

LISTENing

Glossop in conversation with families about SEND:

- What things matters most to families?
- What things would make a difference for families?
- What's important right here, right now?

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Report Compiled by

**Maria McCaffrey Independent Consultant &
Philippa Robinson NHS Tameside and Glossop CCG Children’s Commissioning
Development Manager**

With thanks to Lisa Hodgson Derbyshire Parent Carer Voice Co-ordinator

Report Overview

This report reflects information about and findings from a survey commissioned by the SEND Improvement Group reaching out to families in Glossop where a child or young person 0-25 years has special educational needs and/or a disability and is in receipt of health support commissioned by Tameside and Glossop CCG.

Working collaboratively with a small group of parents, a survey questionnaire was developed with the aim of gathering data and information about the lived experiences of families and suggestions on how SEND services might be improved.

The survey received responses from a total of **30** families and two thirds (**19**) of these families had a child with and Education Health & Care plan. Headline findings reveal high levels of dissatisfaction from families about not knowing where to get help when they first needed it; not receiving support at the right time and a lack of regular updates on their child's progress and development.

Families cite frequent examples of having to **'fight'** and **'struggle'** for their concerns about their child to be heard and long waiting times for assessment and therapies when support is finally provided.

A summary of next step action points is suggested by families which include:

- Promoting a culture of listening to and collaborating with families
- Consideration about locally Glossop based support including early help, ongoing and post-diagnostic support
- Improving the available communication methods for signposting Glossop families to Tameside based health support.
- Maintain regular and routine communication with parents about child's progress
- Prepare and plan for greater involvement of families in person-centred meetings
- Improve waiting time for therapies
- Involving parents and young people in early transition planning meetings

The report recommends that the above suggestions and overall survey findings are used by the SEND Improvement Group to influence and shape changes in the planning and delivery of SEND Integrated support and services immediately and going forward.

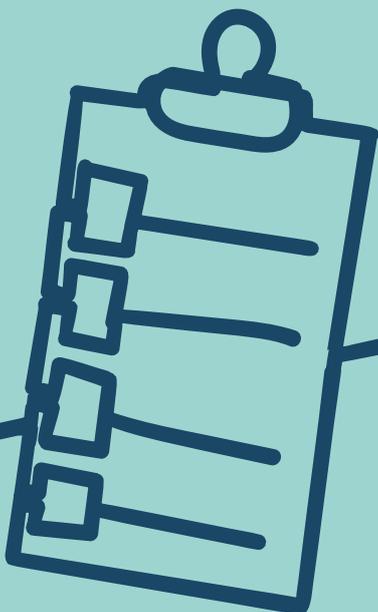


1. Introduction and Purpose

The SEND (Special Educational Needs and Disabilities) Improvement Group in Tameside is made up of senior leaders and planners representing Education, Health and Care services in Tameside and Health services for Glossop.

In July 2020 the group requested an independent consultant to carry out a piece of work to help them better understand and plan for SEND services and support to be more joined up across the borough. As part of this piece of work parents and carers were invited to complete a survey monkey questionnaire asking for information about their lived experience of SEND support from across the joined-up services of education health and care. Families were also invited to give their views on and provide suggestions about what things could be done differently in order to improve their experience of services and support.

The survey opened on Monday 21st September **for three weeks** until Friday 9th October.



2. Consultation Process

In July 2020 the consultant met with a small group of managers who oversee the SEN service and the integrated health and care services for children with additional needs (ISCAN) in Tameside in order to plan how best to reach and engage with the greatest span of parents/carers across Tameside and Glossop.

This focus group of professionals had already experienced a lengthy period of working during Covid-19 lockdown restrictions and knew that the usual ways of reaching out to families was challenged because of these restrictions.

Contact was made with Derbyshire Parent Carer Voice Co-ordinator who agreed to co-ordinate the survey monkey in order to reach out to parents' resident in Glossop and in receipt of health services and support as part of the Tameside and Glossop offer.

Throughout August 2020, a series of discussions took place (virtually and telephone) involving parent's carers and professionals in order to develop, draft, re-draft and road-test the survey questions so that they reflected the best collaborative effort of all involved.

The process and resulting reports were supported and overseen by the expertise and collaborative efforts of two officers in Tameside Policy and Strategy and Commissioning teams in TMBC and CCG.

3. Methodology/Approach

Working in collaboration with Derbyshire Parent/Carer Voice, the organisation's 346 members were emailed the survey link and it was also posted on Derbyshire SEND Local Offer. Social media platforms such as Facebook (closed parent carer groups), twitter and Instagram were also used to promote the survey link amongst the SEND parent carer community of Glossop.

The survey asked a total of 10 open and closed questions requiring responses that would elicit a range of qualitative and quantitative data and information. Additional question options were given to enable respondents to expand on or qualify their responses.

The survey also asked some supplementary questions about demographics and gave parents the option of describing their child's disability or additional need.



4. Key Findings

A total of 30 responses to the survey were received over the three-week period.

80% of the responses related to children between the ages of 7 and 16 years.

19 families (**63%**) identified that there was a child/young person with an Education Health & Care Plan (EHCP) in place. More detailed demographic data can be found in Appendix 2

