



Parent/Carer Survey Workshop Neurodevelopmental Services for children and young people and their families in Sheffield 7 December 2021



Housekeeping



Agenda

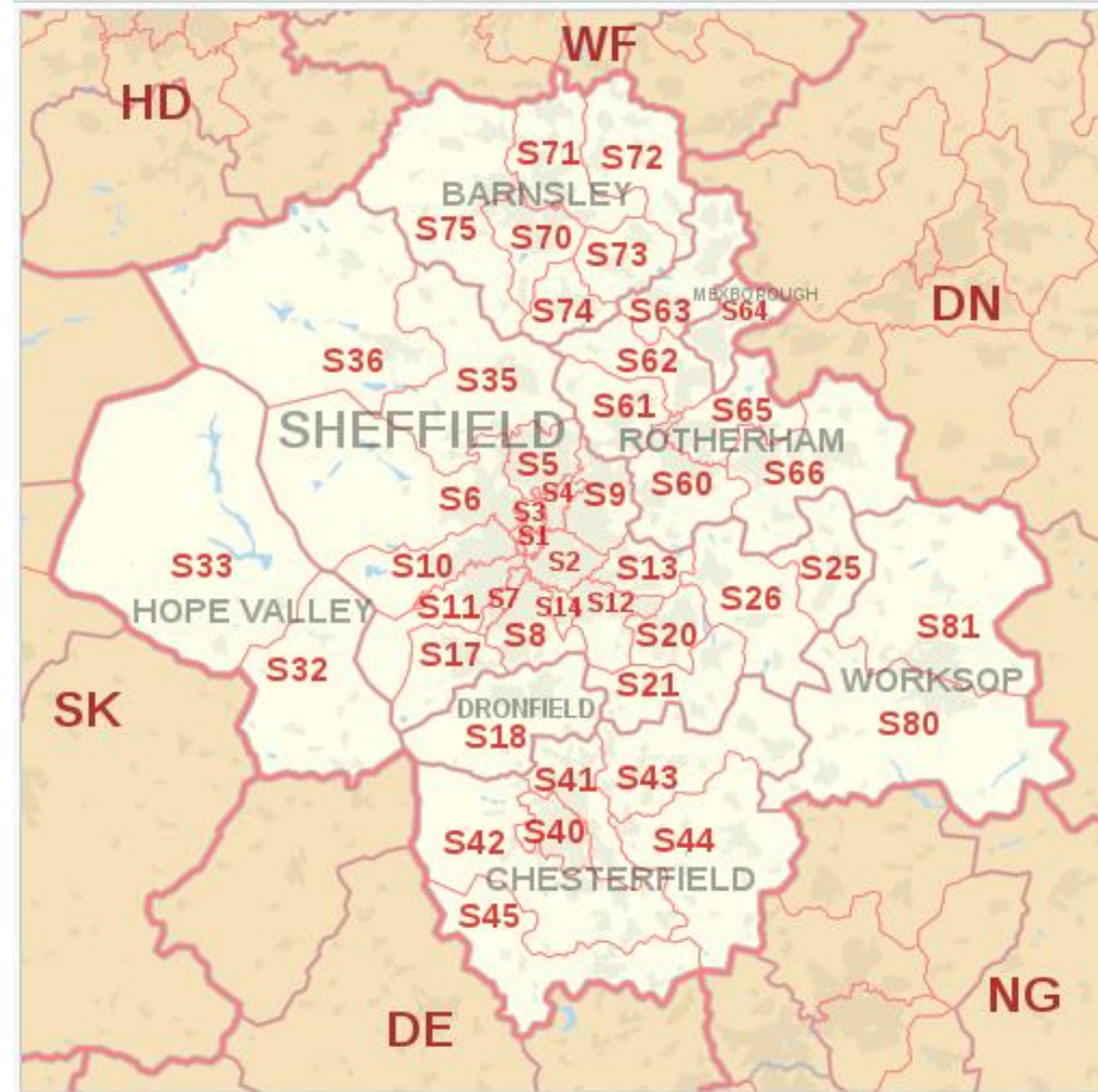
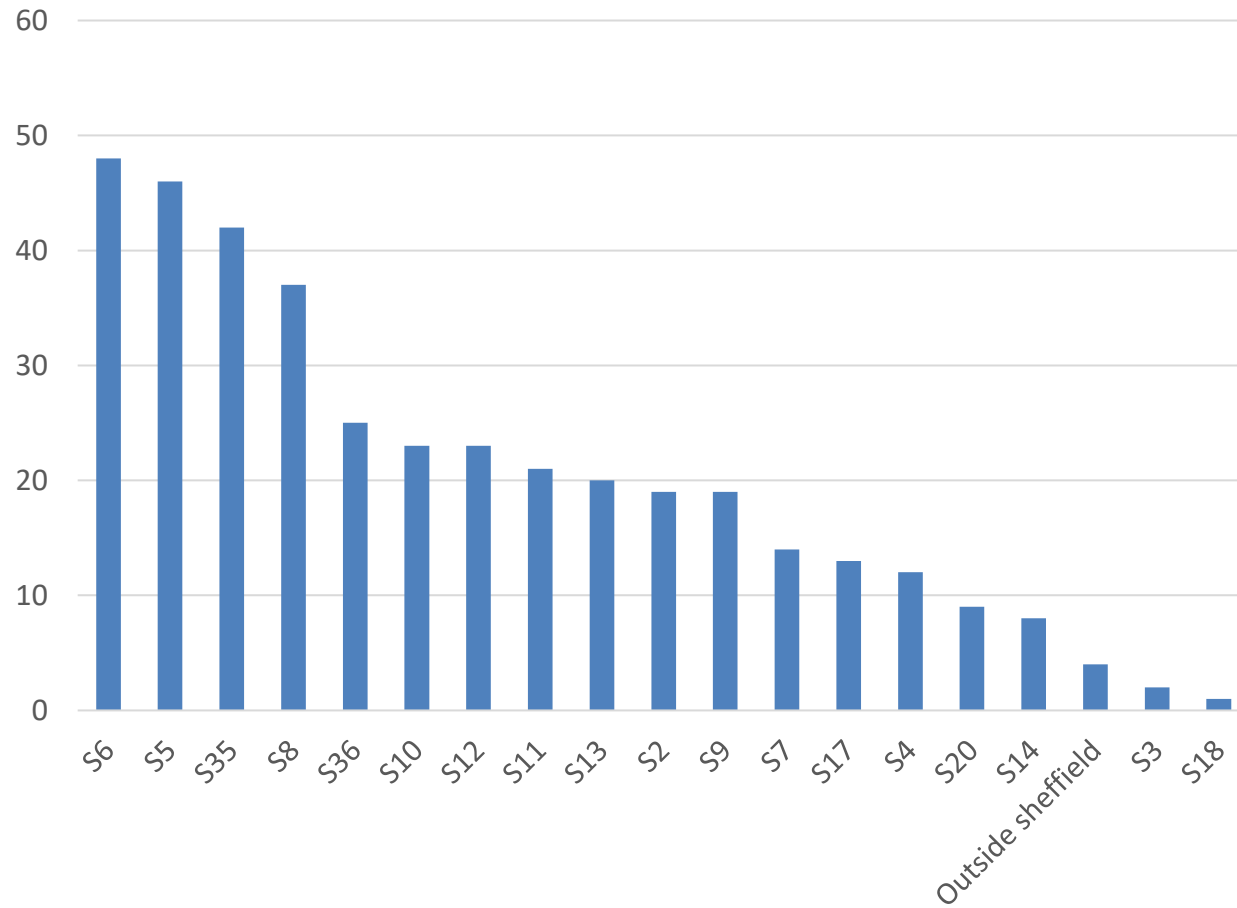
- 1. Introduction**
- 2. Review remaining responses to question 7, 27, 28 from 3 November to 18 November**
- 3. Discuss and identify what the survey is telling us about what support parents/carers want, what is available now, and what are the gaps**
- 4. Next steps**
- 5. Close**



