

# **PARENTS OPENING DOORS PARENT CARER FORUM (REG 1150871)**

# FAMILY EXPERIENCES & IMPACT REPORT Winter 2023 (reported Summer 2023)









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 permissions. Thank you for your understanding.

#### INTRODUCTION

"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 third report we have produced in this format (2021, 2022 and now 2023).

We have helped to reduce isolation and to promote inclusion wherever possible through offering opportunity to participate in activities to improve their health and wellbeing. A poignant reminder of finding the right place to be for our families:

"PODS are AMAZING!! we always tell everyone how fantastic the staff are, the groups and the activities for families and young children. I get so much out of attending pods as a parent, it's empowering to be amongst other who 'get it'. No judgments shame just help, guidance & support."

Thank you to all our families who have shared their experiences with us – these 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 gathered during the Summer of 2023, and reporting taking place Winter 2023/24.

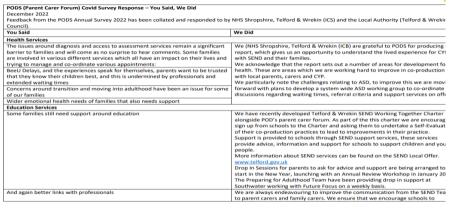
Conversations regarding key elements of this have been shared in comms meetings and through regular updates. This report forms an element of an evidence base with a mix of quantitative and qualitative data responses.

Responses in this survey also represent discussions over the past year.

# PREVIOUS RESPONSES, COMMENTS - "YOU SAID / WE DID"

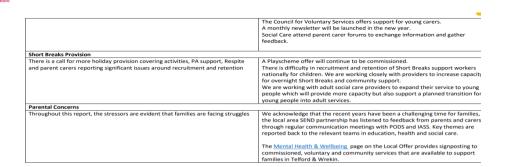
PODS Survey last year was shared with relevant teams. We received responses to core points raised which were shared. You can read this in more detail on the SEND Local Offer website.

Work is ongoing of course, as we continue to represent your views and voices at various strategic meeting across Health, Education, Social Care, with the Local Authority – Telford & Wrekin Council, and NHS Shropshire Telford & Wrekin (and wider Integrated Care Systems).





Please read this in full via PODS Website: <a href="https://www.podstelford.org/wp-content/uploads/2023/02/PODS-Annual-Survey-Response-January-2023.pdf">https://www.podstelford.org/wp-content/uploads/2023/02/PODS-Annual-Survey-Response-January-2023.pdf</a>



#### **SUMMARY**

There's an awareness that the challenges faced by families with children in mainstream or specialist settings often share commonalities. Both 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.

In previous reporting we have split the reporting into mainstream and specialist settings, but this time we collated all the information for reporting purposes.

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 included 'wellness' indicators which mirror national reporting, and the summary results are on page 6 of this report.

We are mindful of the OFSTED/CQC SEND Inspection Result completed in the Spring/Summer and are thankful that recommendations made for local area working continue to be embedded as part of the SEND Partnership reporting processes for which PODS Parent Carer Forum form a part.

"The local area partnership's SEND arrangements typically lead to positive experiences and outcomes for children and young people with SEND. The Local Area partnership is taking action where improvements are needed."

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 own office, emails and through our valued Facebook groups. Peer-to-peer support for families with disabled children 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.

We welcome the work of The Law Society. It is currently undertaking a review of the complexities of legislation relating to Social Care and we welcome this news and will be involving families in the discussions and consultation exercise in the New Year (2024). Furthermore The Education Committee will assess the current system of children's social care in England, focusing on ways to improve early intervention, tackle rising demand and rising local authority spending, and support children with complex needs. The local Short Breaks Forum has been established as a result of direct feedback from families and gives an opportunity to meet with key social care professionals.

