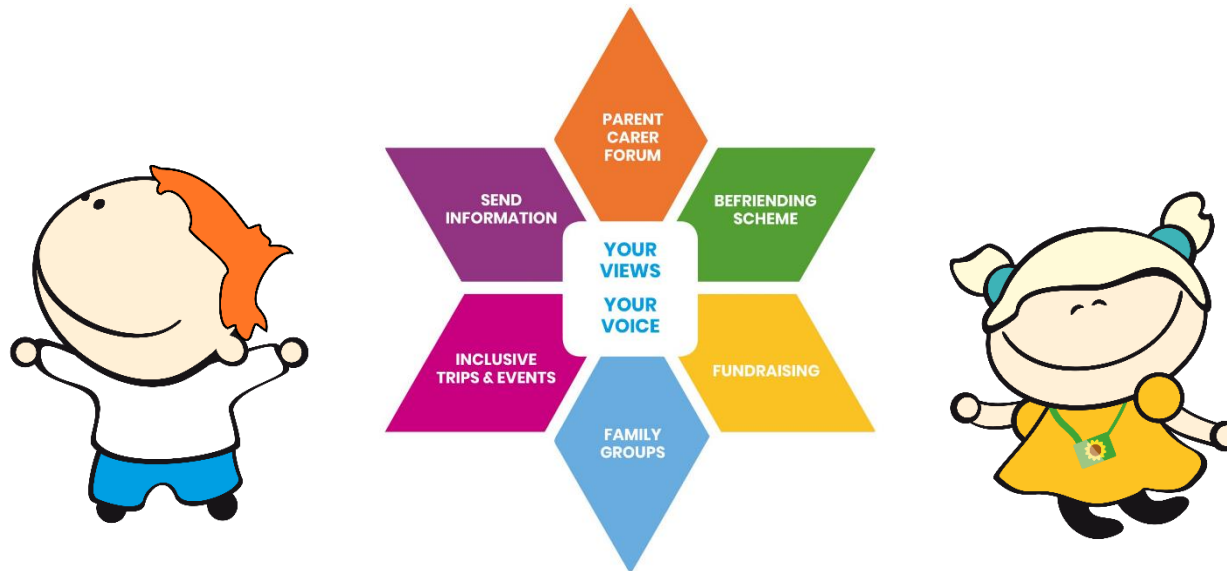




**PARENTS OPENING DOORS CHARITY (REG 1150871)**  
**FAMILY EXPERIENCES & IMPACT REPORT**  
**September 2022 (reported April/May 2022)**



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.

We are aware of the inequalities and that the community of parent carers is disproportionately affected by COVID19, and this has been further evidenced in the national report by Disabled Children's Partnership 'Left in Lockdown' and wider reports, links given in further reading at the end of this report.

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, from a new family:

**"Connecting with other parents of children with SEND. I was feeling quite isolated before embracing what PODS has to offer and meeting other families"**

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 that we pick up at regular communications meetings with key strategic leads across social care, education, health and community partners.

Our Report is based on experiences gathered late Spring/early Summer and collated August 2022.

Over the course of the COVID Pandemic we have had many conversations with families who are worn out with trying to access a service, and understanding how a service works, understanding the criteria.

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 data and qualitative data responses.

Responses in this survey also represent discussions we have had with families via our wellbeing calls, family groups, social media, emails and direct contact support. General comment/quotes have been either summarised or anonymised.

## DATA GATHERING

We received **118 responses** to our 2022 survey – majority of responses from primary (34%) and secondary (35%) and wider experiences from early years (9%), college age (8%) and adults (14%).

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

**63% increase in respondents to our 2021 survey**

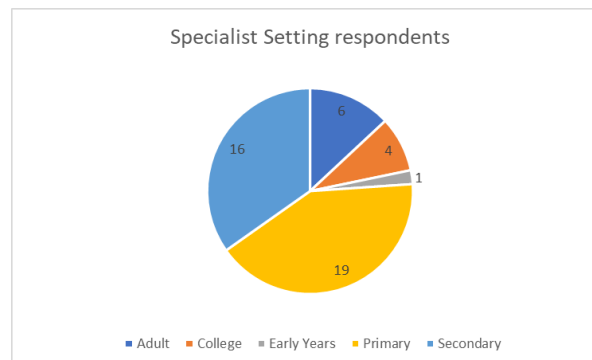
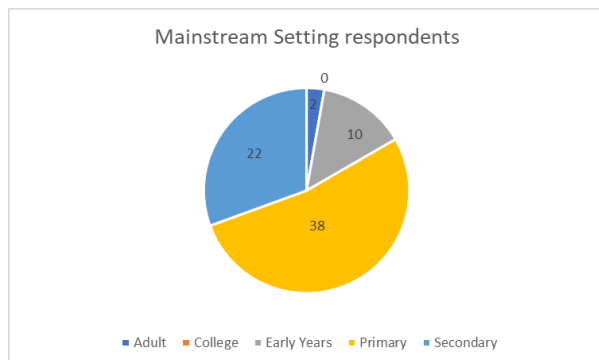


