Information & Support | Influence & Change

Influence & Change

Community Support

Information Provision

Mad Sad Glad- A reflection Report

2025

PARENT CARER COUNCIL
PACC
Championing your voice
SHROPSHIRE

Introduction

The purpose of this survey was for Parent Carers to share with us what makes them Mad, Sad, and Glad about their lives caring for a child/ young person with special educational needs and/or disabilities in Shropshire. 120 Parent Carers responded.

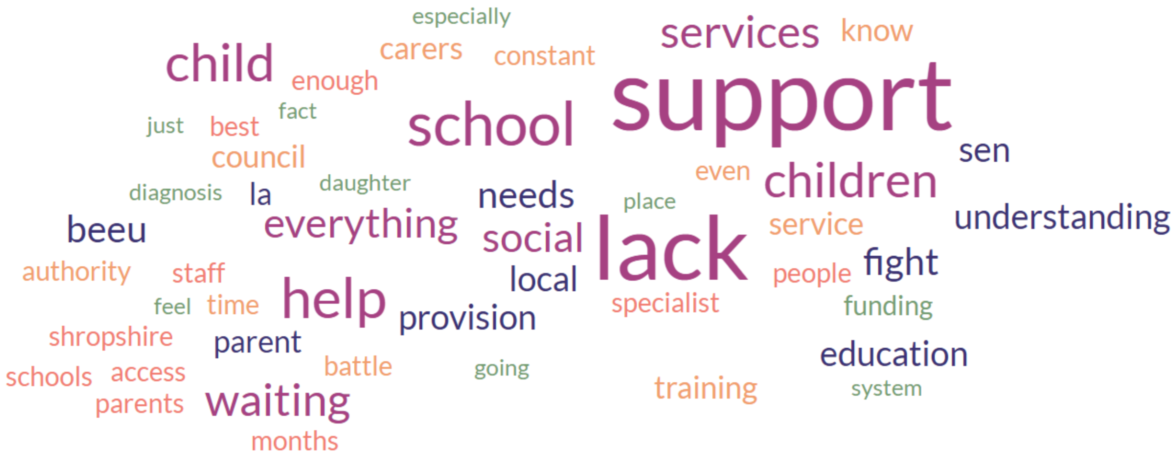
PACC have previously shared this survey in 2011, 2015, 2016 and 2021, creating a picture of how parent carers feel about their lives and shining a light on the key issues that make them mad, sad, or glad.

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

PACC would like to thank the Parent Carers that have shared their experiences with us.

Mad

What makes you MAD about being the Parent Carer of a child or young person with a disability or additional need?



Fight for support

- Even after diagnosis the constant jumping through hoops and battling to get my child what he needs.
- The battle to find the support you need.
- Having doors closed in your face repeatedly.
- Feeling judged and not listened to
- Being made to feel that issues your child is having are your fault as a parent rather than down to your child's additional needs
- The fact that you have to fight for everything for your child
- That we have to fight so hard for basic support. It takes away from parenting, which is more tricky and consuming than "regular" parenting.
- Everything seems so hard … choosing onwards education and post education. Just settled in then must start realms of paperwork and research to find something that might fit the young person’s needs.
- Fighting all the time
- Constant fights with the Local Authority
- Having to battle for everything all of the time
- Always feeling like I am going into battle
- The LA stalling on naming a school- everything with them is a battle

The System

- The LA not doing their job without being forced to
- That our EHCP process took over a year, and even then, the LA didn’t direct their maintained school to take my daughter, and we’ve waited a further term for a school place.
- The fight with the LA to get the help they need. Not being believed
- Waiting 6 months for the SEND manager at the council to get back to me.
- Shropshire council thinking they know best
- The constant fight for services with the local authority- even when they have agreed your child needs the service, they backpedal and delay in the hope you eventually give up and don’t expect it to happen.
- That tactics are used against us, including parent blame. The local authority is most especially the worst.
- Social services and social workers
- Shropshire Council
- Shropshire Council is not fit for purpose
- To the local authority my child is a case number- they don’t care about him as a child
- Social services and social workers
- The process of getting assessments is impossible
- Obstacles put in our way
- All the waiting
- Our education system
- Repetition of forms
- The lack of consistency in callbacks
- Poor communication from SEN team
- Being ignored and views not being heard
- Waiting lists for everything

Provision

- Inability to access any appropriate short break provision
- Lack of access to therapies. Speech and Language primarily. Hydro, bounce. Having to spend months and months to be able to be in control of my child’s best interests just because they have turned 18. After caring for and putting them first above all else for the previous 18 years.
- Inconsistency of the NHS
- That the social workers ghost you - I have been trying for 18 months to get an answer out of that service about direct payments. Initially I thought they were going to help us. They haven’t, they've just made things harder. Yet another thing to chase.

