

# LISTENing

## Tameside in conversation with families about SEND:

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

Thanks to parents Emma, Sandra, Mandy, Hannah, Holly for all their expert insight and overview of this process

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# Report Overview

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

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 **320** families and over half (**178**) of these families had a child who was supported by an 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
- Improving the available communication methods for signposting families
- Maintain regular and routine communication with parents about child's progress
- Prepare and plan for greater involvement of families in person-centred meetings
- Facilitate a range of respite support for families
- Extending the range of social activities for children with different disabilities
- 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.

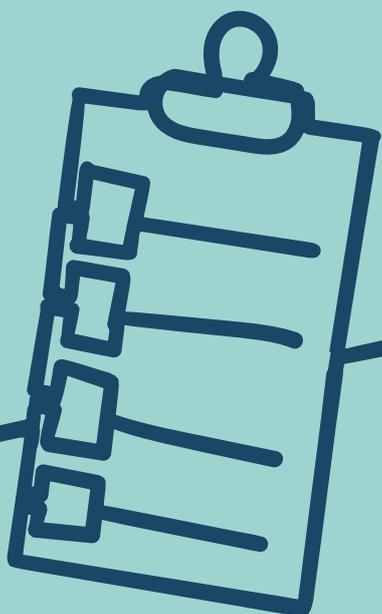


# 1. Introduction and Purpose

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 changes that could be made 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 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.

It was agreed that advice should be sought from the local parent carer forum (OKE) and other groups of parent carers known to services, about the best way to reach out to the wider SEND community of parents/carers during Covid-19 restrictions.

Contact was made by the consultant with parents in receipt of support from ISCAN (Health) and they subsequently offered their time and experience to co-produce a survey monkey questionnaire in collaboration with OKE parent carer members and a parent representative from Glossop.

Contact was also 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 the Policy and Strategy and Commissioning teams in TMBC and CCG.

# 3. Methodology/Results

It was agreed that in order to reach as wide a breadth of parent/carers beyond those already known to the parent carer group (OKE) and/or other organised parent carer groups, a range of contact methods and places should be used.

A distribution list (Appendix 1) was subsequently drawn up which identified lead people tasked with informing parents/carers about the survey and signposting them to it place on the Local Offer landing page in Tameside and Derbyshire. This list ensured coverage of parents/carers involved with Early Years; Early Help; ISCAN; Schools; SEN (Special Educational Needs) Service; General Practice; Community Paediatrics and Healthy Young Minds (HYMS).

A letter (Appendix 2) was produced on behalf of the Chair of the SEND Improvement Group requesting co-operation from all partners across Education Health and Care in Tameside to promote the survey link to families within their services.

For parents/carers living in Glossop, Derbyshire Parent/Carer Voice emailed the survey link to their 346 members.

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 Tameside and 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 **320** responses to the survey were received over the three-week period. **60%** of these related to male children in families. **60%** of the responses related to children between the ages of 7 and 14 years.

**178** families (**55%**) identified that there was a child/young person with an Education Health & Care Plan (EHCP) in place.

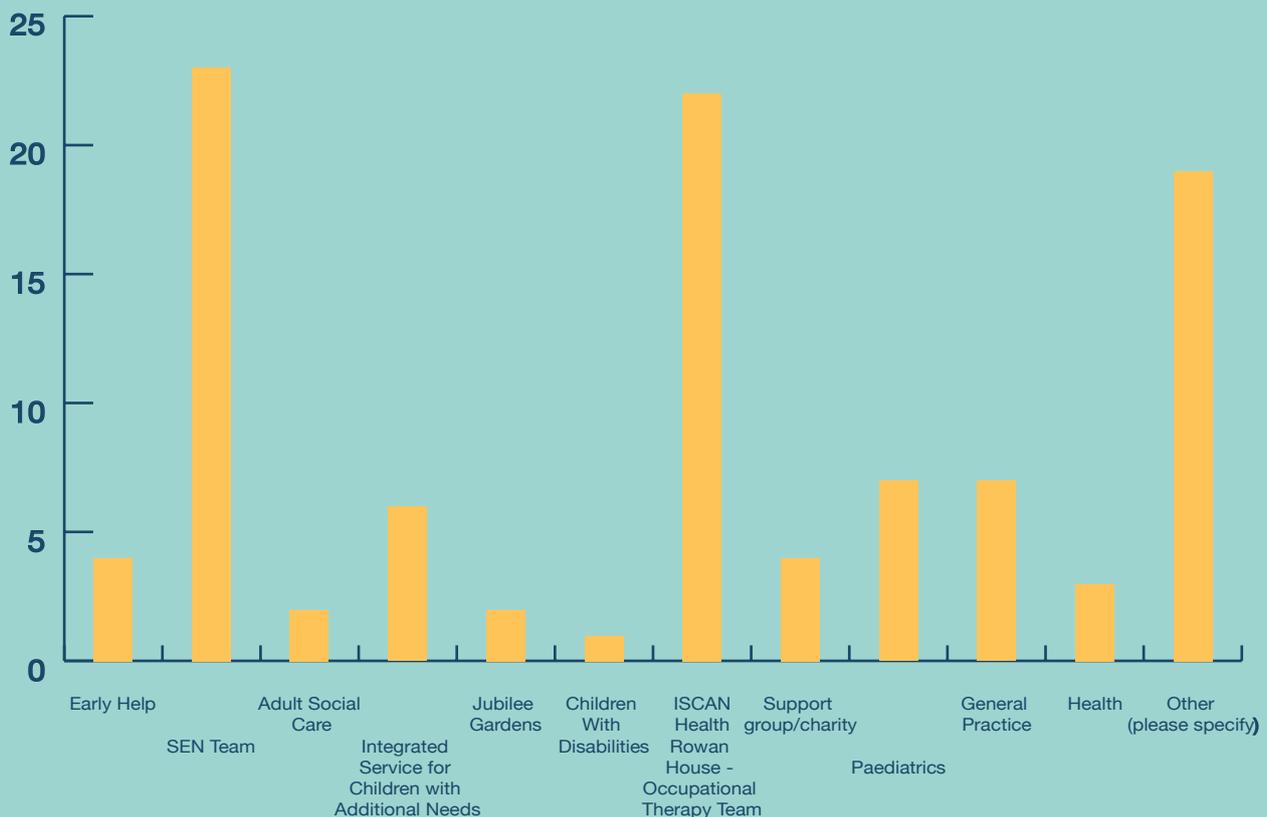
More detailed demographic data can be found in Appendix 4

Parent responses to the option of describing their child’s disability or additional needs Autism (**44%**), Behavioural, emotional or social issues (**43%**), ADHD/ADD (**31%**), and Speech, language and communication needs (**35%**).

