PARENTS OPENING DOORS PARENT CARER FORUM

FAMILY EXPERIENCES & IMPACT REPORT

2024

All responses to this survey have been anonymised to protect personal circumstances. No part of this survey may be used outside of PODS Charity, without further discussion and relevant permission.

Thank you for your understanding.

INTRODUCTION

Thank you to all our families who have shared their experiences with us – these will help towards improved outcomes for families and will go towards helping with service development in the future and for any immediate changes that may need to be addressed and picked up at regular communications meetings with key strategic leads across social care, education, health and community partners.

Our Report is based on experiences shared through the Annual Survey 2024 that was completed during the Summer and early Autumn of 2024 (reported Spring 2025).

Conversations regarding key elements of this have been shared in strategic meetings and through regular updates – led by Jayne Stevens, our Parent Carer Forum/Strategic Lead.

We have a commitment from service leads to respond to this report, and this will be shared in due course.

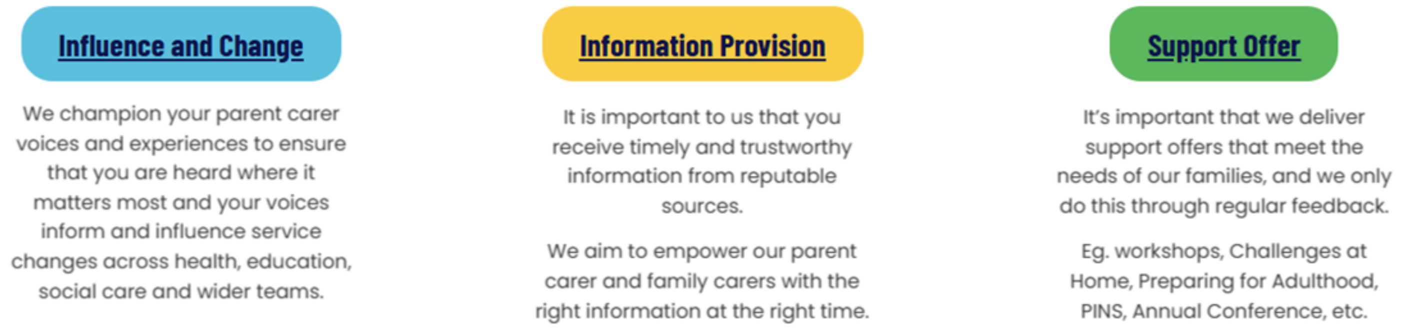
This report forms an element of an evidence base with a mix of quantitative and qualitative data responses.

"A parent carer forum is a group of parent carers of disabled children. Their aim is to make sure the services in their area meet the needs of disabled children and their families. They do this by gathering the views of local families and then working in partnership with local authorities, education settings, health providers and other providers to highlight where local services, processes and commissioners are working well, or challenge when changes or improvements need to be made."

"Parent carer participation is when parents and professionals work together, recognising each other's expert knowledge, to design, develop and improve services for disabled children in the local area. PODS (Parents Opening Doors) is a peer-led charity based in Telford & Wrekin. We involve and support families of children and young people (aged 0-25 years) who have an additional need, or a disability, or SEND."

This is the fourth report we have produced in this format (2021, 2022, 2023 and 2024).

Our key roles to support coproduction and participation:



Influence and Change

We champion your parent carer voices and experiences to ensure that you are heard where it matters most and your voices inform and influence service changes across health, education, social care and wider teams.

Information Provision

It is important to us that you receive timely and trustworthy information from reputable sources.

We aim to empower our parent carer and family carers with the right information at the right time.

Support Offer

It's important that we deliver support offers that meet the needs of our families, and we only do this through regular feedback.

Eg. workshops, Challenges at Home, Preparing for Adulthood, PINS, Annual Conference, etc.

PODS Families tell us they access a lot of support and knowledge from fellow parent carers and their own peer networks – we see this on a daily basis – calls to our hub office, messages, emails and through our valued Facebook groups. Peer-to-peer support for families is vital as it provides a unique network where shared experiences foster understanding, resilience, and guidance crucial for navigating the challenges and celebrations of raising a child with disabilities and additional needs.

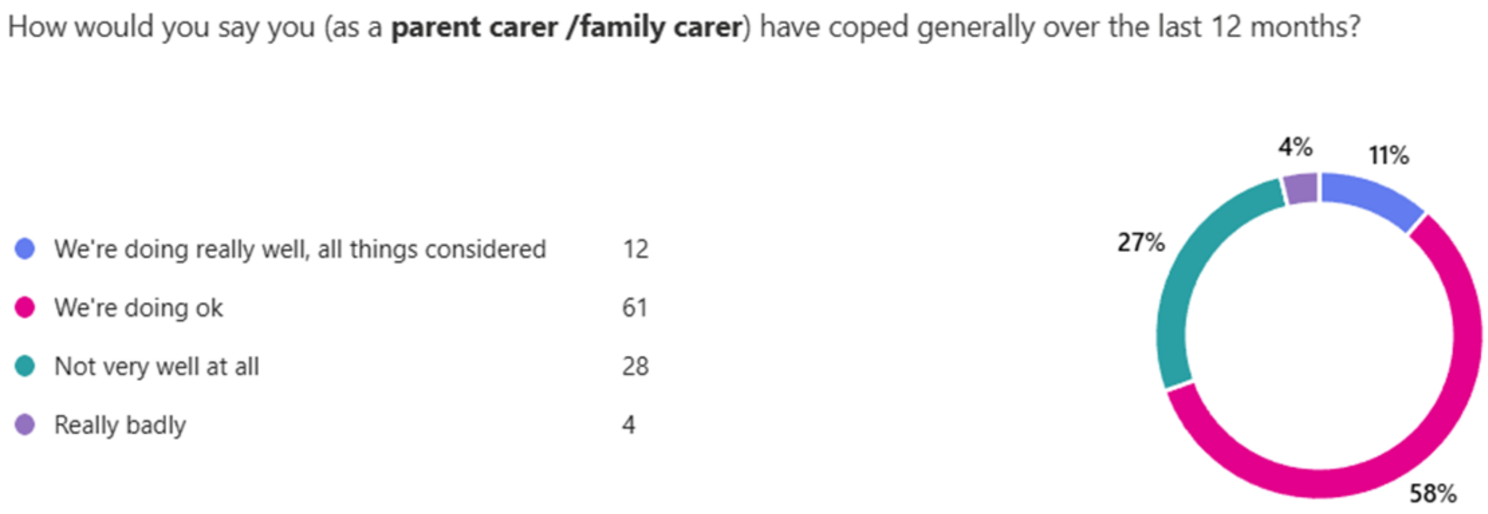
SUMMARY

It is clear from the findings of this report that challenges faced by families with children in mainstream or specialist settings often share commonalities. Both ranges of settings present unique obstacles, yet families encounter similar hurdles in accessing appropriate support, navigating bureaucracy, advocating for their children's needs, and seeking inclusive and tailored education or care. Recognising these shared challenges can promote a more unified approach to addressing the needs of all children with disabilities or special educational needs, regardless of their educational setting.