- NHS not geared up for our children. Urgent training required for staff on how to communicate with, examine and help support children with disabilities in particular ASD and GDD where understanding is limited and child anxious. Separate waiting area. Extra chaperones or patient liaison staff to support parents during appointments who is trained in dealing with SEN disabled children especially at emergency appointments, blood tests etc
- Lack of provisions in place for mainstream school to support Sen children
- Lack of activities for pre-school aged children
- Not enough alternative provision if a child cannot cope in the school environment
- Lack of groups/ activities for teenagers who appear neurotypical and do not want to join disabled groups but are isolated
- Insufficient school provision

BeeU

- Mad we can't see BeeU
- Having to fight for BeeU to even assess my son, taking it to formal complaint level
- The complete lack of any support or contact from BeeU. I cannot stress enough how damaging the complete lack of support from BeeU is. Their service is not fit for purpose, and I actually don't know why it exists. The way they approach their service is all about removing children from waiting lists or kicking the can down the road rather than offering genuine and meaningful help. I no longer have any faith in BeeU and personally will not be contacting them again
- Huge waiting lists for support
- Being at the bottom of the list
- Waiting list for diagnosis
- Waiting times for assessment and support
- Delays in diagnosis
- BeeU waiting times and understanding
- BeeU inaccessible, uncaring and incompetent
- BeeU- total lack of support
- BeeU
- Service deficit and delay for children with ND and mental health issues
- Schools are under pressure to do referrals for SEN but know it is often futile as BeeU will not assess the kids

Lack of understanding

- Other people judging me
- Lack of understanding and empathy, the fact you feel alone having to fight against services that should help.
- How people tell you you're doing an amazing job, but don't see what's going on behind the scenes and offer to help. Help is needed!
- My daughter was struggling at Mainstream school but was still initially refused a place at a specialist setting. Myself and school knew a specialist setting would suit her better but someone came in to meet her for a school day and decided what they thought was best for her based on that one short visit. We didn't take no for an answer and she is now in specialist provision, which was definitely the right decision for her as she is doing so much better in specialist provision but why was it so difficult and so stressful for parents. Every child has the right to education that will meet their needs and help them to thrive.
- Social workers with no knowledge of autism!
- That school staff at her mainstream and the PRU had NO idea about masking and autism in girls and I had to say the same things over and over again.
- Shropshire council thinking they know best
- Lack of understanding and training in schools
- Parental blame
- Not enough training in schools to recognise sensory overload
- Training in schools is not enough for the staff to help our cherubs!
- Pressure on Parent Carers to make children attend school
- Teachers do not recognise SEN (don't know what to look for)
- Lack of acceptance of Parent Carers ability to recognise their childs needs
- As a parent carer everything is up to me to coordinate and manage and keep on top of services/ health/ respite and education
- All the hospital trips, the fact that she misses so much school and that she would be achieving academically more if she was well
- Health services not looking at the child holistically

Lack of Support

- Can't get any help with education system
- No support from school
- No support, life stood, jobs stop, no training, no development either professional or personal. On call 24 /7. People think you do nothing all day. No support at all for carers
- Lack of support for dad's especially and secondary parents get zero help
- No access to support because I live in Oswestry
- That services are Shrewsbury focussed and there is nothing much local to Ludlow for my daughter to access.

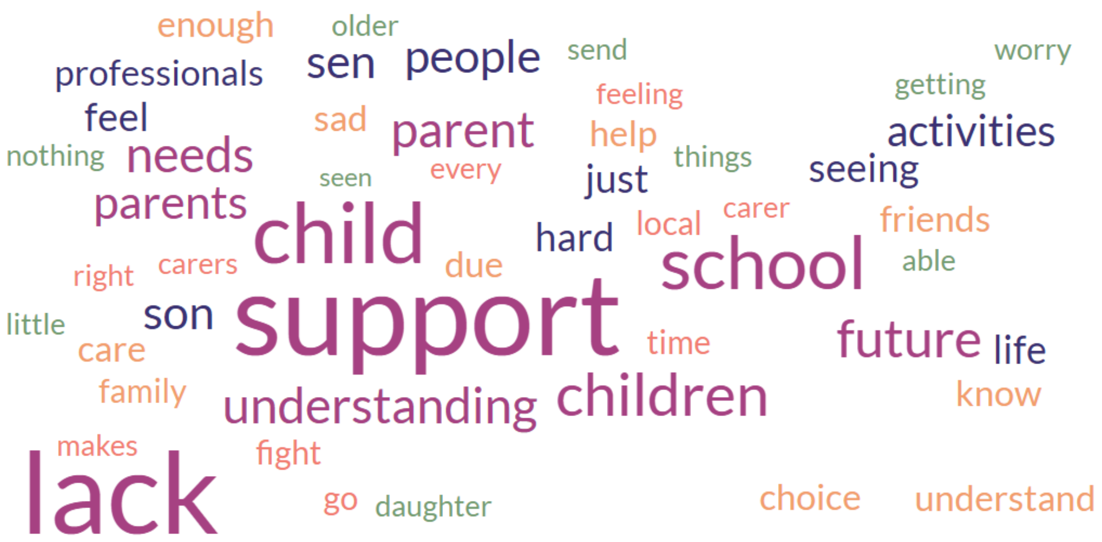
- The lack of appropriate facilities, activities and infrastructure that are available in the local area for profoundly disabled people.
- No social worker support
- Lack of social work support
- Lack of signposting
- I feel powerless to help my son
- The wait for support
- Services vary so much across counties- postcode lottery, afraid to move house and lose support
- Steeping back from career opportunities due to caring responsibilities due to there being no wrap around care/ level of care needed
- Having to be a teacher, speech and language therapist, politician, researcher and understanding law
- Lack of support and communication from LA for our SEN children
- Navigating services
- So much time consuming paperwork and no time to do it

