Children and Young People with Learning Disability, Autism or both Community Keyworking

Children and Young People Engagement Report

May 2021

Contents

Key Findings

- Keyworkers should support the relationships young people have with professionals.
- Support should be available when young people feel they need it as well as for those who are at risk of being admitted to hospital.
- Keyworkers should be knowledge holders of other relevant support available for children, young people and their families.
- Understanding the needs of the individual is important in understanding what support they need.
- Work with the young person and their family to determine how long the help should be available for.
- Reducing help should be done with the young person and their family.
- Provide means for young people to receive Keyworker support again if they need it.
- Keyworkers should hold other professionals accountable on the young person and family's behalf.

1. Introduction

1.1 BACKGROUND

Staffordshire Council of Voluntary Youth Services (SCVYS) was commissioned by Staffordshire and Stoke-on-Trent Clinical Commissioning Groups (CCGs) to engage with children and young people around a new Keyworker role.

The scope of the consultation was to seek the views of children, young people and young adults who are autistic; living with a learning disability or both autistic and living with a learning disability asking how they think a Keyworker can support them at critical moments in their lives.

The Keyworker role is intended to start in June 2021, supporting children and young people who are on what is called the Dynamic Support Register and therefore at risk of an unplanned visit to hospital, or already in hospital and are either autistic, living with a learning disability or both. Previous engagement work had been completed with professionals and the families of these young people, but more insight was required by NHS England relating to the Staffordshire and Stoke-on-Trent CCGs and the cohort of children and young people falling within their geographical remit.

1.2 ENGAGEMENT METHODS

Due to the on-going Covid-19 pandemic, the decision was made to complete the engagement work via an online survey to avoid face-to-face group interactions. The survey was hosted on the SCVYS website, with all responses submitted via this form. A questionnaire version of the survey was also produced so participants were able to see the questions before completing the survey, however paper copies were not accepted and all responses needed to be submitted through the online form. A copy of the questionnaire, which was shared and agreed in advance with health and local authority partners, can be found in the appendices at the end of this report.

Partner organisations were recruited to support the engagement work because of their experience of working with the target cohort. SCVYS targeted VCSE and statutory organisations who worked with children, young people and young adults who were autistic, living with a learning disability or both. Partner organisations were able to conduct interviews or support their existing participants to complete the survey in whatever way suited them, and then submitted the responses on the online form, on behalf of the participant.

To make the engagement as accessible as possible, participants were able to request phone or video calls if they wanted support filling in the survey. Partner organisations were also permitted to meet face-to-face with their participants if this was the best option and national regulations allowed it. The survey was also edited to be 'Easy Read' (checked and edited by Easy Read Online) with icons for

participants to select where possible and a Picture Exchange Communication System (PECs) version of the survey was produced by Becky, a trainee Youth Worker at Liberty Jamboree.

1.2.1 PARTNER ORGANISATIONS

The partner organisations that SCVYS approached were:

- Allsortz
- Asist
- Au-Sums / Midlands Psychology
- BLAST
- Creative Choices
- Disability Solutions
- Eagles Nest Project
- Equal Support Opportunities CIC
- Healthwatch

- Honeycomb Group
- In It Together
- Liberty Jamboree
- Lifeworks Staffs
- Our Space Staffs
- PEGiS / Vast
- National Autistic Society - Stafford
- North Staffs Asperger / Autism Association
- Rockspur

- SENDIASS - both Staffordshire and Stoke
- SPIN
- Stafford Adults Autistic Society
- The Voice Project
- Uttoxeter Autism Pyramid Group

From this list, the following organisations submitted responses from young people they worked with:

- BLAST
- Equal Support Opportunities CIC

- Liberty Jamboree
- PEGiS
- The Voice Project

The engagement project was also promoted directly to all SEND schools in Staffordshire and Stoke-on-Trent, shared in Staffordshire County Council's school e-bag newsletter (distributed to all schools in Staffordshire) and shared via SCVYS social media platforms and e-bulletin throughout the four week consultation period.

1.3 SURVEY RESPONSE AND DATA VERIFICATION

Overall, 93 responses to the survey were submitted. Of these, five were removed due to being duplicated submissions leaving a total of 88 responses. Two of these did not consider themselves autistic, living with a learning disability, or both, so have also been removed as they were not able to complete the questions in the survey.

Four of the participants provided postcodes located outside of Staffordshire or Stoke-on-Trent. Their responses have been included in the relevant sections, due to their participation in activities offered by the partner organisations working on this engagement project. They have not been included in the participant demographics. It will be highlighted in the report where any findings relate to one of these participants.

2. Participant Demographics

2.1 AGE PROFILE OF PARTICIPANTS

Participants were asked to provide their age from a selection of six age brackets. The consultation was aimed primarily at 0-25 year olds, however it was discussed with CCGs that the lived experience of those aged 26 and over would still be valuable to understand the needs they may have had earlier in their lives and how a Keyworker could have supported them. From the participants who lived outside of Staffordshire and Stoke-on-Trent, two participants were aged 19-25 years old; one was 15-18 years old and one was 11-14 years old.

The chart below shows the breakdown of ages within the different age brackets.
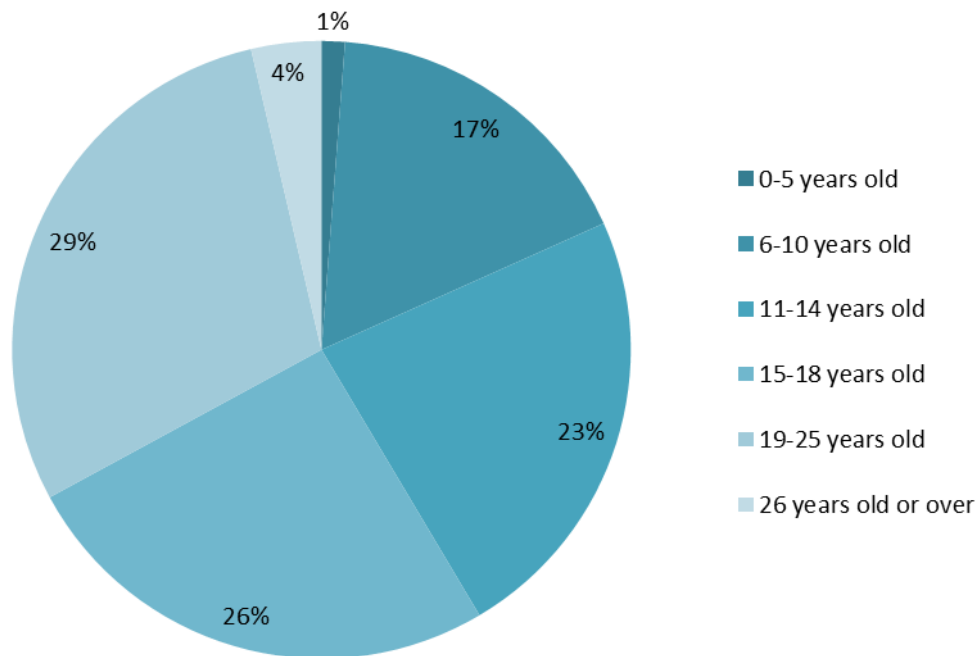
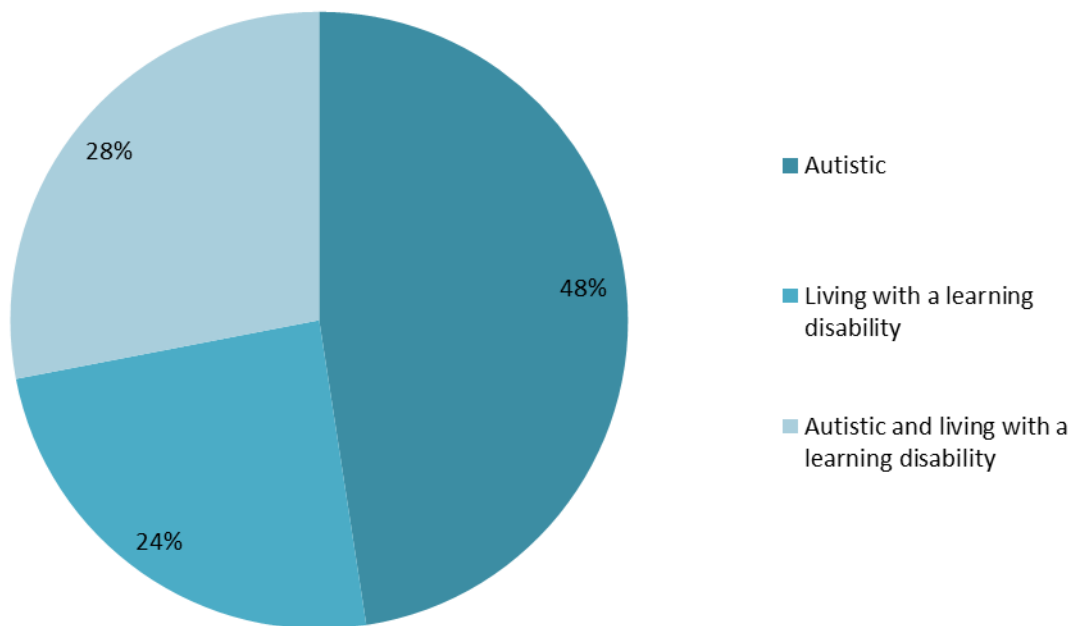| Age Bracket	Number of Participants	Percentage
0-5 years old	1	1%
6-10 years old	14	17%
11-14 years old	19	23%
15-18 years old	21	26%
19-25 years old	24	29%
26 years old or over	3	4%

