

Swindon SEND Families Voice Survey Report

Introduction and methodology

Late in 2019 we invited bids from non-profit organisations in Swindon for a small amount of funding to undertake a survey with their contacts or members. These were likely to be people from whom we were otherwise less likely to hear.

Five organisations¹ were selected by our Advisory Group and a standard survey was developed with the groups' involvement. It was adjusted slightly for each to acknowledge the specific differences of organisations' remits. Four were asked to survey up to 100 participants between April and June 2020. One small activity group undertook to survey its 25 members.

Covid-19 intervened and, as a result, the surveys in this report were all completed online by people involved with [Swindon SEND Families Voice](#). They therefore exclude any participants without online access.

Key findings

- Few participants make GP appointments online.
- People's experiences of the same service varies greatly - from much appreciation to extreme frustration.
- SEND Families Voice observe that the survey did not bring up any surprises. "One thing positive about Swindon is that we seem to know where it isn't working well a lot of the time. The fact that people have conflicting experiences from the same services came out in the Annual SEND Survey the group did with the Swindon Borough Council too." They believe it shows the services aren't providing a consistent enough service.
- There is frustration at the length of time it takes to make appointments and see clinicians and have assessments undertaken
- Waiting lists are such a big concern, however this is also a priority on the Swindon Borough Council Written Statement of Action so there should be some improvement¹.
- Mental health services should be a priority - especially TaMHS and CAMHS.

¹ The organisations were Parkinson's UK Swindon & District, Swindon & Gloucestershire Mind, Harbour Project, Swindon SEND Families Voice and Swindon Interactive Arts Service (SWIAS).

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Who participated?

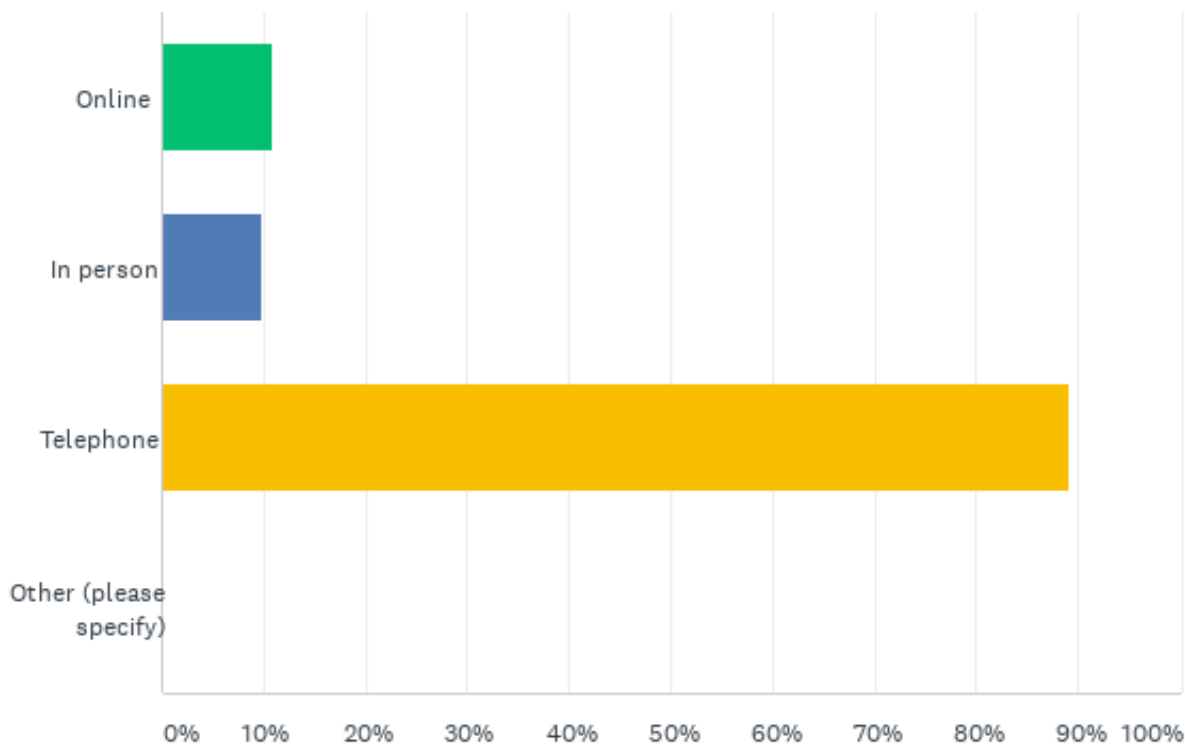
Data was collected between 19 March and 6 May 2020 from 102 people. Not everyone answered every question.

- 97 people were registered with 21 different GP practices in Swindon (out of a potential 24);
- 1 was with a Wiltshire practice;
- 2 were with a Wiltshire practice but attended their branch surgery located in Swindon borough;
- 1 person was with a Gloucestershire practice but was living in Swindon and
- 1 was with an Oxfordshire practice.

What did we hear?

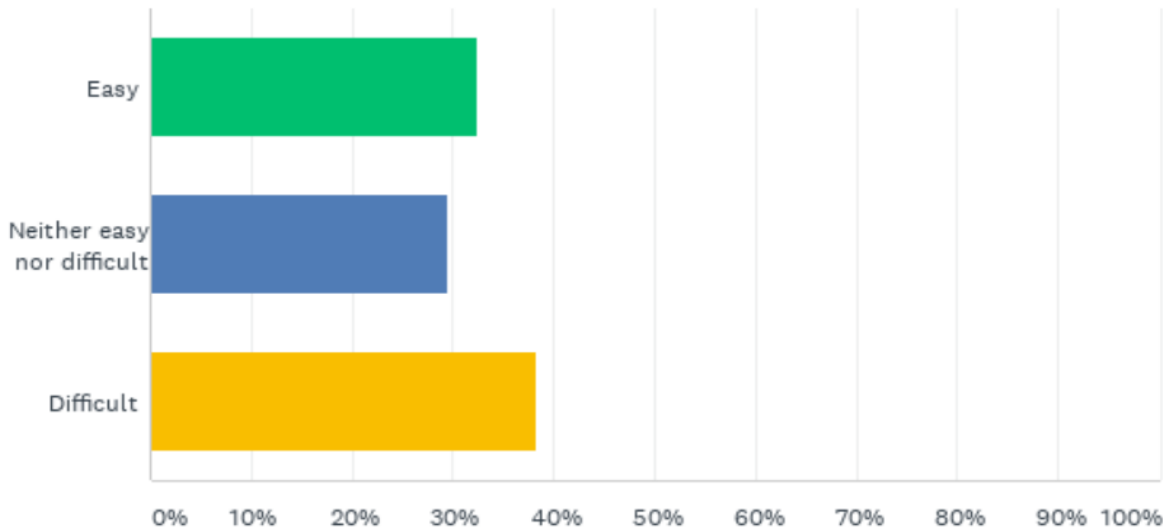
We asked how people made appointments at their GP surgery and how easy or difficult they found doing so.

People do not limit themselves to one way of making appointments; however 91 telephoned, 11 made appointments online and 10 went in person to the surgery.