Finances/ Funding

- The financial cost
- Being penalised for working and not able to get carers allowance
- Childcare fees so high I can't afford to go out to work. Lack of support from others and awareness.
- Ongoing financial burdens imposed by child maintenance meaning I can't afford to hire carers and have to use food banks to feed them
- Lack of benefits for secondary parents creating gulf in living standards between the two family homes and constant discrimination against men / fathers in caring roles
- Financial support
- Funding cuts leading to lack of resources
- All about funding and not the child’s needs
- Everything down to funding
- Everything for SEND children costs so much
- Applying for benefits

SAD

What makes you SAD about being the Parent Carer of a child or young person with a disability or additional need?



Lack of understanding of the life of a parent carer

- I feel my disabled child isn't looked at as an individual they are just seen as another case. Professionals don't understand the impact of having a child with a disability has on the whole family
- That every "professional" we have dealt with makes me feel like I'm a bad parent
- That parents aren't listened to
- Not enough support or out reach for parents
- Feeling alone
- Social isolation and lack of understanding by professionals of our lives
- Judgement from people that are paid to provide a service to those that need it
- Lack of empathy of others
- People's judgmental attitudes in public, lack of understanding resulting in families feeling isolated
- Lack of awareness
- That friends don't realise how hard it is or sometimes make comments which aren't meant to be insensitive, but they are
- That someone who has never met my child and just seen emails thinks they know his needs better than me
- That I am only just realising that I am a parent carer and how much I am juggling, I constantly feel frustrated with myself
- Lack of awareness and recognition of how hard it is to be a parent carer by those not in the SEN world

- Professionals don’t understand the additional responsibilities parent carers have
- Being a pensioner and the father of an 18 year old autistic son- I can be forgetful, and have to support my wife
- Emotional guilt
- I find it difficult to communicate and understand
- Always wondering if you are doing the right thing
- Trying to change my child and not adapt life for them
- People do not understand
- No understanding of my needs as a parent carer
- Lack of understanding from practitioners
- That nobody actually cares. She is just a name and case number
- That the child isn’t at the front of the LA’s decision making
- Every time I ring Bee-U and then come off the phone crying
- My child is alienated in the local community as none of the services or activities cater for his needs. Mainly toileting
- The lack of understanding by medical professionals. Eg when my child has been so poorly he has been hospitalised. The lack of understanding and empathy amongst staff is very distressing. It is hard enough having to advocate for our children when they are healthy, never mind when they are poorly.
- Lack of understanding show from people including professionals
- That people don’t realise just how hard it can be and so don’t offer help or make things easier (I’m talking about services here - they often make it harder)

Lack of support

- With not finding support groups on weekends as mentioned above I have found times feeling lonely as a parent. Luckily I have had friends with SEN children. Personally for myself my children have felt supported by ourselves as parents and school/nursery with provisions they've had but professionals in terms of more intense speech therapy would have helped more and this makes me feel sad because I feel I’ve failed my children in No support
- That my child may not get the same opportunities in life, that he can be judged by people that don’t understand him so quickly. There needs to be more awareness especially to the older generations about SEND
- Lack of support and understanding in general
- People judging him and not getting to know him to see how kind and caring he is, because at times his actions and hyperactivity don’t reflect his true character.
- My 7 year old son being constantly shamed and punished for his impulsive and often innocent behaviours due to ADHD at school and coming home saying he feels like killing himself and that nobody understands him except his mum and saying he thinks he will go to prison when he is older.
- The difficulties they have to face and prejudice from others