Early Years x11  
Primary x57  
Secondary x42  
College x4  
Adults x8

**Responses:  
61% mainstream  
39% specialist**

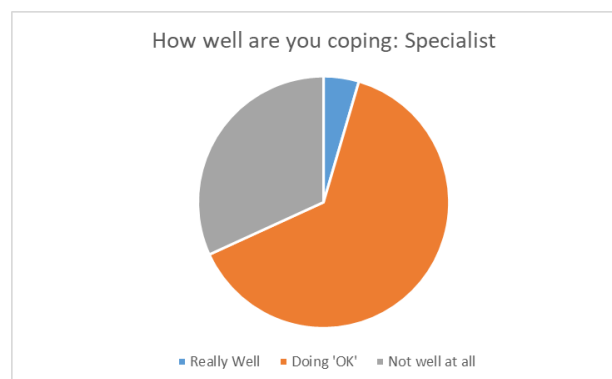
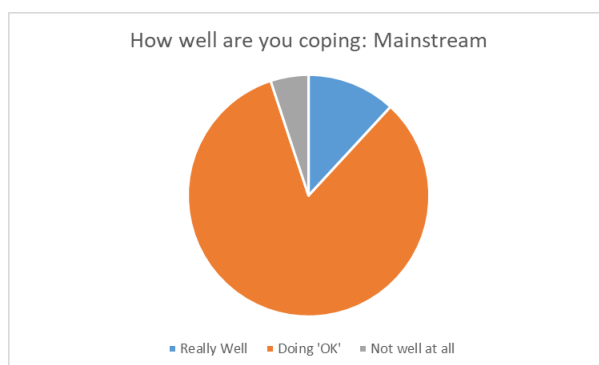
We are very pleased to see this breakdown of respondents for 2022 survey as it demonstrates our wider reach and involvement of more parent carers from across the range of cohorts of ages 0-25 years, particularly school ages in primary and secondary.

## AGE RANGE AND MAIN CONCERNS (Summary for Mainstream v Specialist)



**We asked families how they were coping overall.**

**Since last year, reporting from families with CYP in specialist settings who are reporting 'not well at all' has significantly increased.**



- Unavailable services due to age (early years or transition).
- Meltdowns/ Sleep issues
- School issues
- Battling for support and school to support.
- Extremely challenging meltdowns etc for 4 years however when seeking help – feeling fobbed off by health visitors etc and not listened to
- Violent outbursts
- Children with ASD and I have had no support and their schools have been really unhelpful

- Less services as they get older
- Transition was awful, massive financial impact and feel completely unsupported.
- Majority of families are struggling with challenging behaviour (many families reporting this as significant issue).
- Struggling with the lack of support available for mental health as BEEU are not commissioned to provide mental health services to children who have a diagnosis of ASD.
- Financial struggles for a number of families.

## ACCESS TO INFORMATION

Accessing information is important to families and we take our responsibilities seriously when sharing via our PODS ebulletins and website, 16% of families ↓ are now using Government websites to access information, 59% ↑ are using PODS information (ebulletins) and another 14% ↓ using social media or newspapers.

*“Learning from others and sharing ideas to help when we are out and about”*

Friends and Family have continued to offer much support to our parent carers – for themselves and their children and young people.

PODS Charity wellbeing services (calls and helpline) have been particularly useful, alongside social media).

For support for children, school and college involvement has increased more highly than previous year reporting which is to be expected with return.