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- 39 people found it difficult to make an appointment.



People commented about having to wait to get through on the telephone and about the availability of appointments; they were generally able to get emergency appointments when required.

“Sometimes I have to call at certain times to get an urgent appointment. Other times I have to call back another day because they have no appointments available for weeks.”

“The usual approach is for the surgery to say they have no appointments for children and ask us to contact the children’s clinic.”

“Anything to do with children including my SEN child is always bounced to the children’s clinic - even when it really isn’t appropriate.”

“Poor availability. I struggle to get an appointment even if I phone at opening at 8.30am. If I am able to talk with someone I rarely feel my concerns are dealt with and passed on to a doctor, especially with medical history and medical background.”

One said “The process (for) making the appointment is easy, it’s the availability that is the problem” whilst another said “Excellent availability.”

“It’s not always possible to make an appointment over the phone as by the time I get through the next available appointment is usually several weeks away. If I go in person I usually have more luck, sometimes I’m able to get an appointment later that same day.”

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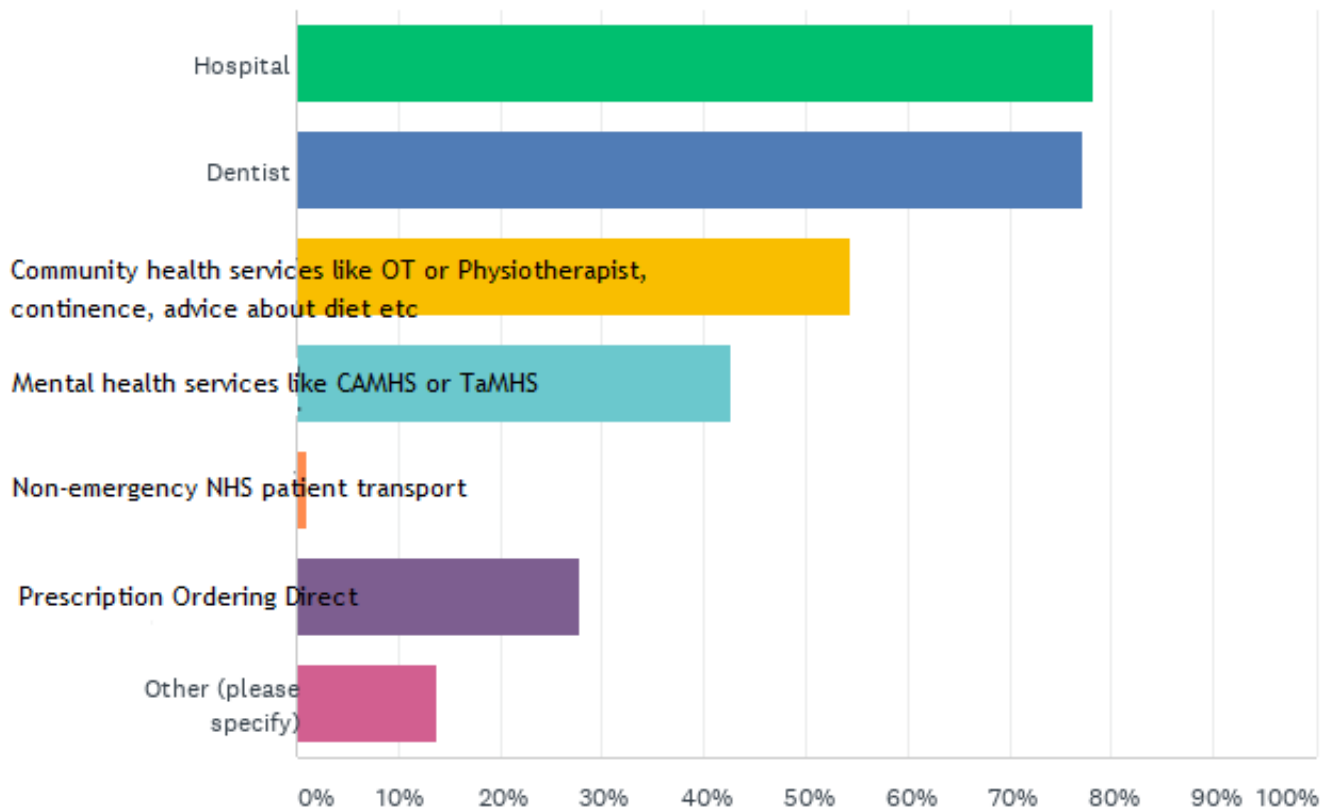
“It’s really difficult to get through on the phone, so usually end up walking down there to make an appointment if it’s urgent, as it’s about 3 week wait online for a non-urgent appointment.”

“Very happy with Hawthorn Medical Centre - Staff are very kind, patient and understanding! On the rare occasion I have been unable to get an appointment for my son at Hawthorn I was referred to Moredon Medical Centre - all good.”

“I object to having to tell the receptionist what the problem is! Sometimes it's really personal. Receptionists are sometimes unfriendly too.”

“Usually have to book a few weeks in advance but they are accommodating if needed urgently. GP surgeries being open on Saturday is helpful.”

Many had had experience of using various health services during the preceding twelve months.



- Others included therapists, podiatry, continence, autism services, health visitor and school counselling and a teacher of deaf people.

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This is what they told us about using these health services - people's experience of the same service can be very varied. The survey was completed during the Covid-19 lockdown period whilst everyone was adjusting to new ways of working.

- *“POD (prescription ordering direct) is easy to use - Staff are friendly and helpful. Dentist is limited - my son has some calculus but (fortunately) otherwise has good teeth. Went to GWH to see new paediatrician. Recently had CAMHS involvement but only just started prior to lockdown - son had school anxiety and we could not get him to school. I have ticked box for OT and PT via school but very limited - yet to have any real assessment.”*
- *“Pod is useless. No answer machines. Never answer. Community paediatricians terrible as make appointment then change 40 times!! Parking dreadful at Savernake.”*
- *“OT - we had a telephone call which was helpful, she gave us hints and tips on what we could do at home to help our boy. She was great at listening and didn't rush us. Speech therapy- Phone call (due to current circumstance). The lady seemed distracted, gave us advice without seeking any info hence all the advice was not appropriate. When asking for help around encouraging my son to eat, the therapist said “try taunting him”. I explained this is not something anyone should do to any child, disabled, vulnerable or neuro typical. I was appalled.”*
- *“TaMHS (Targeted mental health service) referral carried out 2018 and have heard from the worker once since and that was following numerous voicemails left. No support received at all since schools have closed.”*
- *“Hospital has been ok, slow at getting letters and appointments out. Dietician was useless. TaMHS was an absolutely awful service for us. Community paediatricians are fantastic when we eventually see them. Waiting list is far too long.”*
- *“TaMHS good, all others bad.” “Brilliant meeting with the TaMHS team*
- *“Waiting list to see TaMHS is over a year long after assessment, far too long for children in need of mental health services.”*
- *“Very good. Incredibly impressed with the Saltway Centre.”*
- *“The hospital are always great and very accommodating to his needs.”*
- *“The OT has been brilliant. Helpful, supportive to both our family and the school and really friendly. Our paediatrician has been really supportive and helpful too. Getting a prescription (melatonin) has been difficult (I'm disabled so getting to the Boots at the hospital is challenging. Also the GP can't prescribe and the system of getting prescriptions through the general paediatrician email is difficult because of lack of communication, limited supply and long waits), and actually accessing services is not easy either (waiting lists, no way to directly contact services etc). However, I've found that when we actually get to see someone they have been really good. The only service I've felt completely let down by*

