

TORBAY COUNCIL



Torbay SEND Annual Survey 2023

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Contents

Torbay SEND Annual Survey 2023	1
1. Summary	3
Key findings of this report	3
2. Children and Young People's Survey	4
Provision	4
Themes	5
3. Parents and Carers' Survey	7
Background	7
Confidence in services	7
Health	8
Education	10
Social Care	12
SEND	13
Services that you told us you would recommend	16
What is not working well	16
Transition	19
The needs of parents and carers	21
Where do parents and carers get their support?	22
What can we do better to support parents and carers?	23
What needs to change in SEND Torbay?	24
4. What We Have Done in Response to Your Feedback	30
5. Next Steps	39
6. Glossary of Terms	42

1. Summary

Background

Following on from the 2022 surveys of Children and Young People (CYP) together with Parents and Carers, two surveys were carried out in 2023 which were aimed at the same target groups.

Key findings of this report

1.	Children and young people told us that good provision and positive relationships with the people that help them were of greatest importance to them. They rated the professionals supporting them very highly.
2.	The majority of parents and carers are not feeling heard and feel let down by some of the services that exist to support them. They report a lack of joined up thinking.
3.	Parents and carers talked about the need to fight to get their children's needs met, having to chase up appointments and provision.
4.	Many parents and carers felt that it was difficult to get support unless their child has a diagnosis.
5.	Families described difficulty accessing health services and experienced unacceptably long waiting times.
6.	Parents and carers experienced poor communication, having to repeat information, and didn't feel listened to.
7.	Families that received appropriate levels of health and social care praised individual providers.
8.	Some parents and carers described a lack of provision of social care even where funding was available.
9.	Less than half of parents and carers felt confident that their child's educational setting could meet their child's SEND needs. Parents and carers feel that more specialist provision is needed.
10.	Trust appears to be low, with parents and carers stating that they feel unsupported. Many parents and carers felt shamed and blamed.

2. Children and Young People's Survey

The survey for Children and Young People (CYP) ran from the start of June to 2 July 2023 and had a total of 77 responses, compared with the 29 received in 2022. This survey dispensed with the section on personal demographics in order to more deeply cover participants' lived experiences and perceived needs.

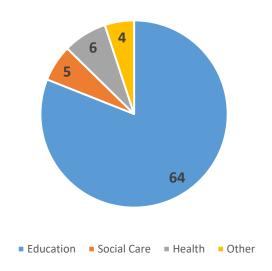
Of the 77 responses, 65 were facilitated face to face with a participation officer. The direct work, in person with children and young people, was more impactful and highlighted a clear support need to assist in understanding some of the nuances of the questions and to support with understanding. The majority of children and young people were visited at their school.

Provision

The children and young people were initially asked if they had a Special Educational Need or Disability. Of their 77 responses 62 (80%) said Yes, 2 (3%) said No and 13 (17%) said that they didn't know.

Following on from this, those who had an Education, Health or additional need were asked if they helped to decide what support they needed. Of the 76 responses, 44 (57%) said Yes, 20 (26%) said No and 12 (17%) said this question was not applicable.

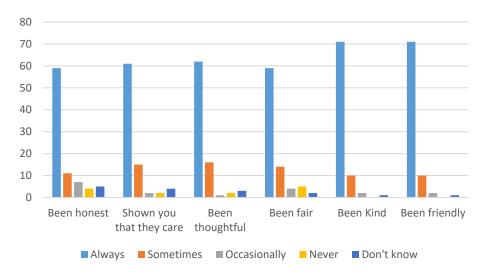
Figure 1- Sources of Professional Support Staff for Children & Young People



One of the areas of the survey was about the SEND Pledge and whether it was being adhered to by the professionals working with them. Children and young people told us how they felt professionals had behaved when supporting them.

Overall, on average, 82.9% of those responding gave the most positive assessment (Always) of the way that they had been treated by the professionals helping them.

Figure 2- Perception of Treatment Received from Professional Support Staff by Children & Young People



The last two questions in the survey were to discover how children and young people viewed how things had gone on for them and how they considered they might be improved for the future. The questions were:

- a. What has worked well for you?
- b. What could be better for you?

Themes

There were two key themes identified from the results of 'what has worked well for you' and 'what could be better for you'; these were Relationships and Provision. There is a crossover between the two themes; where provision has been highlighted as an issue, this could sometimes be rectified if relationships were better i.e. a professional could take the time to get to know the child and recognise what provision is needed to support them.

18% of children and young people told us that positive relationships and 75% told us that good provision was most important. 29% told us that they wanted better relationships with people that support them and 43% said that they required better provision to meet their needs.

Children and young people's voices on positive relationships:

"They understand what I've been through and what I need."

"Mr X - head of year at X. The teacher I will always talk to."

Children and young people's voices on areas of good provision:

"Fidget toys to concentrate more."

"Talking to my 1 to 1."

"10am & 2pm I get a brain break every day."

"I get extra time."

"I get to play with Lego."

"Phonics with a Speech and language therapist."

"No need for EHCP as I've done so well with support."

Children and young people told us what could be better about relationships:

"See them more and be able to talk to [social worker] privately."

"Sometimes social worker is not on time, mum and dad feel angry."

"Nicer teachers."

"Not to change plans with contact with my parents."

"They're swapping and changing all the time so I'm dreading the appointments..."

"I want them to ask me what I need in meetings."

Children and young people told us what could be better about provision:

"I get overloaded with work; wish I had my own room as I feel uncomfortable next to others."

"Brain break time, distracted and need some time out."

"Understand that I can't physically sit in a lesson. I get distracted and hyper."

"I have ADHD & Autism. The school lie to my parents saying they're doing everything they can but they're not."

"OFSTED came and they did everything, but it stopped when they left. Gave me attention, help and brain breaks but nothing now."

"More TAs at school."

"Teachers understand me more and not make feel naughty."

3. Parents and Carers' Survey

Background

During the survey window, from June to 2 July 2023, there were a total of 89 responses. This survey was more streamlined than that of the previous year, having a total of 18 questions which concentrated directly on the participants experiences and perceived needs. The section on personal demographics, which had extended the 2022 survey, having been dispensed with.

Out of the 89 parents and carers, 87 (98%) of their children or young people lived in Torbay.

In terms of perceived needs, 57 (64%) thought that there was need for an ECHP, 21 (24%) for SEND support, while for 9 (10%) the need was not known.

Their children or young people attended a wide variety of educational settings. The table below shows the educational setting of the children that they care for.

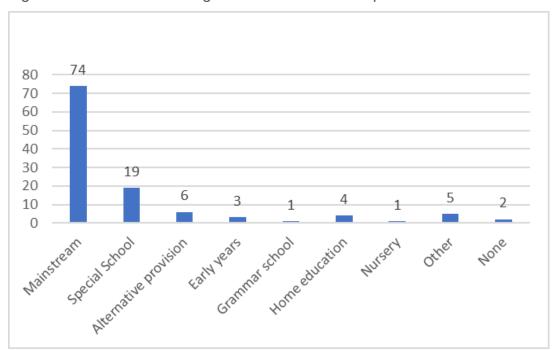


Figure 3- Educational settings of the children of the parents and carers

When asked about the biggest issue affecting their families, there were 81 responses of which 26 (32%) answered that it was a need for support.