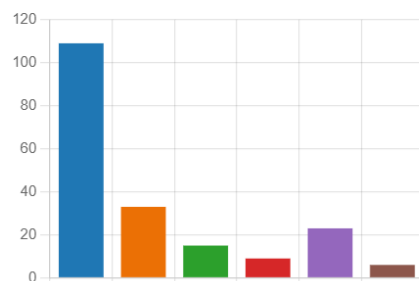
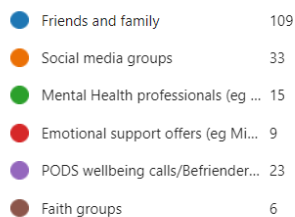


“It has been great to hear other parents’ stories and knowing we are not alone. Feel supported by PODs and the staff are so lovely”

## WHERE DO FAMILIES ACCESS SUPPORT FOR THEMSELVES AND THEIR CHILD/YOUNG PERSON

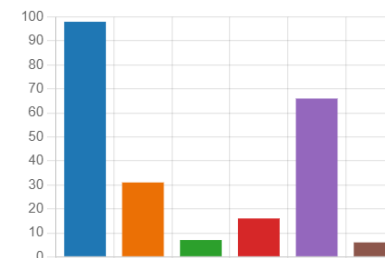
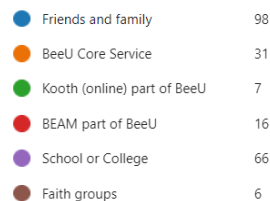
12. Where have you accessed support for your own emotional health as a parent carer? (tick all that apply)

[More Details](#)



13. Where have you accessed support for your child/young person emotional/mental health? (tick all that apply)

[More Details](#)



# APPOINTMENTS



2022:  
61% of families had attended online appointments across the whole range of services and providers



Families have a range of experiences, and many have continued to attend appointments, either virtually or attending in person, including wider reaching appointments outside of Telford, determined by their child’s needs.

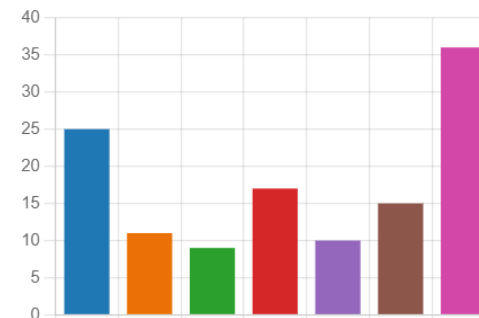
Parent Carers have also had to manage their own appointments – whether that be with therapists, counsellors, and health appointments.

More families have attended online meetings with education – annual reviews etc.

If you have attended appointments like this, what was your experience? (tick all that apply)

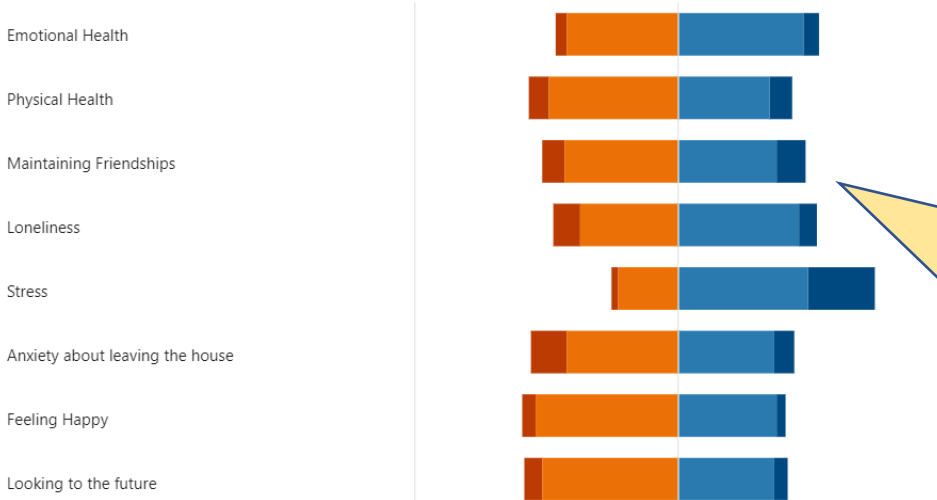
[More Details](#)

|  |    |
|--|----|
| Went really well                       | 25 |
| Much better appointment                | 11 |
| Didn't work for us                     | 9  |
| Less stressful                         | 17 |
| More stressful                         | 10 |
| Would like to do it like this in th... | 15 |
| Saved me having to travel to an ...    | 36 |