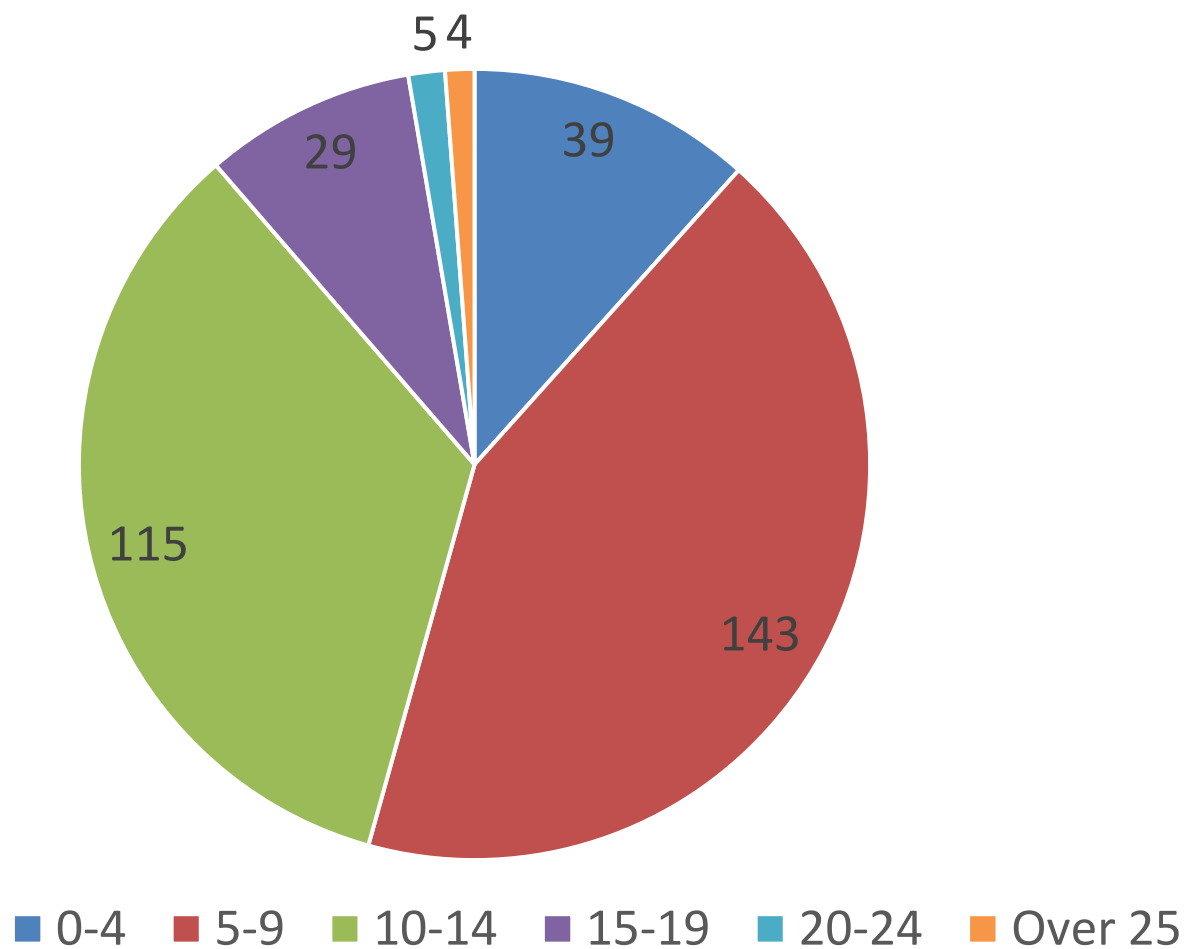
Highlight results from the survey



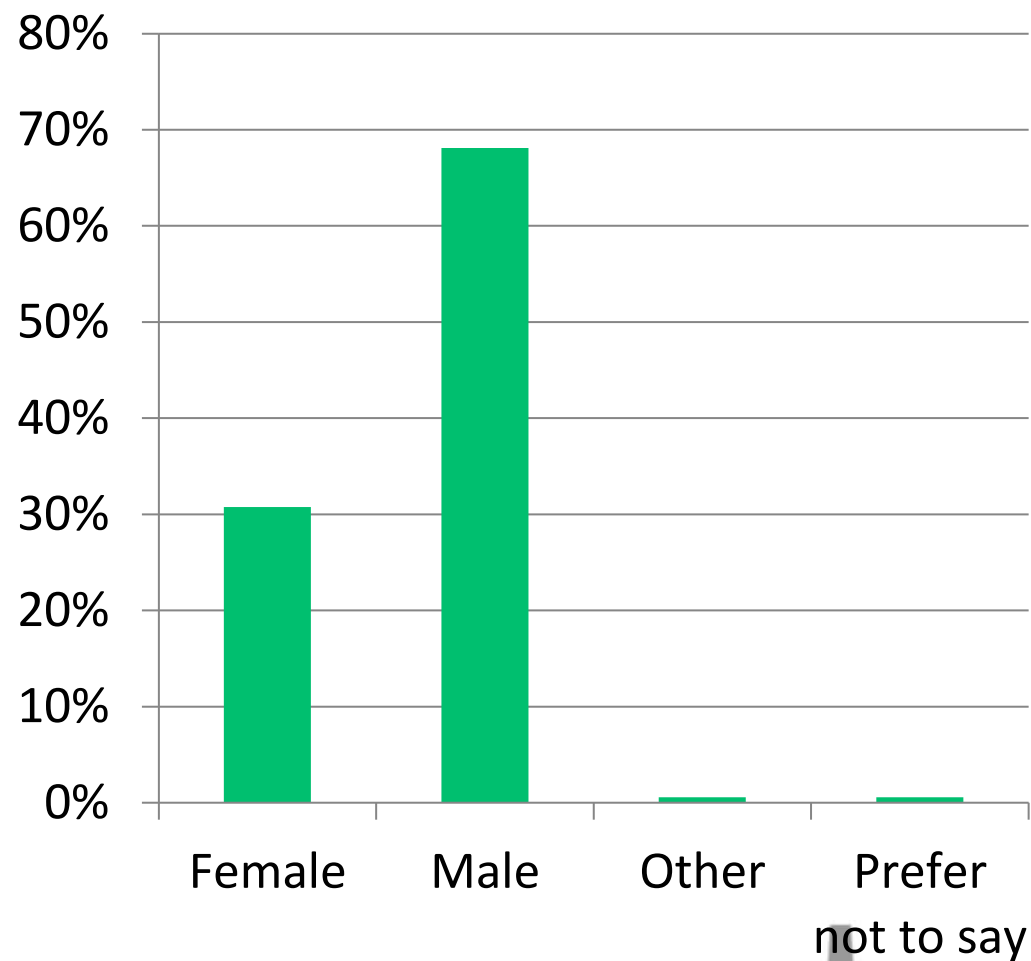