2.2 DIAGNOSIS PROFILE OF PARTICIPANTS

Each participant was asked whether they considered themselves to be autistic, living with a learning disability or autistic and living with a learning disability. This question was purposely worded as how they considered themselves rather than being dependent on confirmed diagnoses. This was highlighted by some of the partner organisations involved prior to the consultation going live and it was agreed that if participants were still waiting for a diagnosis, they could participate in the consultation.

The chart below outlines the breakdown of diagnoses the participants consider themselves to have.

Diagnosis	Number of Participants	Percentage
Autistic	39	48%
Living with a learning disability	20	24%
Autistic and living with a learning disability	23	28%

Of the four participants who lived outside of Staffordshire and Stoke-on-Trent, one participant was autistic, two were living with a learning disability and one was autistic and living with a learning disability.

2.3 GEOGRAPHICAL PROFILE OF PARTICIPANTS

The Keyworker role will cover all districts in Staffordshire and the city of Stoke-on-Trent. To ensure we were collecting views from participants across the county and city they were required to leave their postcode, which has been broken down to district levels (in Staffordshire) and the city of Stoke-on-Trent. 13% of participants provided a Stoke-on-Trent postcode and 83% provided a Staffordshire postcode.

Some districts have higher percentages due to partner organisations delivering their services in these areas notably, Cannock and East Staffordshire.
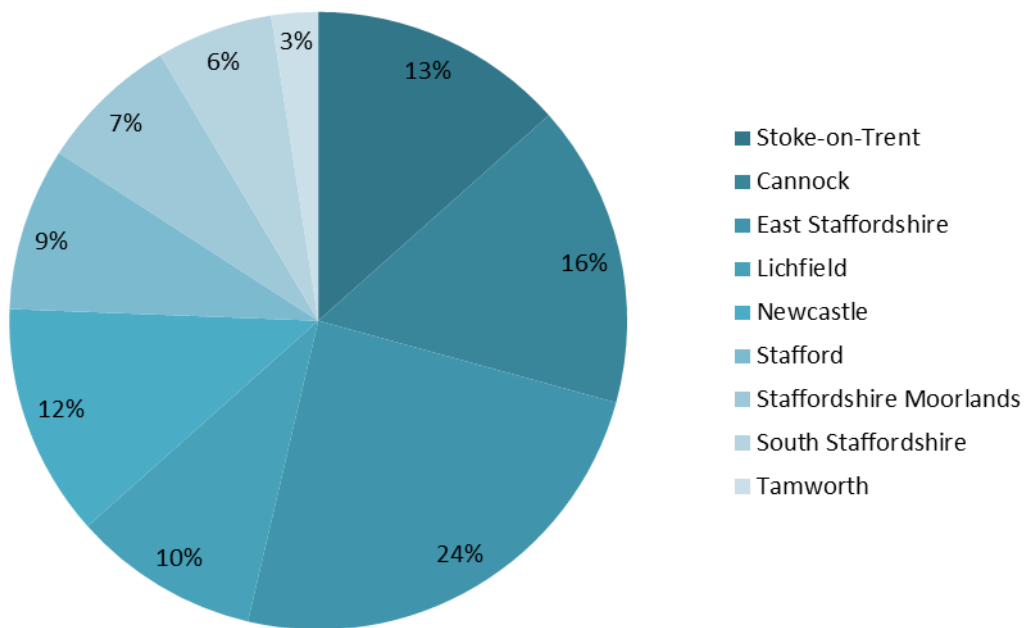
District	Number of Participants	Percentage
Stoke-on-Trent	11	13%
Cannock	13	16%
East Staffordshire	20	24%
Lichfield	8	10%
Newcastle- under-Lyme	10	12%
Stafford	7	9%
Staffordshire Moorlands	6	7%
South Staffordshire	5	6%
Tamworth	2	3%

2.4 ETHNICITY PROFILE OF PARTICIPANTS

To ensure views from a diverse range of backgrounds are considered, the survey also asked for participants to self-report their ethnic background. This followed design guidelines provided by the UK Government and can be found here.

Across Staffordshire, 6.4% of the total population identify as a minority ethnic background. In Stoke-on-Trent, this is higher at 13.6%. Both Staffordshire and Stoke-on-Trent have a lower proportion of minority ethnic residents compared to England as a whole (Staffordshire Observatory, 2018).

2% of participants preferred not to disclose their ethnic background. All four participants from outside the county and city identified as White - English/Welsh/Scottish/Northern Irish/British
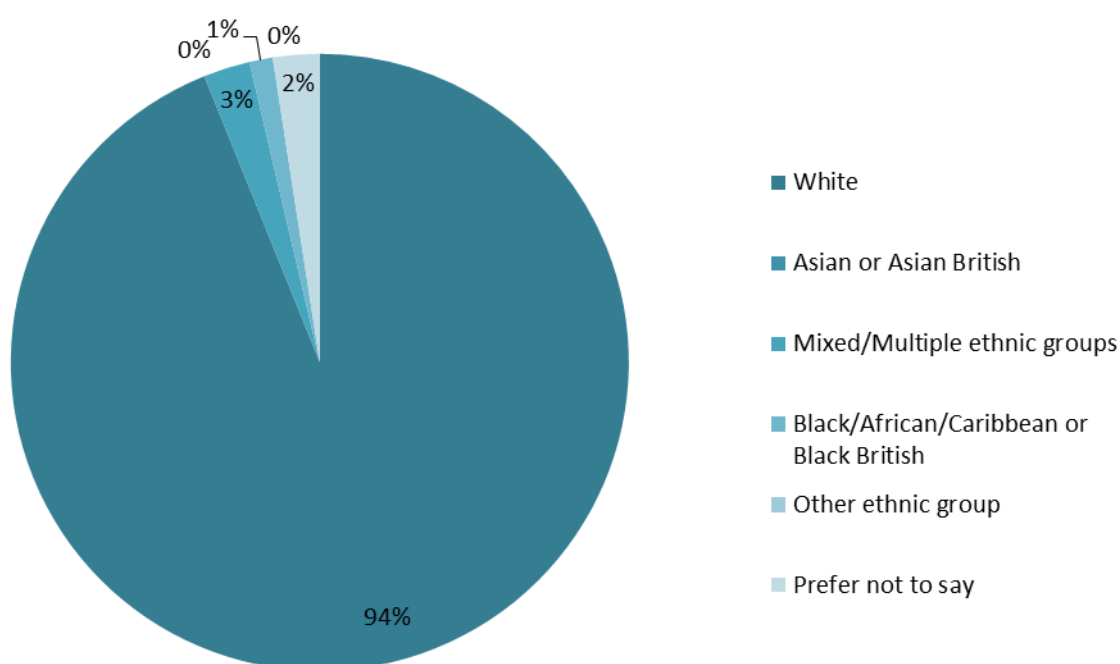
| Ethnicity	Number of Participants	Percentage
White	77	94%
Asian or Asian British	0	0%
Mixed/Multiple ethnic groups	2	3%
Black/African/Caribbean or Black British	1	1%
Other ethnic group	0	0%
Prefer not to say	2	2%

3. Help I receive now

3.1 ONE-TO-ONE SUPPORT I HAVE RECEIVED IN THE PAST

The Keyworker role will offer one-to-one support tailored to the needs of the young person they are working with. To gauge what sort of support young people have received in the past, we asked the question: *'Have you ever had one-to-one support in the past?'*