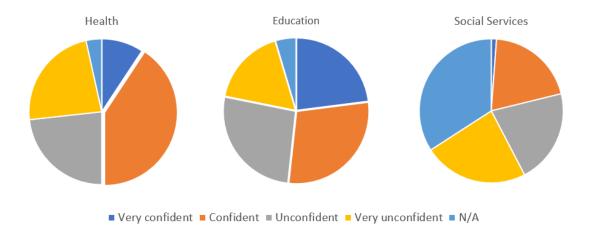
In response to whether their child or young person had a disability, 69 (78%) replied that they had while 18 (20%) replied that they did not.

Confidence in services

The parents and carers were asked how confident they were that their child or young person's needs are being met by each of three services. They were asked to grade each service across the

range from Very Confident to Very Unconfident with an option for Not Applicable. The results were as set out in Figure 4.

Figure 4- The proportion of parents/carers who have confidence in the service that support them



Overall, for Education, 45 (51%) expressed a degree of confidence compared with 38 (43%) who did not. For Health, 43 (48%) expressed a degree of confidence compared with 40 (45%) who did not, while for social care, 18 (20%) expressed a degree of confidence compared with 38 (43%) who did not.

Health

Two thirds of parents and carers expressed negative experiences of health provision whereas a third reported positive experiences of health provision for their child. Only 8 people reported feeling well-supported by healthcare providers, with the majority, 34 people, feeling unsupported. 33 people who responded felt that they were not supported in a positive relational way. 11 people told us that they did not trust service providers. 13 people reported that they experienced poor communication, and 4 parents/carers told us that they didn't feel listened to.

Difficulty accessing healthcare:

A strong theme was around difficulty in accessing appropriate services, particularly for children with autism, speech and language or mental health needs. This led some parents to pay privately for healthcare. Of those who were satisfied with their health provision, many had experienced delay in accessing healthcare, with unacceptable waiting times.

"Most services are supportive and provide the services required. However, their support is hindered by long waiting times for assessments or appointments."

Others talked about the lack of staffing and provision. One parent described the effect on their child of the lack of speech and language therapy:

"[They] clearly don't have enough resources to cover the amount of children that require this type of help/support. The consequences of this is that my child and many others will now face learning difficulties for years and be behind their peers."

Young people frequently wait years for an autism assessment with parents feeling unsupported while they wait:

"We have begged for help but have just had to manage on our own. It's so hard to get support."

Some parents felt blamed for causing their child's difficulties. Several told us that professionals supporting their child had a lack of knowledge of their child's condition, in particular autism and Avoidant Restrictive Food Intake Disorder (ARFID). Others spoke about the lack of mental health provision for their autistic children:

"'He's autistic so we can't do anything'.... No, he's had a nervous breakdown and is suicidal!!!"

Inconsistent healthcare:

Several responses talked about poor continuity, lack of joined up care and inconsistent provision. Sometimes this was due to staff leaving or delays in staff following up actions. Parents explained that they had to be persistent to get their child's needs met:

"I have to chase everything up. We seem to get lost in the system."

"We have to wait constantly; nothing is ever simple and most of the time you have to ask for things multiple times before it happens. I have found I almost need to be rude, and I demand something for it to happen which is not like me at all, but I have to do this to help my child."

Relationships and trust:

Many parents and carers felt that they were not supported in a positive relational way and that they did not trust healthcare service providers. Many people reported that they experienced poor communication and that they didn't feel listened to. This response was typical:

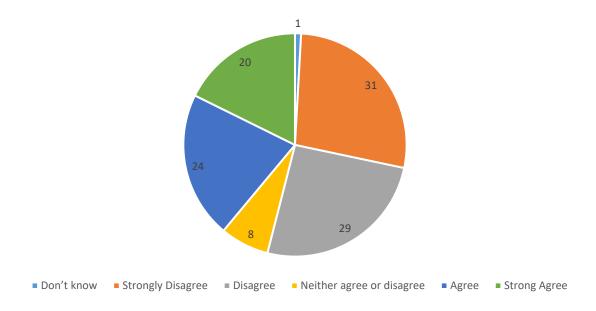
"...[They] don't take on board parents' feelings, wishes and views, dismissed out of hand.

Silenced... Being told one thing but then they do another..."

Education

Only 39% of parents felt confident that their child's educational setting had the skills and knowledge to fully meet their child's SEND needs.53% did not feel confident about this. The responses were broken down in the following way:

Figure 5- The proportion of parent/carers who felt confident that the educational setting had the skills and knowledge to fully meet their child's SEND needs



Parents gave a very mixed response, with some positive experiences reported:

"Brilliant education team and help getting him in the right school."

"The counsellor at her secondary school was amazing and we really miss her post 16."

"The Educational Psychologist was very good and told the school to get a statement of EHCP to get my daughter her need met."

However, the majority reported negative experiences of provision.

Themes

Feeling unsupported by education:

Parents and carers told us that they felt unsupported; felt that they had an "to fight an uphill battle" to get their child's needs met:

"... The school will receive approx. £16000 for our son for all three elements but I don't think he has that spent on him at all."

"...I kept asking when his plan would be reviewed and how things were going and was just told he was fine. SENDIASS brought him up as part of one of their review meetings and it was then discovered that the SENCO was unaware of my child, and he wasn't on the SEN register."

""Educational Psychologists do not speak to parents; they take all their info from the school and there is NEVER any follow up despite the fact that they are meant to operate a review cycle!"

"SENCO educational plan very slow process took quite some time for my daughter to get extra support in primary school."

"My child ...has a letter from the OT stating he needs a scribe or a laptop for exams but I was still told he didn't qualify for any dispensation at GCSE level! After an argument with the school, he has a laptop available for his exams, but to be waiting so long and to have written instructions that were ignored has been disgusting."

"My son has a paediatrician. We have seen a GP regarding anxiety. The school are not supportive at all. In fact, they are quite the opposite."

"She is recognised in school with SEN needs but not much support offered, and I think it is because there is no diagnosis."

Lack of understanding and knowledge:

"Frustrated at lack of understanding."

"XX college excluded my daughter and I believe the school as a whole have a poor understanding of autism. Some staff lower down have a good knowledge, however the knowledge amongst senior managers is poor."

"No understanding of disability. Due to lack of education. No qualifications achieved in 8 years."

Social Care

Nineteen parents and carers said that they had some level of social care involvement. These are some of the social care services that they access:



A further 6 respondents referenced social care within their responses but did not inform that they were currently involved. Out of the comments received in relation to social care, 6 were positive, 5 were positive but also had some negative experiences with them, and the remaining 21 comments were negative about their experiences with social care.

