

# Norfolk Autism Research Project – Summary Report

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## Introduction

Norfolk County Council commissioned a new service that aims to deliver short-term low-level support for autistic adults. The service involves one-to-one work with a coach for up to 12 weeks. The support will focus on a specific issue, for example: life skills, confidence building, or accessing other services. This research project was set up to find out how best to evaluate the impact of this type of service. Norfolk County Council (NCC) and the University of East Anglia (UEA) worked together on this project which took place from October 2023 to March 2024.

This summary report aims to share the key learning from the project. NCC and the UEA aim to use this learning to apply for funding from the National Institute for Health and Care Research to enable a much bigger research project. We also hope this learning will support development of autism support services both locally and nationally.

## Aims: what we wanted to know

- We wanted to understand more about the needs, wellbeing and quality of life of autistic adults in Norfolk. We also wanted to know how we can measure this to evaluate effectiveness of a low-level service.

## Methods: what we did

- **We set up an Autism Research Group** that included five autistic adults. The group met regularly to support development of the work and ensured an autism perspective throughout. The group contributed to developing the survey, interpreting the findings and co-designing this report.
- **We did a scoping review** to understand what research has already been done on low-level and short-term support services, and what similar services currently exist in the UK.
- **We carried out a survey** to find out more about the needs, wellbeing and quality of life of autistic adults in Norfolk, and how we can measure this to evaluate effectiveness of the service.

## Findings

### Scoping review

- There is a scarcity of research into services providing low-level support for autistic adults. Some studies suggest positive impacts, including increased access to education, employment, improved social connections, health and wellbeing, and managing day-to-day life. There is a need for robust research to extend the evidence base to inform policy making and practice.
- There are pockets of practice across the UK where low-level or short-term support services (similar to the Norfolk service) have been established. These services could share learning to better understand how low-level and short-term support services can be most effective.
- Accurate measurement of quality of life is important for evaluation of autism services and trials of interventions. Many different quality of life measures exist, and it is important to use measures which are accessible and meaningful to autistic people. Based on our scoping work and working with the Autism Research Group, we selected two measures to pilot with autistic adults in Norfolk to assess their quality of life<sup>1,2</sup>.

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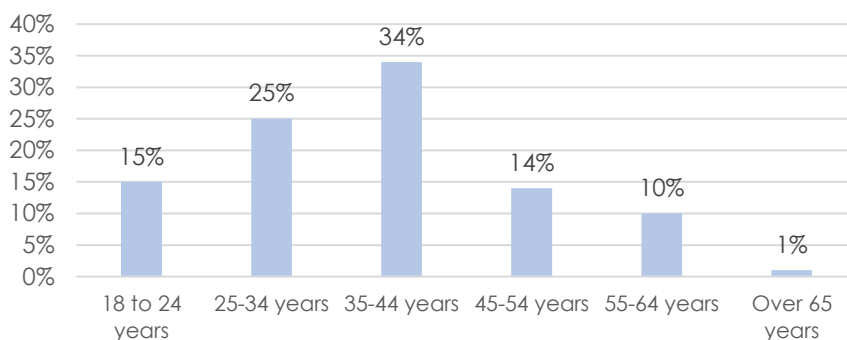
<sup>1</sup> World Health Organisation Quality of Life measure (WHOQOL-BREF): The World Health Organization. (1996). WHOQOL-BREF: Introduction, administration, scoring and generic version of the assessment: field trial version, December 1996. World Health Organization.

<sup>2</sup> Autistic Spectrum Quality of Life measure (ASQoL): McConachie, H., Mason, D., Parr, J.R., Garland, D., Wilson, C. & Rodgers, J. (2017) Enhancing the validity of a Quality of Life measure for autistic people. *Journal of Autism and Developmental Disorders*.