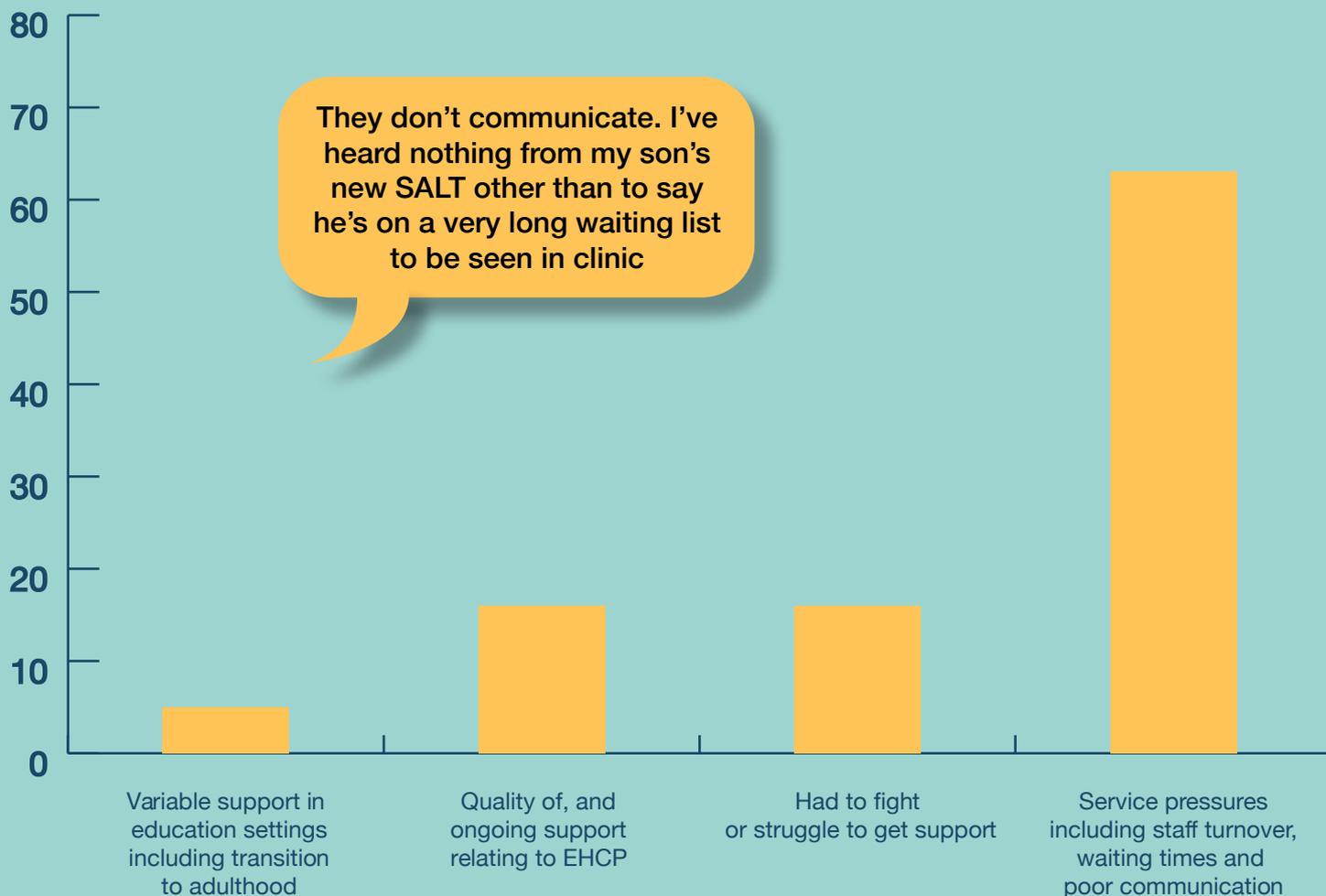
Parent responses to the option of describing their child's disability or additional needs identified Autism (**52%**), Speech, language and communication needs (**48%**), Behavioural, emotional or social issues (**37%**), physical disability or mobility issues (**33%**) and ADHD/ADD (**26%**)

Respondents identified that the services which their responses related most to were:

- ISCAN Health Rowan House **55%**
- Health **22%**
- **Other** responses included Healthy Young Minds, Adult Autism Team and Speech and Language Therapy.

Have you felt supported by professionals in your child's care?

Around half of the families (48%) said **Yes** and the other half said **No (52%)**. The main reasons given for not feeling supported included waiting times, poor communication from professionals and having to 'fight and struggle' to get support.



Lack of support, communication and even advice. Just left to it after diagnosis and ehcp. Paid privately for OT as they didnt assess for sensory issues

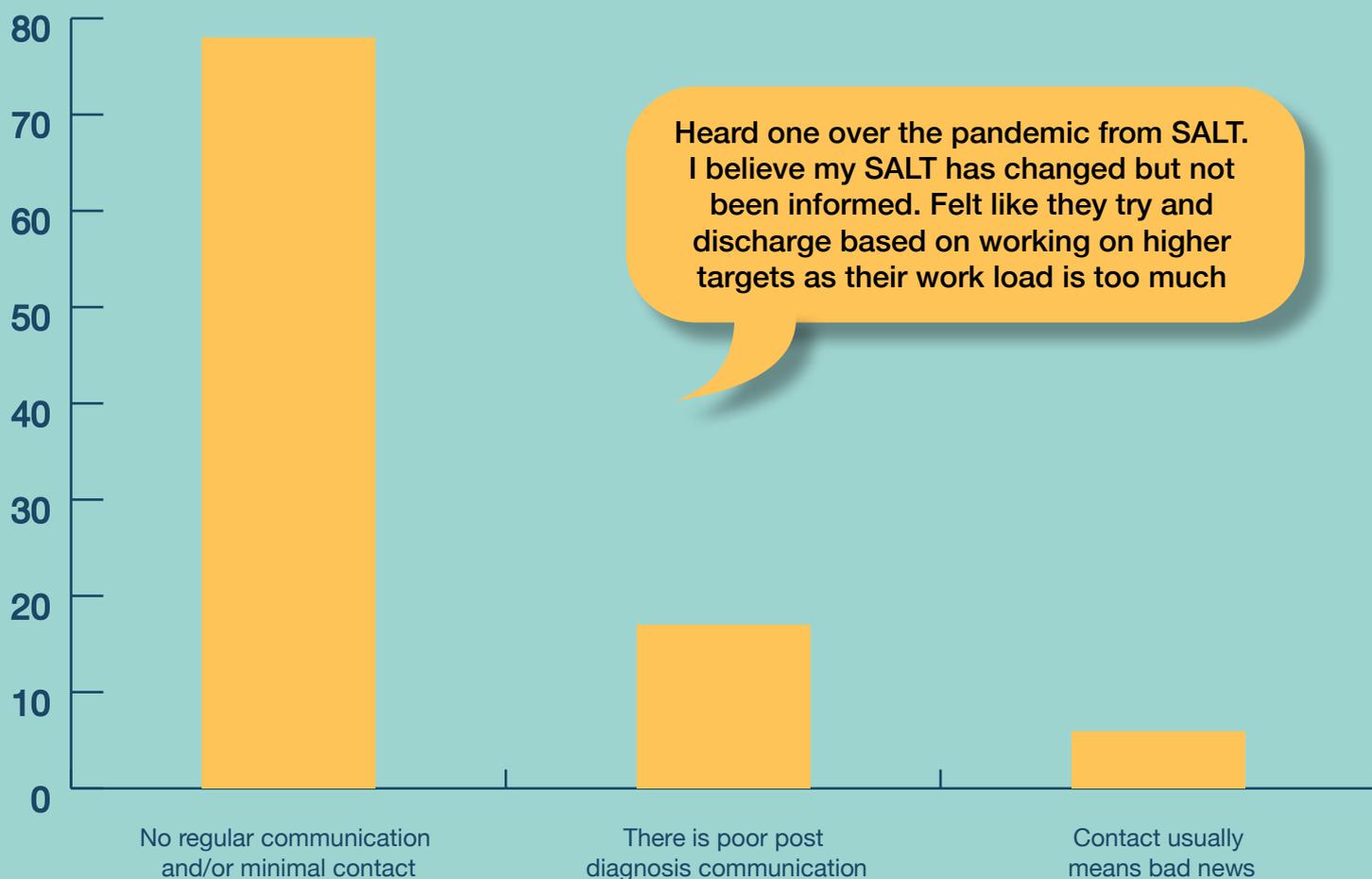
Long waiting lists. Had referrals refused due to understanding. Been treated like a bad parent I.e. being told to "sing more nursery rhymes" to a child aged 4 non verbal as if its somehow the parents fault

It took 10 yrs for my GP to refer to paed's despite concerns raised for 5 yrs

Do you have regular updates with professionals involved in your child's care?