- The worry of what the future holds for my Son and how society can treat people who are seen to be different
- We are lonely and poor
- Seeing my child so overwhelmed
- Seeing my children suffer and knowing they aren't getting the right support and may never get the support they need
- I feel like I still don't know how I'm supposed to handle his behaviours. He slapped his 1-2-1 in the face at school today for no apparent reason and I don't know what I'm supposed to do about it when he can't communicate.
- Seeing the life I used to live disappear as my children's mental health deteriorates during to the lack of support.
- That lack of support has meant my son has missed out on so much - socially and educationally, also sad I can’t make things better for him
- Lack of consistency
- Being ignored
- Some children are not getting an education because there is no support
- Endless searching for the right support
- Seeing my children suffer unnecessarily
- Challenges for those who are not ‘disabled enough’ to get support
- Amount of time it takes to get support
- Life is so difficult and exhausting
- Not enough support from organisations
- There is little support for parent carers
- Have to fight to find help
- Fighting the local authority
- Lack of support for paperwork
- There is little official support- main help is from charities
- Waiting times
- Lack of 1:1 appointments for therapies
- Rejection from CAMHS
- Time for help/ support is too long
- Lack of support for parent carers
- Lack off appropriate/ affordable support
- That we have adopted and we have no support after adoption or from the virtual school
- That she has been in pain and we never knew as we’d put some of her behaviour down to sensory needs. She’s been diagnosed correctly now and it’s due to me querying something with her doctor but it took a lot longer to figure out than it would have done for a typical child who could talk and say something was hurting or uncomfortable.
- Having moments when I think help is finally coming and then realising it isn't meaningful help.

Fighting for support

- Having to fight for basic support
- The fact that we have to fight for every service or thing that could really benefit my child in both the short and longer term.
- Seeing others with the same struggles and feeling that nothing will ever change and we will always be battling
- That forms go on forever and have to be repeated and repeated. My child is never not going to have SEN, she was diagnosed at birth but instead of recognising that we have to reapply for DLA etc and fill in all those forms. Why? Just make it simple for SEN families.
- Life is hard enough without all that crap too!
- Waiting list around recognition of needs
- Our children miss out on so much compared to other kids, and rather than spending the resources to help, they spend more resources to fight against!

School

- Sad that teaching staff don't understand enough
- That her school is now 50 minutes drive away and she will lose touch with her local community
- Being stuck between mainstream education not being able to provide for need and Specialist school places not being available, loss of his education in the meantime
- She probably won’t get the secondary school placement she deserves because there are so few places
- The way my son's needs have been perceived at school. Also, worry about what the future holds when we aren't around.
- The lack of choice available to us as send parents for our children. My son couldn't attend main stream he has send so I actually have no choice in school he attends Severndale or nothing
- The struggles my child faces in school in comparison to his needs
- People judging or not understanding my child
- School don’t help
- Lack of support for post 16 college
- There's no choice for send parents it's one school or nothing

Lack of Opportunities

- The lack of SEN sessions provided by companies. A lot of companies do their SEN sessions between 6 and 7 in the evening. This is far too late for us when my daughter has school the next day. I appreciate this may be better for older children but isn't accessible for all. Our local trampoline centre used to do a SEN session between 9 and 10 on a Sunday morning which was great for us as my daughter loves trampolining. This has now changed to 6-7 on a Monday evening so we can no longer attend.
- The lack of opportunities for them
- The lack of choice of activities that my son can go to
- Parents do get offered some things but there's never a choice like there is for non-send children, my other child has every club at his disposal, he is capable of attending any school, he can choose which underwear he wears etc
- That many of the SEN activities are a long way from where we live - we’re not all in Shrewsbury!
- Not being able to give my son activities in the local area
- It's so hard because the help on offer is not there or just this one choice or nothing.
- Very little clubs/ childcare/ activities for my son due to his sensory needs
- Lack of inclusive sporting activities
- Lack of provision in North Shropshire
- No activity options

The Future

- Worried about how they'll cope without me when I'm gone
- Wondering who will fight for my child when I no longer can.
- The future and what happens when I die. Who will care for my son, the stress on his sibling to make decisions or fight for him.
- Worry about when I'm gone who will care for them
- Anxious about my children’s future, with only us their parents to support them. No family or friends to support us or the children
- Not knowing they will be safe and cared for as much as we have done and continue to do so when we have died
- Thinking about my child's future. Thinking about his life when we've died
- That my child may not be provided for appropriately if we weren't there. I feel sad for those children who don’t have such committed parents
- Worry about when I'm old and dead who will look after my babies
- Worrying about my child’s future
- Also the uncertainty of his future. He is 8 now and attends a special school I would like to know and have some certainty of what happens after that
- The lack of options for supported living

- The fear that if we move house over a county border we will lose our support network
- Not being able to sleep properly due to worrying about the future.
- That I’m unsure what my young person really wants
- The future
- Wondering what my little guys future will look like

Impact on Family

- The main thing that makes me sad is about who will care for our daughter after we have gone. You hear in the press about cuts in council funding regarding the care of adults with special needs, and neglect in care homes. It’s something that is never far from my thoughts
- Only getting to see them weekends and holidays due to Judges sexistly and wrongly assuming mothers do all childcare
- Not being able to engage in family activities, such as days out
- Dealing with the anger and meltdowns each day
- Seeing mine and my husband's relationship deteriorate and become strained due to the pressure on us as parent carers.
- Missing out on days out with friends or time with family due to our children’s additional needs.
- Sad regarding the time taken away from spending with my child in order for me to do what makes me MAD
- That I can’t do the things I’d like to do with my other children because it isn’t right for my SEN child (eg go to the cinema) so they miss out
- Seeing all the activities his older siblings who are neurotypical can take part in but he can't
- Relationship struggles
- Difficulty communicating and understanding my son, my wife is very supportive to both our needs as she is much younger than myself and has a better rapport with my son

