way and enjoy simpler things.
- I'm glad that myself and my husband are here together fighting for both our boys. I'm glad that my boys know and can feel that we truly love them .

Actio/All In

- All in
- All in
- All In activities - the chance to enjoy activities as a family we would not otherwise be able to do. Thank you
- Accessing the Cavalier Centre recently via All In has made a big difference to our lives - a place to go and able to relax knowing they are prepared for behaviours/challenges with my sons condition making us feel welcome and included, enjoyable riding lessons and pony care session so far!
- We feel privileged to have a close insight into the wonderful way our child sees the world. Our child’s class teacher and TAs are fabulous and really listen and champion and support us as a family. Having some days out with Actio All In in the summer that specifically catered for children with disabilities and which gave our child different experiences was amazing, so more enrichment activities like these would be brilliant. In particular, Battlefield falconry ran a differentiated session which catered for a range of disabilities, he made sure every child was included.

Autism West Midlands

- We can access autism west midlands advice, training and support
- All the lovely people I have met in person or on zoom from different groups for example Autism West Midlands, Therapeutic Parenting and the lovely Early Help Worker that is helping us fight for what my Grandchild needs

Lifeshed

- Life Shed makes me overwhelmed with happiness. They are just amazing for the dozen or so children's that they support, what a lifeline!

Negative feedback for what makes parent carers glad about being the parent carer of a child with a disability or additional need

- All those lost children who don’t have a supportive family or school are just going to end up broken.. it’s heartbreaking
- Nothing
- Nothing.
- Moving out of Shropshire in next few months.
- There isn't much to be honest. Maybe the green spaces
- Nothing! Everything is under funded, lack of support, the time and effort of continuous fighting for the basic needs of my child to be met. The worry and effect it has on my own mental health as you can’t get an answer from anyone
- Nothing
- very little
- Absolutely nothing. Every step is total frustration.
- Due to the situation we currently find ourselves in, constantly chasing and fighting for support for our child, I am unable to give an example of anything at this time that makes me glad about being under Shropshire LA. This saddens me as I have always loved living in Shropshire, however we are really struggling with the lack of appropiate support available.

Locality, green space

- That we have beautiful countryside to go and forget about the stresses caused by people who are supposed to be helping us but who actually make things so much worse. We are also glad for out friends 😊
- Access to outdoor space and living in a rural area. Access to activities eg Shrewsbury Town FC (XXX is amazing) and RDA. Sadly, nothing in North Shropshire

Suggestions

- More Parent support is needed to reach these children and family's

Summary

There is a clear theme throughout the feedback of Shropshire parent carers not feeling valued and life being an ongoing struggle to achieve what others might take for granted. Worryingly parent carers identify their child's future as something that makes them sad, because of the level of uncertainty they face and the impact of previous poor experiences on their expectations. These poor experiences are not simply defined in terms of difficulty of access or lengths of waits for services, but how parent carers feel about the way services communicate with them or respond to their request for help. There is a sense of parent carers withdrawing from the wider community and experiencing increasing isolation and loneliness. In this context the value of peer support is clearly high, and we see this evidenced in the responses captured under the heading of 'People who understand'. Throughout all of this however, the pride and joy that parent carers can find in their child is clear, but even that can sometimes be tempered or overwhelmed by the challenges of raising a SEND child.

This Mad, Sad, Glad Survey again highlights the importance of services and strategic decision makers understanding the lives and experiences of parent carers. Parent carers are a key resource in the delivery of good outcomes for children and young people with SEND. They are the person who brings all the different strands of support together for their child, providing the overview and consideration all aspect of their lives, which is particularly important in a system which is frequently recognised as being disjointed. Yet the support needs of parent carers themselves are too often overlooked. Shropshire currently has a Carers Support Team, but it is only open to those who care for individuals who are 18 years plus and it is unclear how support for parent carers of children and young people under the age of 18 is provided. This is despite there being a statutory requirement for local areas to provide 'Parent Carer Needs Assessments' and Shropshire having an 'All Age Carers Strategy' since 2017.

There are repeated national surveys that evidence that parent carers are at a higher risk of experiencing poor mental health than other groups and is essential that we start to see the changes needed to address this. The value of the expertise offered by parent carers needs to be recognised, along with the impact of caring on their wellbeing. There is obviously a need to develop services that can respond effectively to the level of need, but alongside this there needs to be a culture of empathy and understanding, rather than blame or dismissal.

We hope that by sharing the feelings of Shropshire parent carers in this way, we can start a conversation about the wellbeing of parent carers. We know that there are many people working in the SEND system who have the same aspiration and we look forward to working together to support parent carers and to achieve better outcomes for SEND families.