53% of families said that they had regular updates from professionals and 47% said **they had not**.

Reasons for this are categorised below.



Heard one over the pandemic from SALT. I believe my SALT has changed but not been informed. Felt like they try and discharge based on working on higher targets as their work load is too much

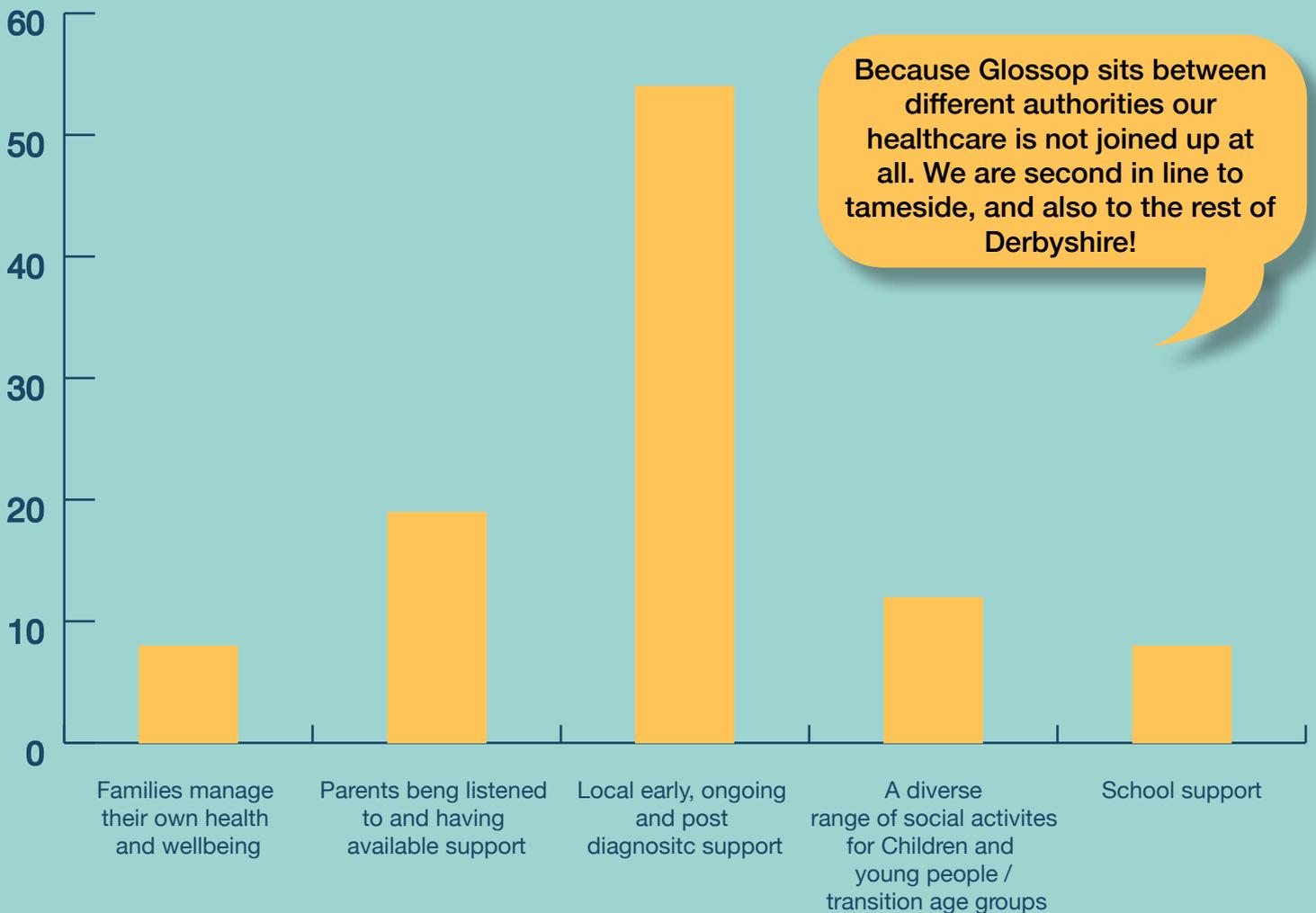
Got his autism diagnosis in April 2019, no support from them as soon as he got the diagnosis they took him off their books

We only get a service if there are problems. We have no annual reviews. It is a deficit medical based mod

I can't access Derbyshire services because of coming under Tameside Health

What things might help improve the health and wellbeing for your child and your whole family?

Suggested improvements given by families from **26** responses related to **parents being listened to** about their child's needs, having **more local ongoing and post diagnostic support** for their children, and **increased support available to parents**.



Because Glossop sits between different authorities our healthcare is not joined up at all. We are second in line to tameside, and also to the rest of Derbyshire!

Speech and language, play therapy and social skills training. There is a massive gap for help with more able people with ASD/C. If they manage academically with the help of an EHCP then their other needs are not really met, particularly if they are fairly well behaved at school

