# Early Help for children and young people with Special Educational Needs & Disabilities

## Shropshire Parent and Carer Council

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**Abi Taylor**
Abi@paccshropshire.org.uk

# Contents

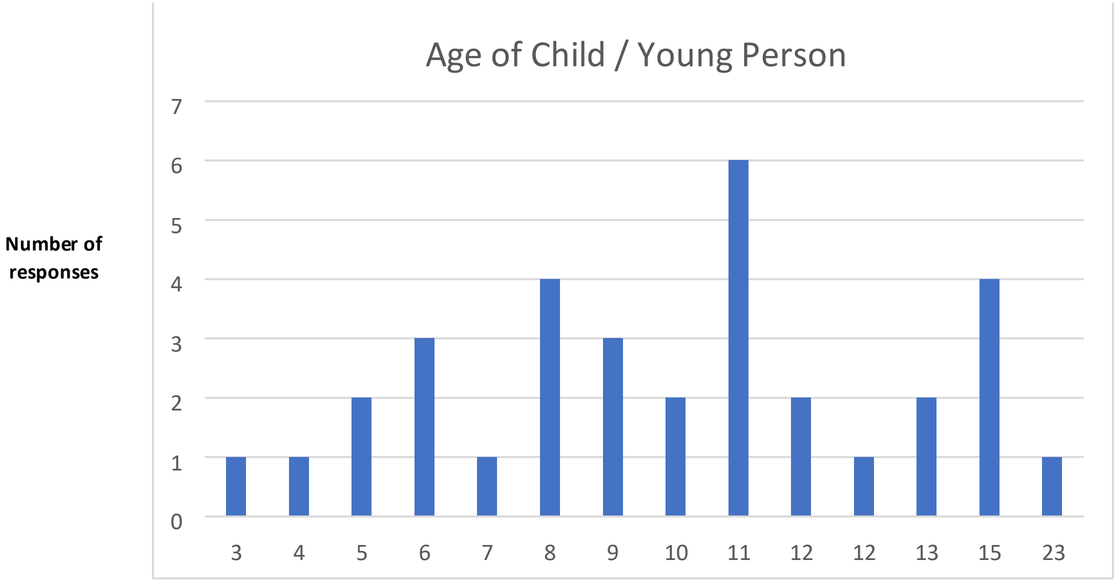
## Introduction

The Shropshire Parent and Carer Council (PACC) believes that all SEND families would benefit from 'early help' but currently this need is not being effectively met in Shropshire. PACC would like to see more opportunities for parent carers to access peer support, more opportunities for parent carers to learn about the new role of parenting a child or young person with Special Educational Needs & Disability (SEND) and a greater proactivity in the system that enables families and young people to plan and prepare for the future.

There is increasing evidence that parent carers are at risk of emotional trauma because of the lack of support early in their journey. It is also clear that children and young people with SEND are more likely to experience poorer mental health, poorer physical health outcomes, and a lack of opportunities to access community activities and support which builds skills and confidence. This lack of 'early help' too often results in an escalation of difficulties, increased risk of distressed behaviours and families going into crisis.

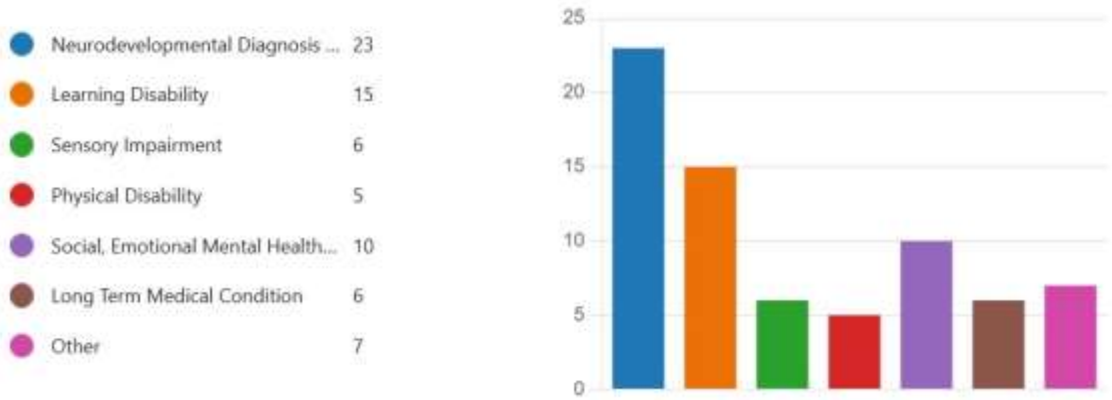
30 Shropshire Parent Carers completed this survey. Parent carer comments are in italics and have been included as they were written in the survey responses to maintain authenticity. In line with PACC's policy any identifying information has been removed however. A glossary of abbreviations has been included at the end of the report.