Reporting has focused around 3 core areas – Education, Health and Social Care.

Celebrating the achievements and milestones of children and young adults with disabilities and additional needs is incredibly important. It helps create a positive and inclusive environment that values their unique strengths, talents, and accomplishments. By sharing these celebrations, families not only spread joy and pride but also contribute to raising awareness and understanding within their communities.

We have again included 'wellness' indicators which mirror national reporting, and the summary results are enclosed.



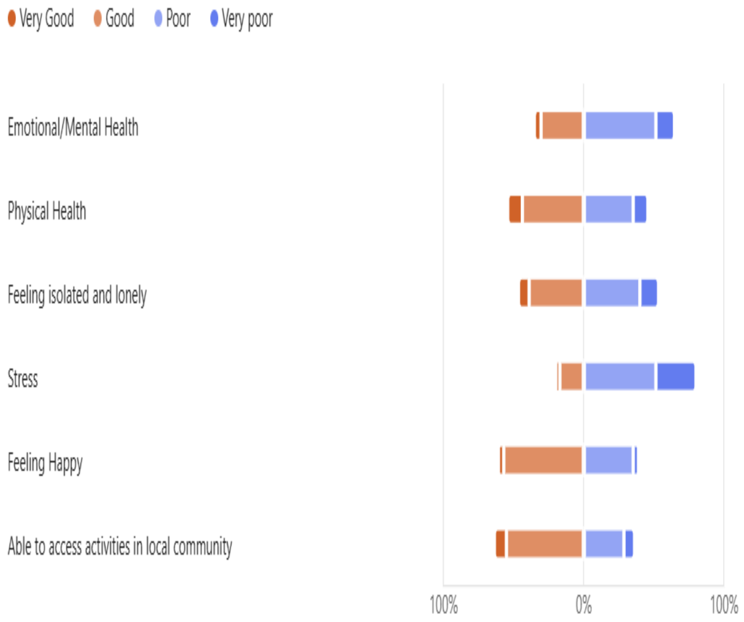
How would you say you (as a **parent carer /family carer**) have coped generally over the last 12 months?

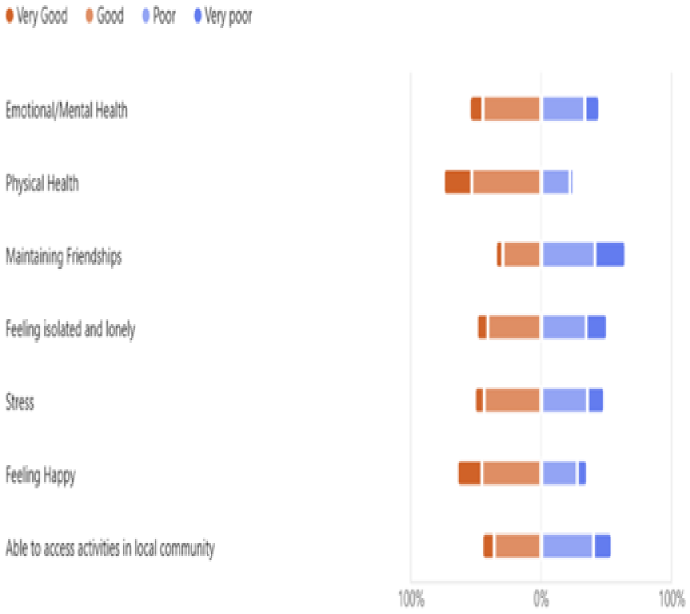
● We're doing really well, all things considered	12
● We're doing ok	61
● Not very well at all	28
● Really badly	4

DATA GATHERING

We received 105 responses to our 2024 survey, slightly lower than 2023, but we believe this is due to lots of requests for input in the previous 12/18 months.

WELLBEING INDICATORS: PARENT CARER & CHILD/YOUNG PERSON





Parent Carer Experiences

Physical health and accessing the community have greatest improvement for parent carers.

Stress and emotional wellbeing continue to be noted as poor or very poor.

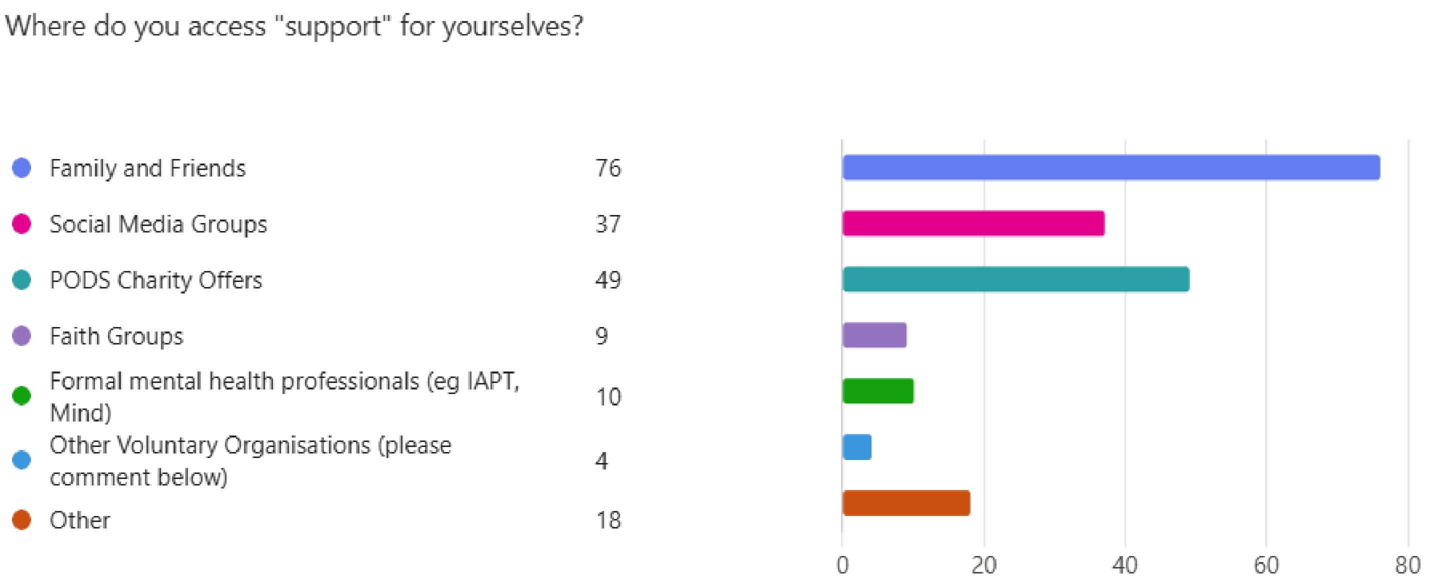
Child/Young Person Experiences (reported by parent carer/family)

Feeling happy and physical health have the greatest impact for children and young people

Friendships and able to access the local community are most challenging.