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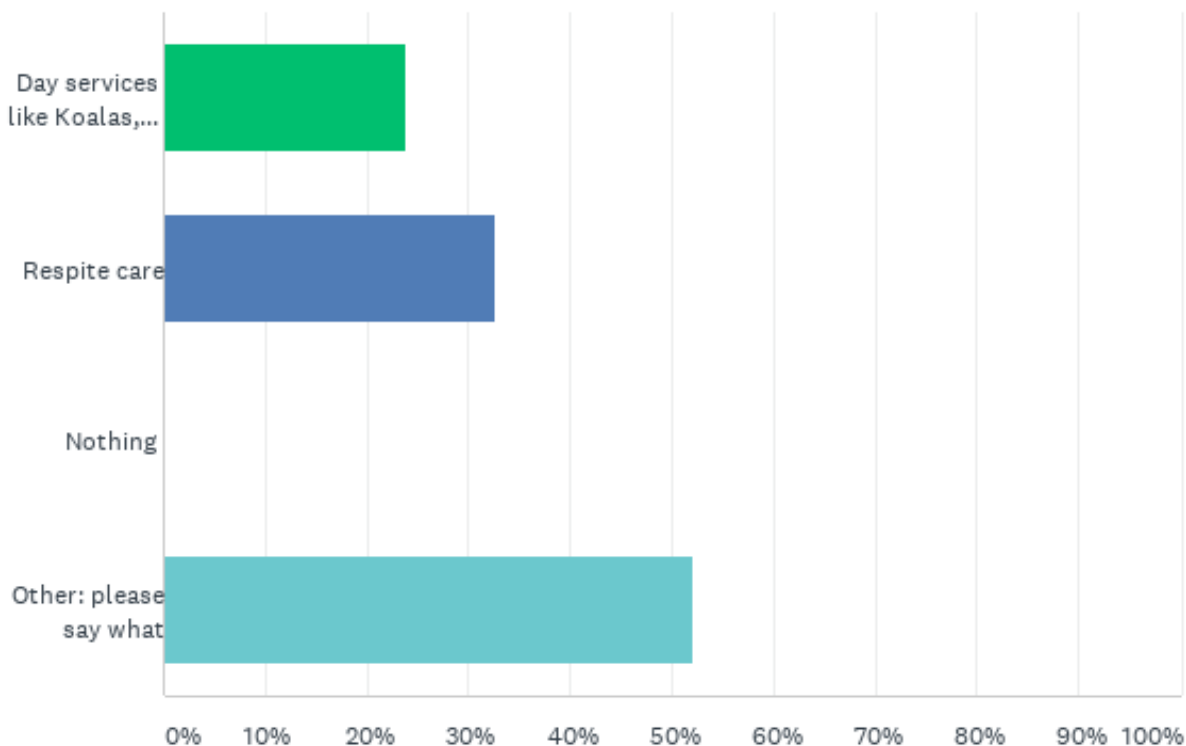
is TaMHS. The mental health provision for children is shockingly bad, largely because they are so oversubscribed and inadequately staffed.”

- *“Special needs dentistry is amazing, they are wonderful with him, can’t fault them.”*
- *“Special needs dentist - excellent with my child. Very patient, builds relationships and we don’t feel rushed do my son is relaxed and not anxious.”*
- *“Used lanyard and much better than previous visit.”*
- *“Hospital was not really good. It took a long time for my son to be seen unfortunately. And I think they should be more sensitive about children with special needs. Dentist was really good. And health visitor is also really helpful.”*
- *“Hospital is always lovely - friendly staff and good waiting areas. Clear signposts and barely have to wait once we’re there. Waiting lists can be long but once in the system, appointments are timely.”*
- *“Enuresis nurse is great, very thorough and doesn’t rush us. TaMHS are very frustrating. They never get back to you - even when chased!”*
- *“Very good. We go to paediatrics at Fairford hospital for a GWH clinic and it is brilliant for children with SEND. It is so much easier than going to GWH as it is much quieter. The staff there are lovely.”*
- *“Dietitian - excellent personalised service. Paediatrician - excellent although appointments very hard to come by. Community dentist - excellent, fantastic at working with special needs children.”*
- *“Dentist can be awkward, Doctors are amazing never an issue always do their best for my daughter, hospital can’t cope with my daughter’s rare condition. OT do review on equipment; sometimes feel it’s too often maybe a just a call to see if anything maybe needed would work better rather than a wasted journey or visit.”*
- *“Physiotherapy was an extremely bad experience! Put in a complaint about 2 members of incompetent staff!!!”*
- *“My son had asthma review recently and the nurse was amazing with him, I use Pod myself and always found them efficient. Now the surgery has gone back to its normal way of running the surgery it heaps better.”*
- *“Hospital Audiology are amazing.”*
- *“Special needs dentist in West Swindon are amazing, GWH were fab in A and E when we used the sunflower lanyard. TaHMS and CAHMS on 3 occasions have been a total waste of time, wait ages for an app then get seen and promised the earth and then discharged twice even though I had a son with suicidal thoughts terrible service who only care about processing numbers rather than actually helping and supporting our children.”*
- *“The services themselves have been very good. But the optometrist at the hospital, the community paediatric team and the physiotherapist based at Saltway have forgotten to send follow up appointments so I have had to chase them.”*

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- *“Dietetics was great, appointments came through when the dietitian advised a review. CAMHS service has been extremely poor and have been waiting to hear back about a follow-up appointment for 5 months now, no other help in the meantime.”*
- *“TaMHS: Awful experience. No contact, stopped sessions 2 sessions early then disappeared. No new appointments booked. Still waiting to hear after over 4 months. GP: Fair service but still not great. Hard to get an appointment. Hospital: Good service but appointments are delayed and cancelled far too often. Audiology: Fantastic service. Community Peads: Terrible. Waiting list is absolutely cruel.”*
- *“Dentist good experience with Sen child. Use Bath hospital for dental services - brace.”*
- *“All wonderful!! My ASD child could not have been treated better.”*
- *“Speech therapy very good. Eye clinic at the hospital don't seem to recognise the Sunflower Lanyards which is disappointing. Had a visit to A&E and the staff were excellent.”*

Fewer people completing the survey receive social care support than health services.