Of those who responded to a question about the range of services their responses were attributed to:

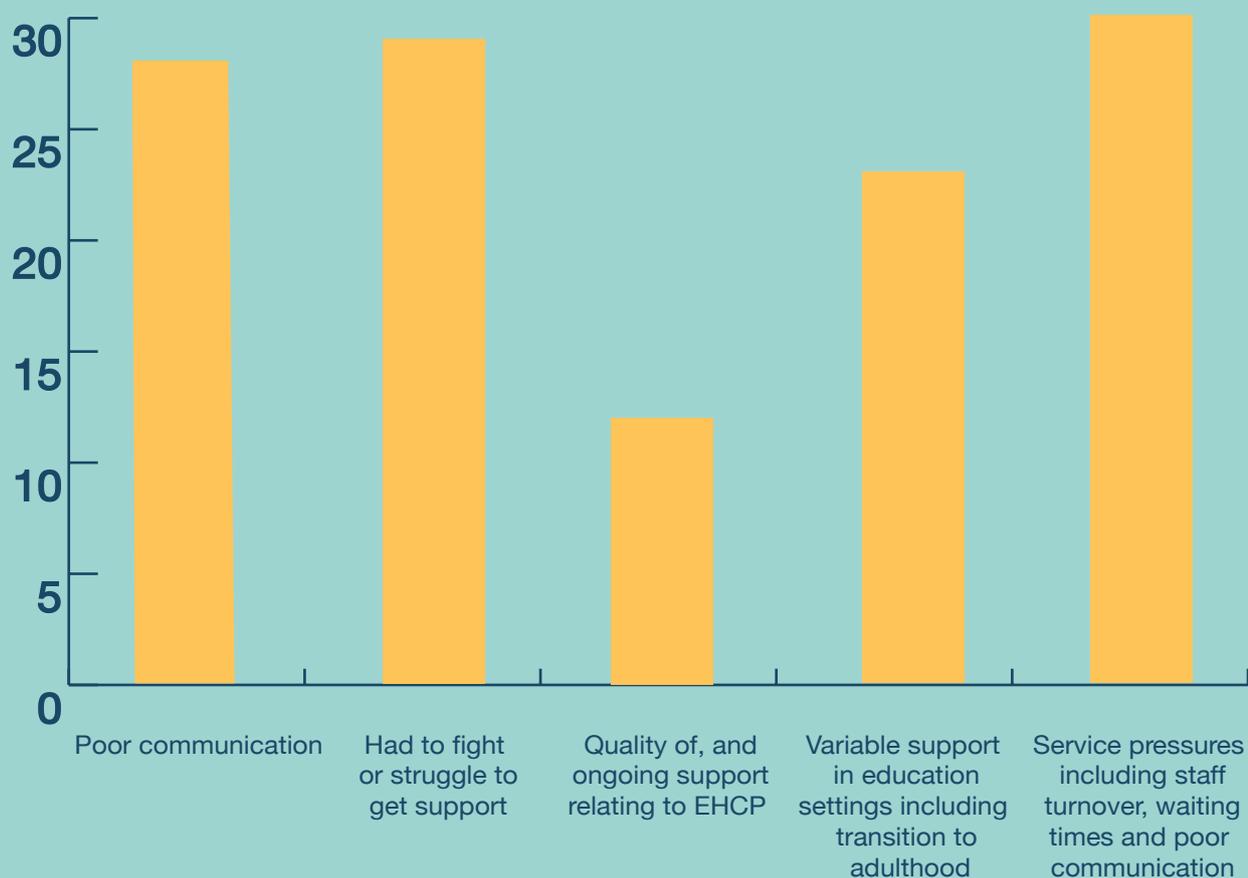
- **23%** identified the SEN (special Educational needs)
- **22%** identified ISCAN Health Rowan House
- **18%** of responses chose the ‘other’ option and this mostly reflected Healthy Young Minds (**40%**)

Detailed findings are illustrated in the graph below.



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

235 families responded to this question with **132 (55%)** saying **Yes** and **103** families said **No (45%)**. Reasons given for not feeling supported included **waiting times, poor communication** from professionals and having to **'fight and struggle'** to get support.



They say all the right things but not good at putting into practice

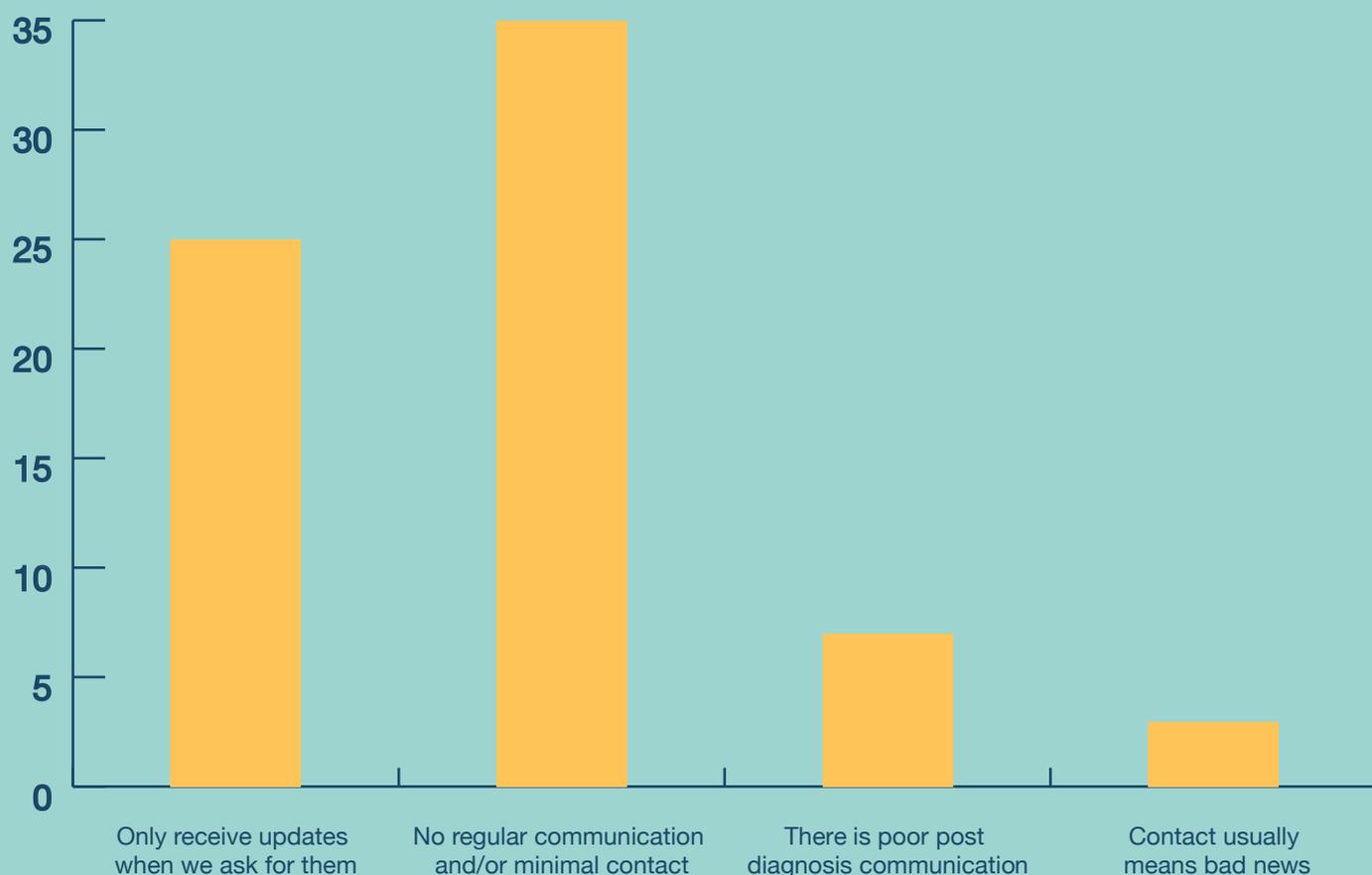
Staffing levels are just not there to provide it

It's not a full yes or no to this. I have been supported, however every single thing is a battle. You have to fight so hard for the support & be at breaking point. I've been in tears pretty much every phone call/ appointment we have & I'm still fighting for the right support for my child

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

60% of families said that they had regular updates from professionals and 40% said they did not.

Reasons for this are categorised below.