Have you ever had one-to-one support in the past?
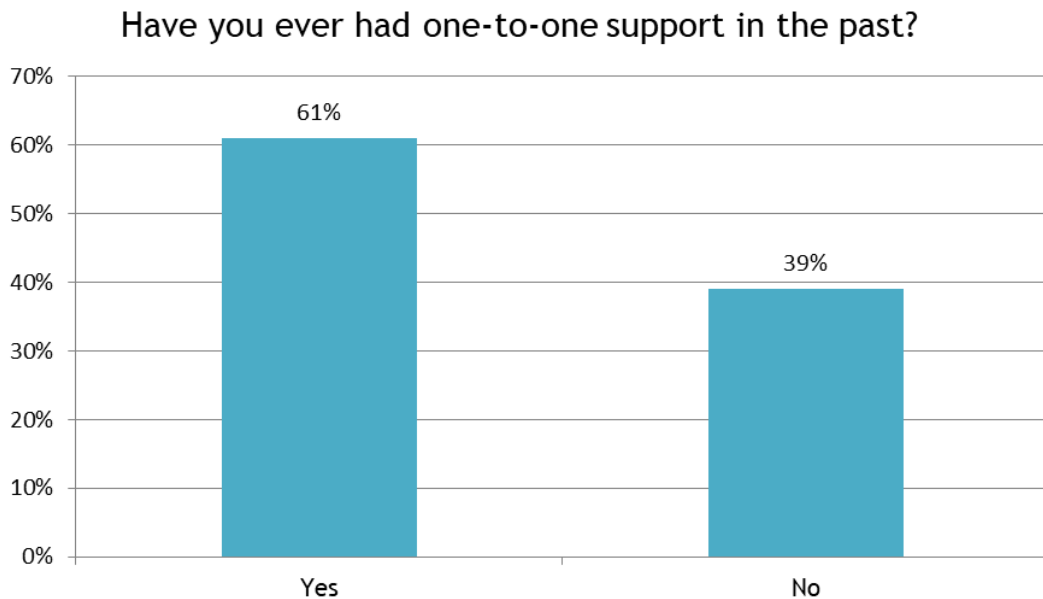
61% of the participants had received one-to-one support in the past, with the remaining 39% saying that had not had one-to-one support.

The participants who stated they had had one-to-one support were then offered the follow up question: *'Who was this and how did they help you?'* The chart below outlines the breakdown of responses once categorised from the information provided by participants. Some participants had received several different kinds of one-to-one support.

Who was this and how did they help you?
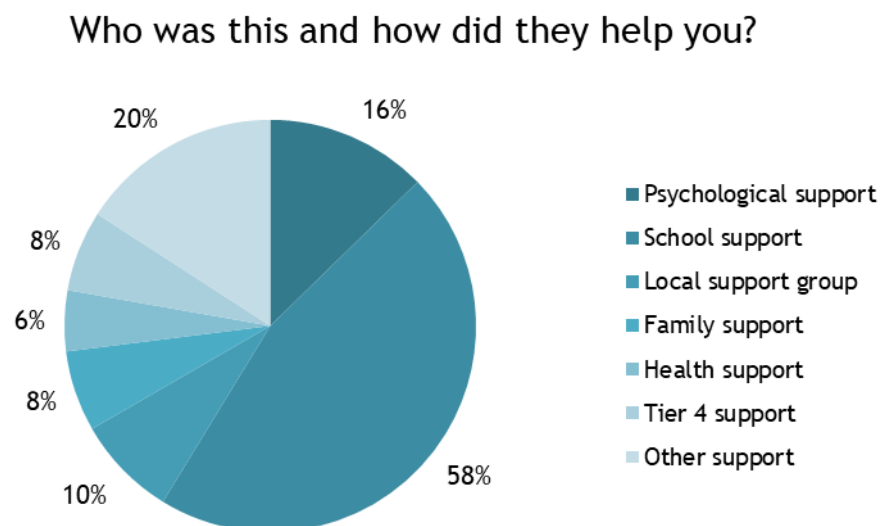
Type of support	Percentage of Participants
Psychological support	16%
School support	58%
Local support group	10%
Family support	8%
Health support	6%
Tier 4 support	8%
Other support	10%

Examples of the different types of support that participants received in these different settings are as follows.

Some examples of how schools have supported young people include teaching assistants teaching life skills and social skills, teachers providing more support to help understand the subject content and support to maintain focus and concentration in school.

Psychological support came from Midlands Psychology, Sustain+ and MPFT CYP Autism Service. These organisations supported participants in helping to deal with mental health issues and providing strategies to cope with them. There were also responses where support workers and teaching assistants supported young people, with secondary effects being that this helped with mental health problems.

Only one local support group was specifically named as helping participants, ESO CIC, however this was mentioned by four participants. Of the participants that said they receive one-to-one support from family, this is mostly by their mothers who support them.

Health support was mostly provided by CAMHS. One participant mentioned support from other medical professionals not being helpful, letting them down and making things worse. They also said that their GP tries to understand their needs, but has limited knowledge on how to support them.

Four participants also referenced specific tier 4 support they received as inpatients on psychiatric wards, or following their inpatient stay.

Examples of other types of one-to-one support provided to participants are social workers, advocates, personal assistants and charities such as Barnardos and Sickle Cell Foundation who helped signpost parents and family to the right support for the young person.

Two participants who lived outside the county had received one-to-one support in the past. Both of these received additional support with their mental health.

3.2 WHERE I GET HELP NOW

Participants were asked the question *'Where do you currently go for information about help and support?'* and were provided with a selection of options. The results below highlight the responses from participants. The question allowed the selection of as many options as felt relevant to participants, so most of the responses included more than one source of information.

Your GP, doctor or nurse	Internet/Online	Friends	Family	Social Media
33%	**20%**	**28%**	**76%**	**15%**

Local Support Groups	At school	Keyworker	Other
27%	**41%**	**16%**	**16%**
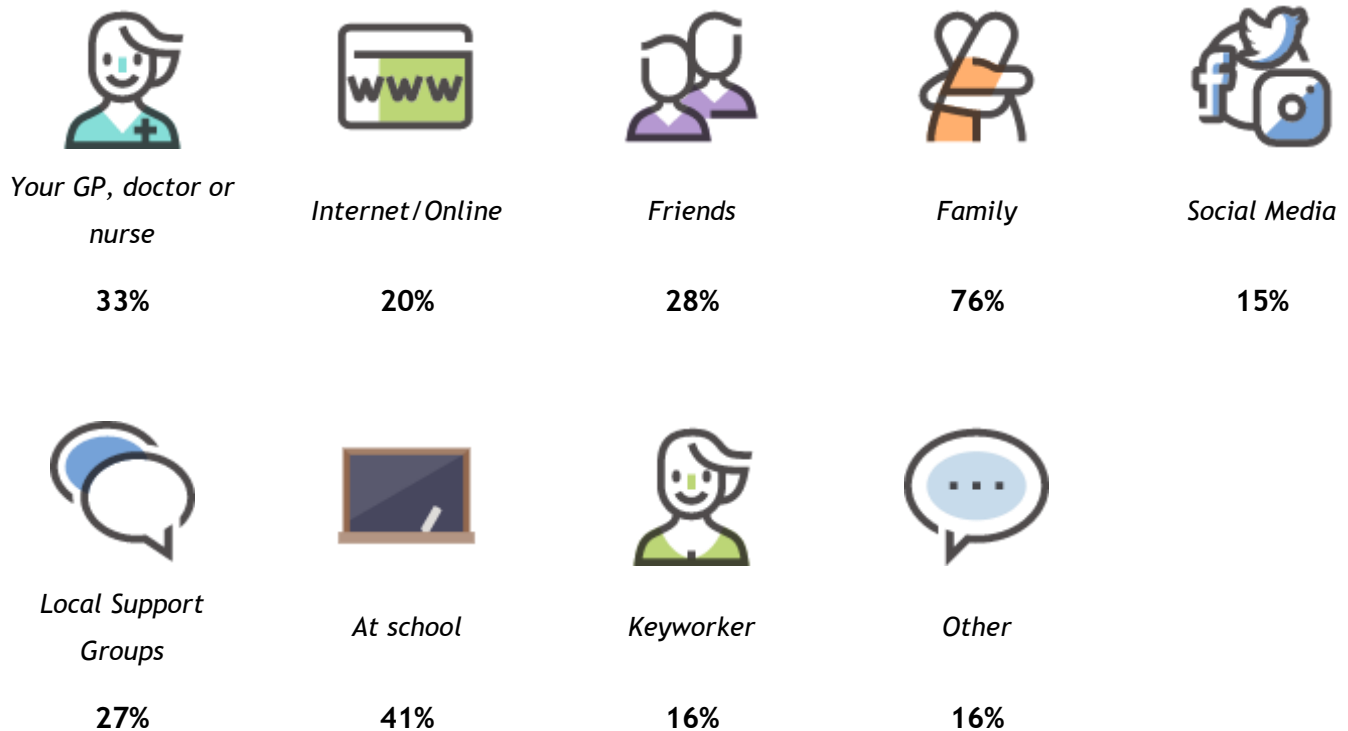
The most common source of information about help and support available to participants was their family (76% of participants). This was followed by school (41%) and GP, doctor or nurse (33%).