- “Other” includes [Aiming High](#) and support through [Direct Payments](#)

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People said

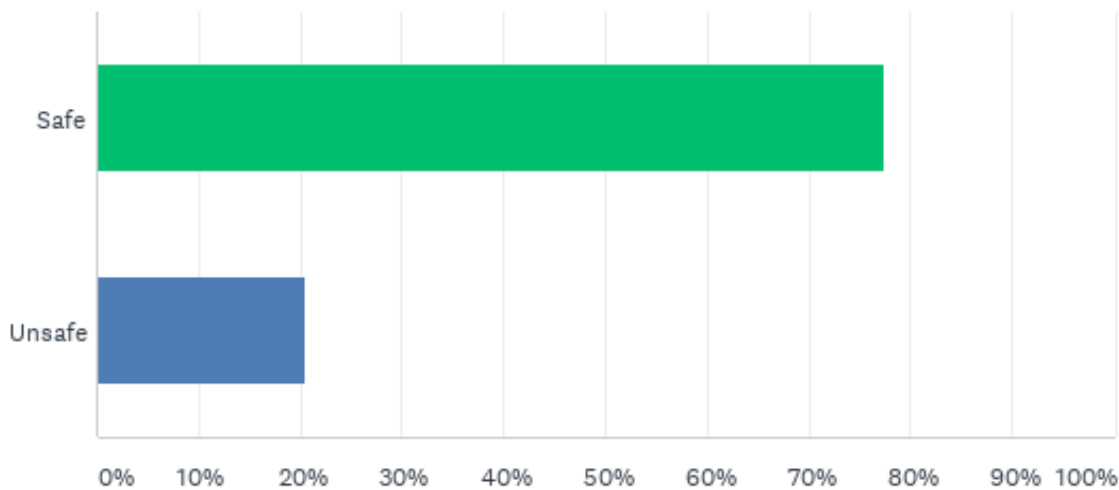
- *“Koalas excellent. Aiming High direct payments great but waiting list for groups too long as need was immediate.”*
- *“We receive direct payments for my son’s grandmother to provide respite for us - it’s only 1.5 hours a week. My son was put on a waiting list for ASD groups but never heard anything further. We definitely need more hours and help.”*
- *“Special tots have been amazing supporting all 3 of my girls.”*
- *“Aiming High is fabulous. So caring and welcoming. Again, long waiting lists are a problem (we waited well over a year for a place) but they are fantastic. My lad skips to go in, which is a huge difference from the anxious screaming or shutdown I get when taking him anywhere else! I value his place with AH very highly.”*
- *“Good experience for him, he is very settled in group. It is a little galling that this is marked down as a respite break for us; there is no transport available so I need to get him there and pick him up which cuts into the 2.5 hours each fortnight, (term time only) that’s 1.25 hours a week, with transport time to be taken out of that. NB this next comment is more than 12 months ago, but I presume situation is the same; when I had a temporary problem getting him there because of my working hours I was told there could be no transport, even on a temporary basis, my only choices were give up work, or take him out of group (and give up my ‘respite’) pretty poor response.”*
- *“Direct payments is a minefield. Aiming High is very hit and miss.”*
- *“Hop Skip and Jump have been amazing. Direct payments respite is tricky having to source own employees.”*



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We asked people how safe they felt in the local community.

Because our surveys are being carried out by five different agencies with participants from different communities of interest, we expected considerable variation in both interpretation of the question and response to it.



Covid intervened again and some responses refer to the lockdown:

- *“I cannot really answer this as we do not get out very often! Even before the lockdown I struggled to get my son out of the house for exercise - he would only go for a walk if we were going to local charity shop (ie there was a reason for him to go). He is very PDA. I am my son’s Safe Person and we work well together. His behaviour and reactions can be very unpredictable but I gauge his levels well. Also he looks older while being functioning cognitively at a much younger age. So far we have managed when actually out and about in the community - however my son has hit puberty and is taller than myself. As a single parent I do worry that he may have an extreme meltdown when out and I will not be able to manage.”*
- *“It’s very hard to manage social distancing and meltdowns, I feel unable to manage that so only go out when my husband is home.”*
- *“(Ignoring the current pandemic which is terrifying) I am happy to go out and about. My lad’s behaviour can be challenging and sometimes risky, but we manage this well so overall I feel safe.”*
- *“We tend to walk around the village and feel safe, saying hello to most people we pass.”*
- *“I am not given enough support. I have been challenged several times by public regarding using my son’s issues blue badge.”*

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- *“I have 2 children with complex needs and a husband who works long hours as the only earner. I struggle to take both my children out and have no family support.”*
- *“There are moments of feeling unsafe when there are big boy gangs around.”*
- *“Am not sure to be honest, my daughter finds it difficult sometimes when out and sometimes can make me feel on edge as she can come across as rude or just non-verbal.”*
- *“My son is difficult to control and keep safe in public. The general public are not very understanding.”*
- *“I live in a lovely community and feel we all look out for each other.”*

Swindon Borough Council and Healthwatch have recently been trying to gauge the extent to which people understand the term “[safeguarding](#)”. Each of our surveys include the question and there was broad understanding of the issue and where to report a concern. But several people said they did not know.

- *“I know there is a difference between Child in Need due to Disability and a child ‘at risk’. [MASH](#) would be first port of call. If safeguarding concerns involved Staff at a School then (in theory) [LADO](#) and [LSCB](#). However, from previous and personal experience it is a farce. Serious concerns about seclusion were raised regarding my son’s previous school - LADO referred us back to School to investigate?! This, despite Complaints Stage 3 Panel confirming it was not their place to investigate Safeguarding concerns.*
- *“I understand what safeguarding is but wouldn’t know who to call without checking online for some form of contact number or agency.”*
- *“Having worked in a school, I fully understand the term and know exactly what to do.”*
- *“I’m a teacher so I’ve had lots of training on this. I would follow the policy of the school I’m working in. I think it’s a bit more challenging as a parent though as there isn’t a clear route outside of education facilities. It depends what the issue is. I might go to the GP, family support staff at the children’s school, or I might contact services directly - I contacted [CAMHS](#) directly when my eldest was suicidal. Not that they did anything. As I said earlier, the mental health service for children is truly shocking.”*
- *“I work for NHS so know channels to go through but I believe it’s not easy for someone whom doesn’t know the system at all.”*

“Sometimes I feel like I’m expected to know more than I do.”

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What could be better?

Most people have views about the improvements that could be made to health and care services they use. We have included all the responses which were primarily about:

- speed of response to telephone calls,
- shorter waiting times,
- more support,
- more coordination between services and
- more funding

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- “Better communication all round. Shorter waiting times. “Adequate funding of course. Sensible caseloads”. Seeing the same person at each visit. Quality respite care. Better information about services available. Better sign posting to support groups or voluntary organisations.”
 - “The only thing I can think of is having appointments sooner, but completely understand the way it is as all services are overstretched.”
 - “For professionals to actually listen and respect us parents/carers - we are the experts when it comes to our children.”
 - “I would certainly prefer a Lead Professional to take some responsibility - Being sent round in circles happens too often; especially with referrals.”
 - “Better communication/clearer guidance especially when they agree to refer on but forget or refer on but close the case so nowhere to turn if the service my child was referred to turns us down for not meeting the criteria. Surely the referring agency/work should know this prior to referral.”
 - “Quality respite care such as Naomi House Hospice for all children and adults with special needs whose families need a week’s break. Currently only available to those with life threatening conditions. Every carer needs one week a year break where they know their child/adult is getting the best possible care.”
 - “Share information between services so information isn’t repeated. Make sure everything is followed up, as a parent it’s the not knowing that’s hardest. Provide interim measures while waiting for specialist support, the problems are still there, they don’t go away. Provide a person to contact who is consistent and understands the case to build relationships with the family.”
 - “For our family I would love to see health care professionals treat us all as individuals and listen. I would also like professionals to realise that our disabled children are still human and do not need to be trained like animals. In regards to wait times, I fully understand why

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these are so long. Maybe to help us parents they could set up something online where you can log in and check the progress of the referral or even if they have it.”