ACCESS TO COMMUNITY SUPPORT

This question was a multi-answer option. We know that many of our members access our PODS offer of course, and it is increasingly important that families access other families for mutual support. Families often tell us that what they learn about the SEND world is from other parent carers and hence our social media private group is ever popular.

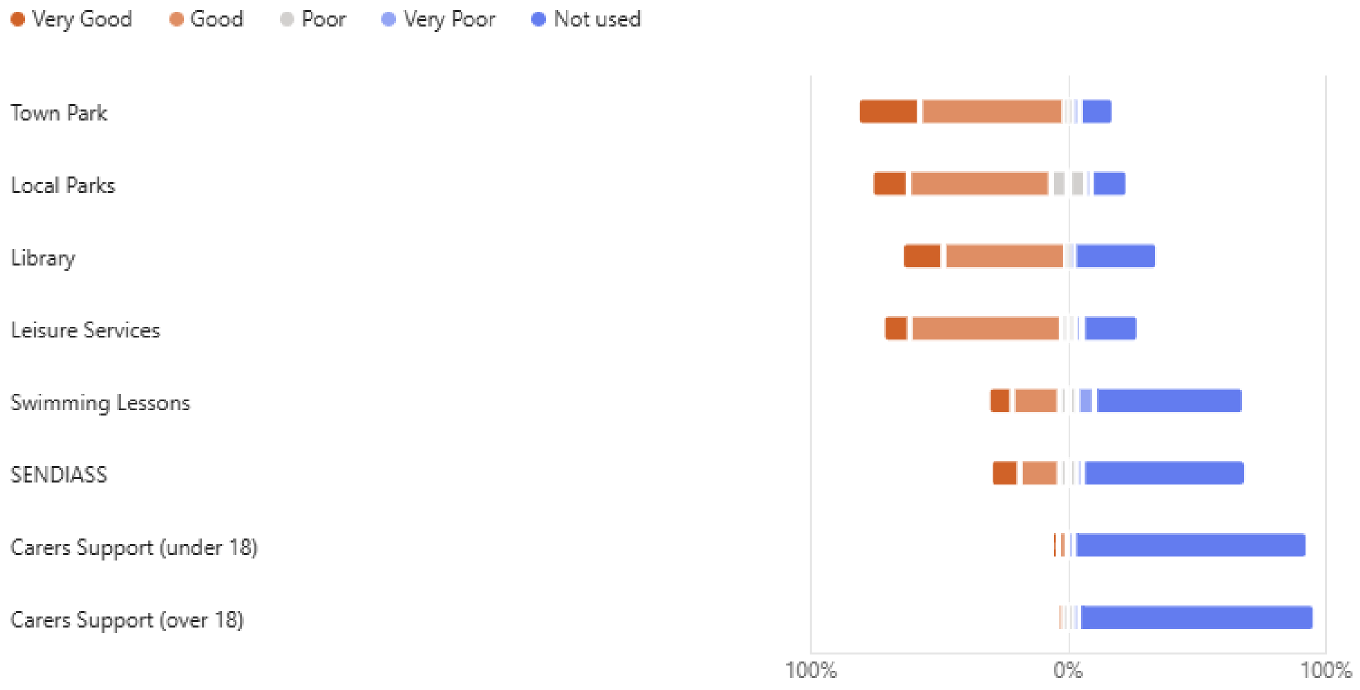


PODS Parent Carer Forum Commitment

Working with wider voluntary partners and different faith groups as more and more families reach out to other organisations will also be important (see previous note regarding Parent Summit).

We know that when families feel supported, it gives them an opportunity to be comfortable in sharing their experiences, look for solutions and discuss these more openly with fellow peers and Parent Reps.

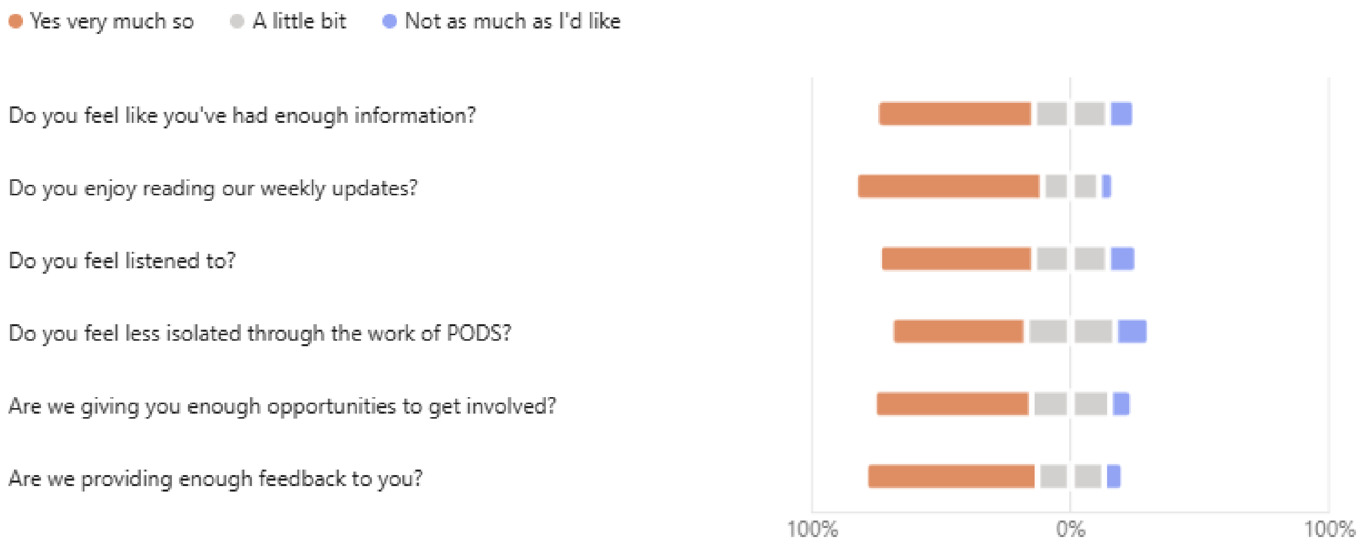
ACCESSING LOCAL SERVICES



PODS Parent Carer Forum Commitment

We will use information from this question to feed into local community based service, leisure centres and with our new seat at the Carers Partnership Board.