## Breakdown of Responses

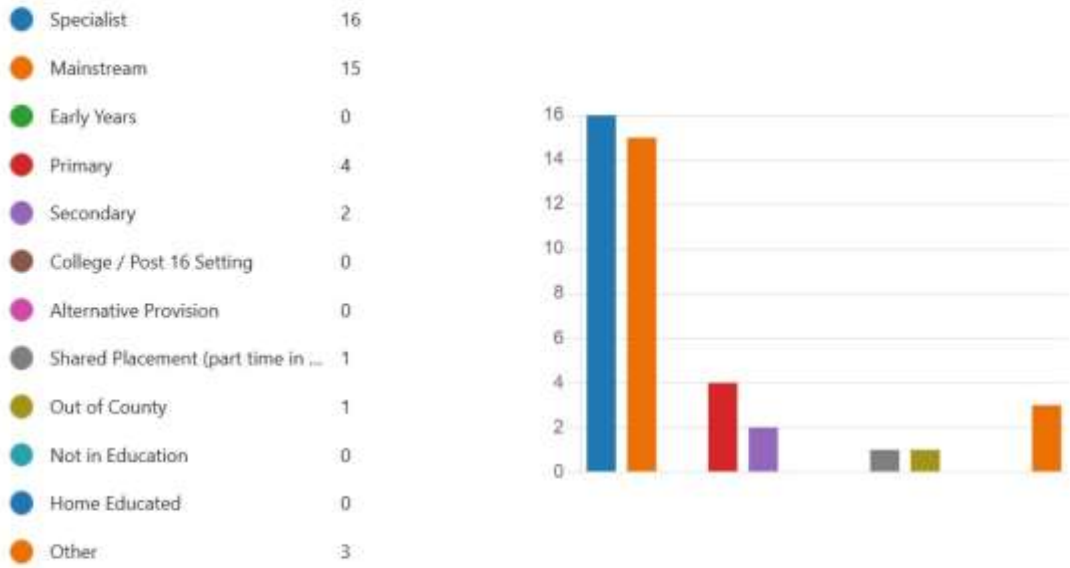


**Age of Child and Young Person with SEND**

**Child/ Young Person's Diagnosis/ Needs**



**Child/ Young Person's Education Setting**



1. **What would a good 'early help' support offer look like at the start of a family's SEND journey? This would be from the point a concern was first identified or a diagnosis received.**

Through feedback received from 30 Shropshire Parent Carers, it is evident through all themes that have emerged in response to the initial question, that the current Early Help service does not have a SEND specific support offer

*The current early help blurb is for when a family has 'problems'. Does not quite fit SEND!!!*

## *Good Understanding and Support*

Feedback from Parent Carers suggests that it is not clear what support is available to them and how to access it:

> *Any support would be great.*
>
> *A clear pathway of support, starting with self-help, I don't necessarily want services involved in my family if I am at the start of my journey.*
>
> *Felt very alone and not sure where to start to get support. Eg GP, School, CDC*
>
> *Parent support/counselling/relief*
>
> *Support, being listened to, more understanding of conditions, more availability in specialist setting, prompt assessments from professionals, knowing what's available.*

Support also needs to meet the needs of CYP and their families, specifically in the context of SEND. Families feel that their needs are not being recognised or acknowledged:

> *Someone to recognize everyone in a family needs help with SEND, not just the child with additional needs. To signpost and support. To remain non judgemental. To have either lived experience or extreme empathy through training.*
>
> *We had Early Help in 2017, but they didn't understand SEND at all. Ex husband had been arrested for domestic violence. They just kept coming round to check he hadn't moved back in; kept looking at laundry (presumably for his pants). Didn't understand disabled women are nearly 3 times as likely to be victims of domestic abuse. Signposted us to websites that were broken and phone lines that were never answered. Didn't understand who the DCT were or what the challenges were. They also had a spiders web to chart emotional well-being, but they were clueless as to the challenges we were facing. Ultimately took up a lot of time and were no actual help. They just didn't know what they were dealing with, what our challenges were or what help was out there.*

This includes support for CYP who are identified as a child in need - where support has not been given:

> *As part of the diagnosis process at the Child Development Centre, Social Care was involved and he was identified as a child in Need, however no other support was offered.......I would like the Early help process kick in at this stage and parents be offered the help they need ..*

In addition, the current level of support they are receiving is limited:

*We have had limited support and all of it has been from the speech and language services.*

Parent Carers also feel that support is needed navigating paperwork and applying for support:

*Assistance with complicated paperwork, eg - DLA application*

*Financial support - DLA, carers allowance, charity funding etc*

It was also suggested in feedback that Parent Carers may benefit from workshops or the opportunity to meet up with other Parent Carers in person for support and advice:

*Early help workshops / parent meet ups to explore topics such as .... MDA assessment process, EHCP info, Health support, Social care support and what is the role / purpose / benefit of a DCT social worker, Social work assessment, Parent carer assessment - you can have this in your own right AND do not have to have your child assessed - type of support available*

*Groups to talk/ share / gain info on: activities available, Sleep support, Diet support, Behaviour support, Sensory support*

As well as support for parents to help then understand their child:

*Therapy was very helpful, help to understand why your child behaves the way they do.*