Postcode Distribution of Respondents



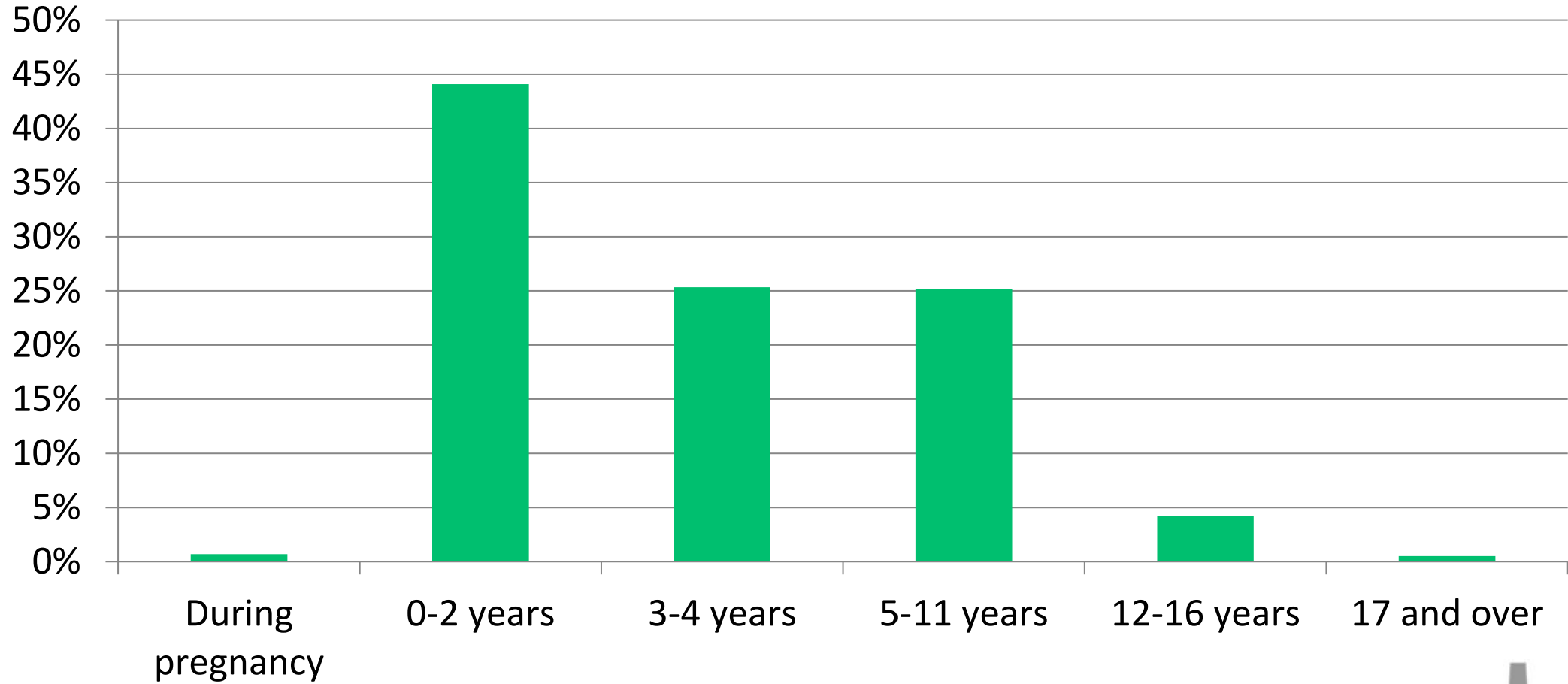
Age distribution of respondents' children