Impact on Work

- The prospect of having to give up work as extremely difficult to find childcare during school holidays
- No child care options for him, so we can't both have proper jobs which then restricts our income hugely
- Being reliant on the county or NHS for certain things is not something we want at all but as we can't work full time due to childcare options for high need children we have no choice and then there is only one choice for things so you have no options it's take that one place or your ungrateful weather that's what's best or

you child or even mediocre or not that's all your allowed. This makes me so truly sad. We try everything we can to stretch to give our son what we'd want for him and what we think is best we can give him.

Friendships

- Her difficulties with making friends and keeping them
- When my daughter doesn’t get invited to birthday parties. She has an invisible disability and gets written off by parents and finds it hard to get close to and relate to peers. She’d love to go to a birthday party and invited people to hers.
- That my child doesn’t get invited to parties as often as her peers as I suppose families are scared or don’t know what to do/ask about her
- That she doesn’t have any friends
- Shrinking social circle
- I feel selfish at times as I have lots of interests and friends

GLAD

What makes you GLAD about being the Parent Carer of a child or young person with a disability or additional need?

Community Support/Friendships

- The amazing community I have for support. Where would we be without PACC
- My amazing community understands and supports when they can
- The friends we have made, the support from the SEND community.
- PACC providing activities and support
- Supportive charities like PACC, other parent carers
- Having other friends in the same situation who are there to share and care
- All the lovely other families I have met through my son.
- That they're able to meet others like them
- Meeting other amazing parent carers and getting strength from them to carry on
- That there are so many wonderful people supporting us on our journey, many of whom are volunteers
- That I have found a community of people who 'get' it through my child's diagnosis
- That amazing people have set up charities to support us, that there is support out there through my phone mostly, but it works and provides most of what I need
- The community of families we would probably have never met without having our daughter - they provide support, laughter, perspective.....
- PACC and other community organisations
- Sense of community and new friends
- PACC

- for the SEND community and friends I have made
- Glad I have found PACC, being a parent carer is isolating
- Friends that support me
- Meeting other parent carers
- Autism West Midlands support
- finding like minded people
- Empathetic friends
- All the wonderful parent carers I know, they are my greatest advisors
- Autism west midlands
- Access to Actio
- Amazing support from local charities- they keep us going

My Child

- Lots of cuddles and get to play Lego forever with Peter pan children
- Having my lovely children
- The bond I have with my son and happiness he gives me.
- My son is amazing and I couldn’t be without him. He has made me a better person.
- My child is amazing
- Seeing he grow and excel at what he does
- He's my boy... Of course I'm glad to be his momma
- My son is an amazing young man, and I know full well I have done that with little help from outside organisations
- They’re beautiful. And remarkably resilient
- She is the most amazing human.
- My child is awesome and worth everything, every long form, every uncomfortable conversation, every time I’ve had to demand for appropriate support.
- Glad my daughter is amazing as she is
- My actual son, he is the most beautiful soul, he is so happy and just really has taught me so very much. He’s taught us all so much, the whole family
- That my child is adorable, very funny, affectionate, unique, uninhibited and mine
- My boy is just the best I would not change one single thing
- My Son is just the most loving child and is so pleased with the simplest things
- She's a wonderful human
- my children are healthy
- My child is wonderful
- My daughter’s happiness
- My children. They are kind happy beautiful and very well loved children by us as parents as well as our family and friends and even with their additional needs they are my everything and therefore as their voice and advocate I’d fight every corner for them both

- He's taught me patience and understanding
- Having gorgeous, affectionate children
- Her resilience
- Spending time with my babies
- Having two wonderful children. Seeing the world through different eyes than before I became a parent carer
- Seeing my child thrive when things are good
- ...... list is endless. They're just my kids and I love them
- He is truly unique, quirky and lovely just the way he is
- That they're wonderful individuals who help us see the world with a unique perspective
- That when my young person laughs it’s the best thing ever - together with small steps of celebrations
- His positive attitude and how much he teaches me. His brain is amazing
- Having a happy little boy who has opened our eyes to a whole new world
- Sharing special moments
- Proud of child's milestones however big or small.
- Give thanks and praise to things others take for granted. Proud of child navigating a world that has been made for neurotypicals
- Finding the joy in everyday things that I wouldn’t have done prior to my son having a brain injury
- They provide an opportunity to see the world differently
- To see the kids enjoying and achieving little goals
- They are special and have to best outlooks if listened too
- Spending time with my kids is a joy not a burden. It can be hard but it's overwhelmingly positive time
- Rewarding
- They show me they can reach their targets with support
- My heart sings when I see her achieve something I wasn’t expecting or didn’t think she could do. she’s fearless and determined and just gets on with it all despite it being harder for her. She’s cheeky and has a fabulous grin. She is defying expectations of teachers and us. She LOVES maths and numbers. She can’t talk but she can read (that blew my mind at first!). She has a great sense of humour and is funny.
- The love and care and amazing intelligence and passion that comes with Neurodiversity.
- My son has a funny, cheeky personality
- Having the perfect child- I wouldn’t choose to change anything
- Having 2 amazing children
- Child manages difference well, despite lack of outside support
- When your child has a good day
- Seeing my children flourish