# OVERALL WELLBEING INDICATORS: PARENT CARER AND CHILD/YOUNG PERSON EXPERIENCES

Very Good Good Poor Very poor



**Parent Carer Experiences**

**Worse here are:**  
**Stress, Emotional Health, Friendships**

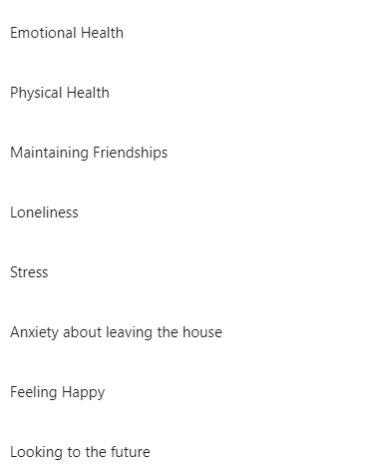
**Less worries for:**  
 Leaving house, Physical Health, Feeling Happy

**Child/Young Person Experiences**  
 (reported by Parent Carer)

**Worse here are:**  
**Friendships, Stress, Emotional Health**

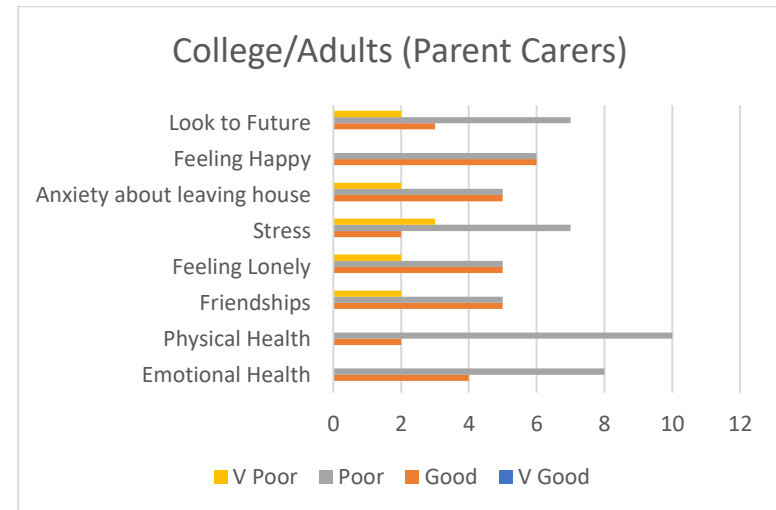
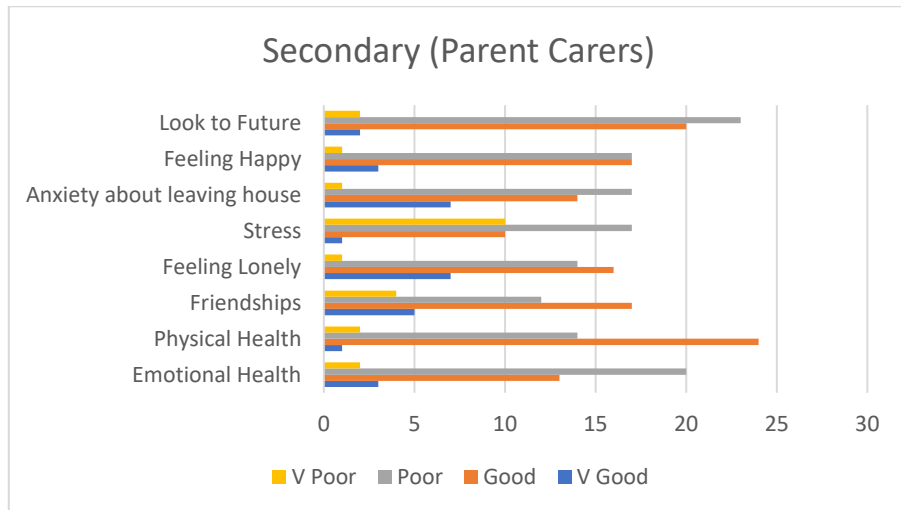
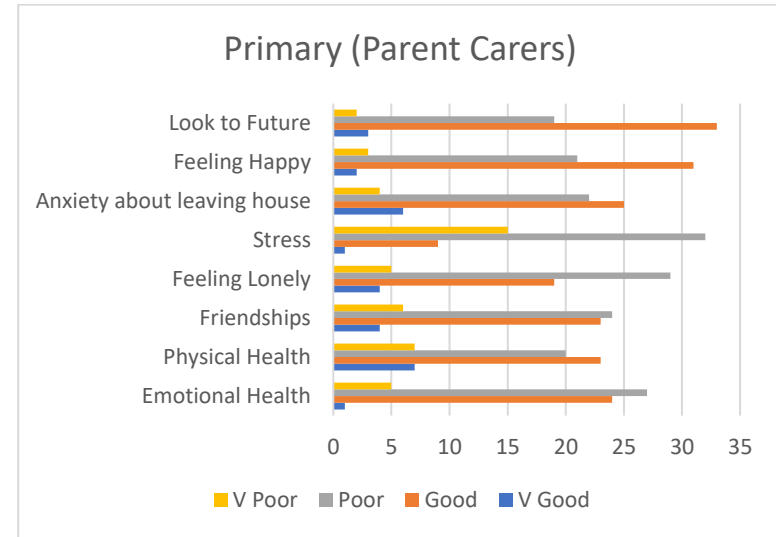
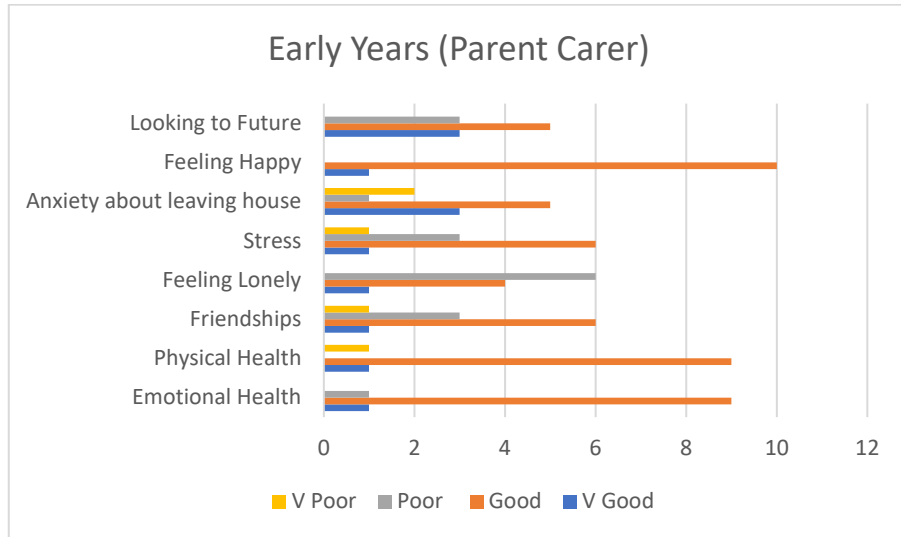
**Less worries for:**  
 Physical Health, Feeling Happy, Future