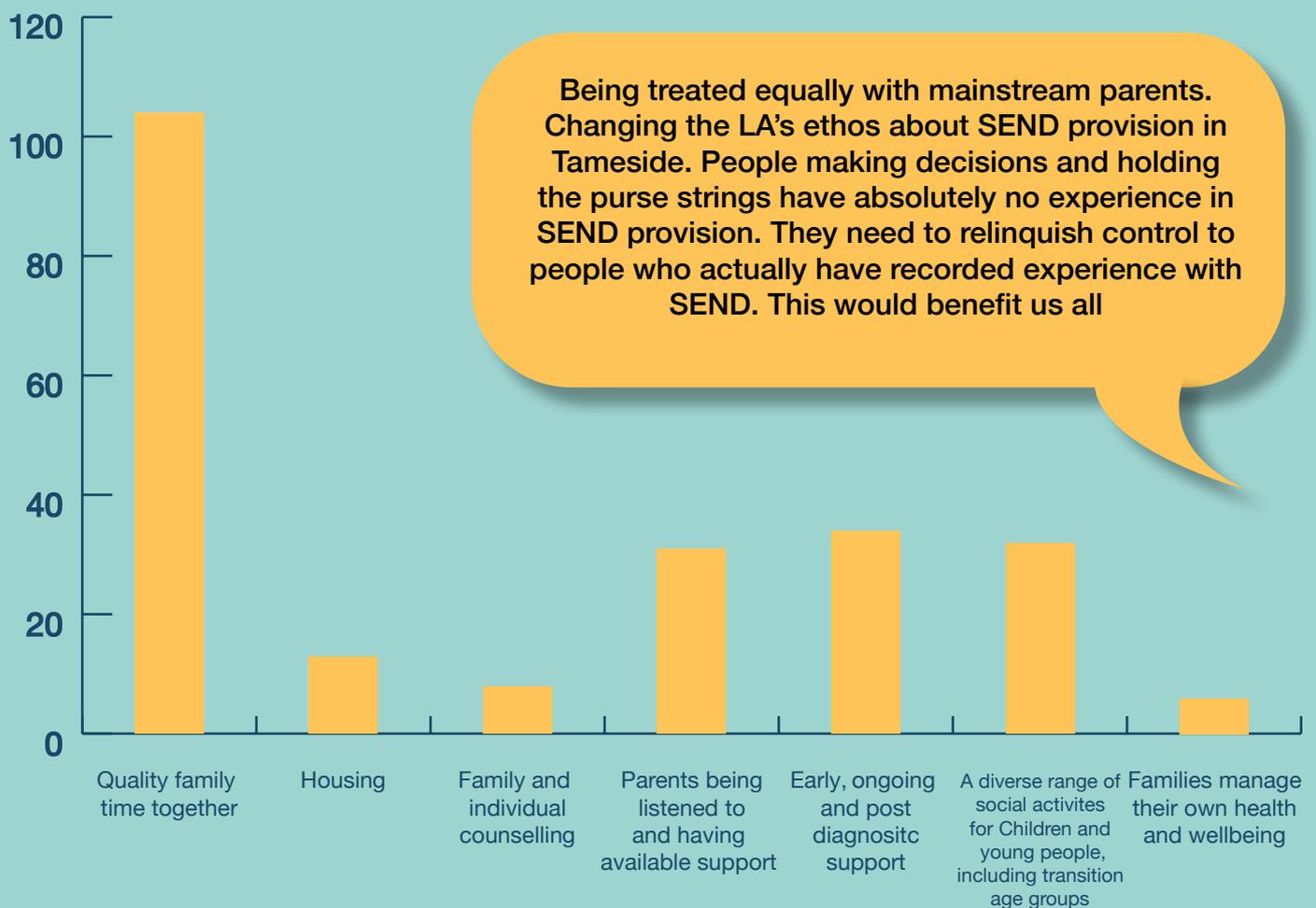
I have to constantly chase for any updates. No one is doing enough for my son

Healthy Young Minds are very responsive but I feel very let down by her school. They do not recognise the stress having an ill child has on the family

They are too overworked, taking on jobs that they can't handle. Staff shortage is a common statement

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

Over **100** responses cited family quality time together, including having respite available to facilitate this as something that might improve the health and wellbeing of the family. Other responses included social activities for children, post diagnostic support and available support for parents.



**Being treated equally with mainstream parents. Changing the LA's ethos about SEND provision in Tameside. People making decisions and holding the purse strings have absolutely no experience in SEND provision. They need to relinquish control to people who actually have recorded experience with SEND. This would benefit us all**

**Maybe having activities that are accessible for children of different levels to access**

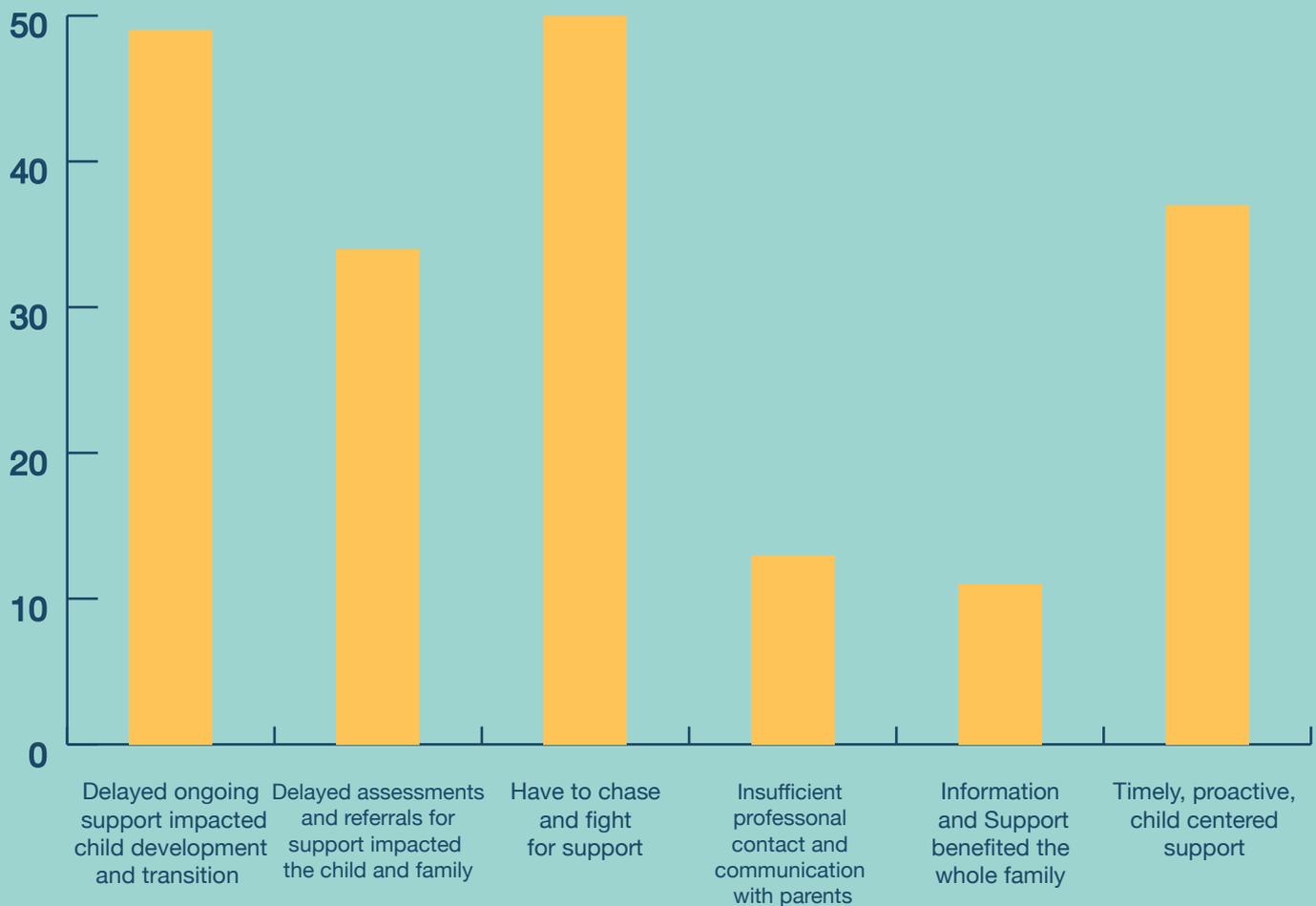
**Having a break. Days out. The same friendly faces supporting the family**

**Stop focusing on the bad things, help him achieve and not fail. Help him with daily functions like making the right decisions. Safety issues, personal safety etc**

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

Out of **227** responses, **60%** of families said the support was not available at the right time. **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.