## Survey response

The survey was open from January to February 2024. 119 autistic adults provided a full response. The characteristics of people who responded are outlined below:

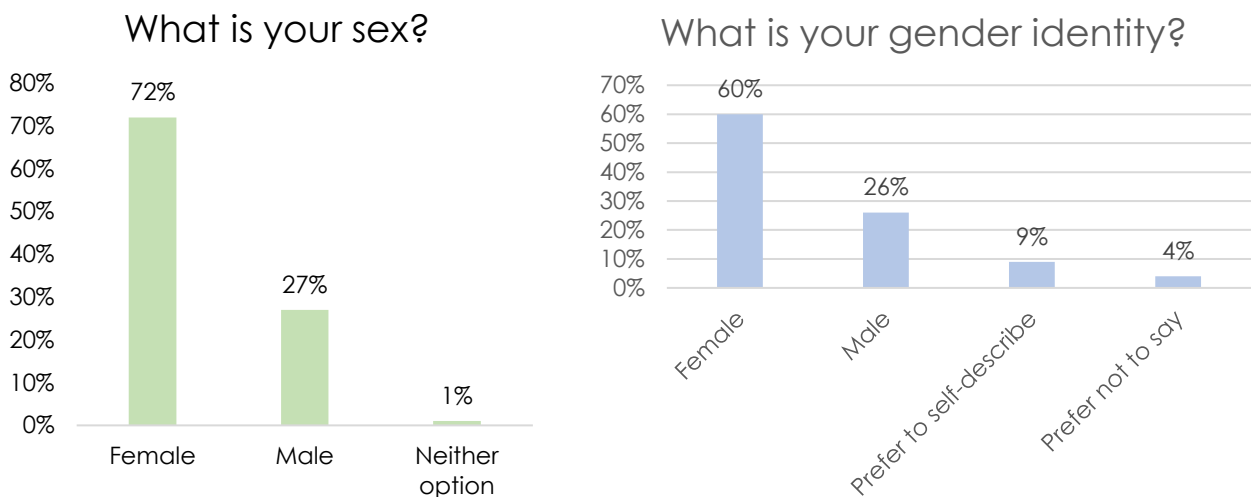
### Age group



- The majority of respondents (74%) were under 45 years old. Of these, the biggest group of respondents were those aged 35-44 years (34%). These findings may reflect:
  - National statistics which show autistic identity is observed at higher rates in younger age groups.
  - The channels used to publicise the survey, which may have better reached younger people.
  - More interest in this type of service among younger people. For example one respondent said they would have benefitted more at a younger age:

“ I definitely wish something like this existed for when I was younger and whilst I was thankful for my eventual diagnosis in adulthood, I think it would have been more beneficial ten years earlier. ”

## Sex and Gender



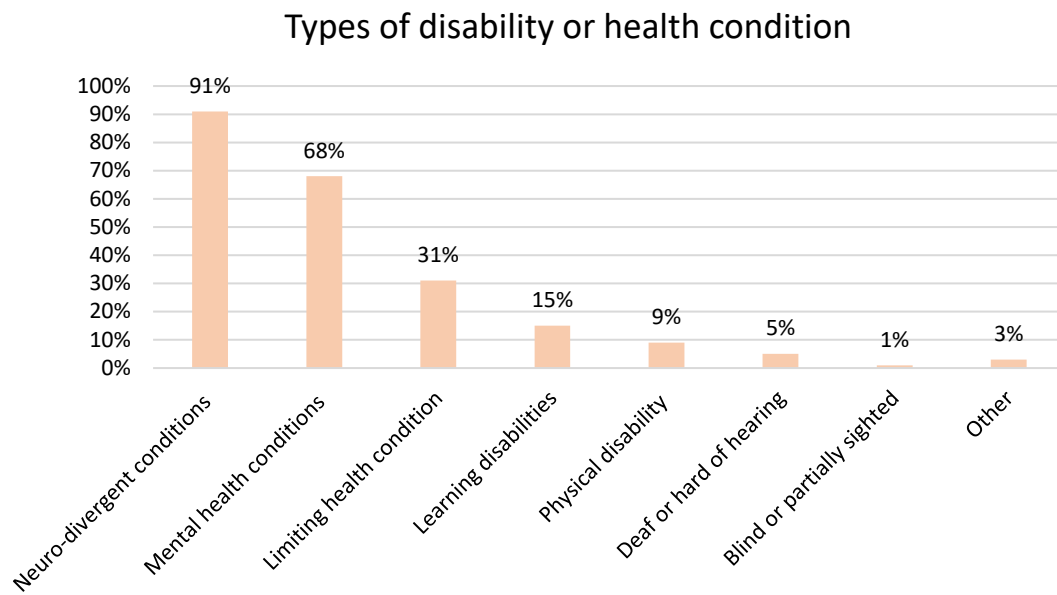
- 72% of respondents were female. Despite active attempts to share the survey with men's groups in Norfolk, men are under-represented. This may reflect the gendered nature of both willingness to take part in surveys and participation in the social media channels or community groups used to publicise the survey.
- 9% of respondents (who also all stated their sex as 'female' or 'neither option') preferred to self describe their gender identity (e.g. agender, genderqueer, non-binary, transgender). This compares to 0.3% of the Norfolk population. This finding reflects wider research which shows intersections between neurodivergence and LGBTQ+ identities.