- Bath time play and bed time cuddles simple pleasures like pushing your child on a swing
- It's made me a stronger, better parent and they have taught me so much
- That having him as a sibling has made our other children kind and patient and tolerant
- That I'm their mum to fight for them
- Spending time with my daughter, knowing that she loves me and enjoys being with me

Success of the Provision - School

- His school is amazing, his teacher an TAs are wonderful. He attends Severndale and I couldn't be happier with the care he receives while there
- Her primary school have been excellent
- That when the right provision and service is in place, it works well
- The support he has in his school are amazing. They celebrate his differences. And every small step is huge progress for him.
- The progress my SEN children make once they have the correct support in place, everyday is a new day and my SEN children are amazing
- I'm glad that she enjoys her independence and is happy when she's at school.
- Achievements made despite the challenges
- That she has a school which is so inclusive and so believes in her and educating her. They're amazing and supportive and we are exceptionally lucky with them (I shouldn't feel like that it should be how all schools are but they're not so I know we are lucky).
- That she's in mainstream education and her peers like her and include her even if she's a bit 'meh' when it comes to playing with others still!
- Level of provision at our local nursery and school

Better Understanding

- Increase in awareness, rare now to meet people who don't understand or at least keep their old fashioned opinions to themselves.
- When people see their positives
- Meeting wonderful people who see your child as a child and not as a disabled child.
- Also the way some people go out of their way to show kindness and will help your child in any way possible
- Being shown a different world
- Being able to coach my son and teach him about how his brain works so he can understand himself better.

- I know my child inside out, his wants and needs I have to tune into such detail because if I can see something coming that will be uncomfortable or overwhelming for him I can avoid/distract or reassure him. Not many neurotypical parents can say they know their child so well.
- Celebrating the tiniest of milestones that can be such a huge thing for SEND children and other SEND parents I know from my child’s specialist class we share in our triumphs and struggles too because we understand how it can be

Some Parent Carers felt that they currently have little to be glad about:

- Right now, nothing. My daughter has had 2 years of inappropriate schooling because staff weren’t better educated in girls and autism
- Nothing at all sadly. I would much rather he didn't have a disability and could live a full and healthy life

Thinking about the services you and your child or young person use, what are 3 things they could do to improve your experience of being a Shropshire SEND family?

Service Provision - General

- Listen, understand and effective communication
- More support
- TRULY working in partnership
- True person centred approach
- Not keep trying to discharge when the need is obviously still there
- I do feel though the services we do use do their upmost to support with the resources open to them
- Less talking (ie support groups and courses) more practical help
- Listen and accept the opinion and experience of parents who have children with SEND, rather than trying to blame the parents for their children's difficulties
- More resilient adult social care staffing
- Long term planning
- Less talking
- Hydrotherapy
- To be treated equally
- One major improvement would be the provision of more changing places toilets in the activities that Actio provides. This would greatly enhance accessibility and comfort for our family
- Services need to be more proactive rather than requiring constant chasing from us, which adds unnecessary stress
- Provide a road map for support indicating who does what and how services can help i.e what departments at the council do what and how they can help. What NHS teams there are and who does what. You go into this blind and have to

battle to get the right information and spend so much time stabbing around in the dark

- Better support
- More outreach
- Less of a battle to get what should be entitled to
- Do their job properly following the law, if say going to do something do it without having to be chased
- More focus on those with more complex needs
- Do your jobs well (I know they are busy and stretched and stressed and underfunded) but don't ghost parents when we're asking for information about our child and just find their EHCPs without having a court tell you to. Help make our lives easier rather than harder - PLEASE!
- Services to apologise when they are at fault
- Listen to us,
- Make things easier
- Make us feel included
- Tell us about things
- A person centred approach.
- Accurate and consistent information from professionals
- Give the child what they need.
- Communication
- Think about the child.
- One to one phone calls to check.
- More engagement with our child to see how his individual needs can be met (not on a group course)
- Not having to constantly fight to get my son help
- Don't dismiss people from paediatric care as soon as they get a diagnosis 😔
- Access to more home help.
- Simplifying processes
- All services just do what they say they will do without excuses.
- Girl specific support for autism
- Work with local kids organisations to help them include SEND kids effectively
- Wheelchair accessible parks would be good.
- Wheelchair services actually understanding our needs and meeting them would be lovely too
- More choice, you can choose between 2 types of nappies, your son has an option of a Tring a club for high need children with sports or sensory play
- Another thing would be the whole push with no holidays in term time this drives me insane. it's the only time that a lot of these children can enjoy the rest of the world. In the summer hols and other holidays it's too busy and they can't access things properly. It should not be made that e can't or are scared of fines to take them out for the day or on a holiday because my son is a different child without

big crowds. I suppose yet again it's taking away the choice we have as parents and the best interests of our children. They can access the community its, days out and holidays best when it's quite so this is ludicrous to me

