



PODS (PARENTS OPENING DOORS)

PARENT CARER FORUM

RESPONSES TO ANNUAL SURVEY 2019/2020

100 respondents

SUMMARY REPORT

People and Demographics

65% respondents live within TF1, TF2, TF3: Wellington, Ketley Bank and Stirchley and surrounding areas.

95% are Female, and 92% White British, 95% have English as a first language

25% report having a long term condition or disability themselves

20% of families have 1 child, and 50% have 2 children, and 15% have 3 children

Of all respondents – 71% have 1 disabled child, 20% have 2, and 8% of families have 3 disabled children

14% also care for someone over the age of 25.

We have a cohort of 18% who are lone parents, and 7% are kinship carers

Age ranges: 0-4yrs 5% / 5-10yrs 53% / 11-16yrs 28% / 18-25yrs 14%

Diagnosis and Needs

50% stated that their main presenting need or diagnosis is Autistic Spectrum Condition, 13% moderate learning disability, and 16% with social emotional mental health (inc ADHD) at 16%.

23% took over 6months to be assessed, 19% more than a year and 20% more than 3 years.

Children and young people are affected by issues with social interactions and making friends (86%), Behaviour that challenges (80%), Sensory processing (oversensitivity to noise or smell) 78%, and sleep (63%).

Child's difficulties and needs affects the following:

Visiting friends and family, having people round to the house, taking regular exercise, going out for the day, going on holiday or doing household chores is a bit tricky/difficult for about 40-50% of our families, with taking regular exercise or going on holiday being impossible for 14% of our families.

The most effect on siblings is that they miss out on attention 62%, miss out on family activities 43%, although for 45% of them it has helped them to be more considerate, patient and understanding.

Families tell us that they sometimes find time for themselves, with majority rarely having time to spend on themselves (27%) or neglecting themselves often (30%).

The impact on caring for a SEND child is mostly on a parent carer's emotional wellbeing with 80% citing this as an issue, sleep at 73%, mental health 67% and physical health at 50%.

26% of respondents have had a day/evening from caring in the last 6 months, 45% have never had a weekend off, and 79% have never had a week off from caring.

Family Training Needs

Asking parent carers a list of training needs identified the top 5 as follows:

- Supporting child's emotional wellbeing and mental health: 65%
- Managing behaviour that challenges: 52%
- Coping with stress: 44%
- Understanding the SEN System: 35%
- Understanding rights as a carer: 34%

Also in no distinct order: Disability benefits, managing personal budgets, transition post 16/18, understanding child's condition, lifting and handling, looking after relationships, sleep, toilet training, eating/feeding, safe in traffic, sensory issues, emotional peer support, support with navigating the systems, information about therapies, adolescence, perform a hold safely, keeping yourself safe.

Caring and Working

28% of our parent carers work part time, and 45% are not in paid work due to caring responsibilities, 3% are in education/training, and 9% do not work due to own disability/condition.

Caring has affected ability to work in some way, for 75% of families with 49% having to give up work

54% couldn't find suitable childcare, and 54% report that caring responsibilities take up too much time and energy. 64% parent carers frequently need time off for appointments which affects ability to work.

50% families are worse off financially since having a disabled child, with 9% reporting they are better off.

56% of families are on means tested benefits.

Where families have looked for paid childcare, just over half 56% found it very difficult or impossible with only 1% finding it easy. Where childcare is being used the majority are looked after by family, friend or neighbour, and 30% access a personal assistant, 14% attend after school club, and 12% in mainstream after school club.

Education

42% respondents attend special school, 35% in mainstream school, 3% of our respondents are from home educated families. 77% Families tell us that their child's needs are being met, with 86% attending 5 days a week provision. 2% are accessing less than one day, and 4% are accessing 2/3 day placements.

For those who do not attend education every day a wide range of care provision is in place with 33% are looked after by family because they are not safe to be left alone, 5% attend a daycentre, 10% with a personal assistant.

67% of children/young people have an EHCP, and 20% are on SEN Support, with 4% who don't know what level of support their child receives.