PODS PARENT CARER FORUM FEEDBACK

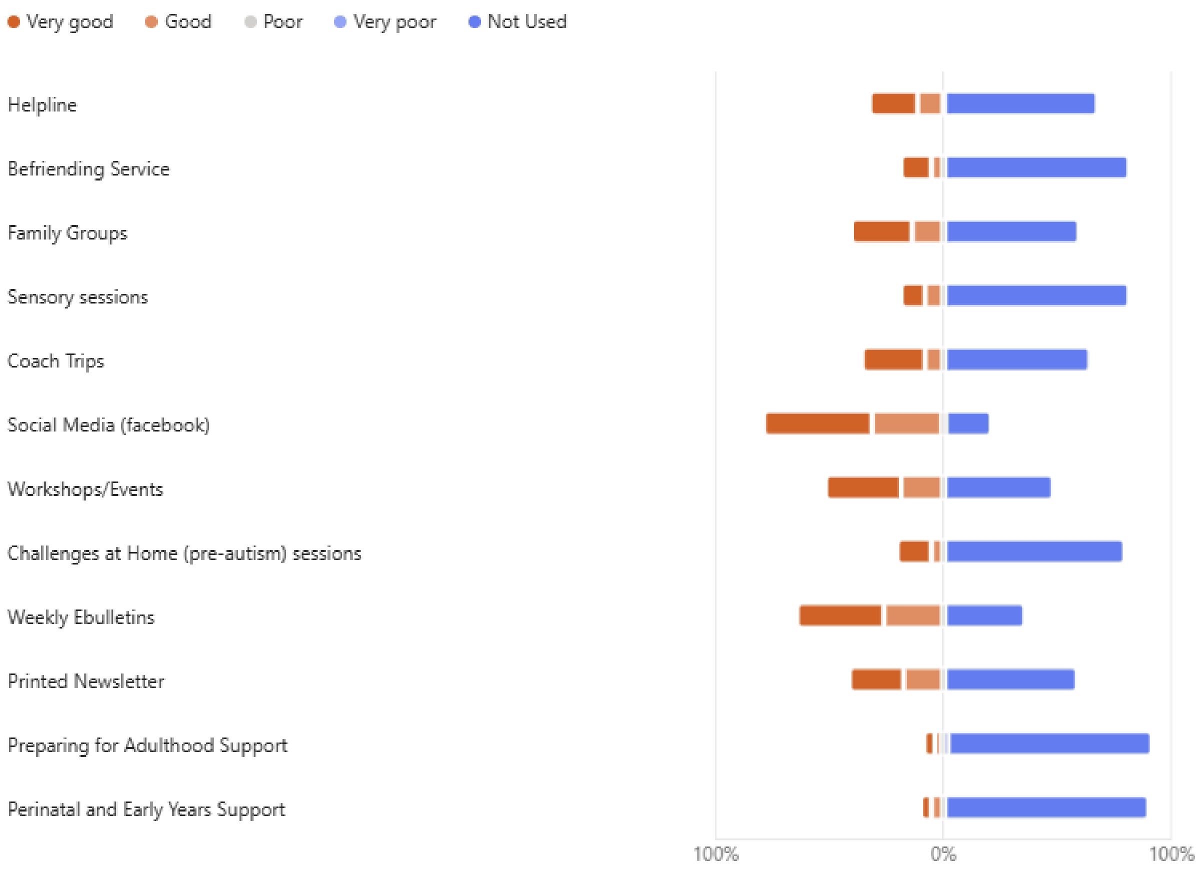


PODS Parent Carer Forum Commitment

We will continue to enhance our offer of opportunities for involvement through networking, using our Parent Rep steering group to share information and opportunities for involvement. We will use different modes of social media, considering how we reach out to wider groups who may not historically be part of our community.

We will demonstrate impact by sharing more regular bulletins, updates, reports and linking this to the ‘we said, you did’ section on the Local Offer (via our comms and strategic meetings).

PODS CHARITY: WIDER SERVICE OFFERS

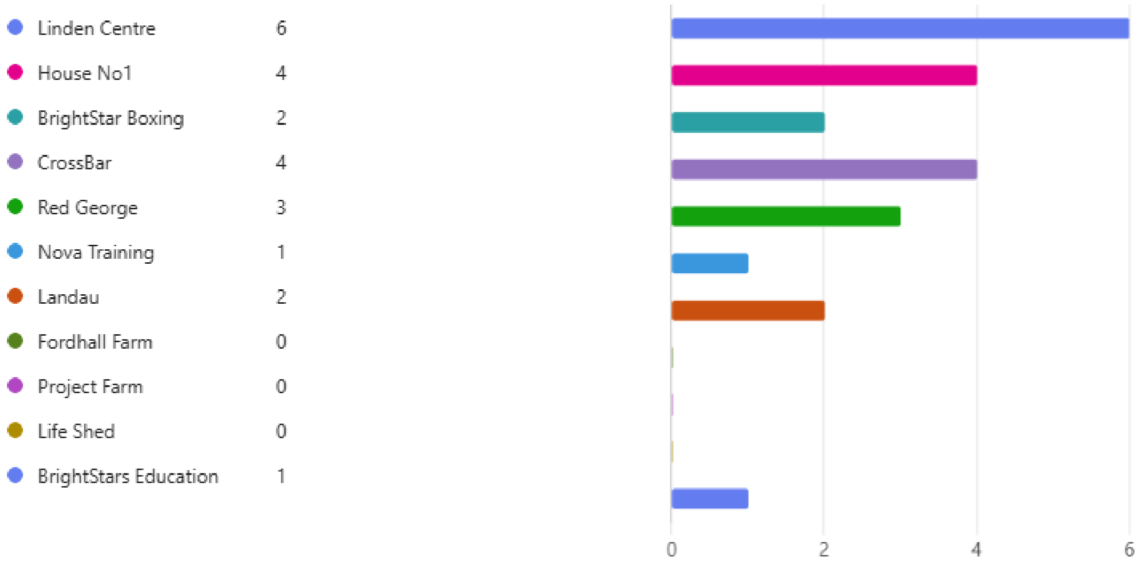


PODS Parent Carer Forum Commitment

All of these service offers and communication links are an opportunity to gather experiences of wider services from families and we are thankful for this. We will use the information from these to feed into our reporting and strategic work.