Lack of provision:

Six parents and carers gave positive feedback in relation to the social care provision which they received, with a further 9 explaining that the provision received is not sufficient:

"We have a social worker involved with little contact and/or communication."

"Have regular CIN meetings with a care package of support that can't be delivered, so it's just a package in name that fails to meet any of its objectives."

"The only help offered has been referral to parenting - these are over-subscribed anyway and there is no space allocated for those who have been invited."

Communication and not being listened to:

All but one person reported negative experiences linked to the levels of communication and how they felt listened to. The one who responded positively was in relation to adult social care linked to the parents' own needs:

"Really good. I feel listened to and respected. Asked what level of support I would like once the daily care was in place."

For those who had described different experiences, the themes show families not having the information available which could support them, having to repeat information and that families' views were not listened to or respected:

"Frustrated. Going over and over the same information. Promises made that fade away."

"Parental opinion is disregarded and obstructed at every decision. We've had to fight at every level to try to get agreement for the child's needs. It's as if the child/family are a nuisance and get in the way of the working of the system. It's as if they hear but makes no difference, it's an immovable wall."

Support:

Three families referred to feeling positive about the support that was in place:

"The social worker was supportive of our situation."

Six families reported the struggles they have experienced in relation to trying to get support:

"Everything has been a continual fight, I'm exhausted, it's impacted negatively on my mental health and my relationship with my spouse, family friends and work."

"Social services were dreadful. I can't believe a service that is aimed to help can fail so badly. We were picked up, had our lives shaken and they closed the case without our knowledge."

SEND

What is working well

The parents and carers were asked what had worked well or made a difference to them and their family over the last 12 months. Of the 122 responses received a summary of the key themes can be identified. It is important to note that 32 individuals chose not to reply with an answer to 'What is working well?' and 27 individuals responded with a negative answer to this question.

The themes identified in the comments provided were as follows:

The role of the SENDCO and staff:

"SENDIASS and SENDCO when I can get hold of them."

"XX Academy have been very communicative and keep me involved with frequent updates due to the SEND manager's knowledge and experience in this area. He is always available to help and advise me and very supportive."

"SENDCO workers at XX school are amazing, XX has been great, Play Torbay have been our saviour through lockdown."

"My child's school are great, down to the people there who want to help the children."

"My experience with XX college has been excellent and the SEND team are approachable and thorough, and I feel they take the holistic approach. They offer great well-being packages to help support my girl's welfare and social and emotional difficulties associated with autism. The ASC department is excellent and treats my daughter with a personal approach where nothing is ever too much! The sensory room there is amazing."

"Schools try hard to support, despite the fact my child has no documentation that she needs additional help."

"Good communication from teacher at school and caring staff."

Health staff:

"Health are good at referring on to other professionals when needed, this process is quick."

Social care staff:

- "... the social worker is supportive and easy to contact."
- "... XX from early help was fab and very supportive. SENDIASS are brilliant."

General staff comments:

"A lot of the staff that provide the support want to help and are willing to do what it takes to bridge the gaps in their knowledge and service."

"Prompt call backs, competent staff."

"The staff we have met have been lovely and enthusiastic. They just have too much of a workload."

Provision and review of EHCP:

"Post 16 provision, reviews are very well adapted and have been great at getting things organised."

"His EHCP is reviewed regularly, and I feel a part of those reviews."

"EHCP completed within the 20-week time frame during covid lockdown."

"I feel very confident in the support that the local authority SEN provide since my child has had an EHCP. However, I did not feel the same way when my child was the SEN support level before SENDIASS and the EHCP was put in place."

"The Plan, Do, Review cycles are very helpful."

"Specialist educational provision once accessed."

Quality of support put in place:

"There are wonderful practitioners who 'get' children. In health, paediatric consultants who really listen to concerns. Good SALT work going on. Lovely SENDIASS information and great parent peer support."

"My daughter has been fortunate in having a fantastic school counsellor, but I know that is pure luck."

"School transport has always been very good in our experience."

"Very positive. Needs identified and support put in place whilst in primary, she continues to get a high level of support in grammar school."

"Local support groups have been fantastic, Tissue for Issues and Play Torbay"

"Special college staff are very good and have happily communicated with me over my concerns"

"0 to 19 Beehive early years team. Completed parenting course and baby massage. Now have family support worker who is great."

"Once in the system and assessments have been done and decisions have been made very good."

"SENDIASS is a really good service. The knowledge and support from the majority of people in health is always incredible when you see them."

Alternative Provision or Education Other Than At School (EOTAS):

"The provisions bought in for EOTAS are fantastic and really are lifechanging."

"Post 16 provision reviews are very well adapted and have been great at getting things organised."

Services that you told us you would recommend



What is not working well

Of the 122 responses received a summary of the key themes can be identified. Twenty-three individuals chose not to reply with an answer to 'What is not working well?'. The themes identified in the comments provided were:

Delay in provision:

"Haven't received her EHCP yet as been long process the wait time is very slow when assessing extra support in primary school."

"Parents with children awaiting diagnosis are being failed, families are left to struggle being told here's websites, wait for diagnosis, this is not good enough..."

"I think that the SEND team at Torbay and within the NHS are under-staffed and therefore waiting times for EHCP are a long time."

Lack of continuity:

"Health visitor team need to start up drop-in clinic as things get missed with 6 monthly appointments. Also, good to have same health visitor each time, not meeting like 5 different people and repeating self each time"

"Social workers/caseworkers change all the time. Have to repeat story/history of son every time. Lots of promises made but they never happen."

Lack of joined up approach:

"I feel that as a family we had to do a great deal of work ourselves to find out what was available – lots of disjointed advice."

"There needs to be more of a multidisciplinary team approach i.e. health and education working together rather than pass the buck from one service to another, many families end up bouncing between the two without anyone taking any responsibility."

"Provision feels very one direction, don't feel that professionals are open to sharing support or working with other organisations."

"EHCP has so few people attending it was more like a parent teacher meeting. Education input was fine, but zero social input and minimal health input...it feels like a cut and paste with no one taking ownership for content."

Accountability for funding that is provided for within EHCPs:

"EHCPs are granted, funding is provided to the schools. Yet what the children are supposed to get support with are often not fulfilled".

- "... Difficult to access funds if you wish to take a portion for tuition."
- "... When her statement was changed to an EHCP I was told it offered personal budgets to buy in services but once she received the EHCP the schools said it was for them to provide 1:1 support and we've never been given the option to use this for therapy or other interventions, why call it a personal budget?"

"Enablers service provision as outlined pays very poor hourly rate... You need a parents' panel, so we have a voice, so managers' start listening to the people who know the children best and stop divorcing them from the process. You really need to have a review process to see how effective the care package is being delivered."

Failure to deliver provision:

"Nothing [is working well]. I don't receive any support or service at all. This affects the wellbeing of the whole family."