Some options from the above list allowed the participant to provide further detail. Those who find information online use a variety of websites, but mainly by searching on Google, using the NHS website or using national support organisation websites (e.g. National Autistic Society).

Almost all participants who selected '*Social Media'* used Facebook to find information about help and support, one participant specifically mentioned a local support group's social media accounts as a source of their information.

Selecting '*Local Support Groups'* also allowed participants to provide which support groups they use for their information. The following groups where listed as examples:

- Liberty Jamboree
- ESO CIC
- The Voice Project
- BLAST

- SENDIASS
- Au-Sums
- PEGIS

Other local support that participants use for information was Child and Adolescent Mental Health Services (CAMHS), Cannock Chase Autism Group, Staffordshire Connects and church groups.

All four participants from outside the county and city sourced information from their families. Two also sourced from friends, two from school and one from local support groups (Liberty Jamboree).

3.3 TALKING ABOUT THE HELP AND SUPPORT I NEED

To understand how participants felt when asking and talking about the help and support they need, they were asked '*How comfortable do you feel speaking with people in these situations about the help and support you need?*' across a variety of settings. The scale ranged from '*Very uncomfortable*' to '*Very comfortable*' and participants were able to select '*Not applicable*',* for example if they were no longer in education or employment. These questions were all compulsory and required participants to answer before being able to move on to the next section of the survey. The scale on the online survey was accompanied by Emoji icons that reflected the emotions felt by each option. These have been included below, with the percentage of participants who selected it.

Overall findings from this section of the consultation suggest that in settings where relationships are long term and more likely to be one-to-one, young people are more comfortable talking to professionals about their needs. Local support groups and social care scored higher, with more young people feeling comfortable or very comfortable talking about their needs in these settings than in others. The biggest discrepancy was in health care, with 44% of participants feeling very uncomfortable or uncomfortable talking about their needs with professionals. A breakdown of the results from each setting can be found under the subheadings below.

3.3.1 MY EDUCATION

To provide a rating for the talking about the support they need with their education, participants were given examples such as teachers, SENDCOs, head teachers or principals. 12% of participants selected '*Not applicable*'; the responses from the remaining participants are highlighted below.

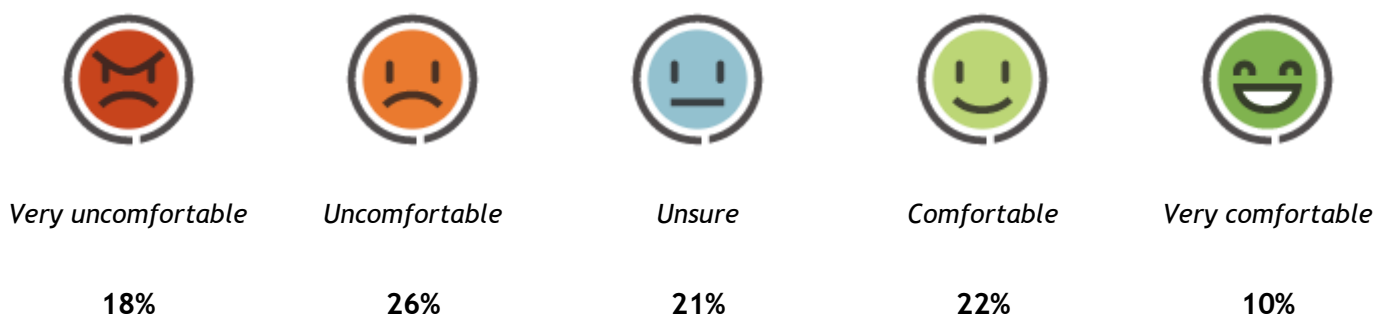| Very uncomfortable	Uncomfortable	Unsure	Comfortable	Very comfortable
20%	15%	22%	21%	11%

It is clear from the results that most participants (35% in total) are to some extent uncomfortable speaking with professionals in education settings about the support they need. However, a similar percentage of participants are comfortable or very comfortable discussing their needs with education professionals (32% in total).

Three participants from out of the county were unsure how comfortable they were speaking to educational professionals, with the fourth participant stating they were '*Comfortable*'.

3.3.2 MY HEALTH

Examples given under this setting were GPs, nurses, doctors or specialists. Of all the responses, only 4% said that this setting was not applicable to them. The following results show the remainder of the participants' views.

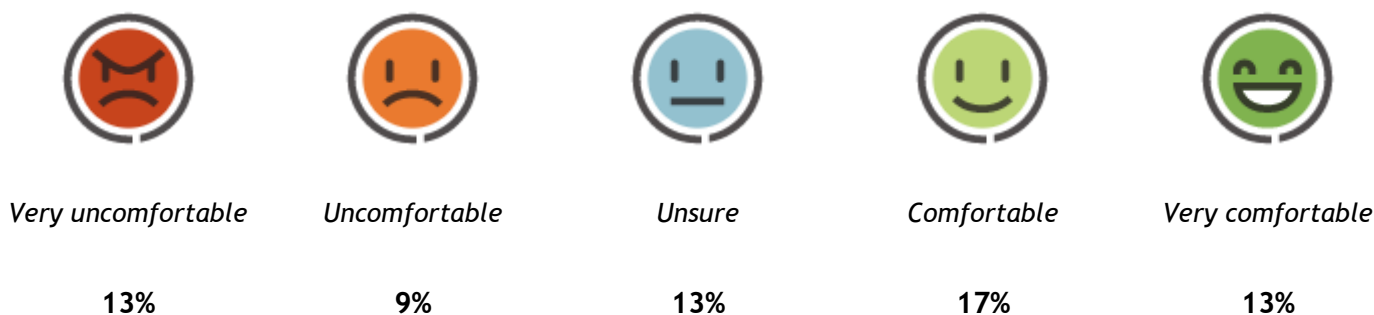| *Very uncomfortable*	*Uncomfortable*	*Unsure*	*Comfortable*	*Very comfortable*
18%	**26%**	**21%**	**22%**	**10%**

There is a high discrepancy between how comfortable participants feel talking to health professionals about the support they need. Overall, 44% of participants were very uncomfortable or uncomfortable speaking about the help and support they need, compared to 32% who were comfortable or very comfortable.

Two participants from outside the county were unsure about how comfortable they were speaking with health professionals about their needs, one was comfortable and one was very comfortable.

3.3.3 MY CARE

The types of care suggested for this setting were social care or support workers. Out of these responses, 34% of participants said that this was not applicable to them.

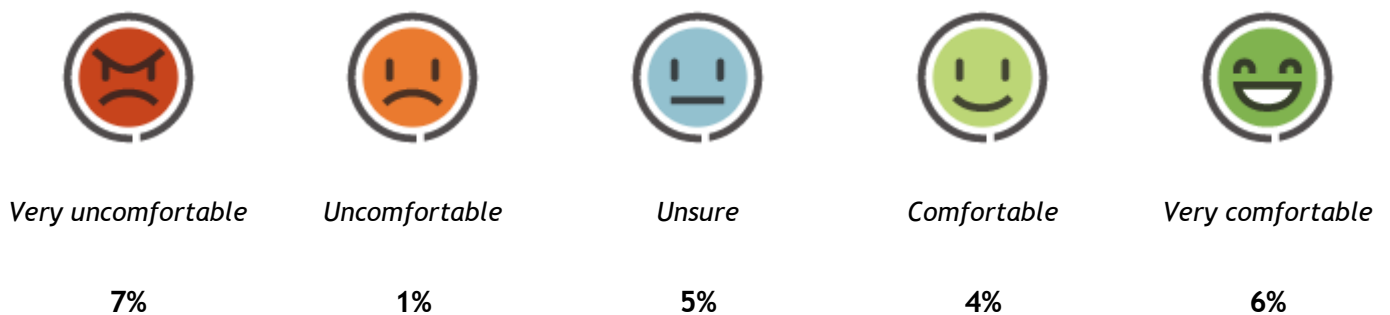| *Very uncomfortable*	*Uncomfortable*	*Unsure*	*Comfortable*	*Very comfortable*
13%	**9%**	**13%**	**17%**	**13%**

More participants were comfortable or very comfortable (30% in total) speaking with professionals relating to their care than those who were uncomfortable (21% in total).