*I've used early help and my support worker was a god send - when I was eventually accepted. Early help would be more beneficial if those who needed to access the service could use it before the home reached crisis point. So, you find out your child has additional needs - you access early help - they help you get the right support in place EARLY ON - EHCP, diagnosis, DLA, targeted interventions, home support: lifts, appropriate bedrooms, etc. support in schools. Appointments. Recommend courses for family parents and children. Give additional children help with being Child carers. As in worries and concerns. Strategies for all family members to manage behaviour and emotions. Give access to outside groups for all the family to use. Allow people to use the early help service until they feel ready to end the support. This is usually ended after a year. Most children and families aren't supported fully after a year given the wait times for appointments and assessments.*

## *Good Communication*

Parent Carers have told us that they feel open and honest communication is vital in any service they are accessing. Specifically with Early Help support, it has been expressed that communication with Parent Carers and with Professionals is important:

*COMMUNICATION NOT ONLY TO PARENT CARERS BUT AMONGST PROFESSIONALS. NOT BEING FOBBED OFF OR FORGOTTEN ABOUT*

It is also felt that the opportunity to have conversations with Early Help to explain their child/ young persons needs to identify support would be beneficial:

*A conversation (not a questionnaire) where parents could meet with a professional from the Early Help team to discuss the implications of their child's SEND; identify areas of need where support is required and receive signposting to the type of support available. This should be from a spirit of partnership between the parents and professionals rather than a 'top down, one size fits all' approach.*

*Professionals who are empathetic, understanding and wish to understand. Not those who wish to parent blame. Someone who is willing to listen without passing judgement*

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## *Good Information Provision*

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Parent Carers feel that there is not enough information for them to be able to understand what is available:

*More information provided, having more suggestions instead of asking the parent/carer what they want. We don't know that's why we're asking for help.*

*I just want to know what's available out there for as and when I need it, like all families not just because my child has SEND*

*For a thorough understanding of provisions to at least be signposted. For parents to be believed.*

*To have an introduction to the send offering.*

This includes being provided with information regarding specific needs:

*I would've benefited from an information session. Which outlined basic information about Autism and global development delay. Even a group session with other families of newly diagnosed children.*

Parent Carers also feel that information they are being provided with is not always correct - when they are asking for help they are being ignored or signposted to other services:

*Good early help should be like ronseal and do what it says on the tin! Stop presenting barriers to those who are asking for help before they are unable to use the help offered! A simple hello and here's what we can offer should be made available to anyone who's child has a diagnosis or is suspected of having SEND. If someone reaches out for help a conversation should be had. Navigators of SEND should be available at all stages, like the old FIS officers used to do and like the PFA navigators are doing at PACC, who are brilliant by the way!*

*Help identifying differences, especially for single child households where extra needs are not immediately obvious by comparison to other siblings.*

## *Clear Diagnosis Pathway/ Criteria*

Feedback suggests that understanding the process and criteria remains confusing and unclear regarding diagnosis. There is no clear information provided about the pathway and it is not clear of the stages of diagnosis:

*Someone assigned from beginning of diagnosis journey would be great to help advise on steps*

*One stop shop for all services via one referral*

*Knowledge of clear access routes to other support organisations and diagnosis pathway.*

*To be able to get any kind of help or even a pathway to a diagnosis without paying*

*Clear explanation of pathway, depending on where you live some children end up via the Telford (stepping stones) pathway rather than Shropshire MDA. Telford pathway doesn't lead to EHCPNA but Shropshire pathway does. Parents are often totally unaware of this. Face to face 2 year check with Health Visitor rather than phone call asking questions to parent so HV can see the child responses. Quicker appointments with professionals SALT and community paeds waiting times are too long. I know that these services are REALLY stretched. Support put in place before diagnosis should be easier to obtain, for example, 24U and nursery grants.*

*Education on the diagnosis stage identifying who and where help can be accessed, which path to take to get what is needed for both child and family.*

*At point of diagnosis having a named/consistent social care practitioner/team providing continuity of support and advice. It would be important for the practitioner to know our child’s needs for building a relationship with our child so that we could be confident of their support*

> *needs being met and providing us as parent carers with the information needed to make informed choices. Having to explain to a different practitioner each time what needs are is off putting/a barrier to parent carers as coping with the day to day is exhausting.*

Parent carers feel that more information should be provided about what to expect - including all aspects of the stages they may experience with their child/ young person:

> *A booklet or pack to help parents once a child is put onto the send register. This should detail what routes are to be taken and by whom. Every step that has to be done, who's responsible and timescales. We are starting our journey and it's full of cross overs and complications and lots of acronyms for everything. No explanations on what they mean, just that we have to*
> *become a child specialist in this area. Seems that Beams do everything to ensure schools dont refer to them to get a child diagnosed. Diagnosis is needed if ECHP is needed to support the child and waiting times are ridiculous, we are dreading it as it's our daughter that will suffer. School seems to be the only one who wants to help but are restricted in terms of time to explain process and budgets. Why have an external company do an initial assessment to then get referred to the NHs Beams to then decide to do another assessment to then get a diagnosis. Everything seems to be down to the school and parent, hardly any input from Beams at all from our experience for a starter pack etc.*

> *Told didn't meet criteria twice though child struggling to attend school, access education, eat, drink , sleep and mother has terminal cancer! So widening criteria to support those families struggling to get diagnosed and needs identified and met.*