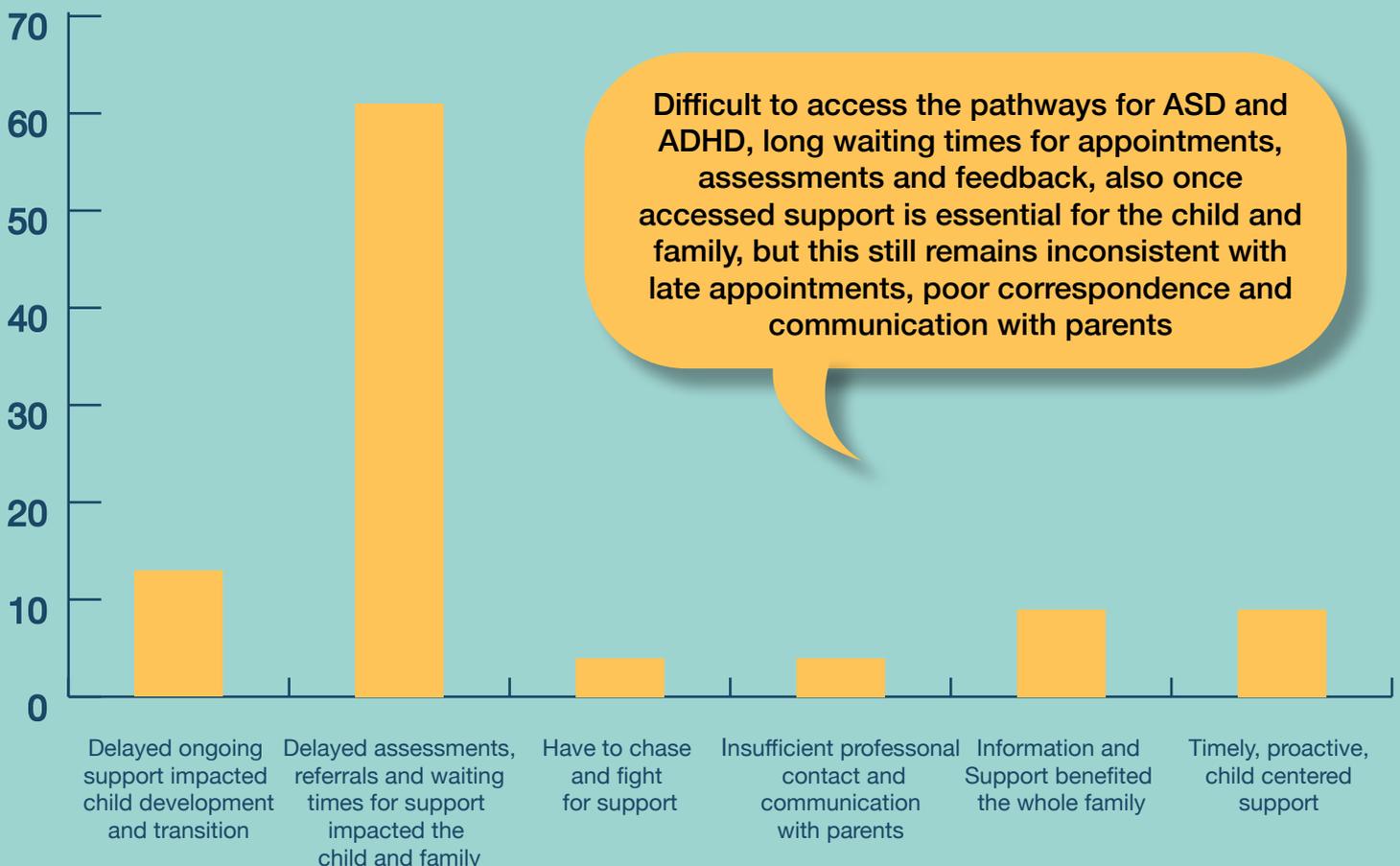
A clear map of the process and timescales so we know how long we will have to wait to receive any support/ diagnosis/treatment

More local support as it's a long way to travel

Based on your experience, was the support you received available at the right time for you and your child?

Out of the responses, **60%** of families said the support was not available at the right time, with delays to assessments, referrals and waiting times being the biggest factor. **40%** of families said the support they received was timely, proactive and child centred, and the information and support benefitted the whole family.

The reasons given for both responses are summarised below.



We had to fight tooth and nail for a referral. The referrals were then 'lost' three times. We waited almost four years in total to receive a non diagnosis due to lack of evidence despite the evidence being provided it just was not used!

Not at all. The waiting list for some services is ridiculously long and the criteria to access these services is too rigid

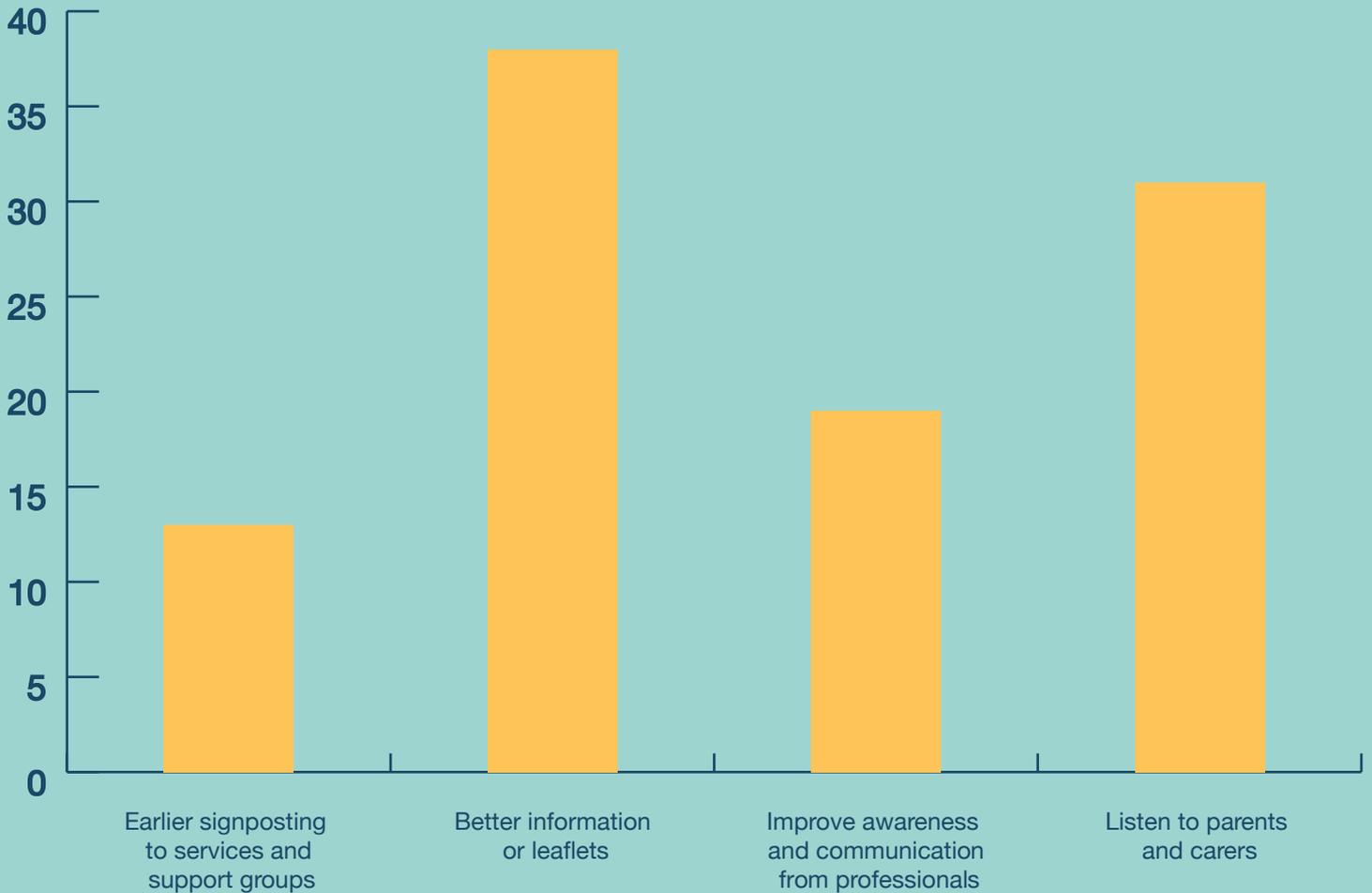
Waited 18 months for physio. 9 months for podiatry. Still waiting to see occupational therapist

When you first needed advice and support about your child's needs, did you know where to go and get help?

In response to this question **just over half** of families said they did not know where to go and get help and **just under half did**. The table below summarises the sources that helped to signpost, ISCAN Health Rowan House made up **half the responses**, while **other** responses included Healthy Young Minds, Adult Autism Team and Speech and Language Therapy.