Two participants from outside the county stated this section was not applicable. One was unsure about how comfortable they were and one was very comfortable about speaking with care professionals about their needs.

3.3.4 MY EMPLOYMENT

The employment section included prompts suggesting job coaches, interviewers, managers or colleagues to ensure that participants could express their views across a range of employment scenarios, such as finding and starting a job. This section had the highest number of people who said it was not applicable, with 77% selecting this option.

Very uncomfortable	Uncomfortable	Unsure	Comfortable	Very comfortable
7%	1%	5%	4%	6%

8% of participants were uncomfortable speaking to people about their needs relating to their employment, with only slightly more (10%) participants comfortable or very comfortable speaking about their needs.

Two participants from outside of the county stated this question was not applicable, one was unsure about how comfortable they felt and one was comfortable speaking to employment professionals about their needs.

3.3.5 LOCAL SUPPORT GROUPS RELATED TO MY DIAGNOSIS

This section specifically worded as '*Local support groups related to my diagnosis*' to highlight that this is about those groups specifically working with young people who are autistic, have a learning disability or both. 27% of participants said that this section was not applicable to them.

Very uncomfortable	Uncomfortable	Unsure	Comfortable	Very comfortable
10%	**11%**	**21%**	**20%**	**17%**

37% of participants were comfortable or very comfortable speaking about their needs with professionals at local support groups, compared to 22% who were uncomfortable or very uncomfortable.

One participant from outside of the county stated this question was not applicable to them. Two participants were unsure and one was comfortable speaking about their needs with local support groups.

3.3.6 OTHER GROUPS AND ACTIVITIES

To contrast with local support groups that are related to a diagnosis, participants were also asked how comfortable they feel speaking to professionals in other groups and activities they may attend that are not related to their diagnosis (for example, youth clubs or sports clubs). 28% of participants said this was not applicable to them.

| Very uncomfortable	Uncomfortable	Unsure	Comfortable	Very comfortable
13%	**15%**	**18%**	**16%**	**10%**

28% of participants were very uncomfortable or uncomfortable talking about their needs, compared to 26% who were comfortable or very comfortable. Two participants from outside of the county stated this question was not applicable to them. One participant was unsure and one was comfortable speaking about their needs at other groups and activities.

4. Getting help in the future

4.1 WHO SHOULD RECEIVE KEYWORKER HELP?

The current proposal suggests that children and young people will receive Keyworker support when they are at risk of being admitted to hospital, or have already been admitted into hospital. Participants were asked '*A Keyworker will only be able to support you and your family if you are at risk of going into hospital, or are already in hospital. Do you agree this is when you should get help from a Keyworker?*'

Do you agree this is when you should get help from a Keyworker?
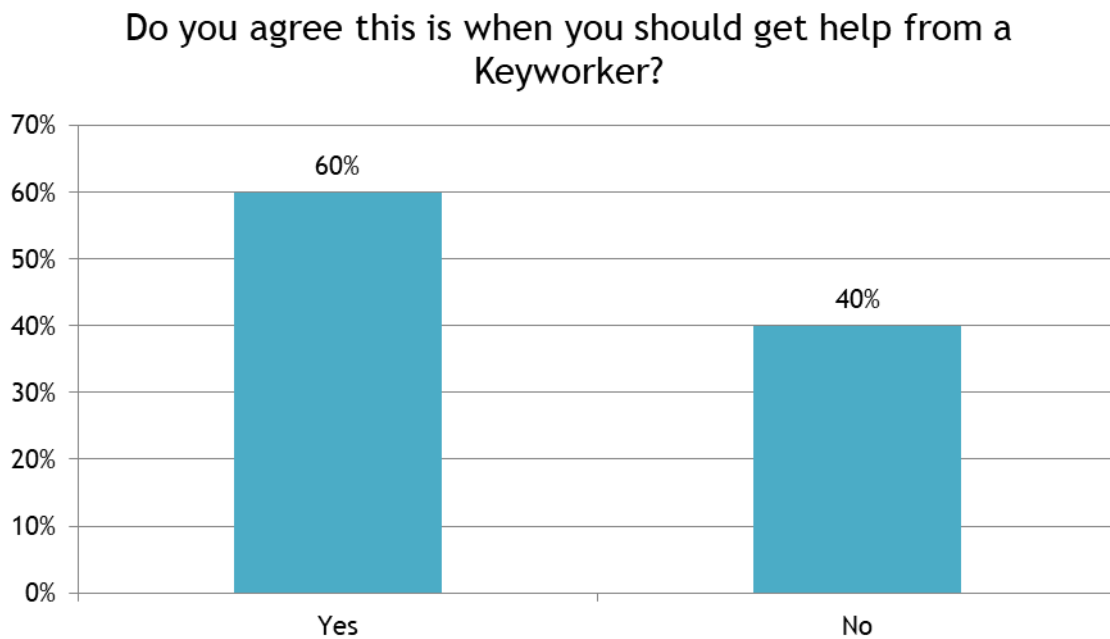
60% of participants agreed that this was the right time to be given Keyworker support and 40% did not agree with this. Those who thought Keyworker support should be available at another time were able to provide further details about when they could access this, as shown in the chart below.

55% of participants who did not agree with the proposed threshold to receive support stated that they would want to access it when they feel like they needed additional support. This is also supported by a further 18% of participants who would like to see the support available all the time, and 15% of participants who would want support before they are at risk of being admitted to hospital to hopefully prevent them from eventually being admitted to hospital.
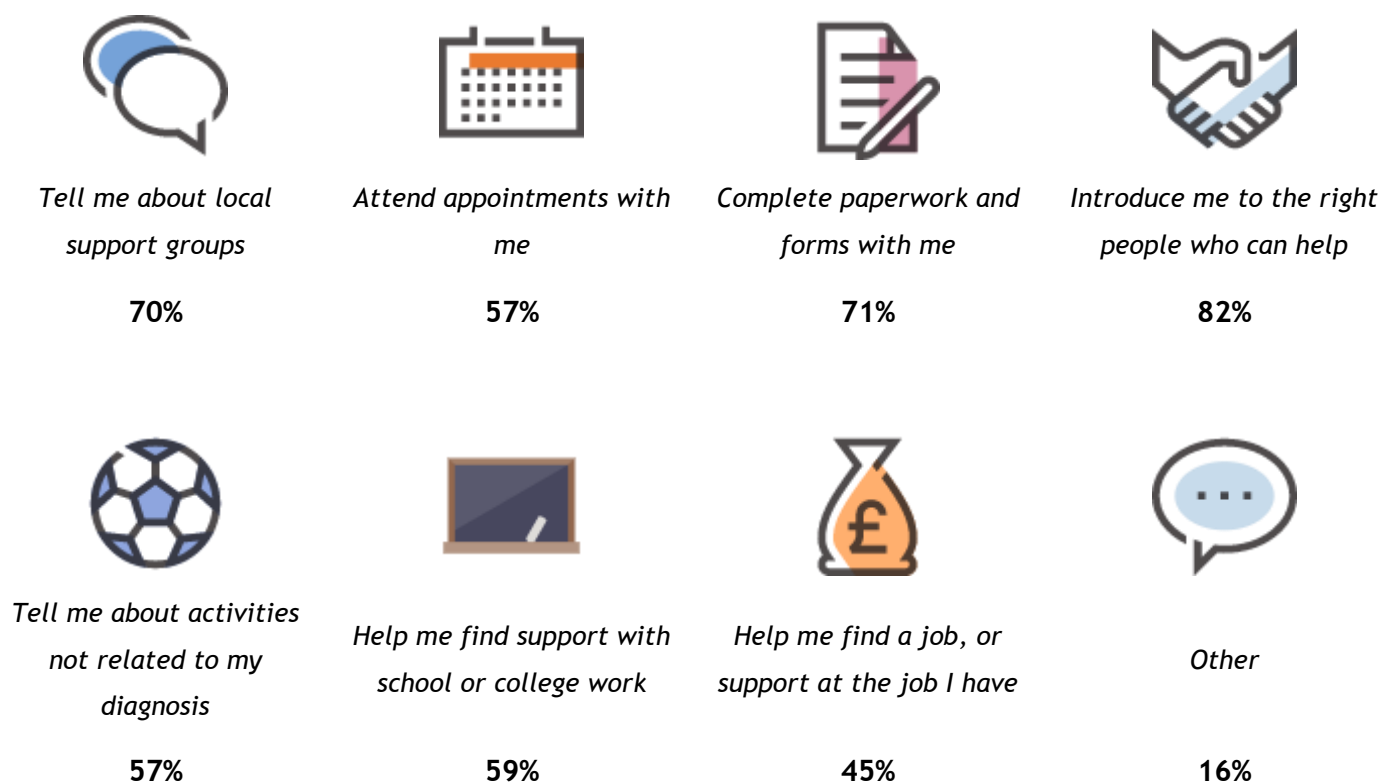
15% of participants also stated that they would like Keyworker support when they are struggling with other health conditions, including mental health. One example given was if a child or young person is diagnosed with a long term condition (such as cancer) they should be able to access Keyworker support to help them through their treatment.