Very Good Good Poor Very poor



## WELLBEING INDICATORS – PARENT CARER BY EDUCATION AGE RANGE

**“You as a Parent Carer / Carer - Please tell us how you feel as a parent carer about each of these areas and how your experiences in the past year have affected you”?**





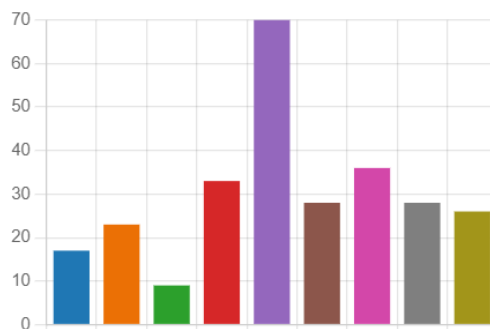
## ACCESSING COMMUNITY AND GETTING OUT & ABOUT

22% of our families have not accessed any community or group activities, of the 78% who had:

17. Have you accessed any 'community' facilities or groups whilst in lockdown.

[More Details](#)

|                                    |    |
|------------------------------------|----|
| Library Services                   | 17 |
| Leisure Centres (Council)          | 23 |
| Scouts/Guides etc                  | 9  |
| National Trust Property            | 33 |
| Town Park and surrounding parks    | 70 |
| Indoor Play Centres                | 28 |
| PODS Activities                    | 36 |
| Independent groups and activiti... | 28 |
| Nothing at all                     | 26 |



59% accessed Town Park or surrounding area

20% have accessed leisure services (council led)



30% accessed a PODS charity activity



PODS Family groups, trips, activities, Pears sessions have continued to run to full capacity during this time.