"It's the schools which don't provide what is recommended."

"The whole thing is dysfunctional. The various agencies aren't seeing the child and meeting the child's needs but passing the buck, avoiding spending any money/ expert resource on supporting the child.... The only support has been paid for privately..."

"I honestly cannot think of anything that has worked well. The services we finally got to see after 2 years of waiting can be good for one or two appointments but then that's it. You just get dropped as they are too busy. You can't get anyone to attend meetings or EHCP reviews."

"The school don't have adequate staff and can't hire them."

"The social care system in Torbay is about safeguarding only and not around individual need. Social care need does not always mean safeguarding!"

Lack of available specialist provision or special school placements:

"Not enough schools with SEMH places and support".

"Not enough special schools for number of children requiring one."

"Mainstream schools are not inclusive, there isn't enough room in the special provision for everyone who needs it."

"When I moved to the area Torbay Council told me there were no spaces in Torbay schools for my son and so placed him in an out of area school that I had already said I didn't feel would meet his needs..."

"Mental health support to SEND children [is not working well]."

"We were told our child didn't meet the children with disabilities team criteria... You have to fight for respite. Even once you have it in place children's services stop it without warning. Then you get pushed on to direct payments... The battle for services just makes you ill."

Communication and not feeling listened to:

"Nothing [is working well]; parents treated like second class citizens."

"The whole bloody system is failing. Why do we have to fight so hard to get our voices heard and then be stuck on waiting lists for years."

'We have had no support from Torbay Council, NHS, social care without having to specifically research what should be available and then ask for it. It took for crisis point to be reached before anyone cared about our family's difficulties.'

"SEND and Children's Services have been absolutely awful. There appears to be an unhealthy culture of bullying parents, ignoring rights."

"Too many EHCP refusals despite masses of evidence, too much chasing of 'professionals' who assure you they'll keep you updated. Everything is a battle, when our time as parents/carers should be spent nurturing and supporting our young people."

"Only contact I have had was with the attendance officer which was insulting and a horrendous experience."

"Sad that so much money is wasted on meetings, reports, suggestions, to no end, it seems to exist for itself not the children it's meant to serve..."

Lack of training and understanding:

"Your child needs a formal diagnosis for school and health professionals to take you seriously."

- "... Nursery staff don't know how to pick up on neurodivergence or how to provide support."
- "... We think it is bad that there is no national framework for progress expectations for different cohorts of SEN children. This would not be acceptable for mainstream children."
- "... Schools need more training, but I think parents can help with this as they have lived experience, not just training out of a book!"
- "...Teachers not trained in SEND and treating them as naughty children instead of special needs."

"It's better to have an obvious or physical disability than autism. With autism no one understands the behaviour challenges you face. You feel so alone."

Transition

Of the 118 responses received the following key themes can be identified. It is important to note that 48 individuals chose not to reply with an answer, and this may indicate that the style of question asked was perhaps too broad. 12 people reported negative experiences of transition. 11 parents and carers identified that their CYP will need ongoing psychological support. 8 parents and carers suggested that early help is needed to support successful transition.

Negative experiences of transition:

"There ARE NOT enough provisions for adults in Torbay who have special educational needs."

"The transition process is very poor, nobody can tell you what will happen, apart from join a waiting list. I currently remain anxious as to what will happen. Nobody seems to be able to sign post me as to what will be on offer."

"My child deals with a lot of loneliness as she goes to a very small school, has lost all her friends from Primary and struggles with not being able to go out by herself."

Education and training:

"Provisions that actually provide jobs for them, even if supported. Ongoing roles such as supported animal care at zoo or RSPCA centres."

"Apprenticeships for neurodiverse young people who are cognitively able."

Counselling/support/social groups:

"Counselling and holistic therapy that isn't CAHMS."

"Support for high-functioning girls who do not conform to the stereotype of autism - sadly, many professionals in Torbay seem to think this is the only type of autism that exists."

"Local groups and therapy sessions age appropriate to learn better coping skills and skills for their futures."

Early advice and support needed:

"To offer the help early as possible to make the chances of individuals with SEN more likely of coping with adult life."

"Discuss options and available provisions. Start the discussion early not last minute. Remember that quiet and well-behaved children have difficulties too and their needs matter."

"Someone who can support us with paperwork, advice, an advocate for me."

Transition support needed:

"Preparing for adulthood without having an EHCP."

"Earlier transition. We are currently in limbo. Our son is almost 18 so Children's Services are not interested and are just waiting for him to move onto Adult Services. But adult social care is not fully involved with him yet because he's not yet 18. So, you are left between services."

"Support should be handed over from school to school, to service to service and support should be available for life."

Other suggestions to support successful transition:

"A family case worker could provide necessary support with independent living..."

"Needs a focussed service to support parents and young people rather than appearing to be concentrating on the fact they are becoming adults and will no longer be the responsibility of Children's Services."

"Enablers for young adults."

"EHCP for their transition through GCSEs and college, a log of information about my child so that we don't have to relive every traumatic detail..."

"It would be nice if she could stay in her secondary school until she's 25years as covered by her EHCP but instead she'll have to leave and go somewhere else at 18 years and that won't be enough time for her to make up for the lost education over the past few years." "An easier system to navigate based more on need and less on parent's ability to fight for support."

The needs of parents and carers

Parents and carers were asked if they felt that their needs as a parent / carer are considered and understood. 115 parents and carers responded, with the majority of parents (89%) reporting that they do not feel that their needs are considered. 2 respondents felt positive about their experiences and how they felt, with one family explaining how proud they were despite the challenges that they faced. 58 families felt negatively about their experiences and how it made them feel. This ranged from sadness, anger, frustration, helpless and lonely. 15 families felt that being listened to would support them with how they are feeling currently.

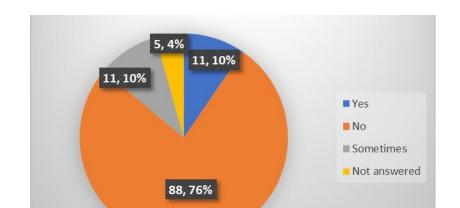


Figure 6-The percentage of parents/carers who feel supported by the SEND process

"Feeling I'm getting nowhere. Frustrated that my child's needs are not met."

"As a parent of a child with SEND you feel every possible emotion, you spend your days fighting for them, fighting for them to be accepted, fighting for the support they rightly deserve, fighting for answers, fighting so that they can be happy and healthy."

"Overwhelmed. Physically and mentally exhausted. Wanting to run away. Having zero life except being a carer. No hope for the future."

"Financial worries, overwhelmed, trapped, exhausted, frightened about the future, depressed, helpless, inadequate, alone, misunderstood."

"Despair. Exhausted. It's been years of fighting to get support. We haven't been heard. We haven't been believed yet we have been honest."

Where do parents and carers get their support?