Of the 12% of participants who provided other responses, these included being able to access Keyworker support at times of stress, such as moving schools or changes within school, moving house or times like Christmas and birthdays that can become overwhelming.

Two participants from out of county agreed this was the correct time to receive support and two disagreed. Both of those that disagreed said support should be available before they become at risk of being admitted to hospital.

4.2 HOW CAN A KEYWORKER HELP?

The most important information to understand from this consultation is what they Keyworker will do to support the children, young people and families they work with. Participants were asked *'How do you think a Keyworker could help you and your family?'* Participants were able to select as many of the options as they wanted from the list below.

Tell me about local support groups	*Attend appointments with me*	*Complete paperwork and forms with me*	*Introduce me to the right people who can help*
70%	**57%**	**71%**	**82%**

Tell me about activities not related to my diagnosis	*Help me find support with school or college work*	*Help me find a job, or support at the job I have*	*Other*
57%	**59%**	**45%**	**16%**

The most popular option participants chose is to be introduced to the right people who can help (82% of participants). This was followed by completing paperwork and forms and being told about local groups that can support them. These findings suggest that the most important support a Keyworker can give is to signpost and provide support in accessing other help that will benefit the young person and their families.

Having a Keyworker attend an appointment with the young person and their families was also important (57% of participants), to ensure that the information relayed is understood and any additional support can be coordinated with the Keyworker.

Keyworkers can also support children and young people in ways that are not directly linked to their diagnosis, but this may be a contributing factor to needing support. Having help to find support with school or college work (59% of participants), being told about other activities not related to their

diagnosis (57% of participants) and having help to find a job or support at their current job (45% of participants) would also benefit young people where they usually struggle.

Other suggestions made by participants included helping with bigger life events, such as finding and maintaining their own house, support before a diagnosis is made and when assessments are on-going, work with people close to the young person so that support continues when they cannot communicate effectively or help with tasks that parents and families undertake so that they can spend more time with their children.

From the out of county responses, support completing paperwork and forms was selected by all four participants. Three participants selected 'A*ttend appointments with me'* and *'Introduce me to the right people who can help'*. Two participants selected *'Help me find support with school or college work'*, *'Help me find a job, or support at the job I have'* and *'Tell me about local support groups'*. One participant selected *'Tell me about activities not related to my diagnosis'*. One participant also suggested that a Keyworker can help their family 'do what needs to be done'.

The free text box at the end of the survey allowed participants to submit other ways the Keyworker could support them.

Several participants suggested that the Keyworker could support hospital staff to understand the individual's needs, for example busy waiting corridors can make the situation even more uncomfortable for the young person or ensuring appointments are prompt, as being delayed makes them feel uncomfortable. Another suggestion was to ensure that correct medical help is provided so that families can stay together.

One participant also suggested that the Keyworker can help with meetings, for example the development of Education and Health Care Plans (EHCP), to ensure information is understood correctly and the plan is suitable for the young person.

Another key point made by the participants was that the Keyworker should personalise their support to the individual. Whether this be emotional or practical support, several participants highlighted that everyone is different, especially those who have been diagnosed with autism or a learning disability. This also comes with a caveat from one participant who said that the Keyworker should not be 'too nosy' and allow the young person to share any information about themselves and their family when they are ready to share and have the Keyworker involved.
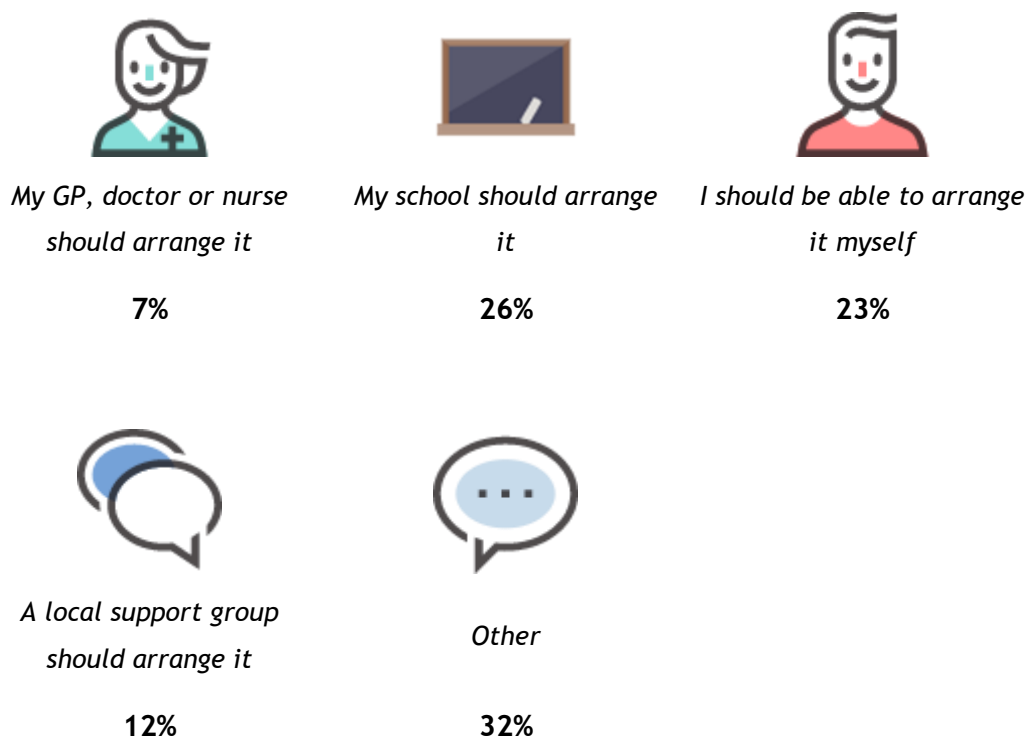
4.3 HOW I WANT TO START GETTING HELP

The current proposal provides Keyworker support to children and young people who are at risk of being admitted to hospital, or already in hospital. Participants were asked what the best way for them to access this sort of support would be, but also generally how they would prefer to access it.

The survey allowed for questions on how to be referred for help, what different types of referral look like and how contact with a Keyworker is initially made and then maintained.

The sections below display the findings from the questions about initial acces to Keyworker support and what this should look like.

4.3.1 HOW I WANT TO BE REFERRED FOR HELP

Participants were asked '*How would you prefer to start accessing Keyworker support if you need it?*' and participants were able to pick only one of the options below (as their *preferred* choice).

My GP, doctor or nurse should arrange it

7%

My school should arrange it

26%

I should be able to arrange it myself

23%

A local support group should arrange it

12%

Other

32%

The most popular response was that schools should be able to arrange this support, with 26% of participants selecting this. Referring themselves was the second most preferred choice with 23% of participants preferring this.

When looking at the responses submitted under the '*Other*' option, most participants referenced their parents or family arranging the help for them. If combined with the 23% of participants who preferred '*I should be able to arrange it myself*' a form of self-referral would become the most preferred choice.

Local support groups (12% of participants) and GPs (7% of participants) scored lower than the rest of the options, suggesting again that relationships are key in understanding who needs help and support and that it shouldn't necessarily be made by people using thresholds as a means of access.

When selecting '*I should be able to arrange it myself*' participants were provided with a second list of self-referral options detailed below.

Online form	*Phone call*	*Text/WhatsApp*
40%	**20%**	**15%**

Email	*I drop in somewhere*	*Video call*
10%	**10%**	**5%**

40% of these participants would prefer to arrange help themselves through an online form. Those who selected '*I drop in somewhere*' were able to provide information on where they would prefer to drop in, with one participant saying school and another saying somewhere local to home.

Participants from outside of the county suggested the following ways of referring into Keyworker support. Two stated that it should be a family referral into the service, one said that their school should arrange it and one said it should be their GP, doctor or nurse that arranges it.