ALTERNATIVE PROVISION

42% of families told us that they had heard of Alternative Provision and the following families have accessed a range of offers outlined below:



PODS Parent Carer Forum Commitment

Alternative Provision is part of the SEND 'Change' programme and it's important to us that families views are represented as part of this workstream.

We will be reaching out to families accessing these services over the coming months to do some targeted work with them to understand their experiences, in readiness for more strategic discussions.

TALKBOOST (SPEECH AND LANGUAGE)

19% of families had heard about TalkBoost (a Speech and Language intervention). Of those who had heard about it 40% said their child had been part of the intervention.

At time of writing the survey, the programme was in it's infancy, but already there are some positive outcomes, quotes from families:

Some improvement

Outcome unknown - progress not reported back to parents

*Talk boost helped * so, so much*

PODS Parent Carer Forum Commitment

Speech and Language interventions – and wider Change Programme ELSEC project are being embedded locally across key schools. We will continue to be involved in this work and use families experiences along the way to ensure improved outcomes for all.

The wider PODS Charity that hosts the Family Hubs is embedded in support around early years language development and we welcome attendance from trained professionals at these sessions.

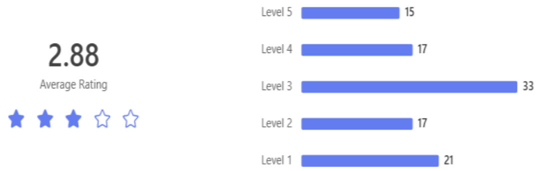
INDIVIDUAL SERVICE AREAS: SUMMARIES

These are snapshot responses from a "5 star rating" overall question. Families were given an opportunity to share more information about their experiences which is summarised on the following pages:

HEALTH

SOCIAL CARE

EDUCATION



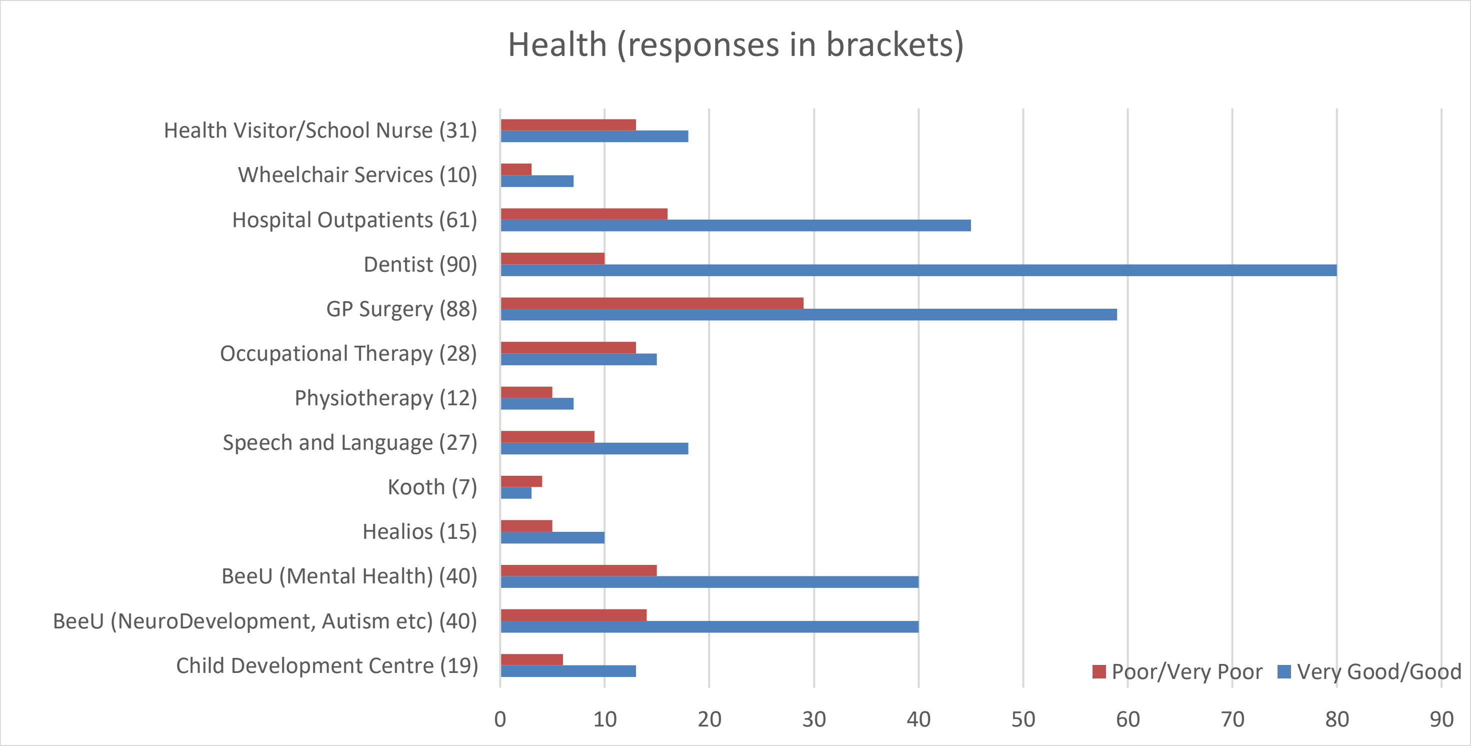
PODS Parent Carer Forum Commitment

We recognise that the current state of all services for children and young with special educational needs and disabilities (SEND) in the UK is under significant strain, with increasing demand, long waiting times, and financial pressures. There are several inquiries and reports from Central Government.

We are dedicated to understanding the impact of these reports and inquiries, responding to them with experiences of families through our regional and national networks (NNPCF) and most importantly working locally to make a difference to our families right here, right now as quickly as we can – through our co-production of services, and participation of parent carers.

Our 2025 Conference focusses on SEND/Education (report available), we have responded to the social care review via Law Commission.

HEALTH OVERVIEW



Summary of Parent Carer comments

Some families have had positive experiences with specific services, such as pediatric ENT, community pediatricians, and physiotherapy. GP practices like Dawley Medical Practice and Linden Hall Surgery have been accommodating and supportive. Families have appreciated the support from private dentists and specific NHS services when they have been effective.

Long waiting times for services like BeeU, OT, and speech and language therapy have caused additional stress and health issues. Families have had

to wait over 12 months for urgent dental work and other essential services. Poor communication and conflicting support for referrals have been common issues. Families have reported being passed between services without receiving the necessary help.