Parent Carers also feel that there needs to be support in place post-diagnosis. Current procedure is discharging from the service once a diagnosis is received:

> *The point of concern can be taken more seriously by listening to parents views ahead of waiting for professional opinions. When a diagnosis is received, an appointment with a support group should be made automatically to discuss next steps rather than being sent home with leaflets and phone numbers.*

## *Effectively Responding to Needs*

Feedback suggests that the current offer is not responding to the needs of services users, in particular SEND service users. Families who are in crisis and in urgent need of support are following guidelines and requesting support, yet are either not being listened to, or those dealing with their enquiries have little knowledge of SEND and are not appropriately dealing with enquiries:

> *Good early help support for send families should involve consistent and reliable support worker's. A team that is matched appropriately to the families needs, including relevant training and understanding around the families needs. The family know what is best for them but are not always in a position to communicate it due to barriers that are in place, or their own needs not being met. There should not be a time limit on the support offered as send families have many complex needs. Each need has to be dealt with separately and possibly regularly re-addressing.*
>
> *It needs to be a pro-active service. The service only seems to kick in a long way down the process and not when we first ask for help. We also were sent someone from a team that visits before early help (compass team?), and whilst she was very nice it was completely pointless e.g. we already had parental controls on our phones but were not even asked.*
>
> *An understanding from professionals re the effects of a complex trauma history. Not to offer yet more training in order to jump through hoops to receive support and to recognise and respect the level of understanding and training the parent already has. Respite put in place where recommended by professionals including post adoption support rather than having to be flagged to social services as not coping which is inaccurate. The BEST approach and interventions if money/funding wasn't a barrier in order to make a real difference in the lives of children and families. I believe this would have a huge impact on health and social care budgets further down the line. Support and not barriers. EARLY help not a battle to meet thresholds. A more efficient and less obstructive pathway and thresholds for the neurodevelopmental pathway.*
>
> *Shropshire council must not be of the opinion that early help should only be offered to ""children at risk"" from harm, which is the impression I am given presently. Send children who are not appropriately supported are at a huge risk of having parent's who are desperate and struggling themselves for whatever reason. If they were supported correctly they could all lead a much more productive, successful and fulfilled life. "*
>
> *Many families are expected to adapt to support worker's who may have no clear understanding of the families needs and therefore cannot support appropriately. Just because of the complexity send brings, half day's of specialists training here and there is not enough. Early help should build up such a relationship and understanding of the families needs they conduct multidisciplinary meeting's to consistently bring the service's that are relevant to the family. The early help should include regular reviews to ensure the families needs aren't increasing. Many send families are offered early help for short periods but the inconsistency of the worker's has*

*detrimental effects on families. It takes huge amounts of trust for families to allow stranger's into their home's and learn their most personal struggles. It is hugely embarrassing to have to ask for help in the first place. So if a family does, this really ought to be taken seriously and dealt with promptly to alleviate further battles ahead.*

## 2. What would a good 'early help' support offer look like in terms of planning for the future and preparation for adulthood?

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### *Support*

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Feedback from Parent Carers shows that there are multiple areas where support is required. This includes being made aware of the type of support that is available to them and how to apply for it; knowing how to access further support; emergency support for when families are in crisis; support relating to diagnosis; support early on to allow children and young people and their parent(s) to prepare for their PFA journey; support relating to education and EHCP's.

### Knowing what support is available and how to access it

*Continued support and also commitment to the child to ensure opportunities are explored. Also support for parent carers to enable them to provide the right and relevant developmental support, and giving parent carers a break when needed.*

*Knowledge of support available and help applying for that support*

*Support on being given information and help to seek what is "out there" for the future of young people reaching adolescence/adulthood*

*A joined up approach with all professionals involved. Not leaving parents to firefight. More supported accommodation across the county.*

*Providing some guidance of what to be thinking about and where to go for advice. Offering send specialist employment services to help out children think about a career and plan their education accordingly. Providing better support to have awareness of basic health and active lifestyles and the importance of having a community to be part of.*

*Simply knowing what's available, the local offer is good for this*

### How to access further support

*Outlining what support is available, outlining what the options are for the child/young person, helping the parent to access further support if needed.*

*Being left with additional service help.*

### Knowing how to access emergency support

*Good Early help would be consistent support (including a 24/7 team phone number for crisis support) from a social care practitioner throughout - from day one (diagnosis) and at all EHCP meetings. To date not one of the EHCP meetings has anyone from social care attended.*

### Support relating to diagnosis

*Early stage help would support parent carers deal with any trauma from diagnosis of a lifelong need that their child might have.*

### Support from the start of their journey

*The social care practitioner would explain during the journey of the child what help and support there is in Shropshire for the child to live as independently as possible and to prepare for adulthood as a pathway rather than a response to a crisis.*

*It should mean help and support during the early years of your child's life. However, I feel like I have had no support whatsoever since my son was diagnosed nearly four years ago.*

*Support in primary and secondary age with earlier preparation into adulthood, as many send children will take much longer to learn, understand and process information and activities than their peers without send.*

*Services that are focussed on support into adulthood.*

*Transition support through education system. Introduction to services in adulthood perhaps.*