The support was finally there but as mentioned before, you have to be at breaking point so it takes a long time

Much too long waiting for referral and diagnosis, all in all from the time of parental concern to diagnosis and EHCP was 4 years, during which time he had to cope with a woefully inadequate mainstream setting

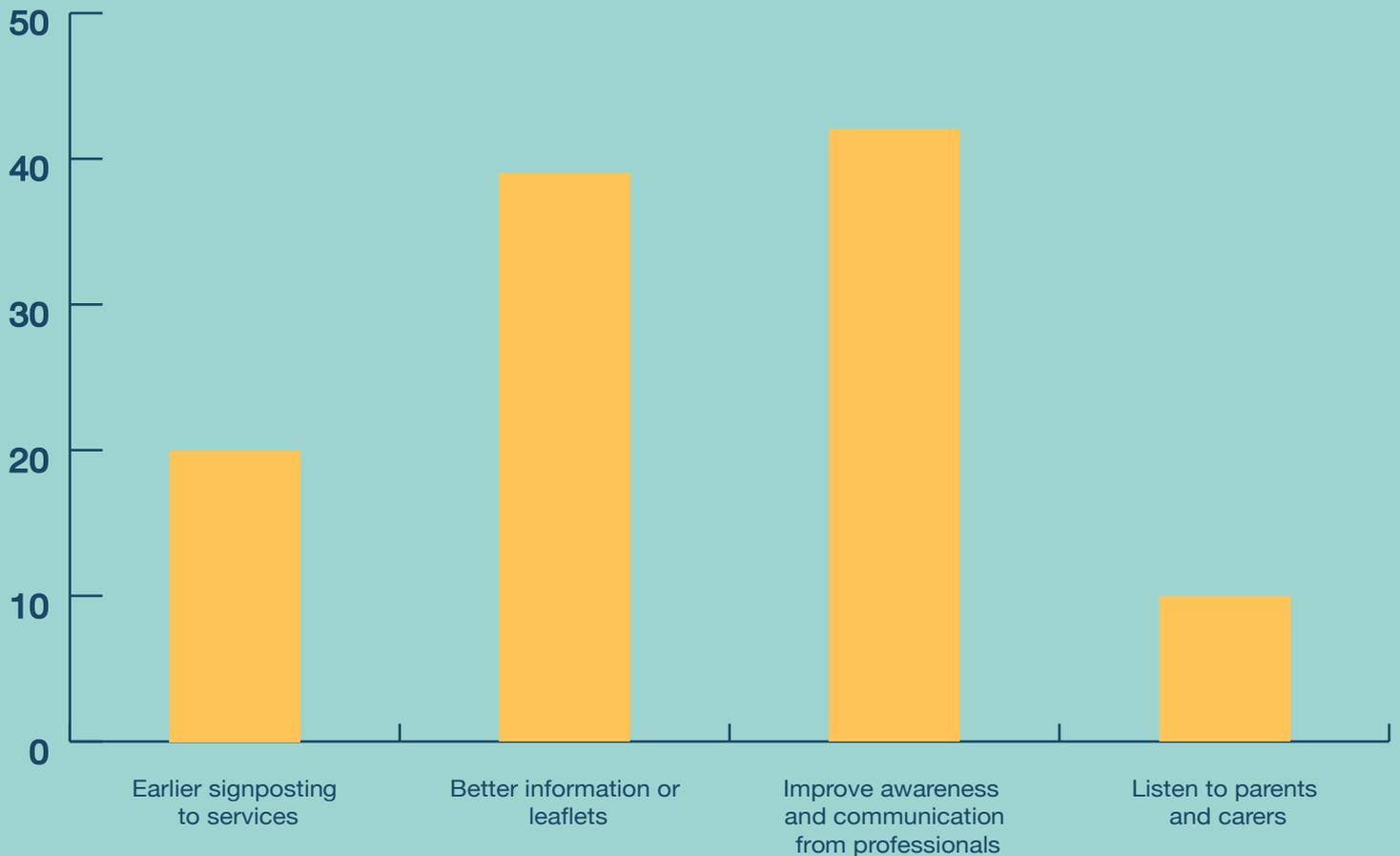
Yeah counselling has brought out a huge difference in our child

## 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 whilst **just under half did**. School and Health or other professionals were cited as places and people that families would go to and the Local Offer was named in **1%** of responses to where families would go to.

Answer Choices	Responses	
Local Offer	1.04%	1
A Friend/Family Member	13.54%	13
Health Care or Other Professional	39.58%	38
School	45.83%	44
Newspaper	0.00%	0
Parent Carer Forum	6.25%	6
Other (please specify)	23.96%	23
<b>Total Respondents: 96</b>		

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 the table below. Improved communication methods were the overarching summary response



School could be better informed / educated

A flow chart on Council website, more information given via schools, a pack given out via schools, posted on schools Facebook page

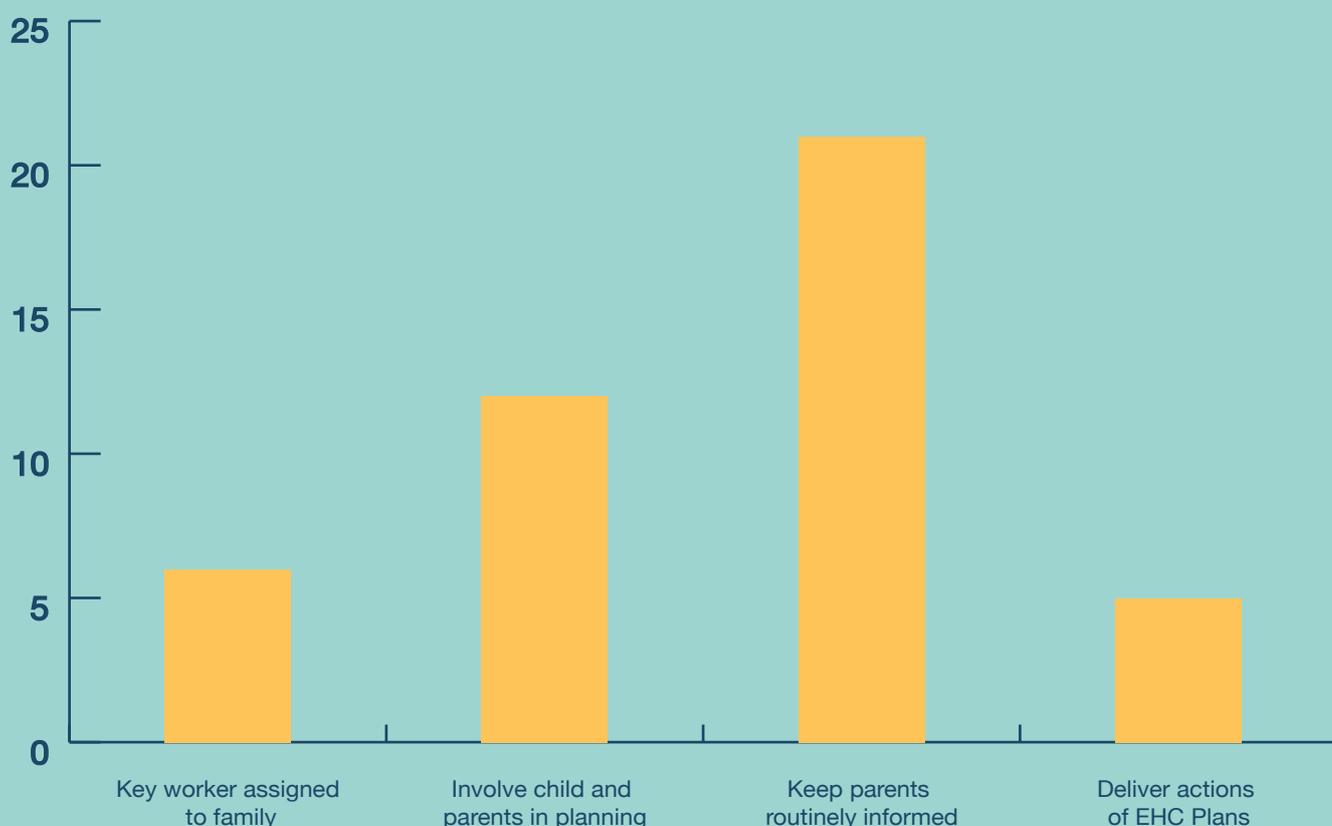
Make information more readily available. Most things I've learnt about support etc has come from other parents. The parents that have been on the journey longer are the ones who support other parents & pass the info along to the next parents that are at the beginning of their journey