- We need to see examples of children like ours thriving not just placid children with MLD that are constantly being shoved down our throats as successful examples.
- PACC need to be more focused on policy, legislation changes and how this affects service delivery in Education, Health and Social Care for SEND families in Shropshire. Less focus and money spent on activities which a lot of SEND young people and their families are excluded from accessing anyway
- DCT staff are not good advocates for the children and young people on their case load, weighed down by hierarchy and red tape which stops the service delivering the best possible outcomes. Staff are not empowered to think outside the box and often families disengage as they are being forced into a one size fits all solution, which ticks the local authorities box but is not suitable for the child/young person.
- NHS overhaul of way they triage, examine and treat SEN children

Local Authority

- More efficiency from the council
- Local authority taking accountability and apologising when they are wrong or committing illegal practice.
- Council to actually engage in the community
- Local Authority simply provide what is required when it is required.
- LA could be more understanding and keep legal timeframe

Parent Carer Co-production

- Believing what parents/carers say to the professionals more.
- Listen to the family as they know the child best
- More support for the families.
- Believe parents.
- Offer more family support
- Longer time working with families

Timescales

- Sticking to legal timeframes for ehcps,
- Making diagnoses easier and quicker
- Faster responses to correspondence from caseworkers
- Improve time on waiting lists

- Actually see and diagnose neurodiversity in more timely manner. Have been waiting over a year.
- Provide appointments when needed
- Time of waiting
- Improve waiting times
- Check in with parents more throughout the wait time

Communication

- Better Communication
- Communicate, communicate, communicate!!!!
- Services to communicate about what's going on!
- Communication more opportunities for carer and child

Understanding

- More awareness from the community so we can feel less judgment.
- More understanding
- An understanding of the impact of having a child or young person with a disability has on parent carers.

Education/EHCP

- More support during permanent school exclusions
- Improve post 16 understanding of SEMH and related neurodiversity
- Educate the education system
- Better help with education, realise that it impacts their schooling even when not in hospital and have some online lessons for maths and English that they can access? Schools only send work home if off for 4-5 days at a time. She misses so much school.
- More consideration of different styles of education
- Automatic EHCP
- Ensuring that an Education, Health and Care Plan (EHCP) is updated and actually sent back to us, along with concerns raised in it acknowledged and dealt with would be helpful.
- Choice in post 16 education
- More training/understanding in a mainstream education setting on SEND
- The whole EHCP process is so slow and secretive, since the review we had at school last summer we've not received any outcome or revised plan. When we moved here and contacted the council about registering our daughter in a school we were directed to a long list of schools and were expected to investigate which

schools were appropriate ourselves. It would have been much better to have been able to speak to someone first and been given a smaller number of appropriate options.
- More specialised SEND education settings so all the families who need it can get access that makes such a difference to their child's lives.
- Support for schools with actual practical applications
- School prioritising use of specialist equipment for those severely disabled students who need it most.

Information Provision/Advice

- Having all the information in one place
- Personal Assistants who help accessing services, both for respite and to help with paperwork and navigating things
- Advice on benefits and support available
- Advertise more the help that's available
- More awareness to other families to normalise disability and help them to teach their children about why other children may be different to them and how the brains work. More empathy and understanding of others should be instilled in children to benefit them all in their futures and level of emotional intelligence. This would go a long way in the mental health crisis we currently face, we have the opportunity to shape our children's generations to be more emotionally intelligent and understanding of themselves and others
- Once diagnoses are received more in depth face to face support should been given to family and just not told to go and venture into the world yourselves with this brand new life and diagnosis
- Simplified run-down of the things available
- Other people's education on people with SEND, I'm a great believer that understanding comes from education

SALT

- Lack of speech services to encourage social skills and lack of after care once diagnosis was given
- SPEECH AND LANGUAGE
- More speech therapy help and support as my first child was failed completely. My second child currently under salt but nervous they will discharge us but feel more intensive group salt therapy sessions could be introduced to help aid children with speech issues and for them to attend schools more
- My daughter has had no speech therapy for the last 18 months, despite stressing at our initial meetings with the how important it was for her. We are now at the

point where we are going to have to make a complaint to the school/local authority. There is a real lack of communication