Children and Young People's mental health services locally mirror the national picture, and this has been a pressing issue for several years now, despite the increased awareness and , demand outweighing resources. The contributing factors have been excessive waiting times, funding, lack of integration, shortage of specialist staff, increased youth mental health. We know there needs to be substantial investment and policy changes – some of that is local, and some of it is part of regional and national discussions.

We regularly have conversations regarding the impact of a diagnosis and the reasons why it's important. Families tell us that

"it means that I will understand my child better and be able to put the most appropriate interventions in place", or

"I will get help from school that's not available without a diagnosis", or

"I can answer my child when they ask why do they struggle or do certain things".

School placements are reported as more challenging now, especially for early years, and we know that the SEND Team are working on more inclusive approaches, with 'every school for SEND'. Criteria has changed and continues to change for specialist placements, and more schools are accepting complex needs children.

Children transitioning to adulthood need a range of specific support, and this has been highlighted in various reports over the years. The importance of the 'Preparing for Adulthood' outcomes has not been lost and should form part of the annual review process.

The JSNA (Joint Strategic Needs Assessment) demonstrates the needs of local children and families across all areas of need and service – health, social care and education, and further education/adult life.

#### **WORKING TOGETHER CHARTER**

You will know that we have worked to develop a local charter to embed coproduction (and Working Together) and this is now completed and we will continue to review and embed this throughout the next year.



#### **DATA GATHFRING**

We received 121 responses in 2023, slightly more than in 2022.

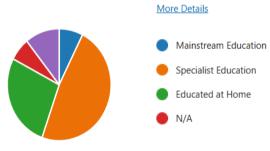
Responses reflect the wider work also going on during 2023 including the formal OFSTED/CQC SEND Inspection that took place in Spring 2023 where families had already shared their experiences.

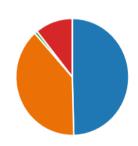
This is an increase from 48 responses gathered in Summer of 2020, and 75 in 2021.

# **Ages and Settings:**

1. How old is your child/young person?

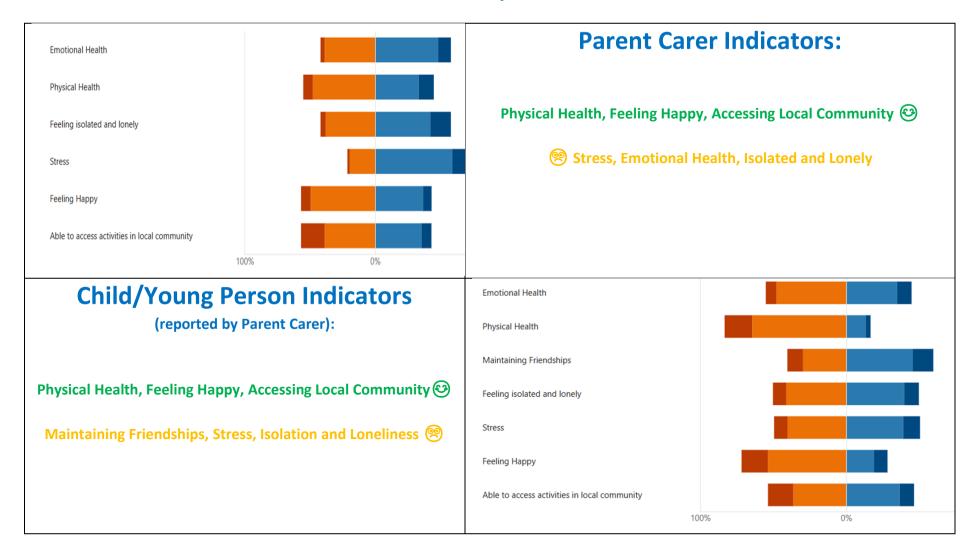
More Details	
Early Years	9
Primary Age	58
Secondary Age	33
College/Further Education	8
Adult (18+)	13





2. What type of education does your child/young person normally attend?

# WELLBEING INDICATORS - PARENT CARER AND CHILD/YOUNG PERSON



#### **WFIIBFING**

How are you coping generally over the last 12 months?:

	We're doing really well, all thing	4
•	We're doing ok	75
•	Not very well at all	37
	Really badly	5



We can see from this data that families are not doing as well as they did last year. We will explore this throughout the survey findings.