The most frequent answer cited by 27 parents/carers was the voluntary sector. The majority of these mentioned services such as SENDIASS, Tissues & Issues, Beehive, Cygnet Team. 11 people said that they seek support through schools. 24 stated that they would seek support through their friends and family. This was identified as an area of strength for many families. 26 responded as unsure, indicating perhaps a lack of understanding around what support is available. Where recorded as "Other", some of the suggestions include relocating, not with local services, and anywhere where they can find it.

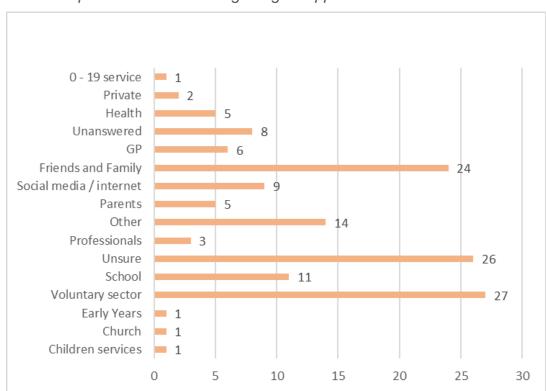


Figure 7- Where parents/carers would go to get support

Where parent and carers get support:

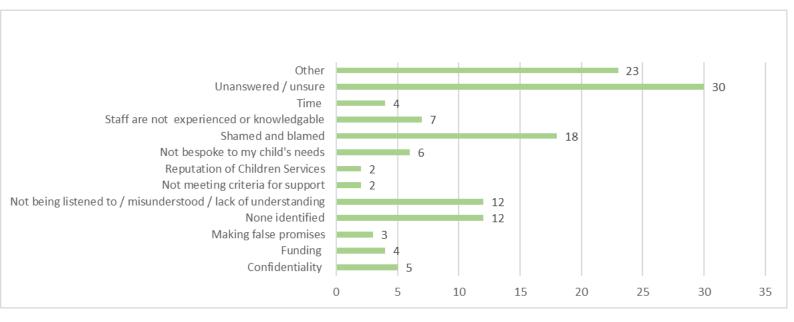
"My family are supportive, but it would be nice to have peers who understand and have things in common."

"Talking to other parents with similar children with similar conditions helps e.g. Tissues and Issues."

Parents and carers were asked what might worry them when thinking about engaging with services. Many parents/carers cited more than one worry or concern which suggests concerns can be multi layered and inter-connected. The majority of parents (30) chose not to answer this question or stated that they did not know. Where recorded as "Other", some issues mentioned drift and delay, being rejected, and waiting lists.

Shamed and blamed was selected by 18 parents/carers, showing that this was a high concern among many parents/carers accessing services. Not being listened to, misunderstood, and lack of understanding was cited 12 times, which could suggest that communication between services and parents/carers is poor. 12 parents/carers were unable to identify any worries or concerns. This could be that they did not see any worries when accessing services.

Figure 8- What might worry or concern parents/carers when thinking about engaging with a service



Parents and carers were concerned about aspects of support that they might receive:

"Lack of experience, qualification and person leaving the service after child has built up a bond, trust."

"The lack of true understanding."

"That you have to start at the beginning with explaining your journey and wasting time repeating yourself."

"In the past we have been told we would get support and it never happened. Hope of getting help and then being let down makes it so much harder. Sitting in meetings begging for help is humiliating, even worse when nothing happens."

What can we do better to support parents and carers? Listen/Communicate:

"I feel that parents and carers of SEND children are often looked down on as uneducated and their needs are easily pushed aside."

"Respect us. Don't make decisions about our children without involving us and considering our views. Listen and hear. Treat us as equals. Don't try to hold power over us. Believe us.

If we ask for help it's likely we need it. Be accountable. Do what you say. We know our children best. Most parents want the best for their children and are honest- remember that! Need a complete culture change towards parents of disabled children."

"Let them know someone is listening, sometimes that's all that is needed."

"Offer a team within the local authority that parents can discuss their grievances with regarding school conduct."

"I need school to listen to me and respect I know my son's needs."

"Changing the whole culture of Torbay and the way that SEND is perceived."

Support:

"Stop having to make us fight for support. Understand what we are dealing with. Don't threaten to take away things that work. Support not blame."

"Provide regular overnight & daytime respite."

"Provide us with a consistent level of support."

"Phone support or drop-in centre for urgent help, support and advice."

"Give me and my children the tools and opportunities to be the architect of our destiny and future. It is ours not yours."

"It would have been helpful to have support there for the numerous hospital appointments he has had for various things. This has been so hard for us at times."

"Focus on the primary to secondary transition. Enhanced transition is promised but not delivered."

Counselling:

"Counselling or someone to talk to."

"Provide a counselling service, not Talkworks! Not an online CBT tool, an actual person to talk to."

What needs to change in SEND Torbay?

Of the 122 responses received, a summary of the key themes can be identified. 89 respondents provided constructive suggestions; 6 individuals responded here with negative criticisms; 28 respondents left this question unanswered.

The themes identified in the comments provided were:

Practitioner knowledge about SEND:

"More knowledge in schools and what they're expected to do on SEN support."

"Have efficient SEND co-ordinators in schools."

"Make sure every teacher in primary/secondary settings know which children have an EHCP and what provisions need to be in place."

"Autism training for professionals."

"Employ more staff to help reduce the waiting times."

"Help navigate what support is needed and help those involved get there."

"Staff need training. They need to gain a better understanding of what it's like to be a parent of a child with autism or additional needs."

Communication with parents and ensuring that it is a true partnership:

"Give parents' options and consider what's best on an individual basis. Tailor the education to the child and not the child to the education."

"Answer the phone. Listen to parents when they flag issues with the school. Accountability for how the funding is spent."

"Unfortunately to do it right will take time, but maybe set up the meetings for parents and carers to see where the gaps are. Then a plan can be made to make things better."

"Set up a parents' panel and stop your managers hiding away..."

"Work with families, attend TAF meetings. Speed up waiting times. Don't discharge kids that will need the services again."

"Increase awareness and understanding with schools and increase the number of autism trained teachers in school."

"Answering the phone would be a start, never calling me 'mum'."

Cultural attitudes:

"Change of attitude - parents are not the enemy."

"A restorative culture within the council that puts the children and families at the centre."

"Stop parental blame and start consulting and listening, working in partnership."

"Staff your team sufficiently so they have time for us. Please stop putting a spin on things. It's not needed and it's not helpful."

Regular contact and an advice service:

"Reduce timescales, check up on us - a quick phone call once every 3 or 4 months to see if the EHCP is effective, not waiting for a 12-month review and another year failed in education." "Consistent support and check ins with parent. Some sort of advice service."

"... a one stop drop-in to help with issues."

"Online or phone support for 'quick answers' for parents. Like a sort of FAQ that is easy to use."

"An information pack with all basic information for parents after a diagnosis: how to claim DLA, how to register on an... appropriate course... info about carers register, automatically be registered as a carer at the GP, information about young carers for any siblings, support group info etc."