*This legally should kick in year 9, this doesn't happen....,.......I would like to see every child be prepared for the future and to leave Education with a full week of activities, so you miss that fall off the cliff*

### Support with Education/ EHCP's

*Ensuring an EHCP/or some kind of educational support is in place.*

*To have an annual review meeting at school from year 9 to 11 regardless of whether the student has an EHCP. This should be to find out what the students wishes are for the future regarding education, employment, living arrangements, health, leisure, finance, relationships and to refer or signpost to organisations able to help to break down any barriers to achieving their ambitions.*

## ***Information Provision***

Parent Carers feel that it is difficult to navigate information - not knowing where to find it and not having information clearly explained and signposted. This includes knowing how to access services; knowing who to speak to and how to contact; a clearly outlined pathway; general guidance and information relating to benefits.

Parent Carers feel that having a point of contact to help with signposting or a clearly outlined explanation of options should be available:

*Help to point in the right direction and someone who can help you chase appointments etc*

*Good Early help would be clearly signposted and explained services and knowing where to go/who to speak to/phone number to call etc with a timescale of waiting times.*

*Good signposting, assistance in form filling, understanding the system etc*

*Clear communication about what options are available for our young people in education and within the community, as they prepare for adulthood.*

*A clear pathway and options depending on child's potential. Better local support and access to leisure facilitiesProviding some guidance of what to be thinking about and where to go for advice. Offering send specialist employment services to help out children think about a career and plan their education accordingly. Providing better support to have awareness of basic health and active lifestyles and the importance of having a community to be part of.*

*Simply knowing what’s available, the local offer is good for this*

Knowing sufficient information about key stages in their child/ young person’s life is also needed - Parent Carers are not always aware of stages or what to expect or how this journey will look for them.

*What does preparing for adulthood mean ... it is not something to be spoke about at age 16/17*

This would also include examples of other young peoples' stories:

*Options - examples of what other young people achieved along their journey and where they are now*

Having clear and honest information provided is also key:

*Realistic information on SALT, OT and physio therapies. It's really poor provision in Shropshire.*

In addition, knowing entitlements such as benefits and where they can go for advice:

*Ensuring families are not in debt and are financially ok and claiming what they are entitled too.*

*Ensuring the families know where they can reach people for advice and assistance.*

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## *Awareness/ Training Opportunities*

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*Workshops in advance of major milestones*

*Household/financial management help and advice*

*Benefit advice - assistance with DLA forms and entitlement check*

*Housing options, Finance – benefits, Deputyship etc*

*What happens when your child becomes an adult in law ... 18 years old ?*

*Appropriate support training for the workers according to the families needs- not one size fits all.*

## *Activity Provision*

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*More choice and availability in Actio all in activities. As my son is only 6 and has a mental age of around 2. He requires a 1 to 1 support which there are no activities suitable for him which he would enjoy. Such as soft play activities or rebound therapy for example. Or even respite during school holidays. As it can be a very stressful time for parents with neurodiverse children as well. There is extremely limited support out there.*

*Having a child with SEND in Shropshire with no early help has been difficult and challenging. In particular, there is no after school care or holiday support as our child needs 1:1 support/specialist support to access these*

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*types of services and this makes working difficult.*

*Activities for appropriate ages fun learning self care (cooking, cleaning ect)*

*SEN leisure services). Easy access to life skills courses and career opportunities.*

*Finding funding to help send experience activities that parents/carers can't afford. E.G animal care (sensory) horse riding*

*Knowing what potential paths and help/support our children could get. What secondary schools are available to them that are specialist or have teachers that specialise in ASD or ADHD. Secondary alternative subjects like managing money, organisation skills, time management, how to wash, cook, clean etc long with other hands on courses which I know are available.*

*Respite - would be helpful for us to recharge - but we don't have any.*

*Independents - 1-1 worker, days out or even just an hour a week.*

*Recognition that children who have physical, learning and sensory disabilities may not want to attend events or settings with children who have SEMH. Everywhere we go in Shropshire that is disability focused is dominated by SEMH; we could really do with separate events and activities and settings.*

## *Empathy/ Understanding*

*Looking beyond behaviour to cause and addressing and supporting that , and the family holistically*

*Good Early help would be empathy for us as parent carers as when we ring, need to be helped quickly as we are too busy and exhausted to 'fill in another form'.*

*Good Early help would be for the service to listen to what parent carers need and a Service Level Agreement made with parent carers; a signposted route to escalate complaints; and knowing who is holding the service to account."*

*Involvement much earlier and listen to what we need rather than tell us what they think we need.*

*Families treated individually and holistically.*

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*Effective communication and understanding of individual families needs to prevent barriers in place.*

*Consistent support worker's with Relevant understanding of send families needs.*

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### *Other Feedback*

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*Needs a coregulator in school to keep her regulated so that she can do her schoolwork and achieve her full potential.*

*Not being dismissed as not having enough evidence at every step*

*Emphasis on everyday activities, achievements, milestones are preparing for adulthood*