2023 Survey 65% of families are doing OK or as well as they can be / 35% of families not well at all or really badly

2022 Survey 75% of families are doing OK or as well as they can be / 25% of families not well at all or really badly

## **ACCESSING SUPPORT FROM:**





This question was a multi-answer option. We know that many of our members access our PODS offer, but it highlights the ongoing needs of our families that there are similar numbers from previously who are accessing mental health professionals.

#### INDIVIDUAL SERVICE AREAS

The findings below show the percentage of families who have used the service (middle row of each box) and the experiences of good/very good for each area or that percentage:

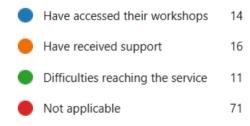
Disabled Children MDA BeeU ASD Team BeeU Mental Health Team 30% used 50% used 50% used 45% used 16% good/very good 11% good/very good 13% good/very good 21% good/very good Health Visitor/School Speech & Language BEAM Kooth Nurse 50% used 38% used 26% used 50% used 13% good/very good 13% good/very good 11% good/very good 28% good/very good Physiotherapy OT My Options (Ican2 etc) My Options (PA) 30% used 43% used 50% used 30% used 17% good/very good 19% good/very good 38% good/very good 18% good/very good **Strengthening Families** Town Park Leisure Libraries 80% used 65% used 63% used 45% used 25% good/very good 66% good/very good 44% good/very good 52% good/very good

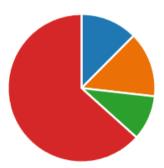
#### **SENDIASS FEEDBACK**

Working with local partners is important to us, and we discussed the question with local SENDIASS team who asked us to gather feedback on a number of points. Responses are shown here.

We also included SENDIASS in our individual services review, and of the of 47% families who used the service, 32% reviewed them as good/very good.

Further questions in our survey, demonstrated the following:

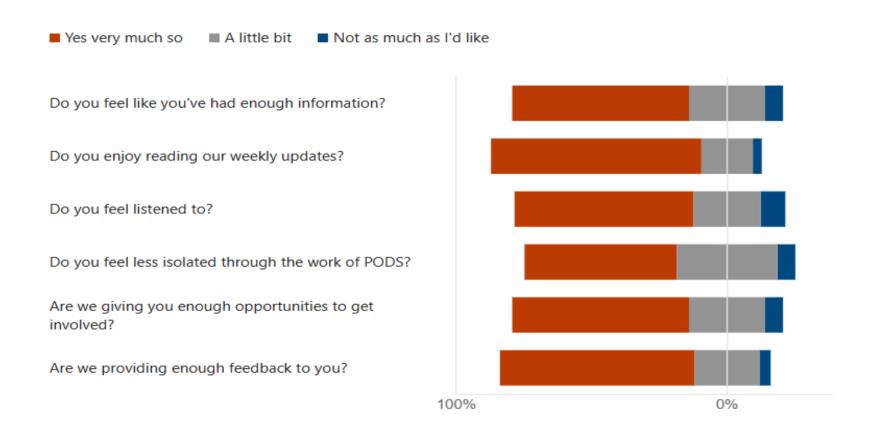




If you want to complete the current SENDIASS feedback survey please use this link: <a href="https://forms.office.com/Pages/ResponsePage.aspx?id=vvhnBQJflkWOjxAVprfciAlfvlVDqG9FjR">https://forms.office.com/Pages/ResponsePage.aspx?id=vvhnBQJflkWOjxAVprfciAlfvlVDqG9FjR</a> <a href="https://forms.office.com/Pages/ResponsePage.aspx?id=vvhnBQJflkWOjxAVprfciAlfvlVDqG9FjR">https://forms.office.com/Pages/ResponsePage.aspx?id=vvhnBQJflkWOjxAVprfciAlfvlVDqG9FjR</a> <a href="https://forms.office.com/Pages/ResponsePage.aspx?id=vvhnBQJflkWOjxAVprfciAlfvlVDqG9FjR">https://forms.office.com/Pages/ResponsePage.aspx?id=vvhnBQJflkWOjxAVprfciAlfvlVDqG9FjR</a> <a href="https://forms.office.com/Pages/ResponsePage.aspx?id=vvhnBQJflkWOjxAVprfciAlfvlVDqG9FjR">https://forms.office.com/Pages/ResponsePage.aspx?id=vvhnBQJflkWOjxAVprfciAlfvlVDqG9FjR</a> <a href="https://forms.office.com/Pages/ResponsePage.aspx">https://forms.office.com/Pages/ResponsePage.aspx</a>?id=vvhnBQJflkWOjxAVprfciAlfvlVDqG9FjR</a> <a href="https://forms.office.com/Pages/ResponsePage.aspx">https://forms.office.com/Pages/ResponsePage.aspx</a>?id=vvhnBQJflkWOjxAVprfciAlfvlVDqG9FjR</a> <a href="https://forms.office.com/Pages/ResponsePage.aspx">https://forms.office.com/Pages/ResponsePage.aspx</a>?id=vvhnBQJflkWOjxAVprfciAlfvlVDqG9FjR</a> <a href="https://forms.office.com/Pages/ResponsePage.aspx">https://forms.office.com/Pages/ResponsePage.aspx</a>?id=vvhnBQJflkWOjxAVprfciAlfvlVDqG9FjR</a> <a href="https://forms.office.com/Pages/ResponsePage.aspx">https://forms.office.com/Pages/ResponsePage.aspx</a>?id=vvhnBQJflkWOjxAVprfciAlfvlVDqG9FjR</a> <a href="https://forms.office.com/Pages/ResponsePage.aspx">https://forms.office.com/Pages/ResponsePage.aspx</a>?id=vvhnBQJflkWOjxAVprfciAlfvlVDqG9FjR</a> <a href="https://forms.office.com/Pages/ResponsePage.aspx">https://forms.office.aspx</a>?id=vvhnBQJflkWOjxAVprfciAlfvlVDqG9FjR</a> <a href="https://forms.office.com/Pages/ResponsePage.aspx">https://forms.office.aspx</a>?id=vvhnBQJflkWOjxAVprfciAlfvlVDqG9FjR</a> <a href="https://forms.of

#### PODS PARENT CARER FORUM FEEDBACK

It's important to PODS, that we provide evaluation of our own service (q21) and these results reflect questions regarding the Parent Carer Forum element of the Charity:



We are pleased that families acknowledge PODS Parent Carer Forum as involving them, receiving enough information and providing feedback as the above chart shows. We will also endeavour to meet our families needs in whatever way works best for them.

#### **PODS CHARITY SERVICE OFFERS:**

Our wider PODS Charity offers – we asked for feedback on these:

Helpline

38% used

33% good/very good

**Befriending** 

45% used

39% good/very good

**Family Groups** 

54% used

51% good/very good

**Sensory sessions** 

45% used

41% good/very good

**Social Media** 

94% used

90% good/very good

**Workshops/Events** 

70% used

68% good/very good

**Challenges at Home** 

55% used

40% good/very good

**Ebulletins** 

88% used

83% good/very good

**Printed Newsletter** 

74% used

70% good/very good

We have received a number of feedback requests around working families, access arrangements, requests for further workshops and support and we will review those as part of our wider Parent Carer Forum strategic meetings and sharing them with Operational Group of the Charity.

We have had some fantastic comments regarding the PODS Charity service offer, and this is encouraging to us as a local peer-led charity.