We continue to use Ironbridge Gorge Museum Trust – Enginuity, Blists Hill and loan passes on a regular basis, Telford Town Park, Wrekin Forest School and PODS HQ where appropriate.

## THE “NOT OK” EXPERIENCES OF FAMILIES – TELL US WHAT COULD HAVE BEEN BETTER?

Please tell us what would have worked better for you as a family over this past 12 months? What help have you needed and not been able to get?

### Mental Health / Neuro Development Pathways

The issues around diagnosis and access to assessment services remain a significant barrier to families and will come as no surprise to hear comments. Some families are involved in various different services which all have an impact on their lives and trying to manage and co-ordinate various appointments:

*"We are told a diagnosis is not needed by everyone, yet to access autism hub you need that diagnosis. Appointments are taking forever, and I feel we as parents have to jump through hoops to even get anyone to listen. We need to see O T and have just been offered parent group thing. My xs mental health is now suffering as we've waited so long for Appointments that now x flapping/behaviour is more obvious to other children, bringing a new set of problems/anxieties"*

*"My older x is waiting to see the camhs core team which he really needs and we have no idea when this will be. And my main child (with SEN) is causing huge issues throughout our family. We have waited for ages for strengthening families and now we have an allocated worker we still have no idea how they are supposed to help. When we talk about all our struggles in the CIN meeting our social worker seems to brush them off and school do not really seem to care as they are not experiencing them"*

*"Accessing GP appointments has been hard. Also dental appointments. Our x has various medical issues which need treatment. But as she has a phobia of people that she does not know and being examined by doctors it has been challenging. I do think they need to have clinics for ASD children where the doctors and nurses are trained specially to deal with issues. It would be ideal for children with additional needs to have a one stop shop for treatment and then they can get used to the one place. Instead of going to various settings"*

BeeU Delays, and the experiences speak for themselves, parents want to be trusted that they know their children best, and this is undermined by professionals and extended waiting times:

*"Delays with BeeU/Camhs ASD assessment took far too long and no support once diagnosed"*

*"We have had access to all things possible in terms of help for anxiety however none of this has worked as it's not just anxiety that is the problem. We are trying to get an ASD assessment and we understand that there are many families in the same boat. It really shouldn't be so hard, parents should be trusted to know their children best and basing an assessment need on school alone is not right"*

*"Finding out after 4 years that our ASD referral was nowhere. We had been patiently waiting for a diagnosis but have now been told it hasn't been requested. It's unbelievable!"*

*"Mental Health support for the children - anxiety should not be ignored just because they have autism"*

*"BeeU have not helped at all, I've been referred to them by the GP many times but they will not see my x for his mental health which is very frustrating. They tell me to take my x to BEAM which I've done in the past and because x can't see the same person every week he struggles to go and also the opening times/days don't work for us as a family due to other commitments"*

### Wider Health

*"It has taken nearly 12 months of constant appointments, complaints, and phone calls to get a referral to ARFID clinic (which is still under review by CCG) "*

*"Being able to have more than a 8 min Telephone Consultation with the Psychiatrist, and listening to concerns about my child's behaviours. Not being able to attend face to face consultations"*

*"If peads had listened but have been referred back and awaiting an appointment"*

*"Paying for private counselling as can't get help otherwise"*

*"Direct support for our x, speech and language therapy, educational psychologist or similar, support for mental health and anxiety"*

*"Hospital appointments that have continuously been cancelled "*

**Concerns around transition and moving into adulthood have been an issue for some of our families as these examples explain:**

*"I don't feel that my x with hearing loss has been given enough extra support with onward choices beyond GCSE. She is worried and cautious about what she will be able to do and who will support her 16-18 and beyond."*

*"Provision seems to be focussed on children and from our point of view appears to dry up and stop as they approach adulthood"*

### **Wider emotional health needs of families that also needs the support:**

*“More on family therapy/ something to improve the family and their happiness. Getting our older x seen by the core team to get some help for him. Having a social worker who would actually listen to us and be understanding of our needs”*

*“Some techniques to deal with anger and frustration” / “Emotional support that has actions ” / "Acknowledgement of child's behaviour difficulties being ASD related not parenting”*

### **Lack of provision regarding council (MyOptions) etc services:**

**There is a call for more holiday provision covering activities, PA support, Respite and parent carers reporting significant issues around recruitment and retention:**

*“More holiday provisions” / No PA support available. / Better respite opportunities / Outdoor activities / I Can 2 to have been reopened earlier”*