Regarding the EHCP process, 48% found it very easy or easy to navigate, and 49% found it difficult or very difficult. Alongside this process, from the EHCP that has been reviewed in the past 12 months, 41% received reports prior to the annual review, and 40% received a letter about the outcomes following review. 52% who requested changes had these made.

From the child/young person EHCP 34% of families say their child is getting the right support (43% most of it), 17% some of it, with 5% saying they are getting none of support identified.

Where families had accessed education support: education psychology is 61% excellent/good, 38% fair/poor; vision support service was excellent/good by 16%, hearing impaired service: 99% was excellent/good; learning and behaviour support, split between excellent/good and fair/poor. Home and hospital service was deemed 70% excellent and good, and outreach at 90% excellent/good.

Experiences in school life for our children and young people results demonstrate an issue with bullying sometimes at 47%, bullying from staff 18%, being left out (eg not invited to parties) frequently at 49%, detentions were sometimes at 13%, fixed term exclusion sometimes at 9%, permanent exclusions sometimes at 3% and unlawful exclusions at 16% with sometimes/frequently.

Transition from primary to secondary school was difficult or very difficult for 62% of our families.

Social Care

79% of respondents do not access social care provision.

Ican2 Offer: 71% stating it is excellent or good; 51% respondents said there is too little

Direct payments/personal budgets: 82% said that were good or excellent; 50% said too little

Children with Disabilities Team: 67% said that access was rated excellent/good; 74% said too little

Adult Social Care: 36%/36% said that it was poor or very poor; 79% responding to say there was too little access.

Health

Speech and Language: 86% found this excellent or good, 65% said too little of it

Physio: 65% found it excellent or good, with 72% too little of it

OT: 59% found it excellent or good, with 62% too little of it

BeeU: 66% found it poor or very poor, with 99% too little of it

GP: 67% found it excellent or good, with 44% too little of it

Health Visitor: 87% found it excellent or good, with 92% said there was about enough of it

Dentist: 88% found it excellent or good, with 87% said there was about enough of it

Continence: 78% said it was excellent or good, with 30% saying too little of it

School Nursing: 61% said it was excellent or good, with 42% saying too little of it.

Families find it difficult to access health services due to professionals not taking concerns seriously 50%, long waiting lists 66%, child finds waiting difficult 53%, unclear referral routes 42%.

72% of our family's children had had their flu vaccine via school or GP.

SEND Services

SEN Transport: 76% deemed excellent or good, 37% too little of it

Independent Travel Training: 85% excellent or good, 65% too little

Early Years Inclusive Service: 70% excellent or good, 61% about right

Portage: 100% excellent or good, 43% too little

SEND Team: 69% excellent or good, 43% too little

Transition

This is a challenging area to navigate for our families with those trying to access Post 16/19 education 65% of respondents, to adult social care it was 80% and adult health services 75% said it was difficult or very difficult. Families received information on transition from a number of sources, with excellent or good support from school/college, IASS or Future focus and poorer support from social worker, health, local offer website.

Communication

Communication is better or excellent/good from nurseries (83%), school (79%), colleges (71%) , although social care are poor/very poor with 68% and health at 48%.

Local Offer

45% have used it, 25% have heard but not used, and 30% have not heard of it – overall rating is 3.5/5.0 stars. From those who have used it, 50% have been directed to it from PODS, 27% found it by internet search and 23% have been signposted by professionals.

51% found it very easy or easy to use, and 49% found it difficult or very difficult to navigate and 68% said they found the information clear and understandable and 70% found it to be up to date.

Complaints

50% of families have complained informally to education, and another 34% have made a formal written complaint, with 9% seeking legal action.

51% have complained to health, with 41% making a formal written complaint, and 4% seeking legal action.

44% have complained to social care, 44% formal written complaint and 11% legal action

Overall 47% families found this easy to do, and 32% found it difficult, albeit 50% resolved the issue overall.

Additional services needed but not getting:

BeeU/CAMHS, before/after school club, activities for under 5s, and over 18s, peer/buddy system, social care, help with housing and adaptations, OT, behaviour support.

Sharing Good Practice

29 responses, Mainly positive – communication, school, EHCP process, travel training, dentist, Kreative Kidz

Report collated January 2020

Jayne Stevens
Strategic Co-ordinator

0777 534 2092 / info@podstelford.org