A joined up service between schools, GPs and other health care professions would 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 two thirds** of families said that they had the opportunity to be involved in plans, and **around a third** 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



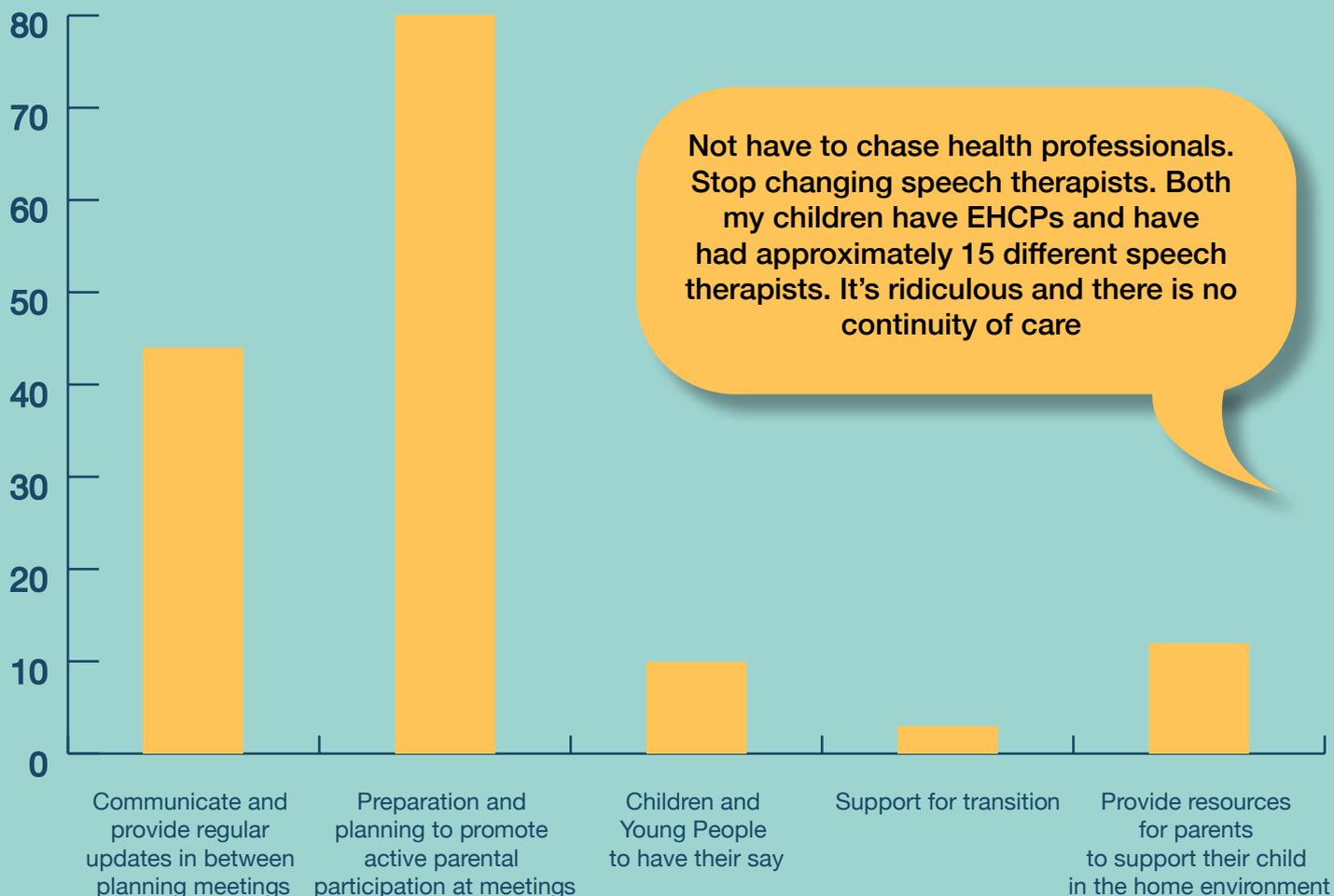
To actually be heard and for people to take notice of the support my child needs

Never been asked or involved in anything done by school to share my thoughts for his ehcp

We feel like we have no say in any decisions

## 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, families gave a range of responses. The most prominent themes were preparation and planning for active participation at meetings, followed by communication and regular updates in between planning meetings



Not have to chase health professionals. Stop changing speech therapists. Both my children have EHCPs and have had approximately 15 different speech therapists. It's ridiculous and there is no continuity of care

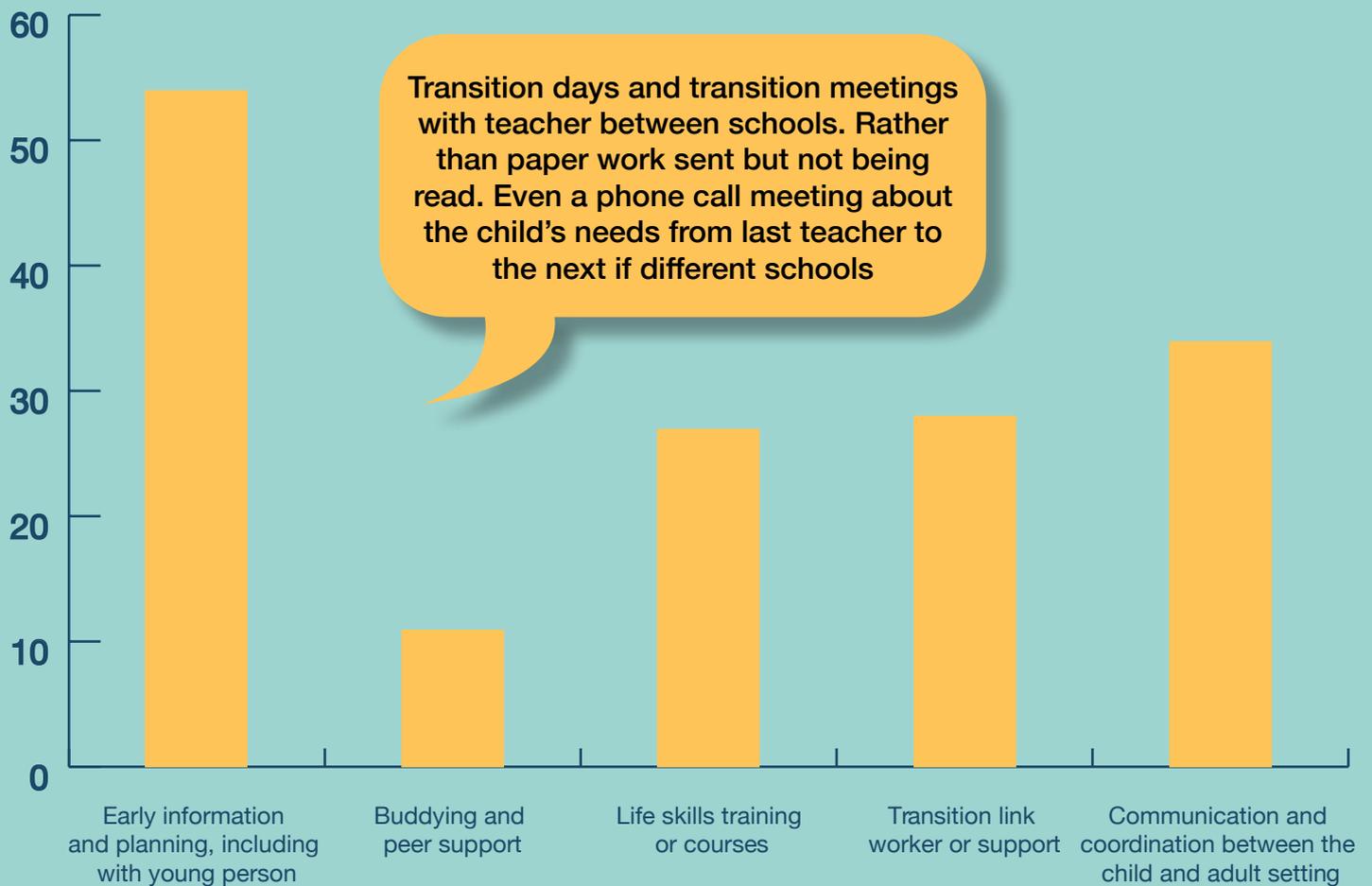
Let my son have his say rather than people assume and guess what's wrong, let him speak and be heard