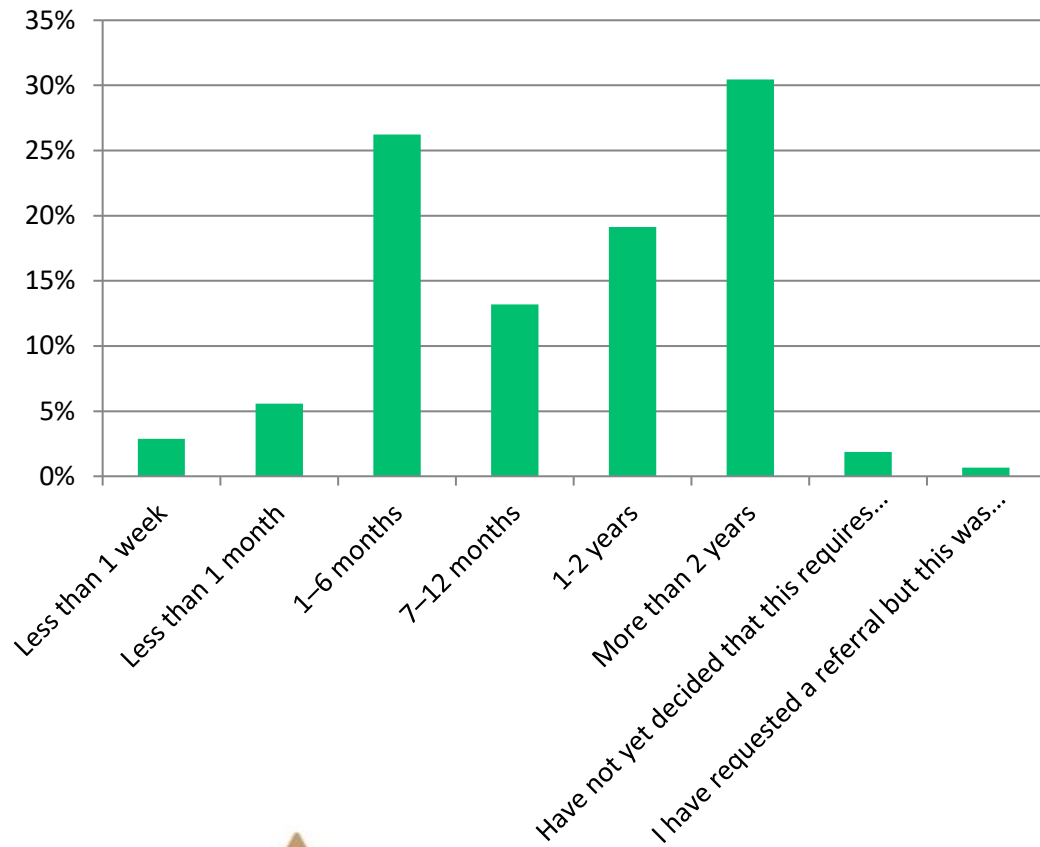
What is their sex?