*What is DoLs / what is MCA - impact child, parent and adult services*

*Making sure all diagnosis concerns have been met.*

*Don't come along and tell our child he can have the Snapchat app on his phone - that was just unbelievable and very wrong.*

*I've not yet experienced this yet.*

*Complaints taken seriously and dealt with appropriately, not brushed over by bureaucracy, enabling families to build trust.*

*Relevant service's working together led by early help.*

*Easier access to social care services from childhood to adulthood without having to be referred again and wait year's for further assessments. Being monitored by service's so families are not lost in the system.*

## 3. As a parent carer what does 'Early Help' mean to you?

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### ***Responding to needs***

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Parent carers feel that Early Help should be provided at the start of their journey:

*If you don't get it right to begin with everything becomes much harder to achieve and it's a continual fight. It has to be right for that particular child and family and relevant.*

*I thought 'early' could mean it is a service for very young children, or that it was a quick service and it is neither*

*Early help means as soon as a difficulty is identified at any age help is offered at the "earliest opportunity*

*Early help is essential. My son was assessed at 3 but not diagnosed with ASD until 7 and then a further 2 year wait for ADHD. The waiting times are way too long. He's in special school which provides him with a good education while also seeing to his needs. So early identification has worked well for us. I think some things should happen automatically with assessment such as joining All In and DLA should be easier to get. Local offers, clubs, groups, events should be emailed to all SEND families. I feel like as a send parent I have to find / research everything from diagnosis pathway to what financial support you're entitled to, to what can be accessed. It feels like a constant battle when life with SEND is difficult and time consuming enough. Doors should automatically open instead it feels like so many close. My son is now 10 so approaching adolescence and adulthood and I have NO idea what is available to him after secondary school. What happens to the support for SEND people after 25?? After all they don't stop being SEND.*

Where a service is provided before the family reach crisis point:

*intervening before a parent or carer is too overstretched*

*A level of intervention before meeting social services thresholds.*

*Families are offered help and support before they reach that crisis point*

In addition to making sure its clear to Parent Carers what is available to service users from the start:

*Help from our local authority or local NHS children's services. Explaining exactly what they do and how they do it. Take responsibility for their actions and timescales and ensure schools regardless of child's age are adhering to that child's needs and requirements and most importantly that it's being met. I see a lot from the school but little to nothing from the local authority and children's services.*

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## ***Being able to access support***

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Feedback from Parent Carers indicates that it is not clear what support is available through Early Help and how they are able to access it:

> *I don't know, as we haven't received any. But what would be good would have been help and support on how best to support our son as we have felt it has been a battle to get school to understand and we've fought it alone.*
>
> *Adequate help given quickly, without long waits and sudden removal from waiting lists*
>
> *Early help to us as parent carers in Shropshire does not mean anything as no support is offered, SEND support is not clearly advertised or explained on the Local Offer website or anywhere else that we can find and the whole thing is confusing. Processes in place for Early Help in Shropshire are confusing, not transparent nor signposted with information.*
>
> *Someone being available to answer questions and provide guidance on what is appropriate to engage with and how we get help from the right people.*
>
> *Knowing that there is someone who I can go to if I need help, and then being able to help me or put me in touch with someone who can*
>
> *To be made aware of the right to have a carers assessment done straight away and help with a referral if agreed to.*
>
> *Early help means getting another agency involved to support me and my family as we navigate life with a child who is neurodiverse. It gives us someone to think of us, in all areas of our lives, and offer support and signposts to anything else that might help us. To coordinate and take charge when everyone else says "that's not our job".*
>
> *Show me what I can be doing at this early stage of things in our family becoming increasingly different and/ or difficult*

Parent Carers have also said that Early Help should provide support to help them understand behaviours and not make them feel like they are alone:

> *Support in helping you manage / understand the behaviour letting a*
>
> *parent or carer know there is support and they are not alone*

Support should also be provided in a timely manner:

> *Provide advice and support before I become exhausted, overwhelmed and / or hit crisis*
>
> *I couldn't access any help I had to pay private*
>
> *Early help meant help that came when I had reached crisis point. When our household and our family unit had fallen apart. When I had no fight left.*

## *Staff with SEND understanding and awareness*

Parent Carers feel that it is important for Early Help to have staff that have awareness and an understanding of SEND. When Parent Carers are contacting Early Help they are in need of support and guidance, and speaking to staff who have no understanding of their situation can have negative implications:

> *An awful experience with an awful worker who lied for self gain, with no experience or understanding of SEN children, who parent balmed, who offered no real valuable support just added more stress and worry at an already difficult time.*
>
> *We had a disability worker that didn't do nothing and signed off after asking for help. "He needs to be more independent" but nothing to help with that.*
>
> *Unfortunately, it currently means multiple assessments, undertaken by suspicious social workers, who seem to have little understanding of our child's needs.*
>
> *A level of judgement of your parenting skills and abilities.*
>
> *A service that is understanding, reliable, trust worthy, proactive, and consistent. A service for families who need help because of many different struggles and difficulties they face and cannot deal with alone.*
>
> *Came too late and there was no help and no understanding of SEND challenges or provision*
>
> *Someone to turn to, understanding, help*

Parent Carers have highlighted the positive impacts staff with understanding can have on their lives:

> *My support worker was amazing - she helped me secure two EHCPs and a specialist secondary school for one child.*
>
> *She attended meetings and fought my corner for me and with me. She offered advice and help. Support and a listening ear.*
>
> *Sent off referrals and convinced me claiming DLA for my child's needs was something we would benefit from and my children did benefit. And they still do. I am able to buy them things to support their additional needs. I would never of claimed it. Didn't believe I was entitled.*

*Understanding the future*

*Help with a KS1 and EYFS child*

*Early from birth to school*

*I'm still waiting be seen....applied months ago*

*A service that is underfunded and under extreme pressure with staff often taking on the role that would previously have been filled by a social worker.*

**4. Is there anything else you want to tell us about the Shropshire Early Help offer?**

*Don't try to hide these children because they are too difficult and take too much time. Parents and carers need support but most of all they need recognition, they live with all the issues and are expected to be super human and tackle everything thrown at them as well as being a SEN child up.*

*Getting people to stop blaming contact*

*My personal experience of Early Help has been very positive, the only thing i would change is the length of time it took to hear about them/be referred to them. the help given would've been welcomed 3 years earlier but we had no idea they existed.*

*I feel early help is failing massively. I am a mother to two children. My eldest aged 6 diagnosed ASD and global development delay and my daughter is 3 and just beginning her process of autism diagnosis. I have suffered from severe depression since my youngest was born. And I self referred myself to the "Disabled Children's Team" as I was in desperate need of help and possible respite for my disabled son and I was just dismissed as being able to provide care for my son. Which if this was the case I wouldn't of contacted the disabled children's team for help. And I was told "Early Help" was what will support me. Even though I was at breaking point hence the reason I self referred myself. No support was received. Even to this day. Change needs to be implemented. As it is damaging parents and children's mental health.*

*The early help system could be brilliant, it could be really useful to families especially those with SEN children, however at the moment it is not fit for purpose and does more harm than good.*

*"We as a family have all relevant information but equally we are always looking for updates and any new ideas. "*

*Currently not fit for purpose as too many send families don't even meet criteria and if do just sent on repeated parent courses and just given traditional behaviour management tips that aren't often effective for send children and just adds more stress to the family.*

*"When a parent carer rings first point of contact a lengthy process of information gathering from the call handler (approx 40 minutes) is taken, there is no information given to a parent carer as to the what the process to get help is or even what help might be available on the call. From experience the calls seem cynical and weighted towards safeguarding rather than finding out what practical support would be needed for our child with SEND and consideration of how this might be important to equip them with the skills they will need to have as they get older.*

*The process is off putting, defensive, multi layered and not user accessible. There is a long delay from initial call to getting an update.*

*Do the Early Help Team have any reasonable adjustments that have in place for parent carers who are neurodiverse or have disabilities themselves to support them through the Early Help process, as nothing was offered at the initial call to first point of contact?"*

*Early Help has been anything but helpful to our family.*

*It is vital for anyone from Early Help to have empathy with how hard it can be to parent children with SEND. How we can be grateful to get them to shower 3 times a week, let alone every night. Grateful that they will eat 1 piece of fruit let alone 5. Grateful they sleep eventually, let alone 9 hours a night. That judgemental behaviour can not shame us into getting our kids to do these things more, only increase our guilt about being a bad parent.*

*I’ve asked for help from early help multiple of times and had nothing.*

*I’ve got three children all got additional needs somewhere (fighting for assessments) it’s hard work especially on my own as a single parent how much crying out do we need to do to be listened too. I feel ignored & useless fighting a battle I feel I can’t win because there’s no support out there.*

*Children’s Services is a mess. In 2022 SEN team is dysfunctional and DCT are a law unto themselves. It’s not joined up. Also they’re so trained on safeguarding, inviting these people into your family home can have unintended consequences. They’ve a really poor understanding of GDPR* *and data protection, they misrecord data, share it with people they've no business sharing it with and refuse to correct it.*

*There's a shortage of family support workers at the moment.  We would need specially trained SEND Early Help, not what we had to deal with."*

*I think it need me a lot more funding*

*Dont make early help / seeking social care support scarey, making parents feel inadequate, fearful of ramifications of approaching social care (family being examined and criticised)*

*Early help should be available and offered to all families with children with send needs.*

*It should be offered at the first instance not when life is out of control.*

*Early help should not be time limited to 12 months. "*

*Quicker service be nice*

*The early help web pages do not mention send, at no point would I think that's for my family, and there is limited description about a limited number of the services they provide... It's useless!*

*It should not be up to a parent or carer to research and then apply for early help, but for those organisations who can help to be made aware of the parent or carer and offer help to them.*

*We are on our own except the team at PACC have been great as they actually listen and try to help within the remit they have.*

*As a Mother of a child with moderate learning disabilities, all the way through his childhood we were told that as he didn't have severe learning disabilities he was not eligible for support from Social Care*