I have my say at meetings but at times it is difficult. It would be great to have an advocate there to support you

Even having a meeting would be a start

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

156 families responded to this question. **Over half** of these responses related to themes of **early transition planning**; **inclusion of young people**; and **early introduction** between the young person and the adult setting with keyworker and/or peer support to facilitate this.



Have all the information in one place. A key worker to help for at least the year.

Being shown that just because they learn differently doesn't mean they can't succeed in life

I believe that more skill based subjects should be brought in before going on to college to help transition and self esteem . Maybe look at going on day release to college to help get used to the journey and routine preferably in a group so that they don't feel vulnerable and overwhelmed.

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

- Schools advice, support and timely assessment
- Improved person centred planning, including transition
- Ongoing availability of consistent professionals / parent helpline



For curriculum to change so children like my son have an opportunity to be good at something and feel proud.

Support respite for siblings

Assessments to be completed in a timely manner

# 5. Covid-19 Lockdown Messages

A consistent theme within approximately half of the survey responses, related to the impact of the Covid -19 Pandemic. Families responses are summarised under the following themes:

## Reduced communication over lockdown period

...You get set on a course or now due to Covid get sent videos and then discharged. No follow up to see if the strategies have worked

... we both felt abandoned during covid

Apart from our lead nurse (who is fab!) we have had little if any contact from professionals since the start of lockdown. We have very much been left to it, or at least that's how we feel. Fully understand these are difficult times, but a phone call or email from Rowan House would have gone a long way to helping us feel less isolated.

## Delayed Assessment and Referral

Sometimes I feel we get lost in the paperwork and Covid made everything worse...

I don't know if he has the support, he had in yr4 now he's in yr5 and with covid restrictions, I'll be waiting for parents evening in a few weeks. If I don't ask the information isn't forth-coming

... Been referred at the end of last year and is delayed because of Covid

... CLASS referral, which has been stalled because of Covid

# Impact on social activities and family wellbeing

...Being able to go swimming and play centres which are not available at the moment

Help with resources at home. Especially when the Covid started we didn't get any professional help to support my daughter. I had phone calls from her school regarding work but nothing from professionals regarding her sensory, behaviour, and all-round needs for her

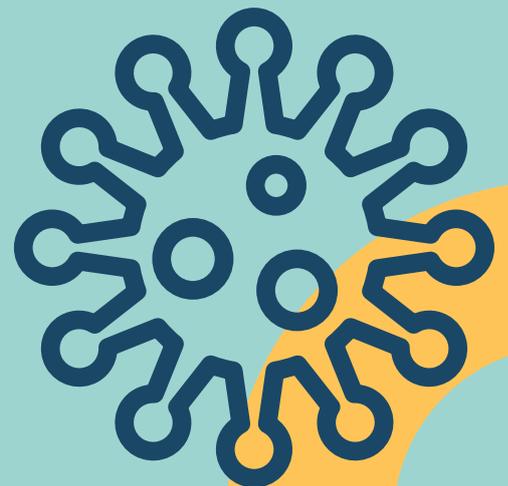
Our d as in accessed disability sports and had support of 6 hours during the week with a support worker. He really enjoyed sports, there hasn't been any communication about when or if they will start again which leads to distress every Wednesday and Saturday

Respite - no one to care for children due to Covid

# Impact on transitions

Sadly, my child's transition to high school was this year and not much could be done due to Covid but this is understandable. However, it would be good to have some support as they go through puberty and into young adults

More support with transition for high school with covid restrictions. And support in adult social care



# 6. Summary Key Messages

The findings and key messages from this survey provide Tameside SEND Improvement Group with a rich and diverse body of evidence and information from the lived experience of those in receipt of ISCAN (Health and Social Care) as well as the wider system of support across SEN, schools, HYMS and hospitals.

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 :

- **45%** of parent carers report feeling unsupported
- **40%** of parent carers report not receiving regular updates from professionals
- **60%** of parent carers report not receiving support at the right time
- **55%** of parent carers report not knowing where to get help when they first needed it
- **37%** of parent carers report not 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 support
- A lack of involvement by young people and families in meetings and plans

In a significant proportion of responses, parents describe their lived experience of having to **'fight'** and **'struggle'** to be heard and to receive the support their child needs.

Schools and health professionals are cited by parents as being integral in sign-posting families for early advice and support.



# 7. 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
- Improve the available communication methods for promoting and **sign-posting families** to SEND support and services
- 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**
- Facilitating a range of **respite support** for families
- Extend the availability of **social activities** across the borough for children and young people with a range of different disabilities.
- 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.



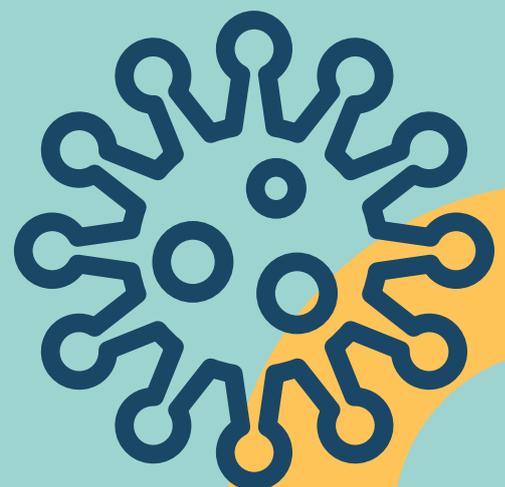
**The top three areas of support** identified by parents as making the biggest difference in the immediate future for their child and family are summarised as:

- **Schools advice, support and timely assessment**
- **Improved person-centred planning, including transition**
- **Ongoing availability of consistent professionals / parent helpline**

### **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.



## 8. Recommended next steps

- This report is delivered to and discussed by the SEND Improvement Group, in conjunction with the Glossop survey report (Appendix 1)
- Findings from the Glossop survey are shared with Derbyshire Parent Carer Voice and Derbyshire County Council SEN lead
- Findings from the Tameside and Glossop surveys are utilised to shape and inform SEND integration plans going forward.
- Findings from this survey are used to influence changes and improvement to SEND support 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



# 9. Appendices

## Appendix 1

### SEND Integrated support 0-25 years Survey target groups Distribution List

- ISCAN health
- ISCAN social care
- HYM neurodevelopment pathway
- SEN teams – Tameside and Glossop
- Charity groups/parent carer forum
- The Amazing Autism Project
- Connect Facebook Group Glossop
- Glossop schools link
- Glossop Parent Carer Forum
- Derbyshire Local Offer
- Tameside school's newsletter
- Adult social care and Autism
- Transitions Team
- LD team
- Children with disabilities team social care
- School nursing
- Short breaks
- GPs – UPDATE 16th September to go out for 24th and fortnightly update 11th
- School and Neighbourhood Links – EWO / PWP / Early Help / Grow
- Youth Justice Service

## Appendix 2

### Letter to partners sent via email

Dear Colleague,

Please can you help us reach families of children and young people with additional needs including special education needs and disabilities?