- “I don’t think it’s easy to navigate services when you are not sure what help and support you need, I find myself asking on SEND group for advice of who to contact. I would be grateful for better signposting of services.”
- “Appointments at the surgery to be available and not be forced to go to the children’s centre. Bring back “family” GP so people can see the same doctor so they have an idea of history and children are familiar with the doctor they are seeing to build trust. TaHMS to be in contact with the family direct not just through meetings with [SENCO](#) at school who passes messages. Clearer guidance of what happens when on pathway, what resources are available - not just be left in the dark for 2 years plus whilst waiting to see the paediatrician following referral.”
- “Better mental health services, including services that actually work when a child is in crisis. Better access to essential services like paediatricians and therapists - waiting years to get help is just not good enough. I also feel the practitioners need much better support as whenever we do (see) them it is obvious they are stretched thin. This is a shame since almost every person we’ve actually got to talk to has been professional, supportive and friendly. The underfunding and resultant lack of staff is putting our children at risk and causing them to spend years struggling when some simple input from good professionals can make things so much better for them.”
- “CAMHS should not affirm children who are autistic who are experimenting with their gender. They should use watchful waiting.”
- “Seeing the paediatrician - last time it was 2 years (Should have been 1 year) between appointments. I complained and they agreed it was too long. It will now be nearly 18 months - I have chased but not had a response! My son is waiting on services that only the paediatrician can put in place.”
- “Shorter waiting times for autism assessments. Some services are not available without a diagnosis, yet waiting lists are more than two years, and it is difficult to get onto the waiting list without evidence from school, which can be a problem for girls who present differently at school (masking) but are violent at home. What support is there for those families?”
- “Wait times, referral process for children not geared up for official home schooling. You can never get through on phones easily and services do not link up.”
- “Additional understanding of autism and learning disability at a GP level although this has improved of late. Better recognition that those with LD should have an [annual health check](#). Easier access and greater availability of GP appointments. Reduced waiting times for all aspects of health appointments.”
- “Understanding of the difficulties of high functioning autism. There is something about our GP surgery that makes my child display disregulated behaviour, especially when waiting to

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speak to reception. It makes it tricky as it seems like he is a naughty child who I have zero control over, but he is just on the verge of meltdown.”

- “Improved diagnosis pathway for children. Assessments should only be done by QUALIFIED professionals ie educational psychologists instead of teachers/SENCOs deciding the educational fate of children with SEND requirements.”
- “Continuity with GP would be welcomed. My son has a complex medical history and it would be much better and easier to see or talk to the same person as each time I have to briefly describe his medical history which is tricky. It can make it very difficult and I am therefore more reluctant to seek local help early on if there is a concern. We never see the same person in primary care.”
- “Communication between services so I don't have to repeat myself at every appointment and if it's not my usual person I see it'd be nice if they actually read our information so again I'm not repeatedly explaining the situation.”
- “Waiting times need to be improved for services such as mental health, (TaMHS, CAMHS) referrals for community paed are notoriously long. OTs have stopped providing services for sensory issues for ASC children. All of these are needed for our children for interventions which would prevent a number of them entering social care services or parents struggling to cope at home. Especially whilst waiting over 2 years for a diagnosis.”
- “More after school groups (not after school clubs) as not every parent can afford these but clubs with life skills provided.”
- “Better access to socialising outside of school.”
- “More Direct Payments hours to help support me taking my boys out in school holidays. It can be very lonely and isolating.”
- “Joined up working: i.e. seeing the child as a whole and how one thing impacts other aspects of the child's development etc. Currently each specialty only focusing on own area of child and not child as whole.”
- “Social care service is poor, not enough availability of staff to fully understand issues and no accountability within social care.”
- “Greater involvement of social care in assessments for [EHCPs](#) - they're not doing what they should. Better quality health involvement - not clear what benefit they add to an EHCP? Paediatric therapy appeared to stop on transfer to college.”
- “I want TaMHS to provide a better service. One that actually listens, does as they say they will and actually get back to us when they say they will!”
- “Staff that don't lie and try to fob you off for months. I think all appointments should be recorded so the professionals CANNOT lie about what was said and the parents have a leg to stand on.”

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Concern about transition from children's to adult services

- “Now my daughter is over 18, there is far less medical support. An adult version of a paediatrician for those with special needs should exist. Seeing your GP is not adequate as there is often not enough time and not enough available appointments. The GP does not know about rare conditions in any detail. You can't take your child to the Children's Ward at the hospital in an emergency, but have to take your chances with all regular adults in A&E.”
- “If there isn't funding then changes can't be implemented. My family are stuck between child and moving into adult services so we don't tend to get help needed and the buck gets passed constantly.”