Health professionals often lack understanding of specific disabilities, leading to inadequate support. Families have had to seek private assessments and treatments due to the limitations of NHS services.

Families are reaching crisis points without receiving the necessary help and support. Reports of health services being unresponsive and unhelpful during critical times.

Many families are unsure of what support they are entitled to and find it difficult to access services. Some families feel that health services do not care about their needs and are not providing adequate support.

Direct quotes:

Too long a waiting list for beeu over 2 years it's just shocking when we need the help now not in 2 years time.

Long waiting times causing additional stress and health issues.

Although waiting times are long. I found BeeU to be very helpful. My Daughter has been accepted for Lego play Therapy and is on the ASD pathway for assessment. I was not expecting to be given the help which was offered due to hearing from others how poor they thought the service was.

Poor and conflicting support for referrals from school, BeeU waiting times atrocious and feel a lot more needs investing here. We ended up paying private for ADHD assessment (diagnosis given) which was with a BeeU clinician, and used Right to Choose pathway for Autism (diagnosis given) after years of being made to feel like I was just a bad parent, and my child was just naughty

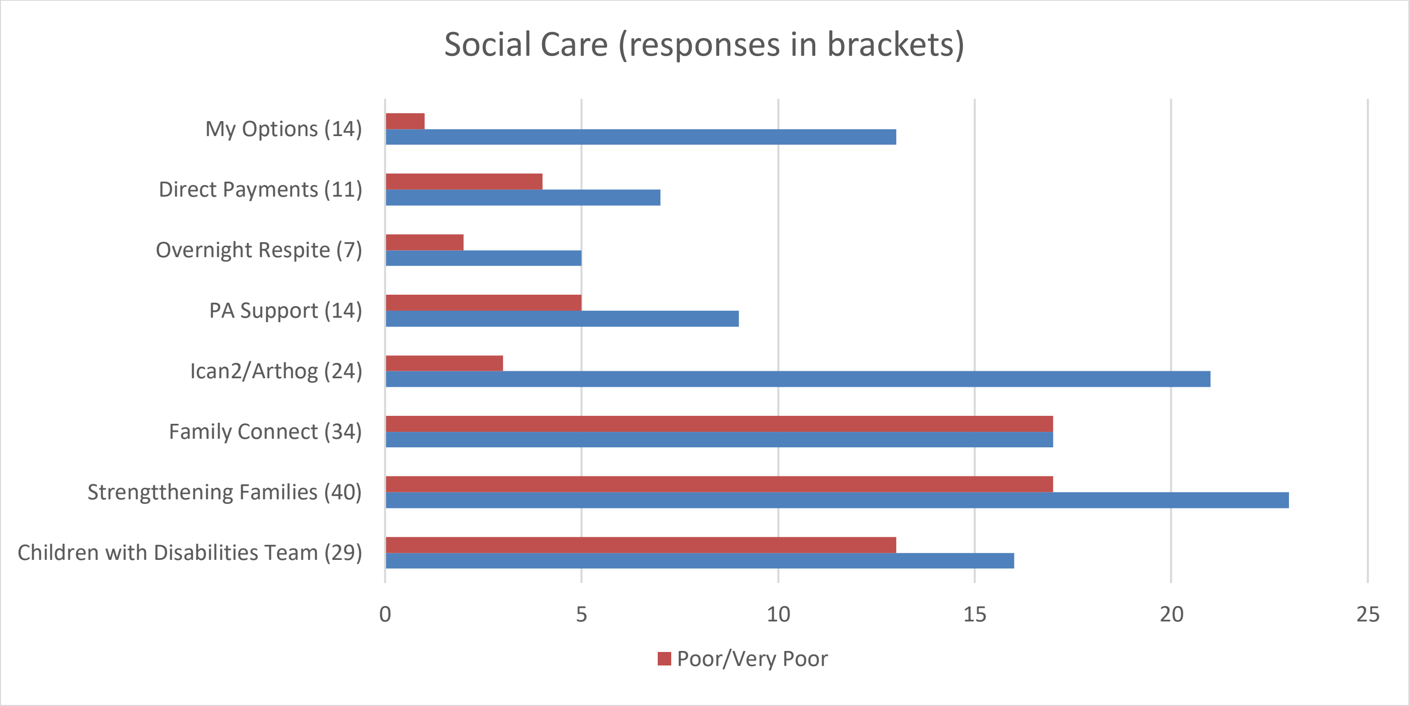
Community pediatricians have been good in clinic but MDA was not a good experience

Also, OT are too overwhelmed with people. I really need a full assessment of my son and a sensory profile done to support him, but they don't have the time to do this, so we get little support in this area.

Underfunded. Potentially don't care, miscommunication at times unprofessional.

I'd like to see more advertising from health groups or support as I didn't know half of them existed.

SOCIAL CARE OVERVIEW



Summary of Parent Carer Comments

Some families have found suitable respite care and appreciate programs like Arthog and the summer playscheme run by the children with disabilities team. Activities provided by My Options groups and youth clubs have been beneficial, allowing children to be themselves and make friends. Difficulty in finding suitable respite care and accessing relevant support. Long waiting lists and poor communication from social care services. Issues with offers like Ican2 – the

advertising and poor booking processes. Strengthening Families have been praised for their support. Families have had some positive experiences with specific social care workers.

Families reported that social care assessments and carers assessments are not easily available.. Social workers and assistants often lack knowledge about specific disabilities, leading to inadequate support. Families feel that social care services are underhanded, unempathetic, and judgmental. Families reach crisis points without receiving the necessary help and support. Reports of social care services being unresponsive and unhelpful during critical times.

Many families are unsure of what support they are entitled to and find it difficult to access services. Some families feel that social care services do not care about their needs and are not providing adequate support.

Direct quotes:

My child is not disabled enough apparently despite having complex hidden disabilities. Met an assistant social worker who knew nothing about FASD as she could possibly know about every disability 🙄

School agreed son needs more help, did an Early help assessment, Family connect make contact.. saying you are on waiting list for a "Strengthening familys worker. / 6 days later family connect phone saying there closing the case and no worker??? / Very confusing and unhelpful.