Under the leadership of the SEND Improvement Group Education, Health and Care leaders have been working together with families to improve integrated support and services for children and young people with special educational needs and / or disabilities (SEND) 0-25 years. One priority is to develop a shared vision on integrated support, to ensure best use of all available resources to achieve the best possible outcomes for children and their families. Critical to this is learning from families about their lived experience of current services and support and ideas for how these could be improved in order to steer the future vision and plans and offer the best level of support right here, right now.

Please can you invite families within your school community/parent carer family network to participate via a survey located on the [Local Offer Home page](#)

The survey will commence on Monday 21st September and will be available for families to complete until Friday 9th October.

Please feel free to also circulate this information to colleagues, peers, and amongst your local networks in order to maximise take-up of this important piece of work.

Some families may find it daunting or lack confidence in completing a survey on-line so we would also ask that where possible, you offer supportive advice or assistance.

Thanking you in anticipation.

Regards,

Tim Bowman  
Chair SEND Improvement Group

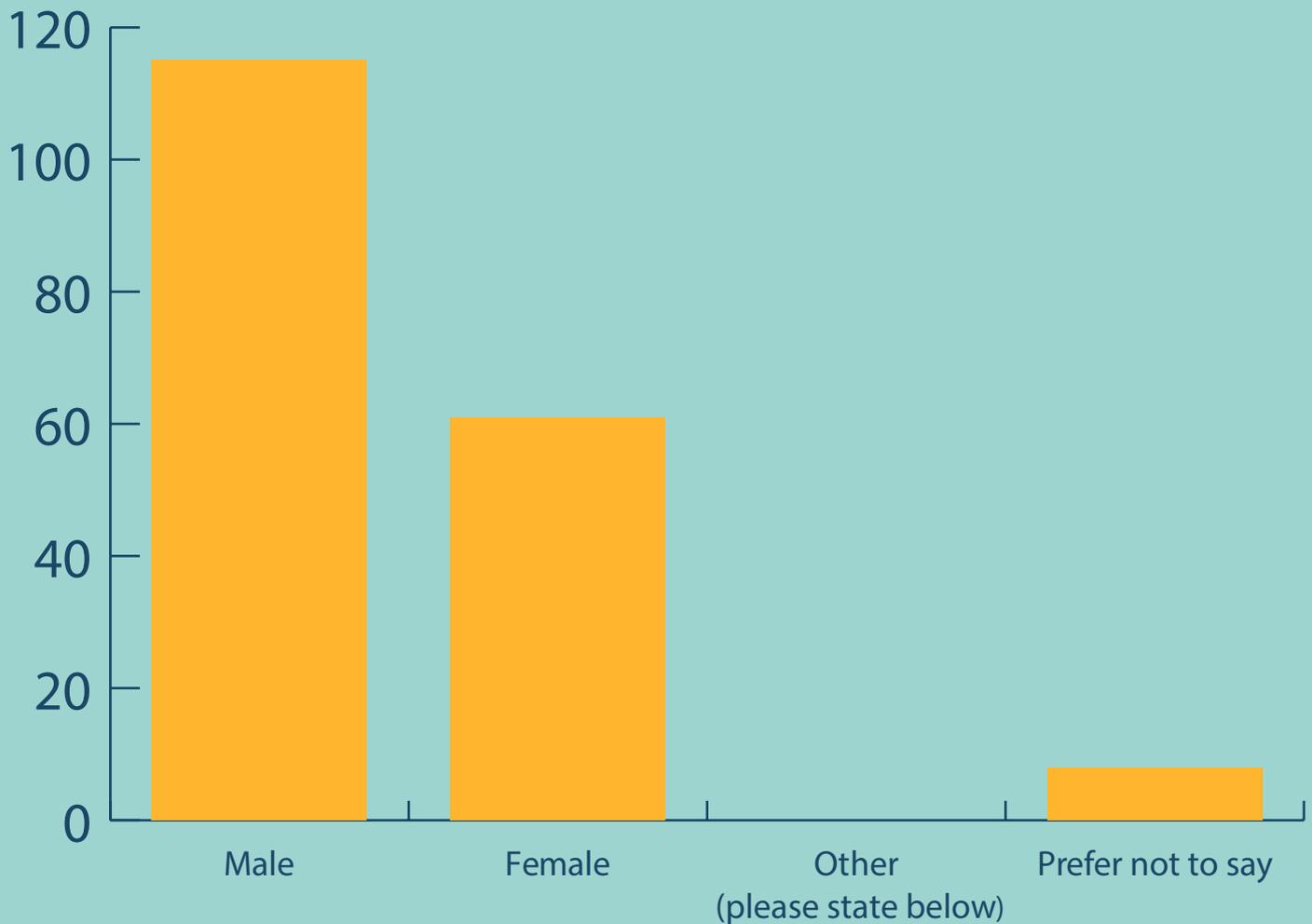
Tim Bowman  
Assistant Director - Education  
Learning  
Children's Services