## Ethnicity

- The majority described themselves as white (92%), with 5% of mixed or multiple ethnic groups and 2% specifying an other ethnic group. This is representative of the Norfolk population (which is 95% white). However one respondent from an ethnic minority highlighted how living in a predominantly white county can impact on how accessible services feel:

“ Being non white AND autistic is different than being white and autistic. It can have a big impact on how people feel accessing groups and areas of Norfolk. For example, as an autistic person, how do you handle being stared at? ”

## Disability



- Overall 92% of respondents said they had a long-term illness, disability or health problem that limited daily activities or work. The types of disability or health condition are shown in the chart above.
- The majority (91%) of those that said they had a disability cited a neurodivergent condition. However not all respondents may have viewed autism itself as what disabled them, as many also reported other conditions such as mental health issues. One respondent commented on the potential interaction between autism and co-occurring conditions:

“  
Autism affects other  
disabilities and vice-versa.  
”

## Survey findings

### Need for a low-level support service:

Comments from survey respondents indicated a sense of isolation, trying to cope alone with a lack of support, with some feeling their needs were considered too 'low-level' to be eligible for help. Many respondents were positive about the idea of a new low-level short-term service:

“ I've been just about holding things like work together because they are so important to me but identified that I can't manage this, asked for help, and been told I'm not eligible because I am (apparently) managing, leaving me until I reach a full on crisis. ”

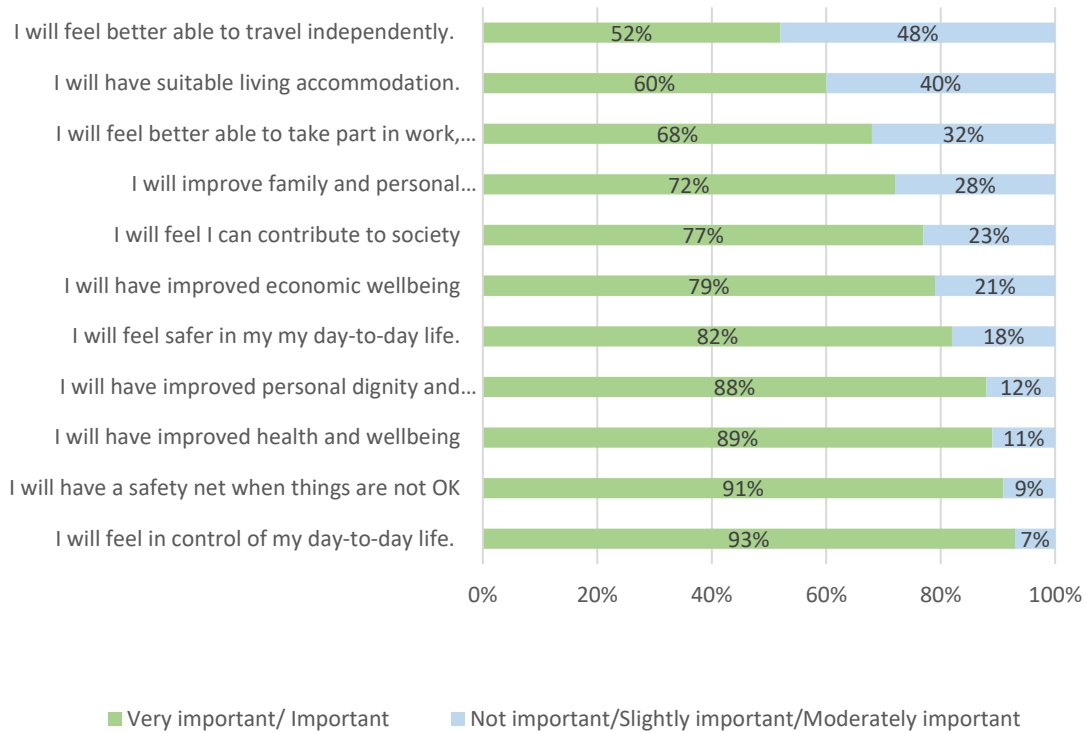
“ My level of needs is too low to meet the criteria for the support offered so I struggle on my own. ”