"Access to a phone number of someone higher up the chain even if that's via a GP..."

Key support worker:

"A key worker allocated to a family who can support the family and help with what support is available."

"Get SEND families a case/support worker that will actively give information on the child's diagnosis, what this means and give practical, helpful and ongoing advice and support."

Inclusive environments, dedicated spaces:

"Mainstream schools need to partner with special schools, special school staff should be given special training and paid more so they can also work with and train mainstream staff."

"Set up a/some focused centres (not schools/or school type provision but more activity targeting SEND provision) with different people/organisations working together."

"Provide respite/short breaks to enable parents to continue caring. It's exhausting!"

"Create and advertise desegregated services and clubs for BOTH SEN and non-SEN children...Think about how children with challenging behaviour can be better "spaced out" through better facilities (classroom space) and better integration. Ensure every child in special school gets one-to-one coaching on core subjects in a distraction-free setting for a period of every day. This could be resourced through smart timetabling."

"Think about how TAs are deployed...Pay TAs better"

"There should also be a region-wide push to get everyone using Makaton beyond foundation stage at primary as it is often the only language LD kids speak."

Improved knowledge on neurodiversity:

"More Teacher/SEN support in mainstream schools needed. More teaching training on children with additional needs, autism and masking..."

"Parents and carers and most importantly children need to be asked what they would like from and for their lives not this being done to them."

"Staff less intimidating. Listen more and dictate less. Learn from mistakes instead of carrying on with old habits."

Individual child approach:

"See where the schools are spending the extra funding and make sure it goes to the child it is provided for and not into a SEN pot in the school."

"Tailor the education to the child and not child to the education."

"...People seem to think every SEND child will fit into a certain box, but they don't, and each child is completely different with unique needs."

"Look at every child individually."

"You could learn a lot from the YMCA model of working with SEMH young persons...Stop trying to make then fit into your boxes and work around the YP in the long run the cost will be so much cheaper than fighting to make them attend the cheapest options available and causing more harm and trauma to both the YP and their family."

Integration of specialist services into schools:

"Screening in nursery. OTs physios and speech therapist in schools. Inclusive school environments. Support for families in schools."

"Be more inclusive and supportive of those who aren't in a SEN school..."

Improve the provision:

"Invest in better post 16 [provision]."

"More support before needing a statement of EHCP - we don't need statements just support in school."

"Additional funding."

"When tribunals agree plans they need to be acted on not ignored."

"More recognition for staff providing mental health support in schools. They do a great job."

"Share case studies of what it is - and what it isn't...Implement robust measures and track intervention is happening. Audit the quality of that intervention..."

"HV [health visitor] clinic bring it back."

"Give us information and support before diagnosis whilst you're waiting for ASD, considering how long it takes."

"Earlybird autism course is great but should come much earlier in process to actually support families."

"More information for parents about what is on offer for children leaving school but that have to stay in education till 18."

"More professionally run activities and events run by trained staff for children."

"More places/support groups set up for parents and siblings to attend."

Respite and childcare services:

"Social care for autistic children."

"Very difficult to get respite. Takes too long to get in place. Hard to keep it once agreed. Instability."

"Local respite unit to replace the lost commissioned service by XX in Ivybridge which was the replacement for JPU. There is zero choice now for me and my child."

"Days out."

"Support for working parents of teenagers/young people who require childcare especially during the holidays. Remove ridiculous criteria attached to accessing holiday play schemes."

Additional support for adoptive parents:

"SEND support through adoption, I adopted my child and for the past 3.5 years it's been a struggle to deal with all of his needs."

"Independent advocacy. Not just SENDIASS but with adoption to tackle issues such as the adoption allowances or schools."

Missing services:

"Offer counselling to parents (especially mums) whose mental health is suffering because of their child's difficulties."

"More support for siblings of children with SEND."

"An autism service which actually supports the families."

"A support for the parents and carers who are waiting on any waiting list."

"Create small area support groups; hubs to make suggestions for autism, ADHD and SEMH with half termly meetings in each area of the Bay for parents and carers to go to and share ideas."

"A buddy system - parents who are happy to provide support to other parents, be matched up with someone who knows the difficulties you are experiencing."

"A 24-hour helpline, possibly manned by people who have 'been there/done that."

"Parent/Carer/child clubs."

Review waiting times:

"The wait time for children potentially on the spectrum is insane! This needs reviewing.

Parents are struggling and being told there's a three-year wait is not acceptable."

"Look at referral process, assessment process and certainly the assessment criteria."

"Cut waiting times on implementing new EHCPs."

"CAMHS is not fit for purpose and needs a complete overhaul."

Changes to funding:

"Make funding more accessible. More support for families and children awaiting diagnosis."

"Fund services that are or already working well and stop trying to find the next buzz service."

"Stop financial contributions for direct payments. Provide a directory of available services."

Help recruit enablers."

"Pay enablers a proper hourly rate and get some availability of people to fulfil it..."

"Start looking at funding an in-boundary respite centre."

Consistent partnership working by creating a SEND hub:

"Support hub type provision (has to be long term commitment): Set up a/some focussed centres (not schools/or school type provision but more activity targeting SEND provision) with different people/organisations working together."

"More joined up thinking. Putting the families at the forefront."

"Be open to working closely with other organisations, support hub type provision (has to be long term commitment)."

"Clear guidance on how to access services, clear timescales and parents to have a visual pathway of the process so they know where they are in the process as currently you get referred and disappear into a black hole."

"More resources and advice available online through a local website."

4. What We Have Done in Response to Your Feedback

	You said:	We did:
1.	Children and young	We have created a 'Point of View' Service to hear and act
	people told us that good	on children and young people's feedback. It was created
	provision and positive	with young people; we set a competition to name and design
	relationships with the	the service which was co-produced completely with young
	people that help them	people. There is also a SEND version of the questionnaire to
	were of greatest	ensure it is accessible: Point of You - Family Hub
	importance to them. They	(torbayfamilyhub.org.uk)
	rated the professionals	
	supporting them very	Our Ways of Working is another way we are listening to our
	highly.	children, young people and families, this was launched in
		February 2023: https://www.torbay.gov.uk/children-and-
		families/our-ways-of-working/
		We have more focus on capturing children's voices in single
		assessments and Early Help assessments and we are
		seeking children's feedback as part of our audit process.
		We have also set up the new SEND Youth Forum, a
		participation group of young people aged 12-25 who meet
		monthly and discuss what is important to them, this feeds
		into the SEND Executive Strategic Board: Volunteering -
		Family Hub (torbayfamilyhub.org.uk)
		Torbay Hospital are running a 12-month Youth Forum pilot
		project. This is for 13–20-year-olds and will run eight times
		per year. To find out more go to:

https://www.torbayandsouthdevon.nhs.uk/youthforum or scan the QR code: 2. The majority of parents We are now reaching more parents than ever with our SEND newsletters - Torbay Council and carers are not feeling heard and feel let down by some of the services We have run an engagement event for parents and carers of that exist to support them. children with SEND needs in April 2024. They report a lack of SEND Family Voice Torbay (SFVT) have been engaging joined up thinking. with parents to provide support around SEND needs. We have collaborated with parent/carers and professionals to develop and run Bridging the Gap workshops in Speech Language and Communication Needs (SLCN) and the Neurodiversity Graduated Approach toolkit. In early 2024 a Devon County Council Autism and Us parent programme accessible without a diagnosis, was trialled to Torbay families which also included 2 follow up workshops in July (Autism and Girls & Demand Avoidance). Evaluation is being summarised by SFVT who coordinated the programme. This is being used for a multi-agency approach with SFVT in developing a Torbay specific programme with intention to have this ready for the Autum term. Social care have reviewed their complaints process, to ensure that all formal complaints are responded to with the offer of a face to face or virtual meeting, in addition to a written complaint response. Parent feedback is included as

		part of the Family Group Conference and as part of routine audit processes.
		Family Hubs have been co-produced with parent carer panels.
3.	Parents and carers talked about the need to fight to get their children's needs met, having to chase up appointments and provision.	The SEND Team have a new duty service responding to parental enquiries on the same day: 01803 208274. The new CFHD website has been launched with a single point of access. This provides information and links to services as well as providing contact details and information on how to refer, what to expect once referral is made, and early help and resources: CFHD providing care and treatment for children and families in Devon Children and Family Health Devon
		All self-referral for support from social care will be processed within one working day.
		We have launched the Family Hubs website, which is intended to be a one stop shop for children and families, and gives a further communication channel. More services available at the universal level via the Family Hubs: Home - Family Hub (torbayfamilyhub.org.uk)
		There is a new Portal allowing easy access for parent/young people self-referrals to Early Help and access graduated response programmes: Early Help - Torbay Council .
4.	Many parents and carers felt that it was difficult to get support unless their child has a diagnosis.	We have been working to transform services for children with Neurodiversity and Speech, Language and Communication Needs (SLCN), to enable the right support for children and young people, without needing a diagnosis.

In 2023 the Autism in Schools project offered training to all Torbay secondary schools to improve staff knowledge and skills, to better support young people with neuro diverse needs.

SEND Family Voice Torbay (SFVT) are building better communication between families and schools and intend to establish 3 autism community networks across the Bay.

In 2024/25 the Partnership for Inclusion of Neurodiversity in Schools (PINS) project will help a small group of primary schools identify and address gaps in their knowledge/skills and SFVT will lead collaborative conversations between schools and their families on neurodiversity.

NHS Devon is working with families, producing bitesize information videos in 2024.

Parental peer support for families with children and young people waiting for autism assessment was piloted in 2023/24 and is now being evaluated, with the intention to inform the development and commissioning of a peer led support offer.

The refreshed graduated response toolkit for neurodiversity provides a range of information, resources and advice based on need rather than diagnosis.

A review of SLCN has been completed and NHS Devon ICB (Integrated Care Board) are working with providers and Better Communication CIC to develop and implement the Balanced System Approach.

A detailed review of the Early Years SLCN offer has been completed and the findings are informing the Family Hub development programme and Early Years action plan. Social care have reviewed their complaints process to ensure that all formal complaints are responded to with the offer of a face to face or virtual meeting, in addition to a written complaint response. **Neurodiversity and Speech, Language and Communication transformation:** acknowledges unacceptably long waiting times for autism assessment and is: Building knowledge and skills through Autism in schools and PINS so that families can get the right support without a diagnosis.

5. They described difficulty accessing health services and experienced unacceptably long waiting times.

Integrating systems to improve the experiences of children, young people and families.

Learning from our Expert Reference Group of families with neuro diverse children, led by Devon Parent Carer Forum.

Understanding what additional resources are needed.

Setting acceptable assessment standards with private providers so that these are recognised, and families no longer need to wait on an NHS waiting list for a diagnosis.

Recruiting new Neurodevelopmental key worker posts to pilot and test the role in providing direct support to children and young people waiting for an autism assessment.

Bringing together the resources available to promote 'Waiting Well' to children and young people and their families whilst on wait lists. The CFHD website has been refreshed and re launched which provides information, advice and guidance as well as useful information whilst waiting: CFHD providing care and treatment for children and families in Devon. - Children and Family Health Devon

Community Paediatrics are working to streamline their referral pathway, increasing capacity for more clinics; have reviewed and updated the First Steps guidance given to families when joining their wait list and transferred this to an app.

Emotional Health and Wellbeing:

Mental Health Support Teams continue to provide early intervention support to CYP working within 12 primary, 8 secondary and 1 specialist school settings. They offer CBT sessions, workshops and a digital offer, adapted to best meet the needs of the children and young people. Support is also available to parents and carers and education staff.

NHS Devon continues to work with NHS England, our local providers and partners on future opportunities relating to MHST.

Young Devon's Emotional Health and Wellbeing Service offers early intervention conversation by trained therapists, individual person-centred counselling, individual CBT, Wellbeing café, single session therapy, MH youth work, and Arts therapies.

Speech, Language and Communication Needs:

A 12 month 'test of change' waiting list programme was devised, delivered and is now being considered with national evidence to transform the offer, ensuring it is integrated, straight forward and efficient; and is delivered in the most

		conducive and functional setting for the child/young person. Careful consideration is being given on how to improve workforce capacity to sustainably meet the predicted level of need within Torbay.
6.	Parents and carers experienced poor communication, having to repeat information and didn't feel listened to.	Children and Family Health Devon have a new electronic patient record. They have integrated mental and physical health pathways which include joint working with paediatricians. This should mean that families and young people tell their story once and experience more joined up health care.
		We will be introducing the 'Tell It Once' Platform through the Family Hubs website to reduce the need for families to repeat information.
		In future, step-downs from Child In Need planning to Early Help do not require a further Early Help assessment. The updated single assessment is used to determine need which negates parents having to tell their story again.
		Torbay and South Devon Child Health Team and CFHD are working together to provide a single point of access for all community referrals. We successfully piloted joint assessment clinics between Paediatricians and CFHD therapists for children under-five. We plan to continue them and consider expanding the joint working to children over 5 years.
7.	Families that received appropriate levels of health and social care praised individual providers.	Feedback received from families is fed-back to teams and is discussed in regular meetings by all of our providers.