## Appendix 3

### Demographic Data from the Tameside SEND Survey

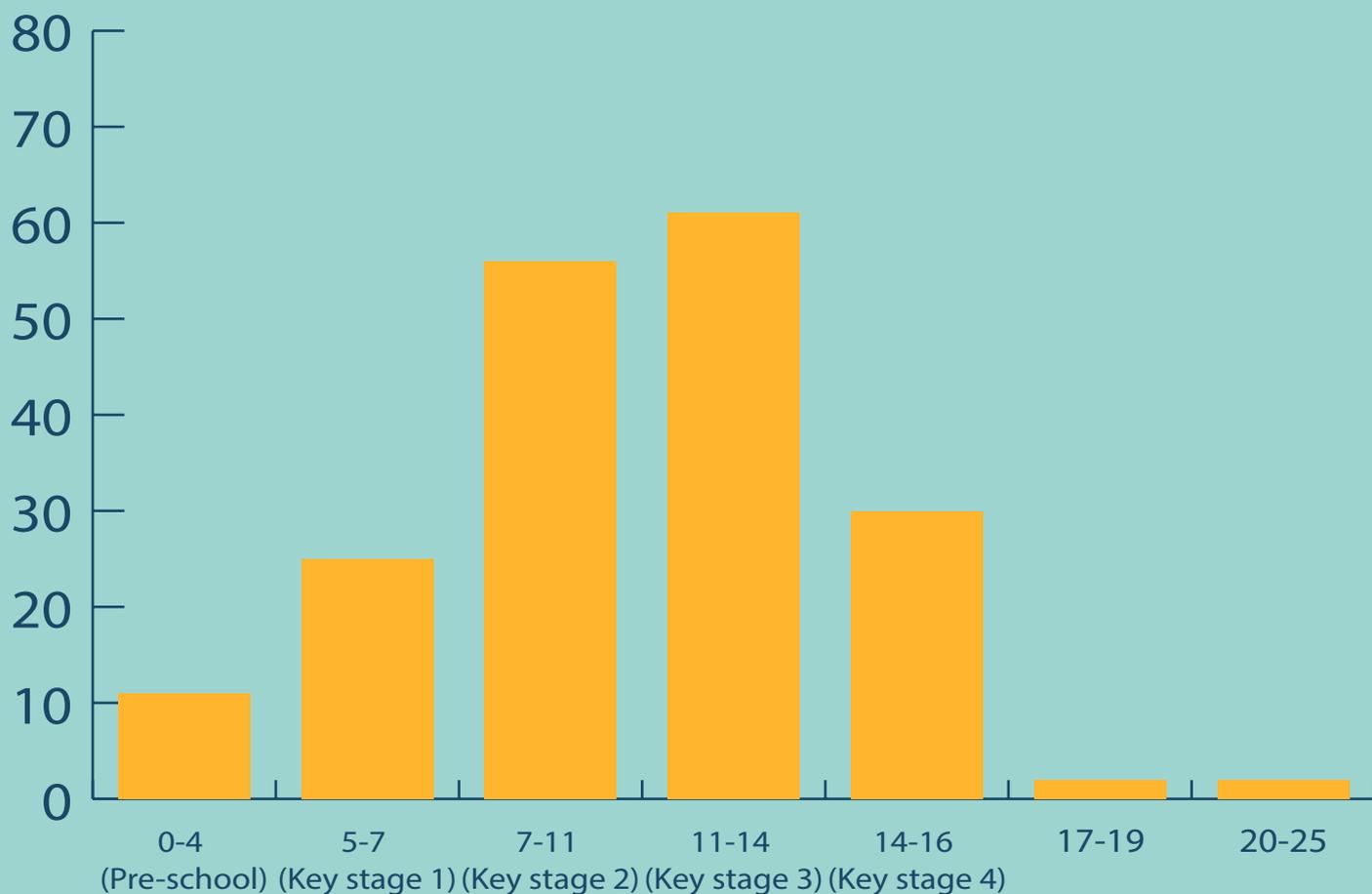
Is your child:

Answer Choices	Responses	
Male	62.50%	115
Female	33.15%	61
Other (please state below)	0.00%	0
Prefer not to say	4.35%	8
<b>Answered:</b>	<b>184</b>	
<b>Skipped:</b>	<b>136</b>	



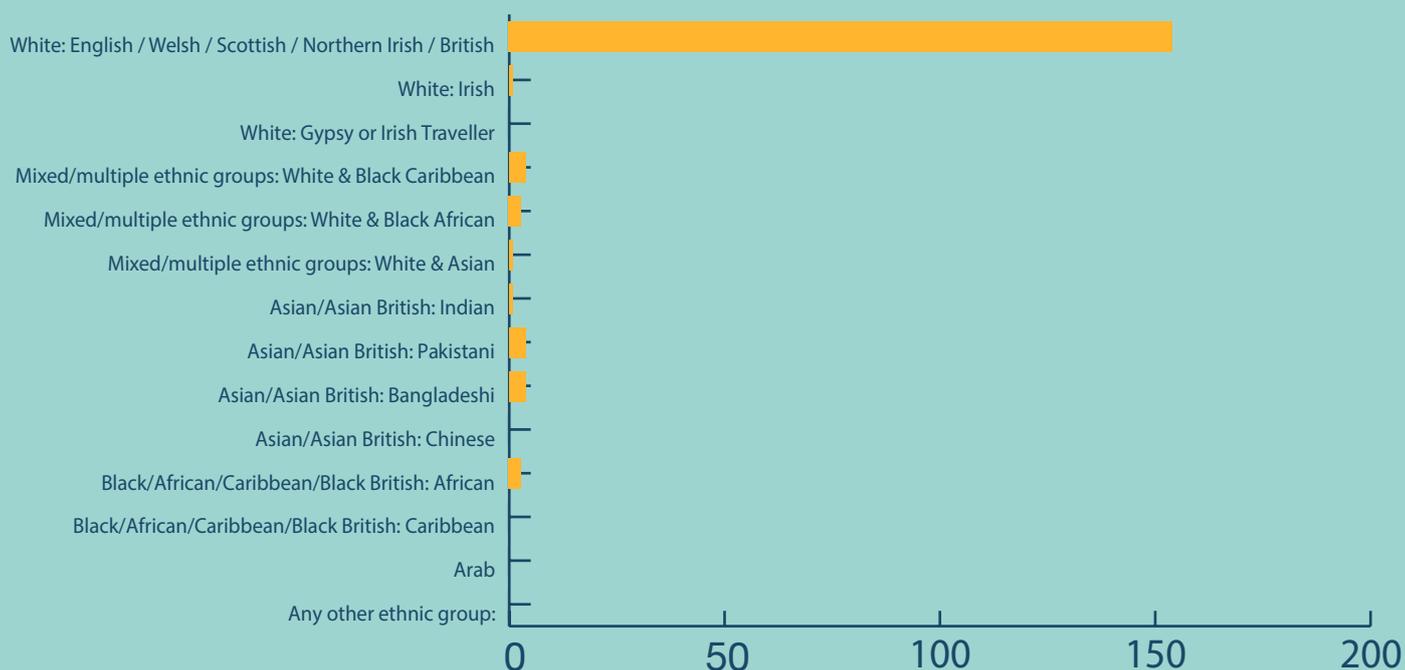
## What is your child's age?

Answer Choices	Responses	
0-4 (pre school)	5.88%	11
5-7 (Key stage 1)	13.37%	25
7-11 (Key stage 2)	29.95%	56
11-14 (Key stage 3)	32.62%	61
14-16 (Key stage 4)	16.04%	30
17-19	1.07%	2
20-25	1.07%	2
<b>Answered:</b>	<b>187</b>	
<b>Skipped:</b>	<b>133</b>	



## What is your child's ethnic group?

Answer Choices	Responses	
White: English / Welsh / Scottish / Northern Irish / British	88.00%	154
White: Irish	0.57%	1
White: Gypsy or Irish Traveller	0.00%	0
Mixed/multiple ethnic groups: White & Black Caribbean	2.29%	4
Mixed/multiple ethnic groups: White & Black African	1.71%	3
Mixed/multiple ethnic groups: White & Asian	0.57%	1
Asian/Asian British: Indian	0.57%	1
Asian/Asian British: Pakistani	2.29%	4
Asian/Asian British: Bangladeshi	2.29%	4
Asian/Asian British: Chinese	0.00%	0
Black/African/Caribbean/Black British: African	1.71%	3
Black/African/Caribbean/Black British: Caribbean	0.00%	0
Arab	0.00%	0
Any other ethnic group:	0.00%	0
<b>Answered:</b>	<b>175</b>	
<b>Skipped:</b>	<b>145</b>	



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

Answer Choices	Responses	
ADHD/ADD	31.02%	58
Multi Sensory Impairment (vision & hearing)	6.42%	12
Down Syndrome	1.07%	2
Autistic Spectrum Disorder	43.85%	82
Physical Disability/Mobility Issues	16.58%	31
Visual Impairment	5.35%	10
Behavioural Emotional or Social Difficulties	42.78%	80
Profound and Multiple Learning Difficulties	8.56%	16
Specific Learning Difficulty e.g. Dyslexia	13.37%	25
Speech, Language & Communication Needs	35.29%	66
Hearing Impairment	4.28%	8
Severe Learning Difficulty	10.70%	20
Medical Needs or Long Term Illness	10.70%	20
Mental Health Difficulties	16.04%	30
Moderate Learning Difficulties	20.32%	38
Waiting for diagnosis	16.58%	31
Other (please specify)	16.04%	30
<b>Answered:</b>	<b>187</b>	
<b>Skipped:</b>	<b>133</b>	