Social care assessments and carers assessments should be made easily available for families when needed. To help prevent crisis point

They don't care about families. They are rude, unempathetic and judgmental. The attitudes from above trickle down to the staff and then to the families. Made to feel you are a pain, useless and that you are begging

Not even sure what we're entitled to access

Our strengthening families member didn't fully help us with an issue we were having with our son at school before signing off

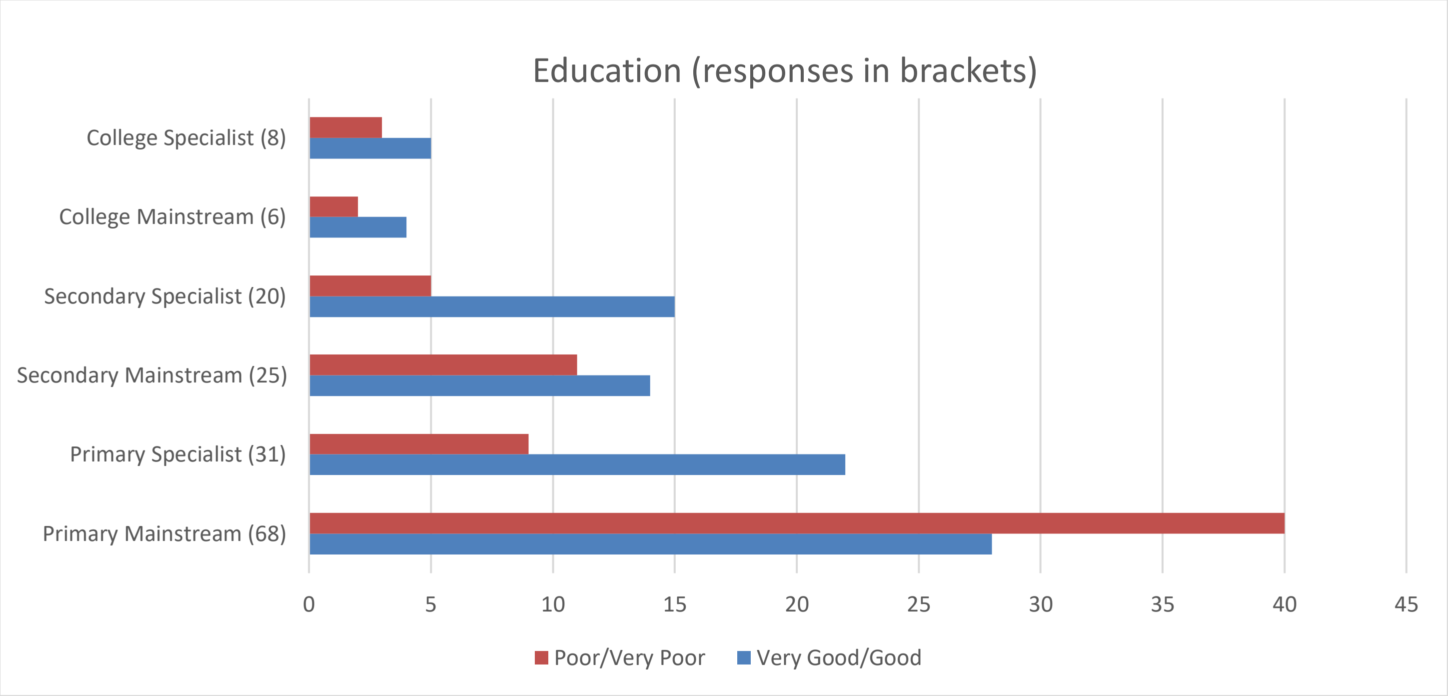
Excellent activities are available for my daughter, she's able to be herself at the my options groups as nd youth club and now has friends.

I don’t use respite myself, I do see the good they do but there is not enough available.

Difficult to access and receive relevant support / Not used- we do not meet criteria for support.

Reached crisis in the summer called for help was told to call someone else, called them told to call someone else...

EDUCATION EXPERIENCES



Summary of Parent Carer Comments

Some schools and teachers have been very supportive, providing regular updates and understanding the needs of disabled children. Specialist schools like The Bridge Special School and Haughton Special Needs School have been praised for their excellent support and development programs. Children have successfully transitioned to specialist settings and have shown significant progress. Hub settings have been effective, providing a balance between mainstream education and additional support.

Despite initial challenges, some children have settled well in mainstream schools and passed their GCSEs. Positive experiences in residential schools and nursery settings that support children's needs.

Lack of Support and Communication: Many parents reported poor communication and lack of support from schools, including SENCOs not addressing their child's needs. Issues with EHCPs, including delays in processing and inadequate support from local authorities.

There is a shortage of specialist schools and hub settings, leading to difficulties in finding appropriate placements for children. Mainstream schools often struggle to cope with the needs of children with ASD, ADHD, and other conditions.

Some children have experienced bullying and lack of understanding from school staff, leading to mental health issues and trauma. Parents have had to fight constantly for even bare minimum support, leading to significant stress and frustration.

The education system is seen as broken, with schools often failing to meet the needs of disabled children. Parents have reported that their children are not being listened to, and their needs are not being adequately addressed.

Direct quotes:

Mainstream secondary hit and miss. He went from being forever in the behaviour room and being out of lessons, and us being told he wouldn't finish school to settling down in the majority of lessons and passing his GCSEs.a real mixed bag.

I have found that Hub settings work perfectly for my son. Specialist settings can't offer him what he needs educationally (he's high functioning) but struggles with full mainstream. hub settings give the perfect balance so he can access mainstream for lessons and get the education he needs but has the hub support when things get too much. However, there definitely needs more Hub settings available so other children in same situation can access them

Fighting for ehcp

There is not enough specialist schools in Telford for the size of our population. My son is year 6 and has had to go through court appeals to get out of a mainstream setting. The SENCO not dealing with our child as other children are more noticeably needing support

School have done their best to support us

Child is due to start reception in September, due to lack of support from LA and refusal to assess for EHCP we're very stressed about the transition, nursery have been amazing and have done as much as they can

Not much communication

CELEBRATIONS AND THE FUTURE: SUMMARY

We have used our survey findings and split these 2 questions into age ranges to demonstrate the celebrations and challenges that cohorts (by age range) of our families have shared with us.

This is just a representative snapshot of the data, to protect anonymity, and to give an overview of the findings:

What can you tell us that you'd like to celebrate over the last year?
What would you like to tell us that you'd like to see changed over the next 12 months?