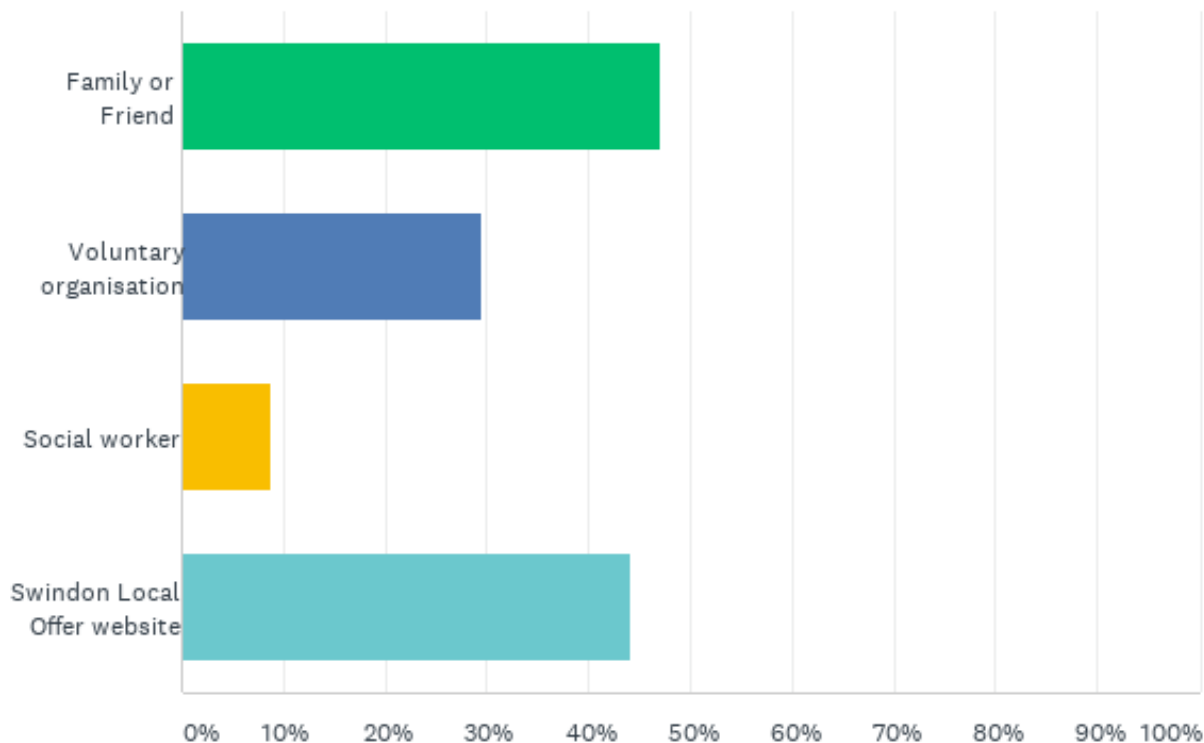


SEND event at STEAM – March 2019

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Where do people go for information?

We wanted to find out how familiar people are with the available sources of information about services and where they go to find out more. Many use the internet to search including [Swindon Local Offer](#); or Swindon SEND Families Voice, Swindon carers centre and “[SENDIASS](#) - Amazing service!”



“...Overall I just (wish) services in both health and social care wouldn’t keep forgetting her or having to wait so long for services...”

We asked what one thing would improve people’s health and wellbeing.

- “One?? Better child mental health services. Appropriate school placements for SEN children. For me? Not having to fight every step of the way to get my son the support he needs to cope and be happy.”
- “A school that really understood the implications of ASD and how to support the child. This would definitely help my child, but would also make my life much easier.”
- “For my son’s voice to be heard!! I feel it is a never-ending battle and that this gets lost in the process - even with bodies/professionals who should be listening as a matter of course.

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There always seems to be another agenda and if it is easier to blame the parent/carer then this is usually attempted!”

- “For me, some time, an hour maybe on my own. So a care provider who are trained and capable of looking after them. For my sons, socialisation. My eldest is so ready to play and engage but we have very rare opportunities to do so.”
- “More of understanding of his anxiety as the source for behaviours and group respite activities tailored to this.”
- “Improve mine would be the LA doing a good job and writing timely EHCPs in accordance with the law without me fighting for support all the time. Just do the job in line with law.”
- “More support to meet families in similar situations. As a full time working mum this is hard.”
- “Being listened to by 'professionals'.”
- “Someone to work with whole family.”
- “Better public transport from our home.”
- “Exercise. To lose weight for the both of us.”
- “Sleep for me, and my child who doesn't sleep well.”
- “Not have to worry about money and respite when needed.”
- “Respite care, I struggle with depression and this reflects on my children.”
- “More respite centres. Especially if Hop skip and jump are forced to close.”
- “More access to extra curricula activities outside of school for child and respite facilities.”
- “Access to free evening childcare to allow hubby and I time together. Faster access to mental health services for my child.”
- “For my health I would say more local parents' groups where parents/careers of children with disabilities can share experiences. Also talks with different health professionals where I could ask questions, learn more, understand more. Maybe an online portal as well... for parents. Especially work parents that can't go to the talks. Or do these talks during weekends too. And to improve my little one's health I would definitely say more special needs groups, special areas where he could develop his fine and gross motor skills, less waiting for appointments, more speech and language appointments... maybe something in a group? Maybe somewhere that parents don't need a referral and can bring their children to develop while having fun.”

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- “Play or art therapy for my child to help manage her emotions. She self-harms and we have no external support for this except privately, when we can afford it. This would improve our whole family life as perhaps we could help her regulate her emotions and have a happier home life.”
 - “Improved access to routine adult GP or nurse appointments would be welcomed. It’s difficult to plan 3-4 weeks in advance when you have a child with special needs. To improve the health and wellbeing of my child, more communication between GP, secondary and tertiary specialists would be welcomed. I would rather have contact with our local Swindon paediatrician rather than a London consultant in our tertiary care hospital as they are very difficult to get hold of and do not treat a child holistically as they are specialists. Local paediatricians are much better at seeing the bigger picture and understanding our needs, but we are not able to contact them in between appointments.”
 - “As a parent, I would like to get a one point of access to reach all workers associated with my child and to know that I am doing my best. For my child - I would like a committed professional to head their care/case, to get the right help at the right time aimed at their level and for that to be checked in on so they aren’t left to be alone, someone looks out for them.”
 - “For people to do their jobs, and properly, and listen to us parents. To show some empathy and understanding of what us parents deal with and impact on whole family.”
 - “My health and wellbeing would be improved by professionals working in partnership with us and being accountable (but this is more education than H &SC).”
 - “I feel I keep myself healthy through exercise and taking time for myself like doing yoga. I encourage my child to do the same and we do things together. But overall I just (wish) services in both health and social care wouldn’t keep forgetting her or having to wait so long for services. We were referred to the OT in sept 2019 (should have been done in May but the therapist forgot) still waiting for an appointment now. School referred to Educational Psychology end of September despite chasing appointment was not booked until after Easter which will now not take place due to school closures. By the time she is now seen by either of these services her needs will be totally different.”
 - “A class that suited his needs and age activity. Plus a meds or investigation into constantly eating never full scans blood tests something at least”
 - “Him being in school full time: been on reduced timetable since October 2018.”
 - “Support, understanding, information of what's available, honesty about process etc.”
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- “Help with our son to understand himself so he can cope without being so frustrated and having lots of meltdown moments.”
- “Face to face support (which is coming soon) for my daughter and a smooth transition.”
- “My son’s health and wellbeing would be improved by adequate funding for the services he uses.”
- “More of an understanding for friends about autism. Not just adults. But while school awareness.”
- “Greater access to medics with a shorter waiting time.”
- “Better communication with doctors, being able to book a doctor appointment and see a doctor within a week.”
- “Having a specified specialist doctor for your adult with special needs, not just the GP.”
- “For it to be made easier to stop/prove parental alienation.”
- “To have time to help independence to give them the chance to be treated like able people their ages do.”
- “I would like my daughter to be assessed for SEN but have found it difficult via my doctor.”
- “Being debt free would improve everything for me. My daughter just needs more time to heal and work on her feelings; my son needs to start counselling and we are currently on a waiting list.”
- “People that have the experience and time to understand the issues we face.”
- “Easier access to services when needed. More workshops or social groups for both adult and child.”
- “More inclusive activities and supported work, a week of quality respite care for carers.”
- “More easy appointment with doctors/hospital.” “Assessments being quicker and completed.”
- “Better self-help advice - having support from services that are available to provide interventions and advice that is useful and relevant to real at home situations.”
- “Offers of help and to be acknowledged without having to beg.”