Several respondents also emphasised the importance of continued engagement with autistic people about development of the service. For example, one respondent commented:

“ When services like this reach out like this, it is more encouraging to participate. ”

### Personal outcomes from a support service

- Autistic adults in Norfolk reported that they would like support from a service across a whole range of outcomes. The top priorities were directly related to mental health and wellbeing. What was especially important to respondents was having a safety net to fall back on to stop problems escalating, and feeling in control of day-to-day life.



The following responses show the kind of issues autistic adults said they would like help with:

“ My physical and mental health is in decline through trying to carry on with life through burn out and no support. ”

“ I struggle with communication with my family, husband, children, and need help navigating this. ”

“ I have multiple disabilities and I'm getting very little support. I have been declined for PIP and...I am getting further into debt. ”

“ I have particular difficulty with getting and keeping suitable employment in spite of being very highly qualified. ”

“ I struggle with noises and interactions with other people even with my kids, as my brain feels fried after having to interact with anyone. ”

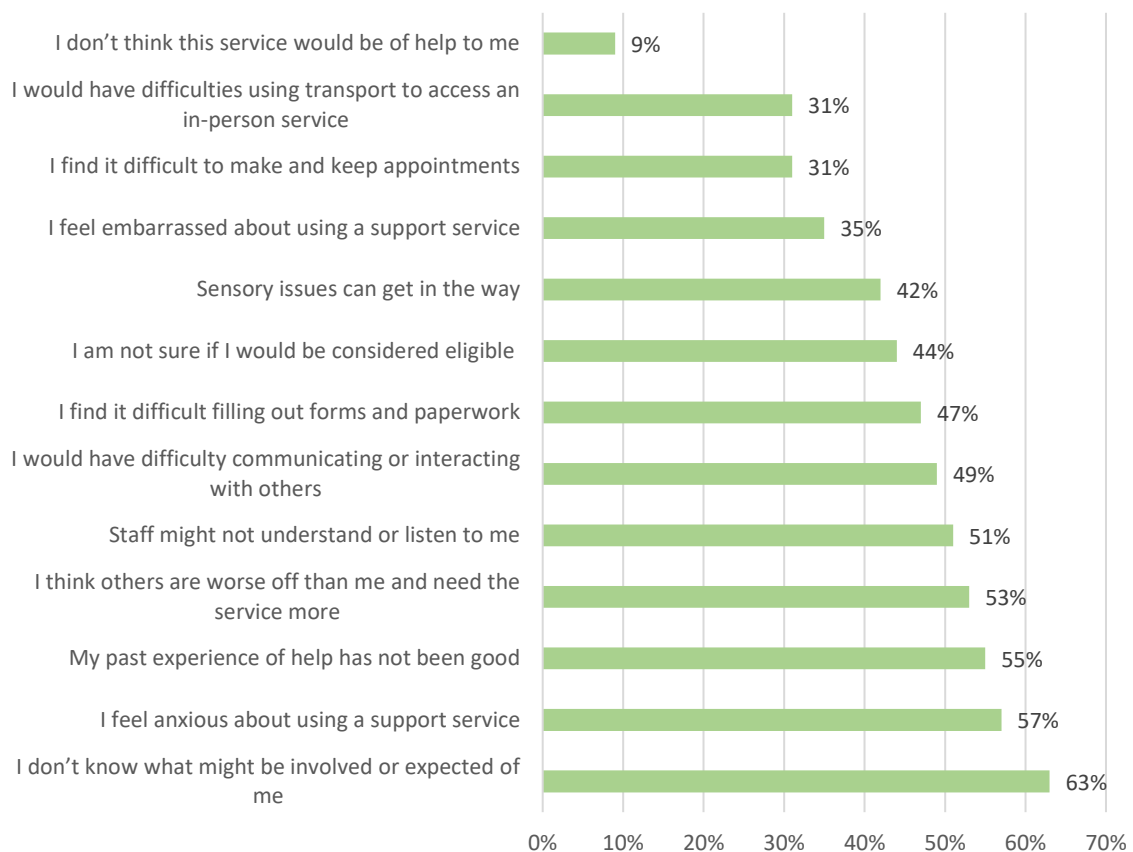
“ The biggest problem I have is knowing what and how I can get support. ”