What can you tell us that you'd like to celebrate over the last year? EARLY YEARS	What would you like to tell us that you'd like to see changed over the next 12 months? EARLY YEARS
Families successfully secured EHCPs, providing essential support for their children. *Children made progress in speech, with some saying their first words and starting to copy words.* *Achievements included riding a bike and celebrating birthdays.* *Families appreciated the support from PODS and other community resources.* *Families celebrated holidays and participated in community activities like the PODS picnic.* *Parents celebrated personal milestones, such as engagements and weddings.*	*More activities in the community for SEND children, including those in nursery.* *Improvements in the local authority SEND department to better support children. Increased help and support for young children with SEN needs.* *Better overall support for families.* *Changing people's attitudes towards things they don't understand about disabilities.* *Addressing issues in the schooling system, particularly with getting children into specialist settings.*

What can you tell us that you'd like to celebrate over the last year? PRIMARY	What would you like to tell us that you'd like to see changed over the next 12 months? PRIMARY
Families successfully secured EHCPs and received school help, leading to significant progress. *Children thrived in specialist settings, with some starting their first year successfully.* *Children tried new foods, gained independence, and made friends.* *Achievements included independent dressing and maintaining friendships.* *Support and Diagnosis:* *Families received crucial diagnoses for their children, enabling better support.* *Support from PODS and access to therapy were highly valued.* *Children participated in residential trips and community activities.* *Families celebrated birthdays and other special occasions.* *Parents completed educational courses and managed life challenges.* *Securing necessary medical prescriptions was a significant achievement.* *Families made friends with other parents through support groups.*	*Better help with EHCPs within schools to reduce the burden on parents.* *More spaces and better support for SEN provision in mainstream and specialist schools.* *Improved understanding and support for conditions like FASD and ADHD.* *Quicker access to professional assessments and diagnoses.* *More opportunities for children to join groups and socialize.* *Better mental health support for children and parents.* *Shorter waiting lists for mental health and assessments.* *More neurodivergent support and better communication from services.* *Increased availability of respite care for children with complex needs.* *More community activities and after-school clubs for SEND children.* *Increased outdoor education and forest school opportunities.* *More variety in activities for primary school children.* *Improved mental health and financial stability for parents.* *Easier communication with local authorities about transitions.* *More support for parents managing SEN children.* *More respite care and supported living options.* *Better routes into therapy sessions and understanding from GPs.* *More accessible activities and support for families in crisis.*

What can you tell us that you'd like to celebrate over the last year? SECONDARY	What would you like to tell us that you'd like to see changed over the next 12 months? SECONDARY
Families successfully secured EHCPs, despite challenges with primary schools. *Children transitioned to and thrived in specialist settings, with some starting their first year successfully.* *Children participated in residential trips and managed new experiences, such as SEN swimming sessions.* *Achievements included children coming out of their shells at school and making new friends.* *Families received crucial diagnoses for their children, enabling better support.* *Support from PODS was highly valued, providing a sense of community and understanding.* *Children engaged in various activities, including residential trips and school events.* *Families celebrated milestones such as leaving primary school and transitioning to secondary school.* *Parents managed to navigate challenging situations, including securing EHCPs and dealing with their children's diagnoses.* *Families highlighted the importance of kindness and support within their family units.* *Celebrating family milestones and achievements was important, despite the challenges faced.*	*More outdoor education and forest school opportunities in schools.* *Increased availability of after-school clubs in special schools.* *Better understanding and support for speech and language difficulties in schools.* *Quicker access to surgery and better mental health support for children and young people.* *More genuinely "quiet" spaces for children with autism to access.* *Improved support for children with complex needs, including more school places and alternative provisions.* *Shorter waiting times for diagnoses and assessments.* *More neurodivergent support and better communication from services.* *Increased availability of respite care for children with complex needs.* *More variety in activities for primary school children.* *Improved mental health and financial stability for parents.* *Easier communication with local authorities about transitions.* *More support for parents managing SEN children.* *More respite care and supported living options.* *Better routes into therapy sessions and understanding from GPs.* *More accessible activities and support for families in crisis.*

What can you tell us that you'd like to celebrate over the last year? **COLLEGE**	**What would you like to tell us that you'd like to see changed over the next 12 months?** **COLLEGE**
Young people successfully passed their GCSEs, even when faced with significant challenges and doubts about their abilities. *Residential and Living Arrangements:* *Settling well into new residential settings, providing stability and support.* *Some families did not have specific achievements to celebrate but continue to support their young people through their educational and living transitions.*	*Better communication and follow-through from social services to ensure promises are kept.* *Support and Diagnosis:* *Quicker and more accurate diagnoses for young people.* *Increased support for children without an EHCP.* *Some families did not have specific changes to suggest but continue to seek better support and services for their young people.*

What can you tell us that you'd like to celebrate over the last year? **YOUNG ADULTS**	**What would you like to tell us that you'd like to see changed over the next 12 months?** **YOUNG ADULTS**
Young adults passing exams and enrolling in college courses. *Gaining independence in the community, though it can be challenging.* *Maintaining health and happiness.* *Successfully settling into supported living arrangements.* *Receiving ongoing support to live independently.* *Engaging in work experience and building friendships.* *Increasing relative independence through various activities.* *Managing life and continuing to support their children through challenges.* *Celebrating the progress and milestones of their young adults.*	*Need for better education and social care support.* *More information and guidance about transitioning to adulthood.* *Availability of supported living options in specific areas like Newport.* *Development of assisted living communities and better voluntary day provisions.* *Addressing specific health concerns, such as bad eating habits.* *Ensuring adequate care and support for ongoing health needs.* *Increased availability of overnight support.* *Short breaks and respite care for post-18 individuals.* *Improved access to transportation services like Dial a Ride.* *Better defined Disability-Related Expenditures (DREs).*

NEXT STEPS

Report will be shared with relevant senior management teams, commissioners and strategic partners and also added to PODS Website.

Individual responses will be anonymised and shared as an additional report, this will give more evidence to the needs of families.

We will discuss content and ask for a response to be made, which will take a format of Frequently Asked Questions or a "You said, We did" response – both of which will be updated to the SEND Local Offer.

PODS Parent Carer Forum Commitment

Open communication channels: ensuring there are multiple ways for parent carers and families to share their thoughts and feedback.
Regular updates: keeping you informed about ongoing projects and how your input is being used – ebulletins, website, Let's talk events.
Inclusive events: workshops, meetings in the community, social opportunities.
Volunteer opportunities: working with our Parent Reps and ambassadors in the community – sharing knowledge and experiences.
Recognition: acknowledgement of the input from parent carers and family.
Partnerships: continuing the ones we have already, and improving links with wider community partners, schools, colleges and those who learn differently.
Accessible and Convenient: make it easy for you to get involved, flexible timings and ensuring venues are accessible.
Feedback loop: "You said/we are Doing" – what difference have your views and experiences made.

Report compiled by Jayne Stevens: Strategic Lead, PODS Parent Carer Forum, Telford & Wrekin.

Please contact directly for further discussion: 0777 534 2092 or jayne@podstelford.org