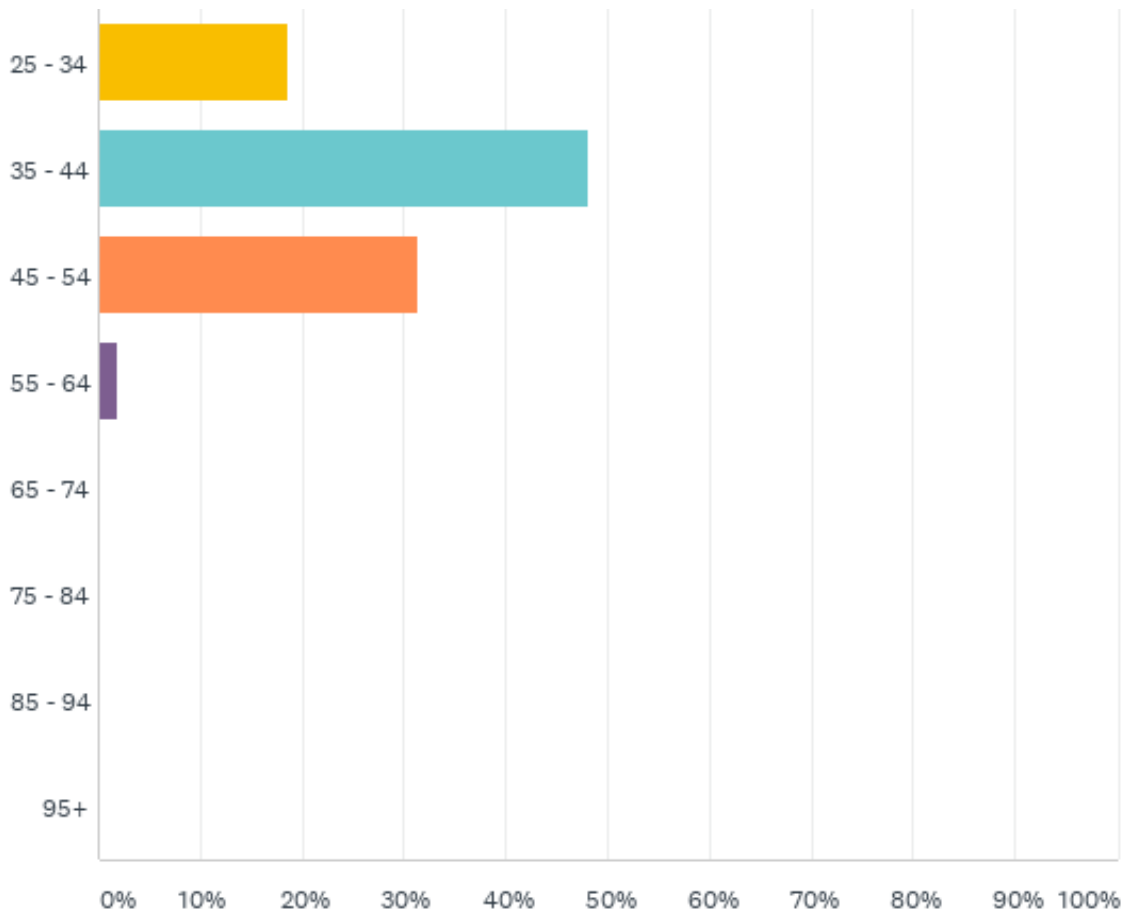
Swindon SEND Families Voice Survey Report

- “Me - I can improve by continuing to take time to plan; reflect; learn and adapt. Child - health is good - main concern is speech; wellbeing - the ability to communicate.”
- “Child - more specialised support for the trauma caused by years of being undiagnosed. We're dealing with the mental health problems caused by being refused services before we can properly support his needs.”
- “Ability to access GP easier and have consistent GP for my child as prolonged health issues and high pain threshold mean some don't believe him.”
- “TaMHS. They choose to ignore the mental well-being of my son. I have had countless conversations with them and school about his well-being, mental health and the behaviours to follow as a result of this. I am now on anti-depressants as I cannot cope and my mental health is deteriorating massively. This also effects his sister as she copies his behaviours.”
- “More support for help me to manage my child's behaviour would help both of us or teaching my child self-regulating skills.”
- “Mine-time away from my child to take some exercise.”
- “People who genuinely understand autistic masking and the toll this takes on him, therefore putting strategies in place to protect his emotional well-being.”
- “People who commission and run services listen to parents.”
- “To have a point of contact. We were just left to our own devices.”
- “Better understanding and not such a fight to get the right support in place.”
- “More understanding from the school setting (main stream) I'm made to feel like a bad mum and the villain in every situation or conversation.”
- “More access to services, not having to fight for it and it being more accessible for parents who are more isolated from being a SEND parent.”
- “Understanding more about Autism and differentiating between behavioural issues and normal teenage moods. Help with whole family understanding our children”

Swindon SEND Families Voice Survey Report

Who completed the survey?

Reflecting the role and reach of Swindon SEND Families Voice, most people completing the survey were aged between 25 and 54.



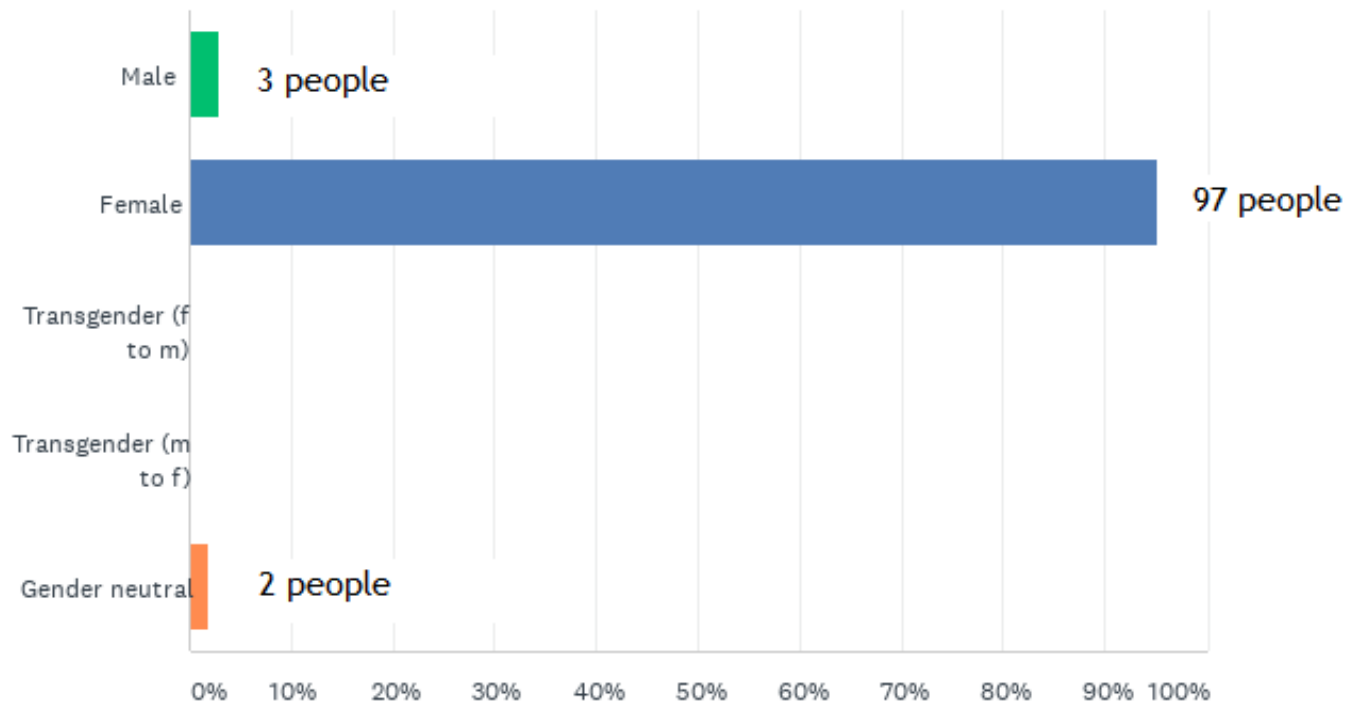
People living in SN postcodes completed the survey (though not all live within Swindon Borough) and the numbers reflect that they were self-selected.

