

EVALUATION OF A SHORT-TERM SUPPORT SERVICE AND MEASURING ITS IMPACT ON AUTISTIC ADULTS' WELLBEING

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Norfolk County Council



**NORFOLK
AUTISM
PARTNERSHIP**

EVALUATION OF A SHORT-TERM SUPPORT SERVICE AND MEASURING ITS IMPACT ON AUTISTIC ADULTS' WELLBEING

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WHY IS THIS STUDY IMPORTANT?

- Although there is a growing recognition of the strengths and positive attributes associated with autism, research indicates that autistic people can be highly disadvantaged as adults. Quality of life for autistic people has been demonstrated to be lower than the general population/neurotypical adults with higher rates observed for physical and mental health problems, unemployment, isolation, educational disadvantage and financial hardship.
- Norfolk County Council commissioned a new service that aimed to deliver short-term low-level support for autistic adults (the Norfolk Autism Adult Support Service). The service involves one-to-one work with a coach for up to 12 weeks and will focus on a specific issue, for example: life skills, confidence building, or accessing other services. The service has been set up in response to guidance (LGA 2022; SCIE 2017) which suggests that low level preventative support should be available for autistic people and is often more appropriate than higher level health or social care support, which can be counterproductive. Anecdotal evidence from other areas of the country suggests that this type of support is considered positive by autistic people and is effective at enabling autistic people to live more independently, preventing

problems escalating to costly and intensive crisis support and reducing the need for longer term social care services.

This research project was set up to find out how best to evaluate the impact of this type of service with the longer term objective of providing groundwork to enable a bid to NIHR Research Programme for Social Care (RPSC) for a larger scale evaluation.

AIMS OF THE RESEARCH

The research aimed to:

- Scope existing research into similar services and appropriate measurement tools for evaluation
- Better understand needs, wellbeing and quality of life of autistic adults in Norfolk.
- Investigate what personal outcomes autistic adults in Norfolk desire from a low level support service.
- Investigate what the perceived barriers are to accessing the service.
- Seek autistic perspectives on potential outcome measures to evaluate effectiveness of a low-level service.

METHODS

The study consisted of three strands:

- **Patient and Public involvement (PPI):** the study involved close working with an experts by experience group of five autistic adults. The group met regularly to support development of the study and ensured an autism perspective throughout. The survey was co-produced with the group, who helped interpret the findings and co-designed an autism friendly final report.
- **Rapid scoping review:** a literature scoping review was undertaken to understand contextual academic and grey literature and to ascertain what research has already been conducted on low-level support services.
- **Survey:** an online survey was developed, informed by both the scoping review and regular meetings and activities with the experts by experience group to co-design the content. It was publicised on social media and via partner networks throughout Norfolk. The survey was live between January and February 2024. The survey was structured using closed (tick box) questions and optional free text comments boxes, and covered desired outcomes from a low-level support service, barriers to access, quality of life, feedback on utility of quality of life measures, and socio-demographic information. 119 autistic adults in Norfolk provided a full response.

KEY FINDINGS

- **Lack of evidence on low-level preventative support for autistic adults:** The rapid scoping review showed a scarcity of research on low level support for autistic people. However, some studies suggest positive outcomes across various domains such as employment, housing, and social relationships. Studies tended to highlight the importance of small settings dispersed in the community and of staff training. Support groups have also been shown to have positive effects on peer relationships, social skills, and decision-making. Few studies have been conducted on low-level, preventative services for autistic people without learning difficulties, to evaluate effectiveness or understand service users' experiences of and satisfaction with the service.
- **Positive views about the need for a low-level support service in Norfolk:** respondents to the survey indicated that they would like support across a range of outcomes from a new service, in particular support related to mental health and wellbeing. Respondents mentioned wanting a safety net to fall back on to stop problems escalating and feeling in control of day-to-day life. They reported currently struggling with 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. Several respondents also emphasised the importance of continued engagement with autistic people about development of the service.
- **Potential barriers to accessing a low-level support service:** respondents to the survey indicated that there were some significant barriers to potentially accessing a low-level support service. These included: understanding expectations for involvement (63%) and feelings of anxiety (57%), poor past experience of support (55%), believing others to be more in need of support (53%), and concerns that staff may not be understanding (51%).

KEY FINDINGS CONT

Measuring outcomes of a low-level support service: the scoping review and work with the experts by experience group resulted in selection of two measures to pilot in the survey with autistic adults in Norfolk to assess their quality of life. The majority of survey respondents found these measurements to be acceptable and relevant. The general quality of life scores of survey respondents in Norfolk scores were very similar to those for UK autistic people for physical health and social relationships. However, scores were slightly lower for the Norfolk sample, particularly for psychological health and environment (e.g. finance, housing, transport).

- Similarly, addressing the barriers to accessing the service needs to be a priority, particularly addressing ‘the fear of the unknown’. Understanding referral and engagement barriers will be vital for effective service delivery.
- The study provided evidence around outcomes that would be important to incorporate in a formal evaluation of a low-level support service. Quality of life was identified as a key outcome and the quality of life measure used in the survey seem to have been acceptable to the respondents and to autistic adults in the experts by experience advisory group.

KEY RECOMMENDATIONS

- The scoping review found a clear evidence gap in evaluating low-level support services for autistic adults. There is a need for more research to explore whether low-level support can be an effective way of improving wellbeing and quality of life for autistic adults.
- On a national level, there is a need for shared learning about the types of low level support services for autistic adults that are being developed and established. There in particular needs to be more learning about the range of models for service delivery, and service provider perspectives on what works well / less well in delivering a service of this nature.
- Outcomes from the survey suggested there are particular areas that the Norfolk support service should be aware of and take into consideration. This includes the importance of monitoring who accesses the support service to ensure the service is inclusive, and that the top priorities mentioned by survey respondents such as having a safety net to fall back on to stop problems escalating, and feeling in control of day-to-day life are supported within the service.

STRENGTHS AND LIMITATIONS

- The study provided good evidence about the need for a low-level support service in Norfolk for autistic adults, some of the types of services that would be welcome, barriers to accessing those services, and how to measure the quality of life of autistic adults. Given the scarcity of high quality research evidence about the effectiveness of these types of low-level support services, this research suggest the need for a larger-scale, longer-term evaluation of the Norfolk services, incorporating ongoing input from an experts by experience group of autistic adults.

IMPACT

A summary report of the study has been published online via the Norfolk Autism Partnership and plans are underway to apply for funding via the NIHR Research Programme for Social Care (RPSC) for a larger scale evaluation of the service.

FIND OUT MORE

[Research on support for autistic adults in Norfolk](#)

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HOW TO CITE THIS RESEARCH BRIEFING

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