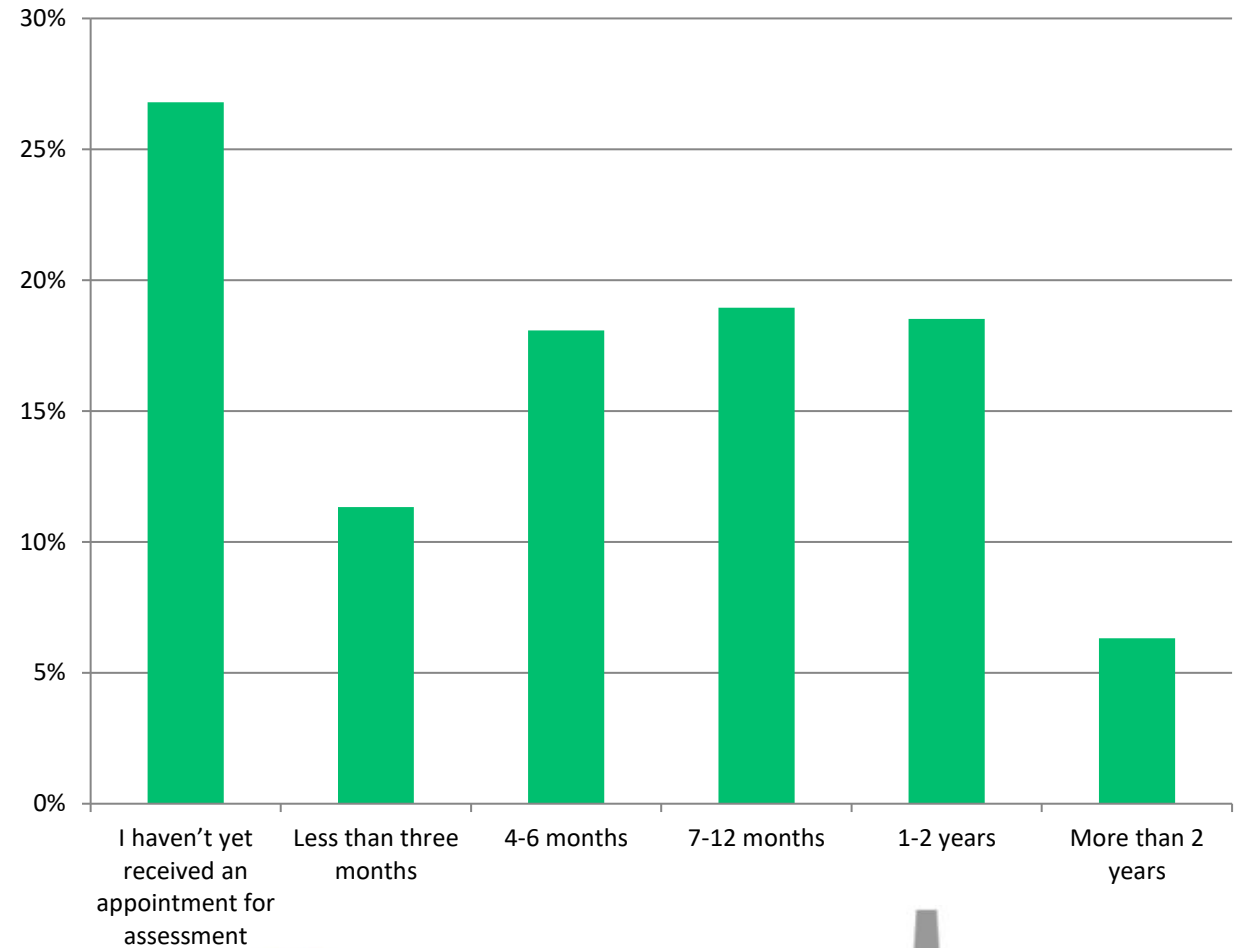
How old was your child when you (or someone else) first raised concerns about their development