### **CELEBRATIONS AND CHANGES: 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? - Q5

What would you like to tell us that you'd like to see changed over the next 12 months? - Q6

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?
EARLY YEARS Families of Early Years children are thankful that they have made small steps in their development, a few words, or a happy child is key and to be celebrated.	EARLY YEARS Changes that majority of families would like to see include early SEN support.
Financial worries are alleviated due to access to DLA and benefits that support our families.	and a wider offer of activities/services, more disability focused sessions, where staff have patience and understanding.
Accessing other services such as specialist hospitals.	Families ask to be seen quicker and improved communication, understanding and patience.
"Ehcp sorted"	"I would like to see more services offered to under-fives with additional needs, including those yet to be diagnosed."
"My * is very happy little boy."	"Waiting lists, support, contact updates about ongoing reviews / appointments."

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?
PRIMARY	PRIMARY
Families are celebrating education placement and getting into settings	Accessing activities (whether in the community generally or with PA
where their child's needs are being met, and they feel supported.	support) is the biggest challenge that families want to see a change –
	including more activities to be SEN inclusive at reasonable times, cinema,
Autism diagnosis was high with 11 families reporting positive diagnosis.	local community, and to include the right facilities (eg toilets).
Other celebrations include getting out and about and meeting other families.	Schools are a consideration for improvement, but not as much as the support for mental health and BeeU.
Young people finding their own voices, being able to celebration festivities. Wider health services access including referrals to Birmingham and hearing test.	More staffing generally across all services, and more understanding and empathy.
	Parent carers tell us they want to be heard and listened to.
A couple of parents have been able to return to work and setting up own	
business.	Parent carers are calling for more therapies and services including Speech
	and Language and OT, Dietician support.
"The Facebook group has been a godsend, even just being able to see other	
people experiencing similar problems and sharing advice has been a huge help."	"More respect and acknowledgement for parent/carers experiences of their children and more branches of help"
"Finally got a place in a specialist setting."	"Pathways to health services to be more accessible. Health service to talk to each other, EHCP's reviewed quicker."
"My * is doing well being integrated into mainstream classes"	Cach other, Error Steviewed quicker.

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?
SECONDARY	SECONDARY
Celebrations for families include their child doing better than expected, and how having the right support in education is making such a difference to them.	More work to do includes access to BeeU for wider needs including anxiety and depression, bullying issues, and confidence in young people and support to deal with worries.
Accessing the community, including swimming sessions - and some activities is going OK and just 'keeping going' generally.	Parent carers want their young people to become more independent and they also request more support for access to the community with activities for older young people and young adults.
Access to the right educational setting.	
"For the first time in years I didn't have to fight for the right setting, eventually it was recognised what child needed as a school but that was	They want increased role in advocacy to support their young person in own right.
due to the support of school staff"	More respite opportunities are required and honesty from professionals and the need to be respectful to families.
"Successfully managing to all go swimming."	"I would like to see a diagnosis for our * and appropriate support put in
"We've kept going."	place for her GCSES"
	"More support for more complex children and their siblings. Sessions where parents don't have to attend"

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?
YOUNG ADULTS	YOUNG ADULTS
Young People accessing college placements and achieving qualifications.	Reporting for things to change includes reference to Ican2 and My Options age ranges
Even leaving the house to access appointments is worthy of a celebration.	The need for more respite and clarity over use of personal budgets and
Placements within day care settings and surviving amongst the challenges.	social care in general.
"Actually, getting my * to leave the house to go to the cinema and not just leaving the house for medical appointments."	Access to transport is still an issue for families.
The state of the s	"Use of personal budgets to access activities. More personalised personal
"We are a family, and we are very close, and we look out for each other".	budgets. Less inflexibility on how they are used".
	"Support for a young person capable of work and to ensure they get right support to do so"

#### **SERVICE AREAS FEEDBACK**

# Overall, what has been your experience of education?

# **3.17/5 (91 respondents)**

# Do you want to tell us more about this here (eg, school, college, SEND Team, SEN Support/EHCP).

"It's a constant battle though of emails, reminders and strategies suggested by us for them to understand the strain that conforming to school life has on our child and the family once the mask comes off at home..../"

"School have been unsupportive, unclear communication, very dismissive of her needs, very uncooperative, argumentative, punishing her hard for being distressed and not recognising when she's in distress and allowing her to get very distressed to the point they give her detentions and exclusions."