8.	Some parents and carers described a lack of provision of social care even where funding was available.	We have established a Short Breaks Task and Finish group, to focus on expanding the Short Breaks provision available in Torbay.
9.	Less than half of parents and carers felt confident that their child's educational setting could meet their child's SEND needs. Parents and carers feel that more specialist provision is needed.	The SEND roadshow visited most of the mainstream schools in Torbay to talk about the new Graduated Response toolkits and supporting mainstream schools to meet need. There has been local engagement in Dingley's Promise training offer, designed to increase staff confidence in supporting Early Years Children with SEND. The Sufficiency project aims to ensure more complex needs can be met through more specialist skills and provision locally. An improvement plan is being developed to support education settings with the identification and intervention of Speech, Language and Communication Needs. A workshop was held on 25 April 2024. Autism and Schools and Partnerships for Inclusion of Neurodiversity in Schools (PINS) offering training and support to improve the whole school approach including environment, workforce understanding and practice and links with parents.
10.	Trust appears to be low, with parents and carers stating that they feel unsupported. Many parents and carers felt shamed and blamed.	Restorative Practice training has been taking place with staff across the SEND partnership. Restorative practice is a term used to describe behaviours, interactions and approaches which help to build and maintain positive, healthy relationships, resolve difficulties and repair harm where there has been conflict.

We are preparing to launch of the Restorative Language policy.

Feedback from the work we did in partnership with Torbay Medical Research Fund has been taken on board and integrated in other programmes of work – particularly the Family Hubs and Breathing Space programmes.

Both the PINS and Autism in Schools Projects will help schools and their families develop collaborative conversations to improve relationships.

Mental Health in Schools Teams (MHST) provide some support to parents and carers to help enable them to support the CYP in their care, this includes understanding children's mental health, supporting transitions, understanding and managing anxiety workshop, a 10-day workshop, support with exam stress, 1-1 and group parent led interventions as well as being present at open evenings and coffee mornings.

Children and Family Health Devon have created 17
YouTube videos explaining each of the interventions
provided by MHSTs. The team has received positive
feedback from parents and carers that they have supported.

5. Next Steps

Over the last few months there has been a strategic shift in how the Torbay SEND Improvement Work is being governed. While still seeking to improve as required by, and in accordance with the Written Statement of Action (WSoA), the improvement work is now being delivered through five priority areas, which are overseen by the SEND Project Board and Executive SEND Strategic Board.

Each of the Priorities:

Priority 1 – SEND is Everybody's Business

The purpose of this group is to embed our values through education, health and social care, with a view to changing culture and reforming the collective workforce. The next steps of this priority are:

- The embedding of the Torbay SEND Pledge and Coproduction Charter across the system: having coproduced the SEND Pledge and Coproduction Charter the next step is to embed these across the health, social care and education sectors so that they are firstly understood and visible to all and secondly seen to be applied in practice.
- The creation and application of a 'Coproduction Quality Mark': presently, there is no
 'coproduction quality mark' or process for qualifying for this kite mark. A group is being
 established to take this forward, building on work that has been done within education,
 health and social care.
- The development of a sustainable model for a lived experience feedback cycle: the publication of the survey report has been challenging due to the scale and complexity of the survey and the limited resources available. For further years, it is recognized that a more 'real time' approach using evidence-based methodologies needs to be implemented to establish a responsive feedback cycle that gathers insights into [1] children, young people and their families experiences of the system at any point in time; [2] their awareness of changes that have been made to improve access, experience and outcomes; and [3] the experience people have had where they have engaged with changes in practice and process.

Priority 2 - Early Intervention & Lived Experience

This priority is concerned with identifying and acting on children's needs at the earliest opportunity, through valuing lived experience and expertise. The key areas of focus for the upcoming year are:

Identifying Needs Early: using the Early Years settings, and with the support of the Family
 Hubs, to create a training offer for the early identification of need.

- Communications: enhancing communication around the early support offer. Core to this is making sure health, social care and education communications incorporate, and are shaped by, people with lived experience.
- Tell it Once: the development of a 'Tell it Once' approach so that children, young people
 and their families do not have to repeat their stories to different professionals. Also, that
 they report feeling like they are partners in the decisions made about their own support
 requirements.

Priority 3 – Needs and Joint Commissioning

The focus of this priority is understanding the needs of our children, young people and families and making sure that joint commissioning supports service delivery; in turn ensuring we make best use of all resources. This will be looking to:

- Join up the speech and language system: working to better integrate the system and making best use of the available resources. The investments already being made by individual schools and the opportunities these bring will be considered as part of this programme.
- Neurodiversity (Support for Families): there will be an evaluation of the 'Autism and Us'
 parent programme that has been coordinated by SEND Family Voice Torbay (SFVT). This
 evaluation will inform the costed options for a sustainable Torbay joint
 commissioned/funded programme. As well as consider a parent peer led support offer.

Priority 4 – Inclusion

The responsibility of this group is to make sure that all Early Years providers and mainstream educational settings, support an inclusive approach to education. The next steps of this priority will be to:

- Embed the Graduated Response in mainstream schools to meet need early and well: following the 'Graduated Response Roadshows' to each school, there will be a programme of training and upskilling, supported by the SEND team and wider colleagues, to deliver this. The training schedule has begun and will continue through the 2024/25 academic year.
- Reduce the number of suspensions and exclusions for SEND Support and EHCP: suspensions and exclusions data show that while permanent exclusions from school have continued to decline, the suspension rates have increased. There will now be a particular focus on addressing suspensions.
- Develop a wider response to inclusion, including the health waiting lists and 'waiting well'
 agenda: there will be a focus on supporting children, young people and families while
 waiting, to access health services as an interim measure.

Priority 5 – Becoming an Adult

The role of this priority is to improve transition for young people moving into adulthood. This will entail:

- Addressing and embedding the recommendations from the Becoming an Adult commissioned Audit Report: in particular, this will involve capturing the lived experience of young people and their families to further improve transitions into adulthood.
- Supporting the ongoing creation and subsequent delivery of employment, training and
 voluntary opportunities across all partners working within the Bay: led by Torbay Council
 and Torbay & South Devon NHS Foundation Trust, work will be progressed with employers
 to increase access to the opportunities available to young people to move into employment.
- To co-produce and further develop information available to individuals so they can be clear
 about their options: this is to help young people, with support from their families, to make
 informed choices about possible next steps in their transition. It will also include more
 webinars to support parent/carers in their own transition as their young people move
 towards adulthood.

6. Glossary of Terms

ADHD Attention Deficit Hyperactivity Disorder

ASC/ASD Autistic Spectrum Condition/ Autistic Spectrum Disorder

CAMHS Children and Adolescent Mental Health Services

CIN Children In Need

CYP Children and Young People

DLA Disability Living Allowance

EHCP Education Health and Care Plan

EOTAS Education Other Than at School

HV Health Visitor

LD Learning Disability

OFSTED Office for Standards in Education

OT Occupational Therapy

PINS Partnerships for Inclusion of Neurodiversity in Schools

SALT Speech and Language Therapist

SEMH Social, Emotional and Mental Health

SENDCO/SENCO Special Educational Needs and Disability Co-Ordinator

SEND Special Educational Needs and Disability

SENDIASS SEND Information and Advisory Support Service

SFVT SEND Family Voice Torbay

TA Teaching Assistant

XX Anonymised school or provider