Answer Choices	Responses
Local Offer	10.53% 2
A Friend/Family Member	15.79% 3
Health Care or Other Professional	42.11% 8
School	15.79% 3
Newspaper	0.00% 0
Derbyshire Parent Carer Voice	0.00% 0
Other (please specify)	31.58% 6
Total Respondents: 19	

A supplementary question inviting families to make suggestions on how things could have been different to make things easier when they first needed advice and support elicited responses summarised in Table 2 below. Parents said they wanted to be **listened to** and have **access to better information**



Signpost to charities/Facebook groups for support

Glossop and tameside are part of a national trial to get schools to do camhs referrals. This relies heavily on schools 'seeing' any issues and actually submitting evidence and forms. For children who mask in school this is not appropriate

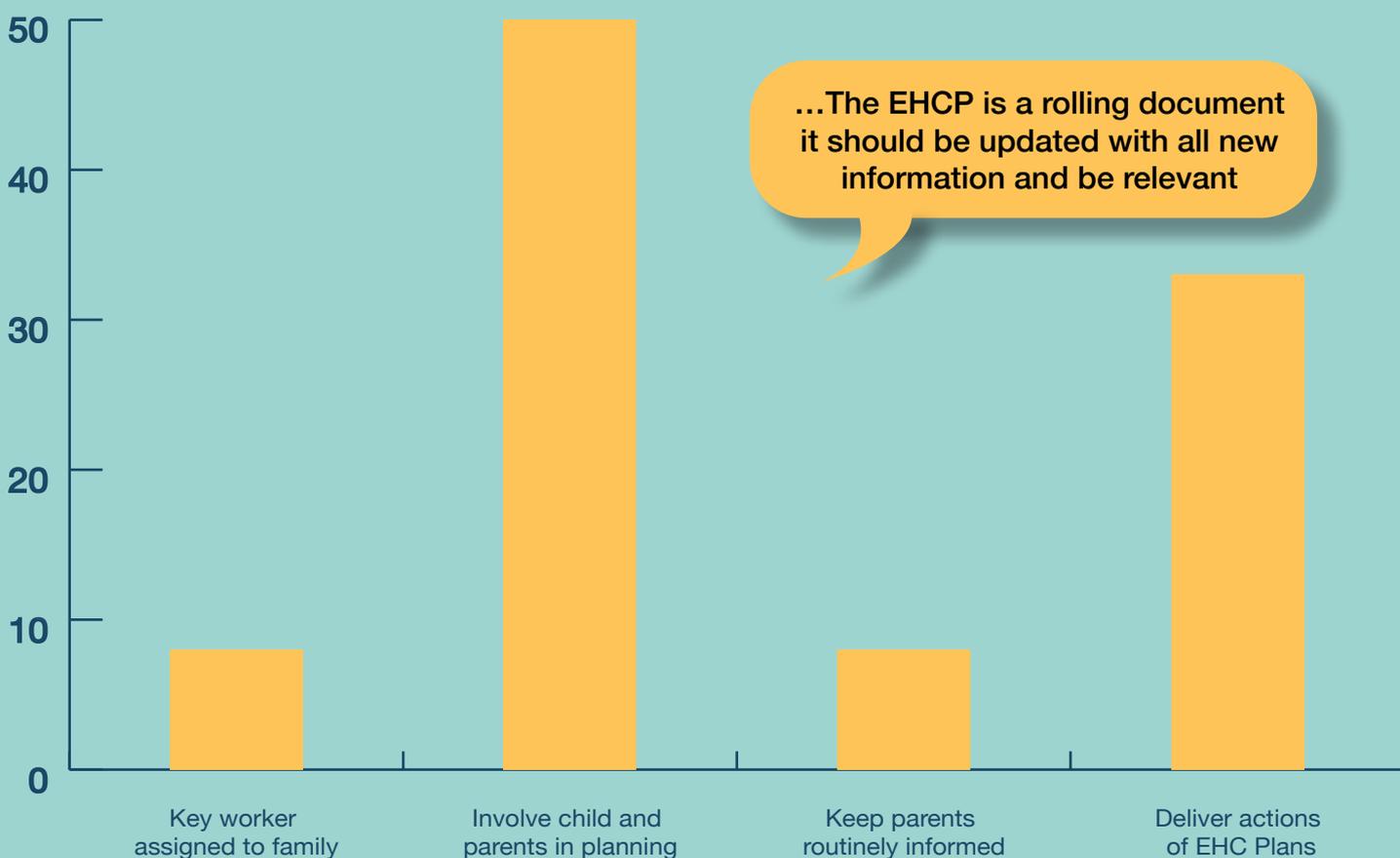
There is lots of advice on the website, actually gaining support from the service is a different scenario. You obviously have to meet certain criteria to have access to the service

Make services actually available! Even school struggles to get help.

In your journey so far, have you had the opportunity to be involved in plans (for example SEN support/EHC/Transition) to improve the quality of life for your child and family in the future?

Around three quarters of families said that they had the opportunity to be involved in plans, and **around a quarter** said they hadn't.

Families who said they had not had the opportunity to be involved made some suggestions on how things could have been planned differently for them. Communication and involvement of families in planning processes were strong themes to emerge as well as implementation of actions within EHCPs and key worker roles.