*“A personal budget rather than PA support with confines on expenditure. If I could find my own support I would look for childminding services or family whom could be employed after TWC clearances”*

*“I just have to try what’s on offer but I do wonder how things work as our children go through adolescence and how easy it is to access activity for those children with very complex needs”*

*“Wrap around care or after school club, leisure clubs and activities which he can attend without needing parents to stay”*

### **Accessing social care assessments:**

**Challenges in accessing social care provision or assessment is frustrating and where families have been told by national organisations, but local policies determine differently:**

*“Being able to have a Parent/Carer assessment to be told my child isn't disabled enough!- I was told by 2 separate assessing social workers he was not able to access respite as they only recognise children with life limiting disabilities, when i know this information is incorrect!”*

*“How can they discriminate towards a child who has Challenging behaviours???”*

*“Trying to access family support without input from school is incredibly difficult. Our x masks at school and therefore school refuse to refer leaving us praying for worse behaviour so that we can access support. Asking for the essential early intervention that professionals say is important but not being listened to. And then being judged for dealing with behaviours in ways we have been advised to! There is no ‘triage’ for families. Yet if school want to push through a referral no one questions this! “*

*“If we had felt listen to and to stop being told that we can't access service because our child isn't 5 years old”*

*“Not able to access disabled social worker with child with complex medical issues and as a lone parent being told not meeting criteria”*

*“Children’s disability team say needs are too variable to warrant any support.”*

### **Getting hold of information:**

We have had requests around more information for adults, for children who are physically disabled and for wider siblings and ensuring the right information is available at the right time. Families are struggling with information, accessing information and need help with guidance around forms and are calling for a triage sort of system to support them with this, an easy to understand guide of what to expect and when and a more co-ordinated approach when dealing with more professionals.

*“Joining groups and been given advice on clubs that helps children with challenging behaviour to join in”*

*“Just the basic knowledge of what's available and help and support, feeling included would be nice. More fun activities trips for adults”*

*“I'm new to this so more explanation about how it all works would of helped as I had conflicting advice. Help/advice with forms”  
Maybe a directory of services available, what they actually provide and how to contact them*

*“More coordinated approach from professionals involved in care”*

*“We need help with our youngest x who is showings behaviours of concern in addition to personal hygiene, food restriction & sleeping issues”*

*“It would be great to have a single point of contact to access support as it can be overwhelming trying to navigate a complex system”*

*Clearer information from Telford and Wrekin Council, social services team, and the Local Offer site to be easier to navigate"*

*"How to see what is available for both my x who have ASD in regards to support"*

### **Some families still need support around education:**

*"More opportunity of support for our young man and in regards to his age and help with EHCP and making decisions about his future. We've been left under a rock and now it's too late to challenge decisions"*

*"Extra curriculum support for Maths for my x. The school only provide it at dinner time. I asked if she could be assessed for maths dyslexia, I have had no feedback from it"*

*More personalised learning at school. Support in order to help catch up lost learning time (due to condition, not Covid)*

### **And again better links with professionals:**

*"Some kind of better coordination between school and services. Like a team/coordinator. When using strengthening families this was there"*

### **Working Parents:**

*"There is no support for single parents who work full time - support groups etc are always within the school day"*

*"We are a full time working family and do feel sad that we can't attend the family groups as they are in the day or get involved as much as we would like to so we rely on the information shared on other platforms"*

### **Parent Stress**

*Throughout this report, the stressors are evident that families are facing struggles and a quote from a mum, summarises this for so many: "I have really suffered with stress, depression and anxiety, couple this with Ill health and ...../ and I am not having a fun time"*

## THE “OK” EXPERIENCES OF FAMILIES DURING – TELL US WHAT WORKED FOR YOU?

The Difference it makes to a family to have support from peer led group is very noteworthy in the responses we received and we have summarised these as part of our reporting here:

We’ve also had feedback from the ‘new’ Educational Psychologist sessions that were started, thanks to funding received.