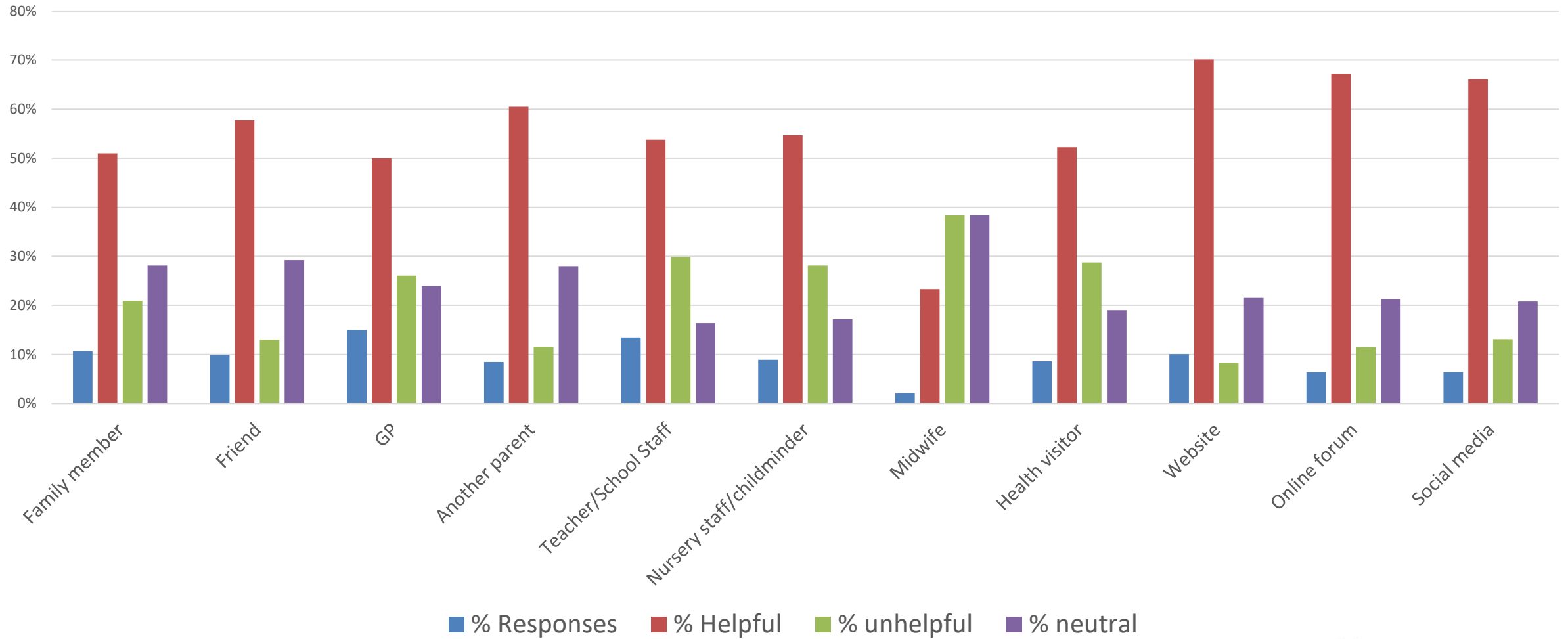
How much time passed after your child's needs were noticed and a decision was made to request further investigation? e.g. an assessment