“ [I would like help] navigating the day to day issues. ”

“ I need to see a dentist, however my fear & anxiety inhibit this. ”

Barriers to accessing the service

- The most significant barriers related to ‘the fear of the unknown’: understanding expectations for involvement and feelings of anxiety.
- Other significant barriers were poor past experience of support, concerns that staff may not be understanding, and believing others to be more in need of support.





The following responses tell us more about how autistic adults felt these barriers affected them:

“ I have very big anxiety difficulties around actually leaving/ going places so it's actually a big struggle to get basically anywhere. ”

“ I think there are definitely imposter syndrome aspects to autism. Especially if you believe...you're not as autistic as someone in a direct comparison. So overcoming that barrier. ”

“ I get anxious going to new places and interacting with new services. ”

“ I don't really speak on the phone so if I can't email from the start then that's a problem for me. ”

“ I need to pre-plan conversations... if discussion topics are presented before hand, I can formulate my questions so the meetings can be productive. ”

“ I am not good with time management so if support can only be accessed in-person this would be a big barrier for me. ”

“ I worry the 'help' would make things worse not better, e.g. triggering staff and lack of knowledge and understanding. ”

“ I can commonly struggle to get the words I want out and also knowing what to say/how. ”

“ I find often a barrier to asking for and receiving support is that the instructions to get help aren't clear and simple enough. ”

## Quality of Life

The measures used in the survey help to show what quality of life is currently like for autistic adults in Norfolk.

**General Quality of Life:** The table below shows scores using the WHOQOL-BREF measure, compared to those for the UK autistic and general population.

- The scores are similar to those generally found for autistic people in the UK. These are lower than the average scores for the general population<sup>3</sup>.
- The Norfolk scores are very similar to those for UK autistic people for physical health and social relationships. However, scores are slightly lower for the Norfolk sample, particularly for psychological health and environment (e.g. finance, housing, transport).

Quality of Life score (WHOQOL-BREF measure)

Quality of life domain	Average score (out of 100)		
	Norfolk	UK – autistic people <sup>4</sup>	UK – general population <sup>4</sup>
<b>Physical health</b> (e.g. mobility, pain, sleep, daily living activities)	47	48	76
<b>Psychological</b> (e.g. positive or negative feelings, self esteem, body image)	37	44	68
<b>Social relationships</b> (e.g. personal relationships, social support, sexual activity)	40	40	71
<b>Environment</b> (e.g. finance, home environment, transport)	48	56	68