4.3.2 HOW I WANT MY KEYWORKER TO MAKE CONTACT WITH ME

Participants were asked how they would prefer the initial contact after a referral to a Keyworker to be made with them from a list of options. Again, this question asked for their preferred option and so participants could only select one of the choices.

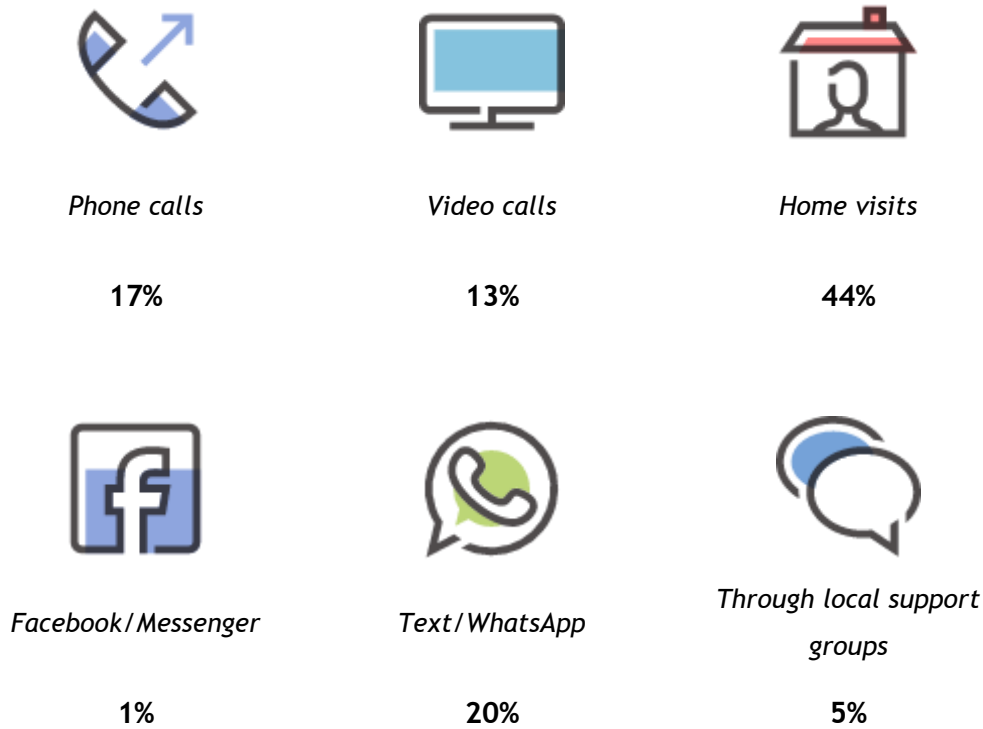|			
Local NHS website	*Through my GP, doctor or nurse*	*Facebook/Messenger*	*Email*
5%	**13%**	**0%**	**16%**
Text/WhatsApp	*Phone call*	*Video call*	*Through a local support group*
26%	**20%**	**11%**	**10%**

The most popular choice for initial contact was to be made via text and/or WhatsApp messaging services (26% of participants). Second to this, participants would prefer a phone call (20% of participants).

No one would like to receive initial contact through Facebook and/or Facebook Messenger, and a very small proportion (5%) would like to see this from a local NHS website.

Two participants from outside the county would like the initial contact to be made via a phone call. One of these participants stated they would want this via text/WhatsApp and one stated that the initial contact should be through their GP, doctor or nurse.

4.3.3 HOW I WANT TO STAY IN TOUCH WITH MY KEYWORKER

Following initial contact, young people would need to remain in contact with their Keyworker to ensure that the support they are receiving is working. Participants were asked *'How would you like to stay in touch with a Keyworker?'* and again this question only allowed for their most preferred option to be chosen. The options available to choose from are listed below.

Phone calls

Video calls

Home visits

17%

13%

44%

Facebook/Messenger

Text/WhatsApp

Through local support groups

1%

20%

5%

The most preferred method of staying in contact with a Keyworker was for them to undertake home visits (44% of participants) with the young people and their families. Following this was text and/or WhatsApp contact (20% of participants), phone calls (17% of participants) and video calls (13% of participants).

Very few participants would like contact to be maintained through local support groups or Facebook/Messenger services.

Three of the four participants from outside of the county said that Keyworkers should stay in contact via phone calls. The fourth participant suggested this should be maintained through text/WhatsApp.

4.4 ENDING THE HELP I RECEIVE

A vital part of ensuring Keyworkers can support as many young people as they can is being able to reduce and end support with young people who no longer need it. Participants in this consultation were asked their views on how they would like to see support reduced when they no longer need it and after how long they would like to start reducing the support offered.

4.4.1 HOW LONG I WANT TO BE HELPED FOR

Participants were asked *'How long do you think a Keyworker should help you and your family?'* and asked to pick one of the following options: 1 month; 3 months; 6 months; 1 year or other. The chart below outlines the results from this question.

How long do you think a Keyworker should help you and your family?

- ■ 1 month — 5%
- ■ 3 months — 12%
- ■ 6 months — 10%
- ■ 1 year — 17%
- ■ Other — 56%
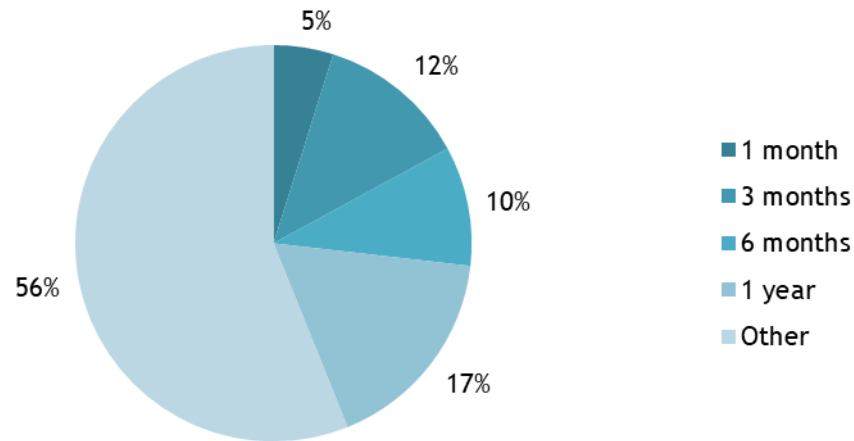
As can be seen from the chart, more than half of the participants did not want to select a specific time frame for support from a Keyworker. Of those that selected '*Other*' 72% said that support should be available for as long as it is needed. Some participants provided longer time frames, such as for two years or lifelong, and some suggested that Keyworkers should still maintain contact with individuals and check in on them a couple of times a year to make sure they are still coping without additional support.

One participant from outside the county stated that the Keyworker should support them for a year. The remaining three participants selected other, with two of these saying that the support should be there as long as it is required. The final participant said that the support should be for 'a short time before, during and after hospital'.

4.4.2 HOW MY KEYWORKER CAN REDUCE THE HELP THEY GIVE ME

The survey allowed for participants to select ways in which the support they are given by a Keyworker can be reduced or ended. The question asked was '*When you feel you no longer need help, how should a Keyworker reduce their support?*' and participants were able to select as many of the options below as they wanted.

Meet with me and my family so I can tell them I do not need any more help

35%

Give me contact details to use if I feel like I am struggling again

51%

Occasionally meet with me and my family to see how I am doing without their help

72%

Visit me at a local support group to see how I am doing without their help

13%

Arrange for me to have additional help from other local support groups

15%

Other

2%

The options with the highest responses were occasionally meeting with the young person and their families (72% of participants) and being given contact details to use if they feel they are struggling again (51% of participants). These choices suggest that children and young people would value the independence of not receiving Keyworker support when it is unnecessary, but also the opportunity to return to it if it is needed in the future. Having other help available when needed was also mentioned in one of the '*Other'* responses.

Meeting with the young person and their family so they can explain that help is no longer needed is also important to the participants. Over a third of participants selected this option which supports the findings from the length of time the support is available, where most participants said that the support should be there for as long as it is needed. This was also mentioned in one of the '*Other'* responses.

Local support groups also have a role to play in the reducing of support, either by being a place where Keyworkers can visit and meet with the young person, or be a source of additional support in the long term once the Keyworker support has ended.

The participants from outside of the county responded to this question in the following way:

- Two participants selected '*Meet with me and my family so I can tell them I do not need any more help'*;
- one participant selected '*Give me contact details to use if I feel like I am struggling again'*;
- all four participants selected '*Occasionally meet with me and my family to see how I am doing without their help'*;
- one participant selected '*Visit me at a local support group to see how I am doing without their help'* and
- one participant selected '*Arrange for me to have additional help from other local support groups'*

5. Recommendations

This section utilises the findings in the report to suggest recommendations to be considered and implemented in the Keyworker pilot project.