"Attends the Bridge, communication between school and home has improved, have been able to go into school and take part in school activities. EHCP review was completed on time, SALT have reviewed in school. My child loves going to school. Would like to see some after school clubs and some integration with mainstream though."

"Having had to fight to get him in to SEN school, he has thrived".

"Send team don't monitor ehcp in anyway. Overdue reviews, take too long to do anything".

"School have taken so long with everything been battling with them for 6yrs to refer for assessment which was finally done last yr. but ehcp still hasn't been completed."

"\* loves the specialist college he goes to & gets on well with Staff. 4 stars because Send team took 9 months to send me the final EHCP after we'd had the yearly EHCP meeting with college after chasing a number of times."

#### **SERVICE AREAS FEEDBBACK**

# Overall, has been your experience of children's social care?

# 2.83/5 (70 respondents)

# Do you want to tell us more about this here? (eg, Strengthening families, social work team, MyOptions, Ican2, PA support)

"MyOptions always have same activities & never mix it up so we don't use them"

"I have applied to ican2 due to my \* struggling socially and can't participate in clubs that he used to such as football or swimming as they trainer has no time and doesn't understand my child. I've been declined for my \*to access ican2 as he has no diagnosis..../"

"I was struggling with my health and limitations so got referred to strengthening families and the support was fantastic, just being able to talk with someone who was neutral and make a plan really helped."

"We have been referred to strengthening families, however we don't feel they genuinely understand the complexities of parenting a child with asd who masks heavily. The amount of times that bad parenting has been mentioned or a parenting course-this is terrible and seems to the be way. Go on a parenting course....this will solve the problem. It is quite demoralizing".

"Not been able to get a PA in nearly 2 years no help from our case worker."

"Just lengthy wait for assessments"

"....my child doesn't attend anything other than a Specialist setting and we have no personal budget for PA etc"

#### SOCIAL CARE ASSESSMENTS

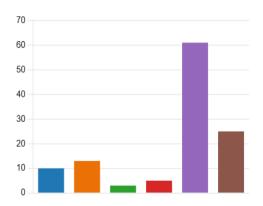
We asked a question about social care support as this has been one of key areas of discussions from our families over the past year (q 19)

We have welcomed the opportunity of the development of the Short Breaks Forum that are held regularly. Feedback from families have led to in-depth discussions and also a review of Short Breaks statement is currently underway.

A review of the Working Together Guidance has taken place and recommendations made.

The Law Society is currently undertaking a review of the complexities of legislation relating to social care and we welcome this news and will be involving families in the discussions and consultation exercise in the New Year (2024).





#### Comments from families:

- We received the statutory assessment through the EHCP process but have been declined for further assessment or support.
- We have received some support it not enough in our opinion and we're not listened to when we ask for help.
- Same help as before, same budget but nowhere to actually get respite.
- Named Social worker left, we were not told. Very disappointing as she had been helpful.
- We receive support but the whole experience was very stressful and took weeks and weeks. No transparency on funding, unfair treatment of families.
- Used to have a budget but now don't meet criteria now it's changed apparently.
- Need one, but\* refused to be assessed.

#### SERVICE AREAS FEEDBBACK

# Overall, what has been your experience of health services?

# 2.71/5 (84 respondents)

# Do you want to tell us more about this here? (eg, GP surgery, A&E, Minor Injuries Unit, Mental Health, BeeU Assessment, Crisis Team)

"GP is excellent, Respiratory Consultant is amazing, BeeU has been a long wait, OT has been appalling... 2 years for a Safespace bed, Dietician has been good but not enough staff as with most of the listed services."