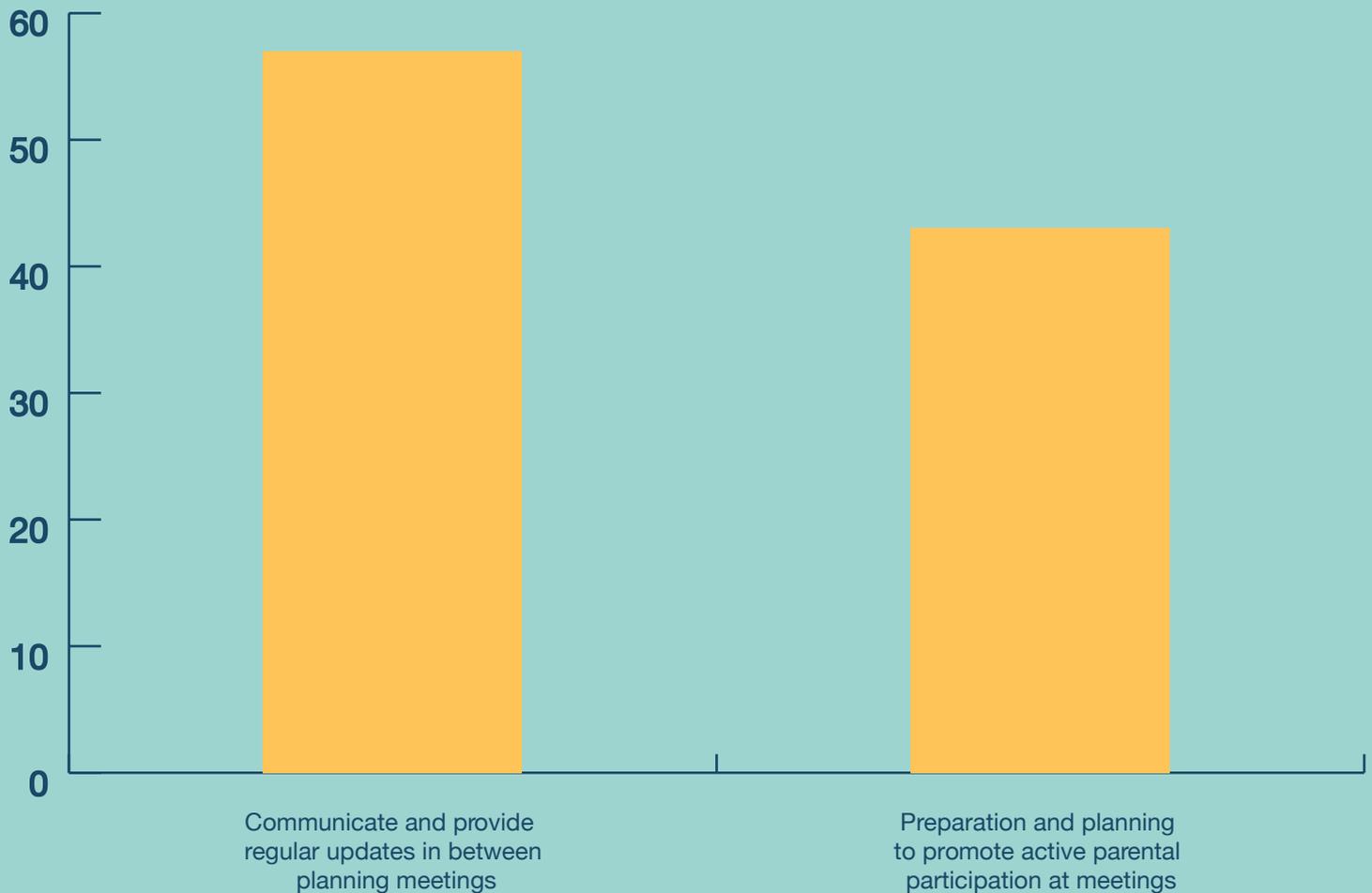
...The EHCP is a rolling document it should be updated with all new information and be relevant

Despite being involved in health plans and various surveys, none of them ever actually change anything. They just pay lip service to the parents and professionals who actually want to change things

The EHCP should have SMART Targets, they do not address who will do the support, where this should happen and how often. They use vague statements such as use strategies but not what these are, when and how often this should happen. who should use them etc.

What could we do to make you feel more included in future planning for your family?

When asked about what could help them feel more included in planning, the most prominent themes from families were **communication** and **regular updates** in between planning meetings followed by supporting with preparation and planning for **active participation** at meetings.



Tell us about services. Ask us what we need. We are always fighting for our children

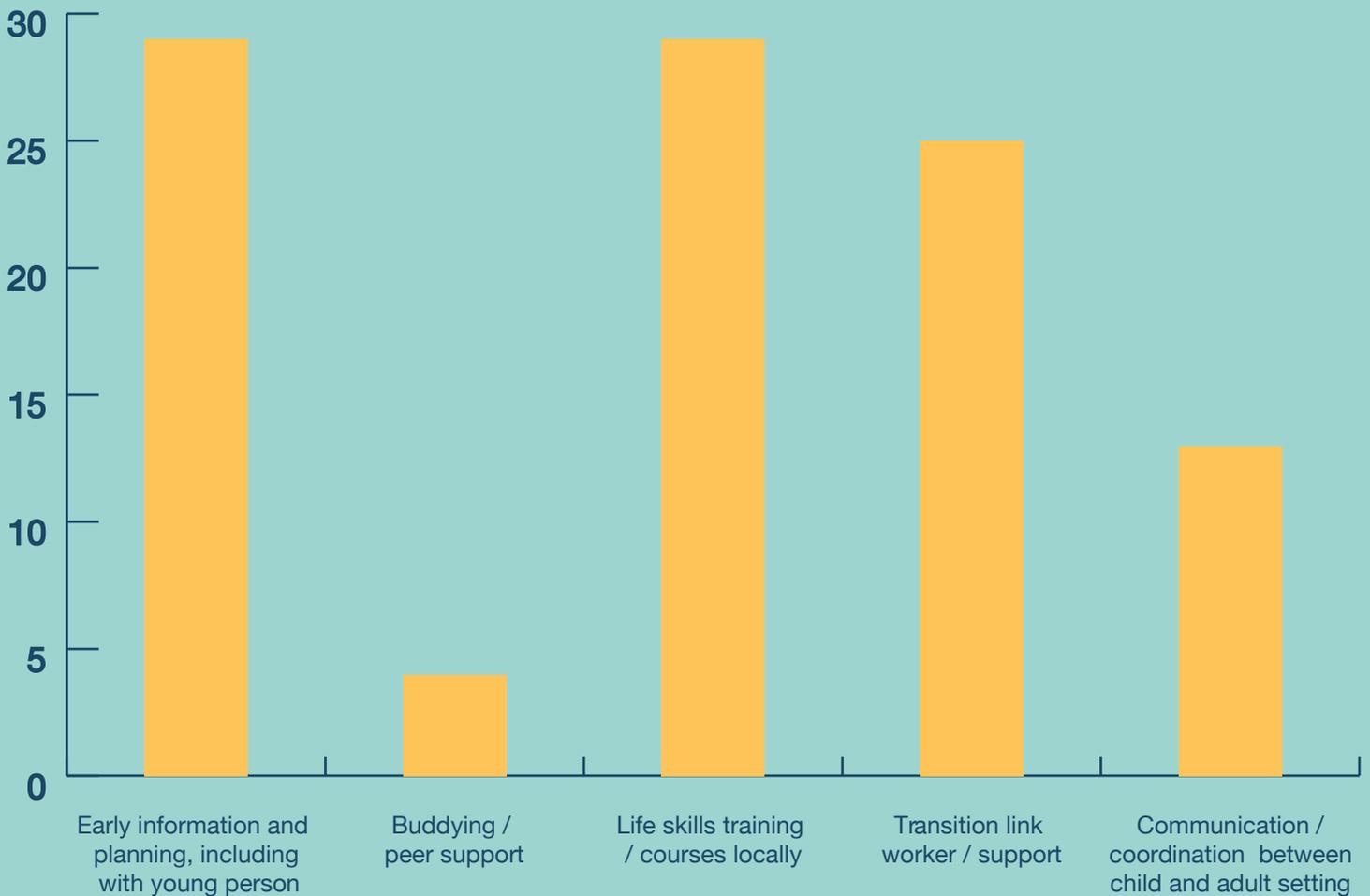
Being involved in meetings, asking my views, consistency between tameside and Glossop healthcare. Services differ but under same health authority

Our kids are not a burden to your service we need support, signposting and an advocate for us as a family of a child with SEND

To feel supported and believed and not blamed

What do you feel would best help to prepare your child and your family for the transition to young adulthood?