*I have adopted two children with complex trauma, both of whom have learning disabilities, behavioural difficulties and display neurodivergent characteristics. It feels like a constant battle trying to get services and support, from education, mental and physical health, mountain of paperwork, a token gesture of All In activities locally which both struggle to attend without support so not really respite, work. Post adoption support have been great but they are really stretched. We are fully aware of the long term effects of Adverse Childhood Experiences on both mental and physical health and the limited timeframe within brain development to make a positive impact. Sadly we only come across barrier. I understand the pressures on budgets but the future costs and social impact would be much greater in my opinion. We are ultimately saving social care a huge amount of money.*

*We have previously had our commitment to our children questioned when we have asked for help. Many professionals including psychologists have stated respite as being essential due to our children's complexities but no one will either fund of give us a list of respite carers so we can fully or partially self fund"*

*As a family who has been referred several time's to Early Help in Shropshire and been let down several time's too, I think this is absolutely paramount Shropshire Council makes relevant changes and listens to families. To be told you don't meet the criteria when clearly you 100% do is detrimental to the whole families mental health. If a family asks for help, they will most definitely need it. People don't ask for help for no good reason. A send family being turned down for early help because the service is in disarray is not acceptable, this will do more damage in the long run. It is usually the mother who is trying to do her best to keep her family supported and together against all odds.*

*On a personal level, I'm disgusted and disappointed with the early help department at Shropshire council, I am disabled myself and have 2 disabled children, 1 with very complex needs and a 3rd child with physical needs also. I had support in place which ended due to the support worker leaving her job in 2019. I was referred again, after month's of waiting our family had support but during lockdowns so we couldn't access many relevant services. Then without any of my family being included in a review, we were discharged without any option or choice to voice our opinions. When i referred myself again i was turned down because apparently we didn't meet the criteria. This is so bizarre considering we met the criteria the first 2 time's being assessed. Additionally the high level of complex needs would of ticked the boxes. I'm very angry and feel let down by early help. I feel it will take so much effort to trust this already broken service that we won't be let down again. This is something one would have no idea of how detrimental it impacts families unless one is in the position oneself. If families were appropriately supported and listened to i strongly believe it would prevent many tragic circumstances occurring.*

## Summary

There are clear messages about the need for the Shropshire Early Help Service to have an improved awareness of the lived experience of SEND families and how SEND impacts families. The need for ‘empathy and understanding’ is repeatedly highlighted by parent carers, indicating that Early Help must show improved recognition of the challenges that supporting a young person with SEND can bring for parent carers. This understanding needs to recognise that SEND might result in a young person and their family having long term needs, requiring support for the transition to adulthood, along with what might be termed specialist support right from the beginning of their SEND journey. A family might be thriving in all other areas of life, but the impact of SEND and working to meet the needs of their SEND child, alongside the rest of the family, can place considerable strain on parent carers, which if not addressed can escalate into crisis.

Ensuring a good understanding of the challenges faced by SEND families will enable an appropriate Early Help support offer to be developed. This should include opportunities for parent carers to learn about the SEND system, understand the condition that they and their child is living with and to meet other parent carers. This offer should be co-produced. Families are clear that any Early Help offer for the SEND community should include more opportunities for young people with SEND to access activities in the community. Access to these experiences is vital for the development of young people’s confidence and resilience, but young people with SEND often are excluded from accessing these opportunities and the benefits they bring, resulting in isolation, low confidence and poor mental health outcomes.

Families have highlighted the need for information about any offer to be clear and transparent, so they can understand what support is on offer and what to expect from services. It is also important that those working in the system understand the local support offer and how SEND families can access it. Good quality and clear information will also help practitioners to sign post SEND families to the right services and to respond appropriately to requests for help. It will help practitioners to take a proactive approach, addressing issues before they develop into crisis, building resilience within families, and offering a chance to live positively with SEND.

PACC would like to thank all the parent carers who responded to the survey and shared their experiences.

## Glossary

PACC - Shropshire Parent and Carer Council www.paccshropshire.org.uk

SEND - Special Educational Needs and Disability

CYP –children and young people

GP - General Practitioner

CDC - Child Development Centre

DCT - Disabled Children’s Team

DLA - Disability Living Allowance

MDA - Multi-Disciplinary Assessment

EHCP - Education, Health and Care Plan

EHCPNA - Education, Health and Care Plan Needs Assessment

HV - Health Visitor

SALT - Speech and Language Therapy

BEAM – Beam is an emotional health and wellbeing service for young people under 25 who are registered with a GP in Shropshire and Telford and Wrekin https://www.shropshire.gov.uk/the-send-local-offer/mental-and-emotional-health-andwellbeing-service/beam/

COMPASS - Compass is the front door for children’s social care for receiving new enquiries regarding concerns for the welfare or protection of children and young people in Shropshire. Compass promotes the offer of early help to children and families in the first instance, where it's safe to do so. https://www.shropshire.gov.uk/earlyhelp/practitioners/compass-childrens-social-care/

PFA -Preparation for adulthood

OT - Occupational Therapy

ASD - Autism Spectrum Disorder (now known as Autism Spectrum Condition)

ADHD - Attention Deficit/Hyperactivity Disorder

SEMH - Social Emotional and Mental Health’

DOLS - Deprivation of Liberty Safeguards

MCA - Mental Capacity Act

GDPR -General Data Protection Regulation