"BeeU is a shambles the waits are too long and when go to a&e they don't believe you that your child has that diagnosis."

"Such a long wait for everything"

"Bee U wait and communication very poor. Appropriate services such as OT and SALT not involved as no one has made referrals. No one coordinate health support. Bee U diagnose and discharge. Would be helpful at diagnosis to then refer to appropriate health services to support child. My child has a diagnosed physical health condition, however not supported by a consultant following moving into the area 2 years ago. Poor communication between health services"

"Struggle to get to any service as they are very long waiting list or massive paperwork included to fill to even start the process."

"My \* sees his Diabetes Nurse every three months and she's amazing. We've recently had to access our GP for a medical issue and we've seen the Nurse Practitioner and they've been very helpful"

"Over 12 months wait for BeeU but once we got appointment it's been brilliant."

"BeeU inconsistent with different drs & meds. Talk to parents as if we have never tried anything like bedtime/calming routines etc., I find this patronising."

### **SERVICE AREAS FEEDBBACK**

Overall, what has been your experience of adult services? (education, health or care)?

# 2.54/5 (50 respondents)

# Do you want to tell us more about this here? (eg, My Options, Health teams, activities)

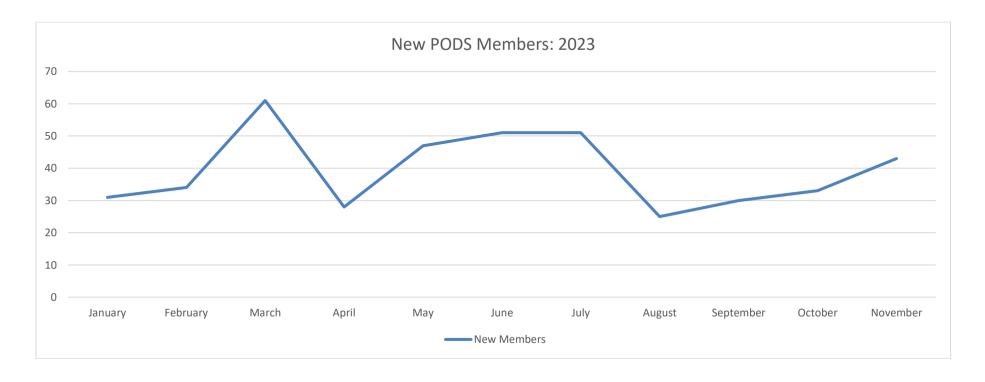
"Poor communication and no fun activities or outings for him or us as a family to do."

"Did get amazing community care until a few weeks ago, now services are closing down and being referred to local GP to pick up the services provided."

"My \* whom I also care for who has Moderate Learning Disabilities is at the adult Centre in Horsehay. And has only recently been under the GP LD Nurse but does no seen her regularly. Supposedly I can't get her assessed for ASD through the Telford ASD hub because she is supposedly under LD team but has not been seen or contacted by LD team in at least 3.5yrs.

"Lack of access because \* deemed to have full capacity and he made a choice not to access, this is despite him having needs that need to be addressed."

# **MEMBERSHIP**



# **NEXT STEPS & INFO**

Thank you for reading our report.

Report to go 'live' January 2024

All responses to this survey have been anonmymised to protect personal circumstances.

No part of this survey may be used outside of PODS Charity, without further discussion and relevant permissions. Thank you for your understanding.

Commitment from Service Delivery Manager (SEND) to respond to issues raised. Recommendations to be worked through with PODS and SEND Partnership Board.

Individual Service leads and commissioners aware of report and action plans for each area updated appropriately.

"You Said, We Did" section of Local Offer to be updated with key themes and responses from this report.

Continued sharing of parent carer experiences and ongoing experiences gathered under key themes as above.

Report compiled by Jayne Stevens Ba(Hons), Strategic Co-ordinator, PODS Parent Carer Forum, Telford

Please contact directly for further discussion

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