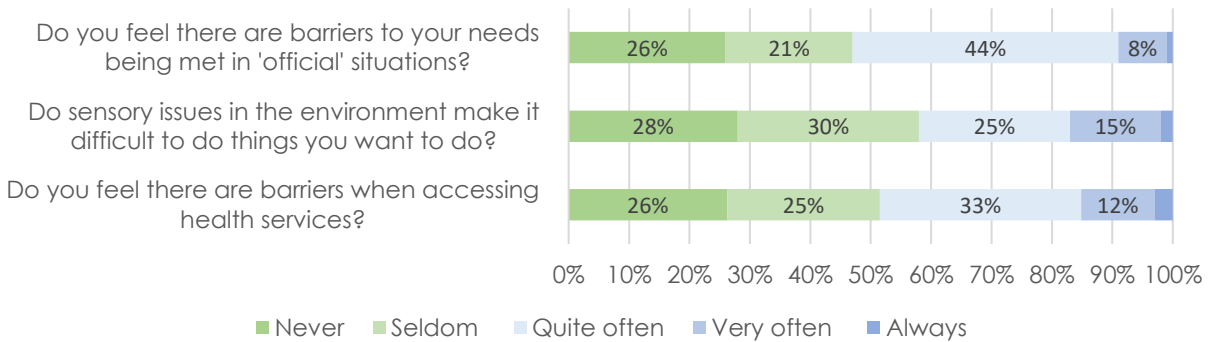
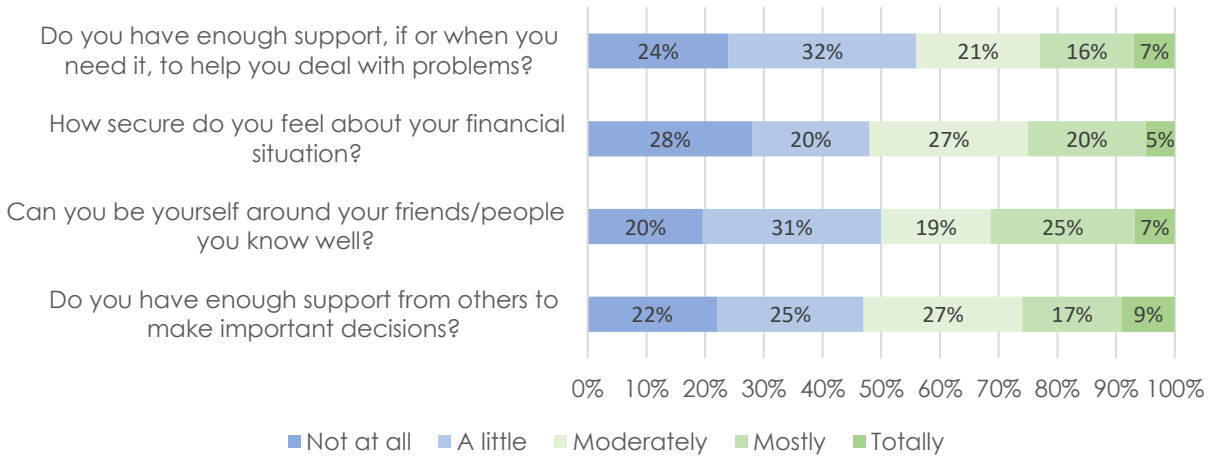
**Autistic Spectrum Quality of Life (ASQoL):** The ASQoL is a 9-item measure of self-reported quality of life, designed specifically for use with autistic adults. The scores for all nine items are shown in the charts below.

- There was a wide range of responses for each area of quality of life.
- For all areas approximately half of respondents reported that they were experiencing notable challenges.

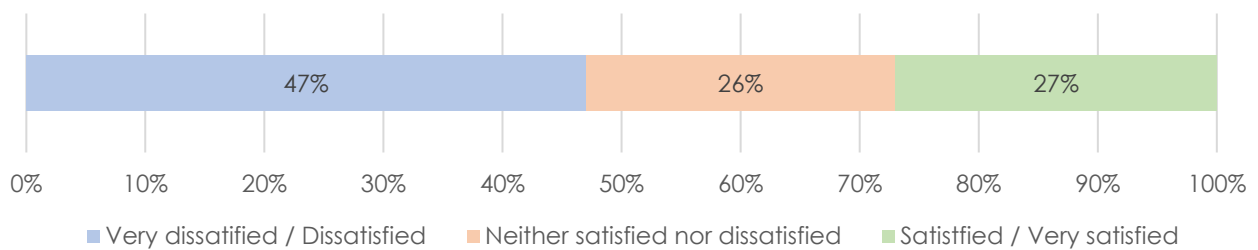
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<sup>3</sup> Note that comparator data is from 2018, since when other factors such as covid and the cost of living crisis may have impacted quality of life scores. Mason, D., McConachie, H., Garland, D., Petrou, A., Rodgers, J., & Parr, J. R. (2018). Predictors of quality of life for autistic adults. *Autism Research*, 11(8), 1138-1147. <https://doi.org/10.1002/aur.1965>