Local Support

- Offer weekend activities in south Shropshire
- More services in south Shropshire
- Harmonise services across counties
- More facilities across the county to be able to administer personal care. Not just in the major towns but countryside too. We should never be more than a half hour drive from a proper fitted out changing facility anywhere in the county
- Stop expecting us to travel to Shrewsbury for everything
- Services being more local to us
- Have services near where we live. I'm a working parent with other children, I can't go to Shrewsbury for everything. Please think wider than there! Whitchurch is getting a new swimming pool next year please put SEN swimming on there! That would be a start!!
- More local support
- There is nothing in south Shropshire and no infrastructure to access support
- Be more available locally, nothing in Whitchurch
- Services local to Ludlow

BeeU

- I have no time for BeeU absolutely hopeless
- Reduce waiting times particularly at BeeU
- Provide timely feedback on assessments - we have been waiting 8 months since a BeeU assessment
- In my opinion Bee-U should be scrapped and they should start again. They do not offer any kind of service and are not fit for purpose. They do not have the funding to provide an effective service and our young people are suffering as a result. My youngest had been on a waiting list for urgent support due to suicidal ideation. We have been waiting since Jan 24. He has just been placed on the waiting list for an ASD assessment and I've just found out that now he's on that waiting list he's been taken off the list for urgent support. Apparently he's not entitled to any support whilst we await an assessment which is likely to be 18 to 24 months away. To me whether he has ASD is neither here nor there, he needs support now. It really feels like they are hoping he will kill himself and then it will be one less person on their list to worry about. I've never heard something so ridiculous in my life! The focus should be on what the child needs right now and if that is support then that support should be given no matter what the eventual diagnosis is

- More funding for BeeU to focus on mental health
- CAMHS could do more than say “ there’s nothing we can offer “ when child out of school 12 months plus and suicidal ideation

Short Breaks/Respite/Activities

- Better short breaks provisions especially for younger children
- more holiday clubs or more inclusive HAF providers in secure locations (ie the sports club is inclusive but not secure enough for my son to attend as he elopes)
- Provide really inclusive short breaks opportunities. We have two children with SEND and are always rejected when we apply for activities, such as holiday clubs, etc.
- More respite options
- More options in school holidays that are NOT expensive
- More activities
- Local offer is poor with little choice and frequency. No suitable holiday clubs or extremely difficult to find appropriate clubs. Clubs like Project farm only found by word of mouth
- More holiday club availability and regular respite care availability without having to be referred to yet another service
- I feel not alot of help in terms of holiday clubs for Sen children in school holidays as little rascals only do Mondays with a waiting list and other than that not a lot I am aware of then there's getting pa support and don't really know very much about this. Therefore, parents having to use our annual leave
- Easy to book respite options.
- More SEND sessions at attractions/extra curricular activities so they could experience more
- Have SEN leisure sessions split out by age group as soft play etc can be dangerous mixing teenagers and young children. SEN sessions at more sociable timings. At the moment a lot of the SEN sessions are evenings which feels an afterthought and affects bedtime routine which is important to many SEN children
- Increase holiday provision for SEN children
- Offer more respite days through AFC (I understand staff shortages)
- More available for children with challenging behaviour complex learning difficulties
- More clubs for 11+ children who are non verbal severe ASD
- Offer more drop in sessions on weekends
- More choice
- More flexibility in service provision
- Have a bank of vetted 1:1s for the holidays. Trying to find someone to support my child in holiday clubs is nearly impossible- I desperately need support with this

to enable me to work but it’s so hard. It could be students at Shrewsbury college, or teaching staff that want some extra money, or retired people etc but please please this would help so much!
- Groups for parents to meet support network

Funding/Financial Support

- Stop telling me that if the funding was there then the service needed for my child would be made available
- Financial support. Paid properly!!!!!
- Cheaper parking- I have to pay £3.50-£4.50 a time sometimes £8.50, for her hospital visits. It can be 40 odd pound a month.
- Direct payment should be used for anything they need and they need a car more than a PA!
- Secure more funding so more holiday club days could be allocated
- Financial support
- Help with child care
- Sharing of DLA/blue badge/Motability car/direct payments to allow them an equal standard of living between two homes
- Increase funding
- Benefits being divided between both households, a blue badge fit both households, a Motability vehicle for both households
- Increase funding so provision can be more readily accessible and isn't so difficult to access,
- Help with cost of living. Payments for carers are useless when we have no heating. Support food banks and uniform exchanges and acknowledge cost of living for disabled and single parents there is money there but it all goes to the other parent even though they spend half their life with me
- More funding

Transport

- I also have huge concerns about school transport and the constant hovering possibility that the council will think our young people no longer need it funding for school so they can use the money on the ridiculous and unwanted pedestrianisation Shrewsbury project.
- I need help with transport. My ex wife gets all the DLA and mobility car and I'm driving an unsafe old banger
- Help with transport to activities