Over half of these responses related to themes of early transition planning; inclusion of young people; a link worker to facilitate and support families; and **around a third** of families wanted to see more life skills opportunities locally.



I think it would be great for someone to guide you through the process including assistance in the various forms to be completed & be knowledgeable in this field. Advising of what you're entitled to & how to obtain help & assistance going forward. This would reduce stress.

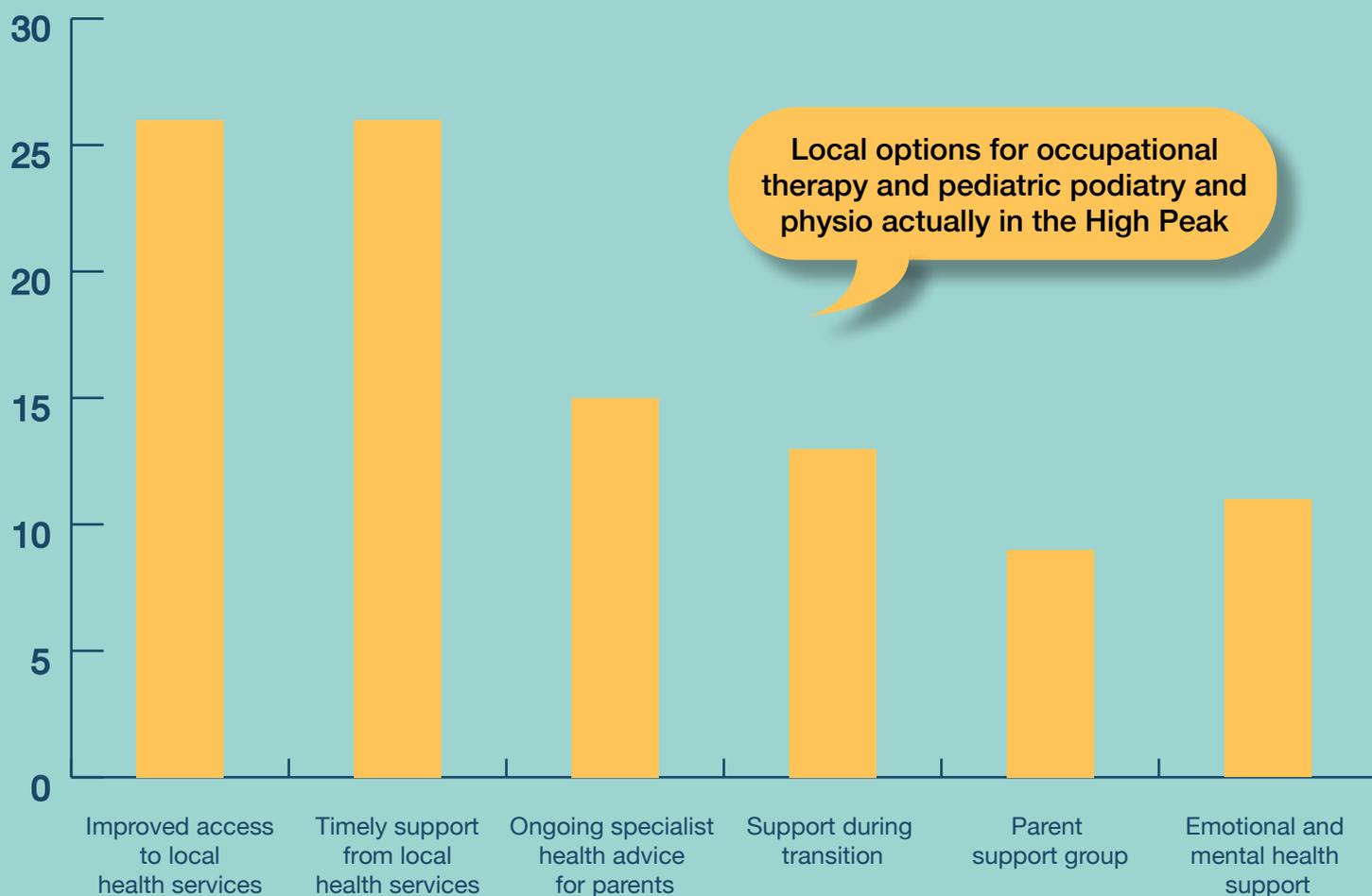
Transitional sessions. More life skills support. An education system that promotes these life skills rather than worrying about levels and scale scores. A focus more on what will make the child succeed as an independent adult than can they do algebra etc. A bespoke plan rather than a standardised plan with the odd tweaks.

More local facilities available, so that travel could be reduced to a minimum

The final question of the survey asked families to consider their circumstances in relation to the immediate future and identify **three areas of support** that might make the biggest difference in the immediate future for their child and family?

The top three identified areas were summarised as

- **Improved access to local health services**
- **Timely support from local health service**
- **Ongoing specialist health advice for parents**



Understanding what to do if anything happens.

Help with sleep issues

Access to assessment and clearly marked pathways in order to prevent time wasting.

5. Summary Key Messages

The findings and key messages from this survey provide Tameside and Glossop CCG and SEND Improvement Group with a body of evidence and information from the lived experience of those in receipt of ISCAN (Health) and other health-based services in Tameside such as HYMS. The survey findings provide some raw data about the parent perspective on timeliness and quality levels of available SEND support for young people and families and reveal that:

- **52%** of parents carers report feeling unsupported
- **47%** of parent carers report not receiving regular updates from professionals
- **57%** of parent carers report not receiving support at the right time
- **53%** of parent carers report not knowing where to get help when they first needed it
- **77%** of parent carers report having had the opportunity to be involved in plans for their child

Common themes arising from responses by parents expressing dissatisfaction within all of the above question areas relate to:

- Poor (irregular and infrequent) communication from professionals
- Waiting times for assessment and post diagnostic health support
- A lack of involvement in meetings and plans

In a significant proportion of responses, the terms **'fight'** and **'struggle'** are referred to as parents lived experience.

What things matter most to families?

Information and testimonials reflecting the lived experience of families illustrate a story denoting the very best of professional multi-agency practices and associated positive family satisfaction.



What things could make a difference for Families?



6. Summary areas for action

Suggested improvements for the future from family respondents are summarised as:

- Promote a **culture of listening** to and collaborating with families
- **Local support** including early help, ongoing and post-diagnostic support
- Improve the available communication methods for promoting and **sign-posting** Glossop families to Tameside based health support
- Maintain **regular and routine communication** with parents about child's progress; family wellbeing; waiting times; available post-diagnostic support; involvement in meetings; plans
- Preparation and planning for greater involvement of families in **person-centred planning**
- Improve **waiting times** for therapies and/or review how they are delivered to families
- **Early transition planning** including parents and young people in meetings; key worker/peer support; introductory conversations between child and adult settings.