Keyworkers should support the relationships young people have with professionals.

Children and young people were more likely to feel comfortable talking about their needs and the help and support they wanted with people they knew better, for example, teachers, social workers and adults at local support groups. Keyworkers could focus support on building and maintaining relationships with other professionals, such as in healthcare as more participants felt uncomfortable talking to these professionals about their needs.

Support should be available when young people feel they need it as well as for those who are at risk of being admitted to hospital.

40% of participants disagreed that a Keyworker support should only be available to those who are at risk of being admitted to hospital or already in hospital. The offer of Keyworker support should be made available for children and young people who feel they need additional support, to try and prevent them becoming at risk of being admitted to hospital.

Keyworkers should be knowledge holders of other relevant support available for children, young people and their families.

Young people do not just want support related to their diagnosis and have reported that Keyworkers can inform them of other activities and support not related to their diagnosis. The Keyworker does not necessarily need to know all of this information, but should know where they can go to find it and support the young person and their family to access other support.

Understanding the needs of the individual is important in understanding what support they need.

Several participants have stated that their needs are personal to them and any support should be tailored to the individual. The Keyworker should work with individuals and families to ensure that the support they are offering is suitable and will be beneficial. Familiarity is key for autistic people and maintaining a longer term relationship would be preferable to different Keyworkers working with the young person.

Work with the young person and their family to determine how long the help should be available for.

There should not be a set time scale for the support given, but this should be discussed with the family at ongoing intervals to determine the appropriate levels of support required to meet the presenting needs of the young person.

Reducing help should be done with the young person and their family.

The help offered by a Keyworker should be reduced eventually with some participants stating that they want the independence of looking after themselves. This should be done with the young person and their family, with many still appreciating occasional check-ins to make sure that they are still coping without the Keyworker help.

Provide means for young people to receive Keyworker support again if they need it.

Young people still want to know they are able to access support when they feel like they need it. This could be through providing contact details for the Keyworker, or the service in general or through occasional check-ins with the young person once more intense support has been reduced.

6. Conclusion

The Keyworker role should be informed and shaped by the young people that they are working with. Keyworkers should ensure that the decisions agreed are to the benefit of the young person and their family and actioned with the child, young person and/or family. The Keyworker should provide professional accountability to other partners supporting the young person and their family, but not necessarily challenge the decision made by professionals. Challenge should arise when outcomes are not being met and the child or young person is not receiving the support they need in a timely, responsive way.

Engagement of service users due to their 'expertise by experience' is vital to ensuring the role remains relevant and useful for the children, young people and families Keyworkers are supporting. Engagement should be built into all levels, from recruitment and appointment of Keyworkers, to ongoing evaluation and feedback. This will ensure good practice of engaging with service users becomes embedded into the role. Embedding this practice will also improve co-production in future services with the cohort the Keyworkers are targeting.

7. Appendices

7.1 QUESTIONNAIRE DOCUMENT

Consent

If participants do not want to take part in the survey/interview then we are unable to take their views.

Thank them for their time so far. If they want more information they can contact Josh Armitage on josh@staffscvys.org.uk or 07429 748227.

I understand the supporting information and am happy to participate in this survey.					
Yes		No			
Do you consider yourself:					
Autistic		Autistic with a learning disability		Living with a learning disability	

About help you get now

Where do you currently go for information about help and support? (Pick all that apply)					
Your GP, doctor, or nurse		Internet/Online		Friends	
Family		Social Media		Local Support Groups	
At school		Keyworker		Other	
IF OTHER: Where else do you go for information?					

IF INTERNET/ONLINE: *Which websites do you use for information?*	
IF SOCIAL MEDIA: *Which social media so you use for information?*	
IF LOCAL SUPPORT GROUPS: *Which local support groups do you use for information?*	
Have you ever had one-to-one support in the past?	*Yes* *No*
IF YES: *Who was this and how did they help you?*	

How comfortable do you feel talking to people in these situations about the help and support you need?

Please select 'Not applicable' if the situation does not apply to you, for example if you are not in education any more.

My education (e.g. teachers, SENDCOs, head teachers or principals)

Very uncomfortable		Uncomfortable		Unsure		Comfortable		Very comfortable		Not applicable	

My health (e.g. GPs, nurses, doctors or specialists)

Very uncomfortable		Uncomfortable		Unsure		Comfortable		Very comfortable		Not applicable	

My care (e.g. social care or support workers)

Very uncomfortable		Uncomfortable		Unsure		Comfortable		Very comfortable		Not applicable	

My employment (e.g. job coaches, interviewers, managers or colleagues)

Very uncomfortable		Uncomfortable		Unsure		Comfortable		Very comfortable		Not applicable	

Local support groups related to my diagnosis

Very uncomfortable		Uncomfortable		Unsure		Comfortable		Very comfortable		Not applicable	

Other groups or activities that are not related to my diagnosis

Very uncomfortable		Uncomfortable		Unsure		Comfortable		Very comfortable		Not applicable	

Getting help in the future

A Keyworker will only be able to support you and your family if you are at risk of going into hospital, or are already in hospital. Do you agree this is when you should get help from a Keyworker?

Yes		No		

IF NO:

When should you be able to get help from a Keyworker?

How do you think a Keyworker could help you and your family? (Pick all that apply)

Tell me about local support groups		Attend appointments with me		Complete paperwork and forms with me	
Introduce me to the right people who can help		Tell me about activities not related to my diagnosis		Help me find support with school or college work	
Help me find a job, or support at the job I have		Other			

IF OTHER:

How else could a Keyworker help you and your family?

How would you prefer to start getting help from a Keyworker? (Pick one option)

My GP, doctor or nurse should arrange it		My school should arrange it		I should be able to arrange it myself		A local support group should arrange it	

Other		**IF OTHER:** How would you prefer to start getting help from a Keyworker?	

IF I SHOULD BE ABLE TO ARRANGE IT MYSELF: How would you like to arrange Keyworker help for yourself? (Pick one option)

Online form		Phone call		Text/WhatsApp	
Email		Video call		Drop in	

IF I DROP IN: Where would you like to drop in to access Keyworker support? (Pick one option)

GP Surgery/Health Centre		Library		School	
Local Support Group		Other			

IF OTHER:

Where is the best place for you to drop in to self-refer?

How would you like to first make contact with a Keyworker? (Pick one option)

Local NHS Website		Through my GP, doctor or nurse		Facebook/Messenger	
Email		Text/WhatsApp		Phone call	
Video call		Through a local support group			

How would you like to stay in touch with a Keyworker? (Pick one option)

Phone calls		Video calls		Home visits	
Facebook/Messenger		Text/WhatsApp		Through local support groups	

How long do you think a Keyworker should help you and your family? (Pick one option)

1 month		3 months		6 months	
1 year		Other			

IF OTHER:

How long should a Keyworker help you for?

When you feel you no longer need help, how should a Keyworker reduce their support? (Pick all that apply)

Meet with me and my family so I can tell them I do not need any more help		Give me contact details to use if I feel like I am struggling again		Occasionally meet with me and my family to see how I am doing without their help	
Visit me at a local support group to see how I am doing without their help		Arrange for me to have additional help from other local support groups		Other	

IF OTHER: How else could the Keyworker reduce their support?	
Do you have any other suggestions or comments on how a Keyworker can support you and your family? (Optional)	

About you

Postcode						
How old are you (or your child)?	0-5 years		6-10 years		11-14 years	
	15-18 years		19-24 years		26 years or over	

Ethnicity				Prefer not to say	

White		Asian or Asian British		Mixed/Multiple ethnic groups		Black/African/ Caribbean or Black British		Other ethnic group	
English/Welsh /Scottish/ Northern Irish/ British		Indian		White and Black Caribbean		Caribbean		Arab	
Irish		Pakistani		White and Black African		African		Any other ethnic background	
Gypsy or Irish Traveller		Bangladeshi		White and Asian		Any other Black background			
Any other White background		Chinese		Any other Mixed Background					
		Any other Asian background							
Please state other background:									

Keeping in touch

We hope to be able to share findings and recommendations in June 2021. If you would like to see a copy of our findings and recommendations please leave your details below.

I am happy to be contacted in the future with information about the findings and recommendations from this research.				
Yes		No		

I would like to be contacted to take part in the interview process with applicants for the Keyworker role.				
Yes		No		

IF YES TO EITHER OF THE ABOVE: Your email address	