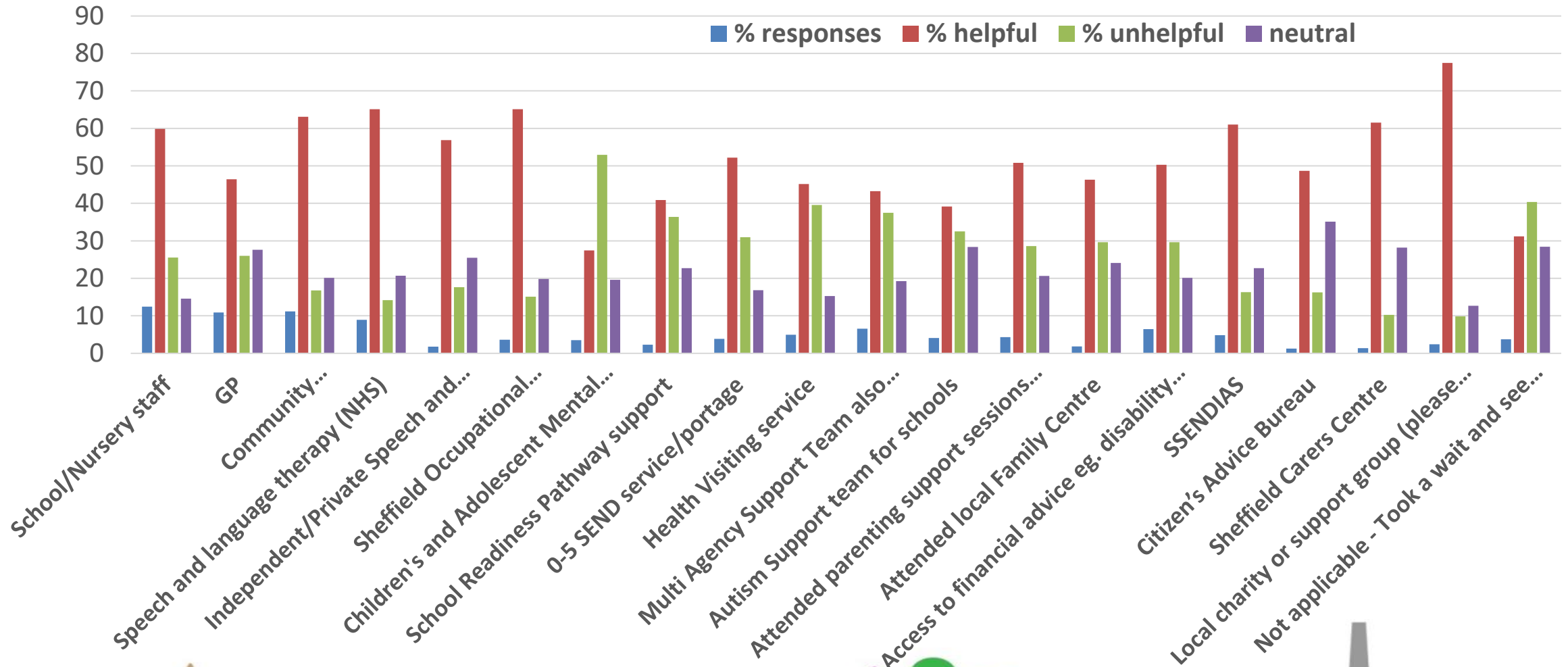
Once referred for this assessment, how long did you have to wait for your child's appointment?



Q3 Once you became aware of your child's needs, where did you go to for further information, and how helpful was this?



Question 5 Where did you receive further support from, and how helpful was this?



Themes from last workshop



Key themes from responses up to 3 November identified at workshop on 9 November 2021

- **Reduce Waiting Times for assessment appointments at Sheffield Children's**
- **Regular and consistent support and advice for families both pre and post diagnosis eg. one point of contact**
- **Join up services/teams to make it easier to communicate with each other for those who have more than one neurodevelopment condition eg. for children who have both autism and a learning disability**
- **Regular communication from Sheffield Childrens to update on waiting list and likely waiting times – helps to manage expectations.**
- **Schools/Nurseries - increase support to children and families in schools/nurseries and increase awareness of staff on neuro conditions.**
- **Tailor services to the needs of children eg. differences in presentation of autism in girls and boys, post 14 teenagers, young carers**
- **Listen to parents, don't dismiss what they are saying eg. some parents said that they had raised concerns early in their child's development but were dismissed by professionals.**

Link to jamboard: https://jamboard.google.com/d/15XktAqID_fzbvtxiAdDUk_zmPG5EUqQszD8sCL9-GS8/viewer?f=19

What one thing would you change to improve the service

General actions for programme to address

- Shorter waiting times for assessment
- Better communication whilst on waiting list
- Easier access to professionals
- Early identification of need
- Raise awareness of conditions in schools
- Age specific support
- School support based on need - don't wait for a diagnosis
- Improve autism and portage team support in Council.
- Joined up services for neuro conditions.

Specific actions to support parents:

- Access to therapy to come to terms with diagnosis.
- Named keyworker role for pre and post diagnosis advice and support
- Helpline for parents
- Booklet provided with details of help, support etc.
- Take a whole family approach – if one child has autism, diagnose siblings as well.
- Treat parents as experts with regard to their children's needs.



Next Steps

- We will share all write ups on the Sheffield CCG website.
- <https://www.sheffieldccg.nhs.uk/get-involved/neurodevelopment-transformation-programme.htm>
- Continue analysis on other questions.
- Continue discussion on how we provide support for parent/carers via Workstream 2
- Report findings to senior decision makers.





THANK YOU

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