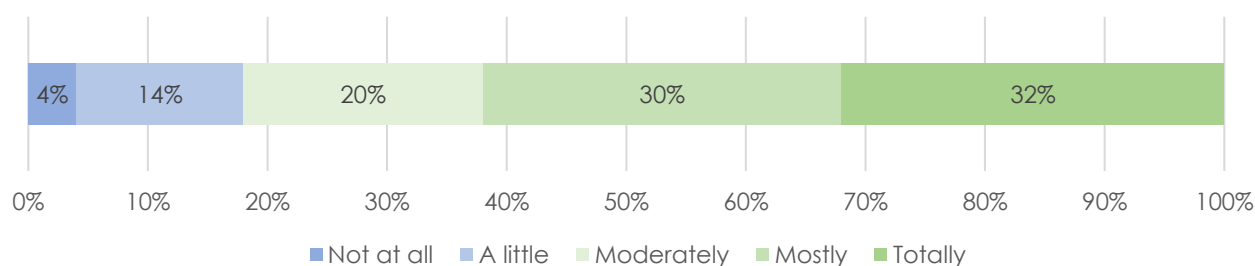
- Only 27% of respondents were currently satisfied with their friendships.
- Most respondents reported feeling at ease with their autistic identity, with only 18% responding 'A little' or 'Not at all' to this question.



### Are you satisfied with your current friendships?



Are you at ease (OK) with 'Autism' as an aspect of your identity?



### Feedback on 'Quality of Life' measures

- We asked survey respondents for feedback on the quality of life measures they filled in. Most respondents reported that the measures felt easy to use and relevant. This indicates that these measures may be appropriate to use for further evaluation. However, 10% needed help filling in the survey as a whole.
- Some respondents (less than 25%) said there were other aspects of quality of life they would like to have been asked more about. Suggestions included the impact of co-occurring conditions, burnout, stimming and routines, parenting, sexual and romantic relationships, and long term hopes and prospects. This highlights wider areas of quality of life that are important to some autistic adults.

## Implications and next steps

This survey has provided a valuable insight into current experiences of autistic adults in Norfolk. There are implications both for the new service and for future research.

- **Inclusion:** Men and older people are likely to be under-represented in this survey. It is not yet known if this will be reflected in who accesses the support service itself, but the finding shows the importance of monitoring who the service supports. A comparatively high proportion of gender non-conforming people and people with co-occurring physical/mental health conditions responded to the survey and this may indicate areas where particular staff expertise is required. Further research will need to consider who the service reaches and also build in ways to support those who need help to complete the quality of life measures.
- **Outcomes:** The survey shows that access to a new support service would be valued. Comments from survey respondents indicated a sense of isolation, and lack of support, and that support was desired in relation to a range of outcomes. The top outcome priorities were having a safety net to fall back on to stop problems escalating, and feeling in control of day-to-day life. Finding ways to support these outcomes may be an important focus for the service.
- **Barriers:** The findings give a good picture of the range of barriers to accessing services experienced by autistic adults in Norfolk. The most important barriers related to 'the fear of the unknown', and finding ways to address this may be particularly important for the service to prioritise. Understanding referral and engagement barriers will be vital for effective service delivery.
- **Quality of life:** It is concerning that average scores for quality of life were low for autistic adults in Norfolk, supporting the need for this type of service. There was also a wide range of experiences around different areas of quality of life, which supports a tailored approach to support individual needs. The low rate of satisfaction with friendships indicates that this could be an area for the service to focus on.
- **Further research:** This scoping work has shown that more research is required to explore whether low-level support can be an effective way of improving wellbeing and quality of life for autistic adults. The survey has provided evidence of the kind of outcomes that will be important to evaluate, and the type of measures that can be used. Building on this initial scoping work, NCC and UEA aim to apply for a larger grant from the National Institute for Health and Care Research to enable longer term evaluation. This work could also widen the reach beyond Norfolk to include similar services operating in other parts of the UK.

## **Acknowledgments**

This report has been co-produced with the Autism Research Group including: Laura Edwards, Cade Emerson, Sally Matthews and Catherine Stannard. Their input has been invaluable at every stage of this work.

**Thank you** to all the respondents who kindly took the time to respond to this survey.