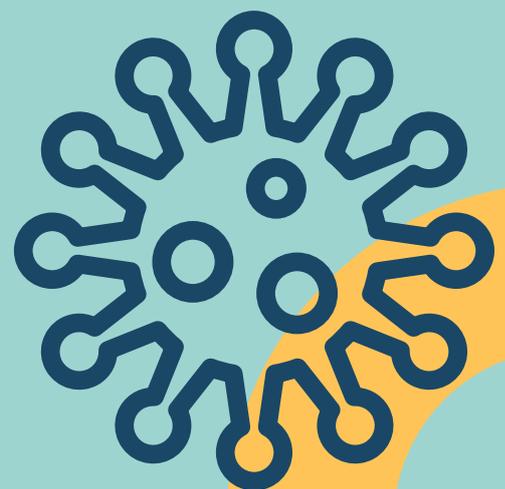
The top three areas of support identified by parents as making the biggest difference in the immediate future for their child and family are summarised as:

- Improved access to local health services
- Timely support from local health services
- Ongoing specialist health advice for parents.

Covid – 19 Lockdown Messages

The impact of Covid-19 lockdown restriction featured in a significant proportion of survey responses. Family responses shared a common theme of isolation and a sense of abandonment during the lock-down period. Suggestions for how this could be improved included:

- The availability of a crisis helpline for parents
- Regular safe and well telephone calls/ messages from professionals to families.



7. Recommended next steps

- This report is delivered to and discussed by the SEND Improvement Group, in conjunction with the survey report for Tameside (Appendix 1)
- The findings from the Glossop survey are shared with Derbyshire Parent Carer Voice and Derbyshire County Council SEN lead
- The findings from the Tameside and Glossop surveys are utilised to shape and inform SEND integration plans going forward
- The findings from this survey are used to influence changes and improvement to SEND in key areas
- The SEND Improvement Group to provide written and publicised feedback on next step actions to all families in Tameside and Glossop who participated in this survey
- The SEND Improvement Group to formally thank Derbyshire Parent Carer Voice for undertaking the Glossop survey on their behalf.



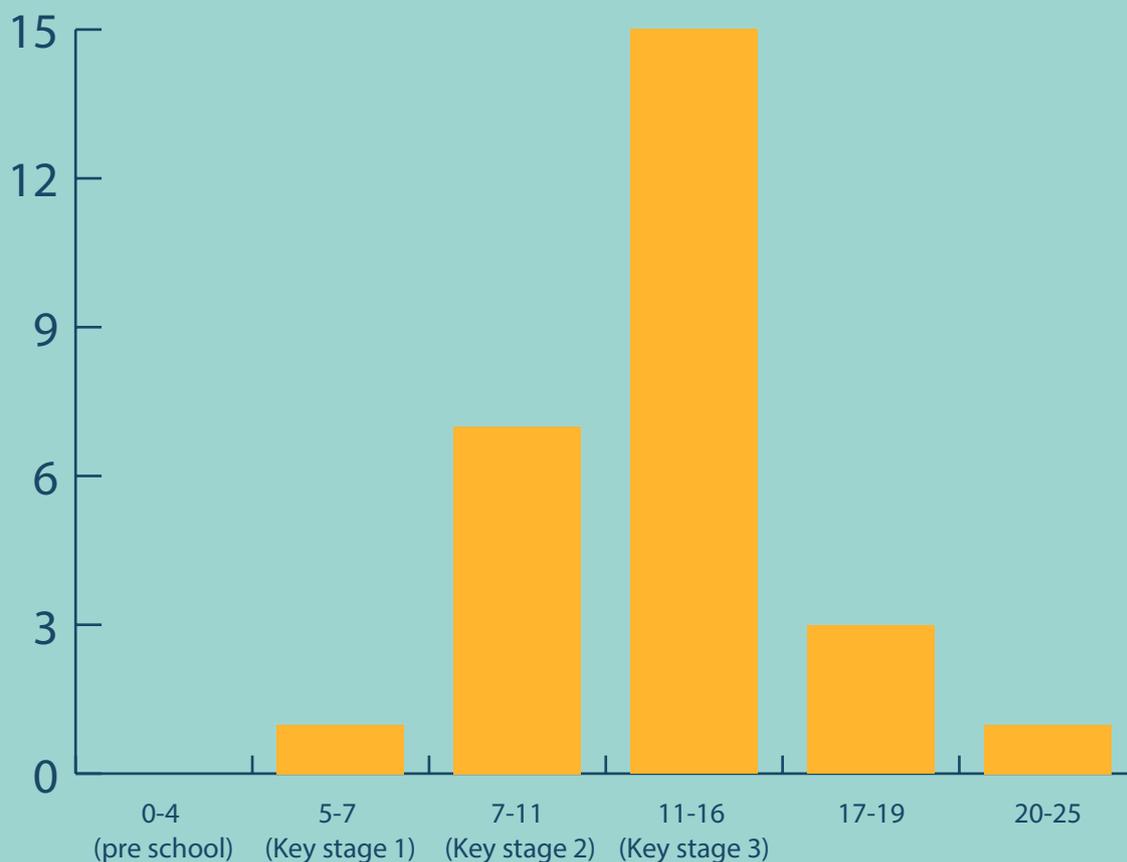
8. Appendices

Appendix 1

Demographic Data from the Glossop SEND Survey

What is your child's age?

Answer Choices	Responses
0-4 (pre school)	0.00% 0
5-7 (Key stage 1)	3.70% 1
7-11 (Key stage 2)	25.93% 7
11-16 (Key stage 3)	55.56% 15
17-19	11.11% 3
20-25	3.70% 1
Answered:	27
Skipped:	3



How would you describe your child's disability or additional needs?

Answer Choices	Responses	
ADHD/ADD	25.93%	7
Multi Sensory Impairment (vision & hearing)	11.11%	3
Down Syndrome	0%	0
Autistic Spectrum Disorder	51.85%	14
Physical Disability/Mobility Issues	33.33%	9
Visual Impairment	11.11%	3
Behavioural Emotional or Social Difficulties	37.04%	10
Profound and Multiple Learning Difficulties	22.22%	6
Specific Learning Difficulty e.g. Dyslexia	3.70%	1
Speech, Language & Communication Needs	7.41%	2
Hearing Impairment	25.93%	7
Severe Learning Difficulty	48.15%	13
Medical Needs or Long Term Illness	14.81%	4
Mental Health Difficulties	18.52%	5
Moderate Learning Difficulties	0.00%	0
Waiting for diagnosis	11.11%	3
Other (please specify)	22.22%	6
Answered:	27	
Skipped:	3	

Other responses:

- Sensory processing disorder.
- Rare mitochondrial disease. Also affects heart neuro muscular disease progressive.
- Why on earth isn't dyspraxia on the list? It is so upsetting you have not even listed it.
- Son feels may have autism of a kind but not been assessed. No knowledge of how to be assessed
- I have more than one child with needs, the question needs to be updated so I can tick more than one age bracket.
- Sensory Processing.