Routine and getting back to normal has featured in some of the responses, mainly around schools:

*“Also getting back to routines back to school and college / Routine”,*

And new ways of working for families have benefitted some with a hybrid split of home and office based working:

*“Back to school & college. Working from home. Online virtual meetings instead of face to face”*

Where families have complex children, it’s good to know there have been some positives:

*“ Newlife charity have been amazing. Hope House have kept in regular contact. Case worker is always in contact with us”*

*“Now our x is in a specialist school she is coming on with her speech and language and behaviour. Her understanding has also improved. So we are really pleased for this accomplishment..../.....She struggled in a mainstream nursery so to now have her in a specialist school with the facilities and support of the teachers is invaluable as a family”*

*“Great support from college on getting J a supported internship work placement ”*

*“We have started to use our personal budget to access Bee Happy Support - fantastic company. The children are well supported by and enjoy going out with the PA's”*

Activities coming back on line – especially those in the community, and where they have been inclusive have been welcomed:

*“Outside of school we go to quiet places such as the park. We attended a SEN session at area 51 which was great as it was quiet and the environment was considerate to children with additional needs”*

*“Joining mainstream beavers group, they have been so accepting, x joins in with everything and they have been amazing. x confidence since going there every week has soared. x is non-verbal and shares the Makaton signs x is learning with the other children”*

*“The reopening of services, I Can 2, Club 2000”*

**Health information is really important to our families and there have been some good experiences regarding more general health appointments and also wider services and organisations specialising in needs.**

*“Information is really important: Good information from Downs Syndrome Association throughout the pandemic as people with DS were classified as Clinically Extremely Vulnerable which was very worrying”*

*“Online speech therapy with an excellent practitioner in London on Zoom. Unlikely to have accessed this without Zoom.*

**It is well recorded, the importance of diagnosis for families, and whilst there is a delay locally families are reaching out to private organisations:**

*“Receiving a private diagnosis for both my children has helped us as parents to understand what our children’s needs are”*

**As PODS Charity, our wider offer in supporting and involving families covers a wide range and families have very much benefitted from this over recent months:**

*“Newsletter and bulletins are great, love seeing what’s upcoming. The pods parent meet ups really good”*

*“Before pods my family and I were feeling isolated and alone regarding our child’s extra needs. Since coming to pods the support has been amazing, nothing is too much too trouble and it’s so nice to talk to others who have experience of what we as a family are dealing with .I have nothing but praise for pods”*

**It’s important to us that families feel welcome and supported and one of the ways we do this is via our social media:**

*“Info in the Facebook group and bulletins has been great, the workshops and Ed psych have been so very useful! I came off the first one I attended feeling so much less alone!”*

*“Connecting with other parents of children with SEND. I was feeling quite isolated before embracing what PODS has to offer and meeting other families”*

*“Going on group trips and not being judged /Family sessions with pears, picnic in the park and Pods holiday lead activities”*

*“Evening sessions have meant I could access some support”*



It's important to us that we have direct contact with families who need it. In addition, all our new members receive a 'welcome' call to help to introduce to PODS wider offer and to signpost where needed.

*"Direct contact with PODS: I have only been in contact with PODS within the last couple of months, however \* (spoke to in length on the phone was amazing! "*

## NEXT STEPS

### ***Report to go 'live' September 2022 as part of JSNA Process***

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.

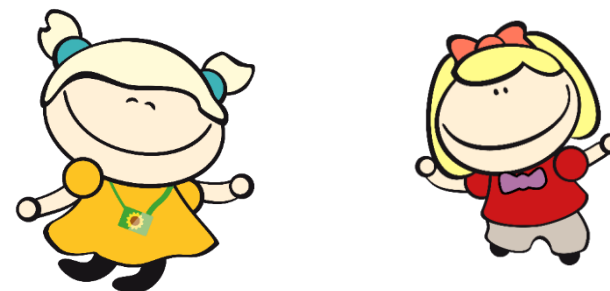
**Commitment from Service Delivery Manager (SEND) to respond to issues raised.**

**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.**



## SUGGESTED FURTHER READING

Disabled Children's Partnership Campaign: The Loneliest Lockdown

[The Loneliest Lockdown - Disabled Children's Partnership \(disabledchildrenspartnership.org.uk\)](https://www.disabledchildrenspartnership.org.uk)

COVID Experience Report 2020 (PODS Website)

<https://www.podstelford.org/wp-content/uploads/2021/02/COVID-Report-for-Public-Health-West-Midlands.pdf>

All Parliamentary Group for SEND: Forgotten. Left Behind. Overlooked.

<https://www.naht.org.uk/Portals/0/SEND docs/APPG for SEND Report Spring 2021.pdf?ver=2021-04-27-112014-380>

Carers UK: State of Caring Survey

[State of Caring Survey - Carers UK](#)

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

Please contact directly for further discussion

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