SN7	1
SN26	1
SN1	8
SN6	8
SN4	9
SN5	10
SN2	17
SN25	21
SN3	25

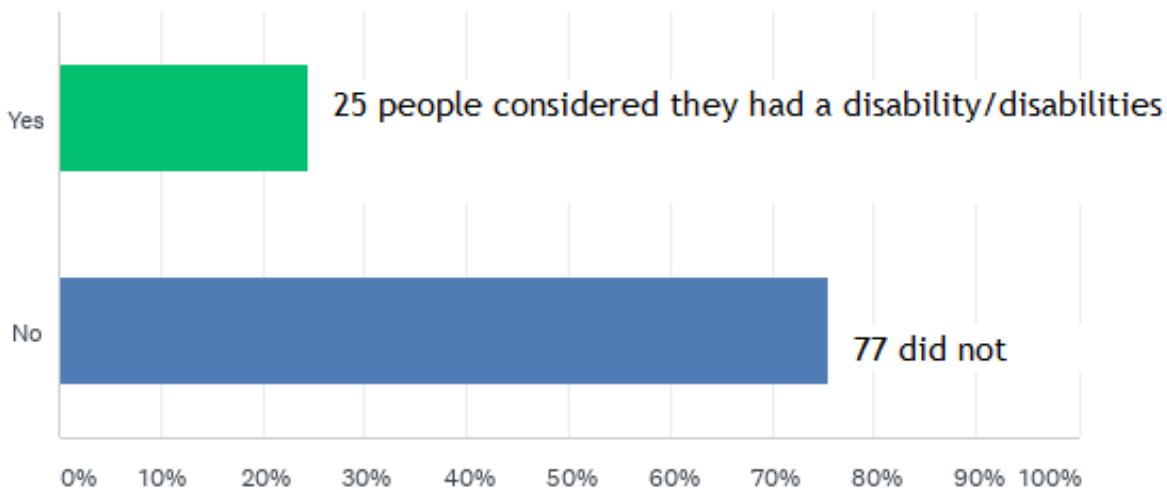
All but 5 identified as White/British. The five identified as British Arab, Islam, Irish, White/Other or mixed.

Swindon SEND Families Voice Survey Report

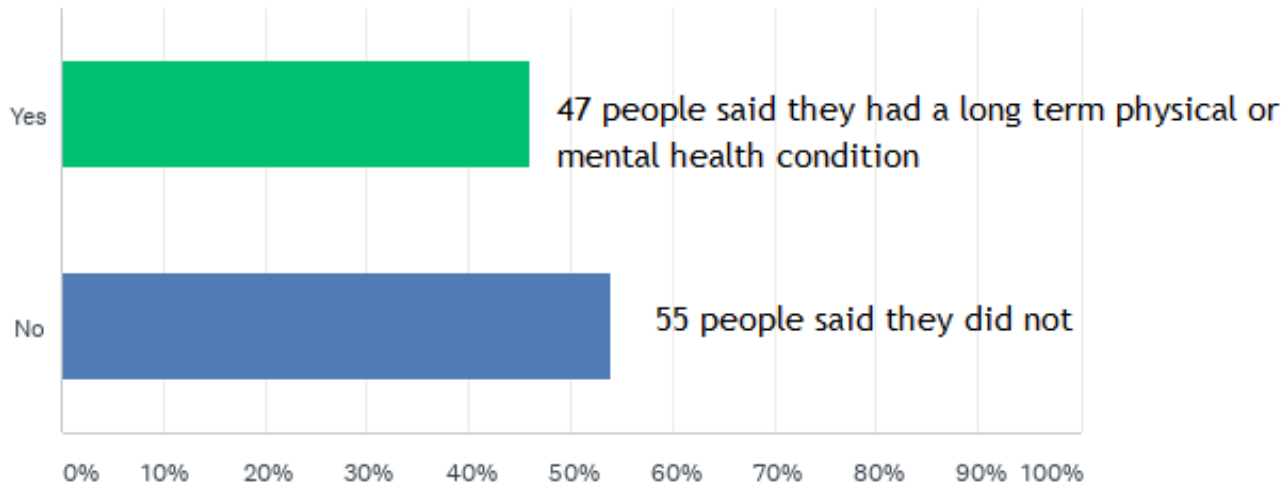
We asked people to identify their gender



We asked people if they (rather than their children) had any disabilities, physical or mental health conditions



Swindon SEND Families Voice Survey Report



Of the 47 people, 23 said they experienced depression, anxiety or a mental health condition. Others included asthma (7), fibromyalgia (6), diabetes and a range of other conditions.

Ten respondents gave us their contact details to follow up specific queries or comments.

Conclusions

- The survey confirmed the need for consistent assessment, provision of services and communications which are timely, well understood and seen to be fairly applied.
- The endnote from Swindon SEND Families Voice news (below), links to the latest information from Swindon Borough Council and the clinical commissioning group.

We would like to thank Swindon SEND Families Voice for supporting this piece of work and their contacts for sharing their views with us.

Swindon SEND Families Voice news

30 July 2020

“Statement from Jo Godwin the Interim SEND Lead at Swindon Borough Council: “In 2018 following the SEND Local Area inspection, Swindon were required to produce a Written Statement of Action (WSOA) outlining the improvements that needed to be made against the 8 priority areas in SEND. We would like to share with you the progress that has been made so far. Whilst we still have a way to go, we hope that sharing with you some of the impacts seen so far will provide assurance of the work that is happening in co-production with key partners including Swindon SEND Families Voice to make positive changes for our children and young people with SEND.” [WSOA Progress July 2020](#)

16 July

“We have received lots of feedback where you have expressed your concern over the effect of the Coronavirus on the waiting times for the ASD/ADHD diagnosis. We shared these concerns and asked the CCG (who manage the process) if they could update us on the numbers waiting, and what they are doing to combat the additional delays Covid-19 has had on the list. For their response, including the latest figures please click here: [NDC Waiting List Update June 2020](#)