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Engaging young service users with neurodevelopmental conditions in shaping their daily living support – a preliminary evaluation of a new tool

Submission date
24/10/2023

Recruitment status
No longer recruiting

Registration date
25/10/2023

Overall study status
Completed

Last Edited
28/06/2024

Condition category
Mental and Behavioural Disorders

[X] Prospectively registered
[ ] Protocol
[ ] Statistical analysis plan
[ ] Results
[ ] Individual participant data
[ ] Record updated in last year

Plain English summary of protocol

Background and study aims
The transition from adolescence to adulthood can be particularly challenging for people with neurodevelopmental conditions. In Sweden, young adults with autism spectrum condition or attention deficit hyperactivity disorder are increasingly accessing housing support, a form of practical, educational, and social support in daily living provided by the municipalities. Some municipalities have recently started delivering this support remotely, with support workers expressing both positive experiences and concerns. There is a limited understanding of the practical and emotional barriers that support workers and their young service users might encounter in implementing and receiving support remotely. In addition, the support needs, preferences, and values of the young service users are not fully understood. Service user engagement will therefore be necessary to ensure that the service is person-centred and of high quality. A new tool has been developed to help young service users with neurodevelopmental conditions develop a structure for their own support in close collaboration with their support worker. The tool was co-produced with young service users with autism spectrum conditions or attention deficit hyperactivity disorder and support workers. The aim of this study is to evaluate the feasibility of this tool in practice.

Who can participate?
People with an autism spectrum condition or attention deficit hyperactivity disorder who are aged between 18 and 29 years old and granted housing support service.

What does the study involve?
All participants will be offered the tool in conjunction with the support they already receive. The tool is text-based, consisting of a series of questions to help the service user think about their support and how they feel that it should be structured to meet their needs and preferences. Three themes are explored: personal aspects and preferences, how the support ideally should be structured in different support areas and productive ways of communicating remotely. The service user can read through and think about the questions in advance, and then continue the

discussion with their support worker. Based on these questions, the service user and support worker decide how they should continue with the support. Participants will rate their quality of life, self-efficacy, and perceived participation before they use the tool and 4 weeks later. They will also be asked to complete a survey on the usefulness and relevance of the tool and to take part in a brief interview on the same topic.

What are the possible benefits and risks of participating?
The tool can help service users engage in their support service, to make it more responsive to their needs, values, and preferences. As with other interventions, it is unlikely that all participants will benefit from this tool. There are no known risks of participating, but it cannot be ruled out that some participants will experience some transient emotional distress related to some of the personal aspects raised by the tool, and that some expectations might not be realized.

Where is the study run from?
Karolinska Institutet (Sweden)

When is the study starting and how long is it expected to run for?
July 2021 to September 2024

Who is funding the study?
FORTE: Swedish Research Council for Health, Working Life and Welfare (Forskningsrådet om Hälsa, Arbetsliv och Välfärd) (Sweden)

Who is the main contact?
Dr Ulf Jonsson, ulf.jonsson@ki.se (Sweden)

Contact information

Type(s)
Public, Scientific, Principal investigator

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Additional identifiers

Clinical Trials Information System (CTIS)
Nil known

ClinicalTrials.gov (NCT)
Nil known

Protocol serial number
Nil known

Study information

Scientific Title
Feasibility and acceptability of a tool for engaging young service users with neurodevelopmental conditions in designing their daily living support: a non-randomised mixed methods study

Study objectives
The aim of this study is to assess the feasibility and acceptability of a new tool for engaging young service users with neurodevelopmental conditions in designing their daily living support. The study is not designed for formal hypothesis testing. However, within-group changes in quality of life, self-efficacy, and perceived participation will be assessed.

Ethics approval required
Ethics approval required

Ethics approval(s)
approved 25/01/2022, Swedish Ethical Review Authority (Etikprövningsmyndigheten Box 2110, Uppsala, SE-750 02, Sweden; +46104750800; registrator@etikprovning.se), ref: Dnr 2021-06924-01

Study design
Non-randomized single-arm mixed methods feasibility study

Primary study design
Interventional

Study type(s)
Other, Quality of life

Health condition(s) or problem(s) studied
Service user engagement among young adults with autism spectrum condition or attention deficit hyperactivity disorder.

Interventions
This feasibility study will employ a single-arm design, where all participating service users will be offered the tool for increased service user engagement in conjunction with their support as usual. Housing support is a form of practical, educational, and social support provided by the municipalities in Sweden for people who live independently but have support needs in their daily living. Outcome measures will be collected at baseline and after 4 weeks (post-intervention). The tool was co-produced in a series of workshops with young service users and support workers. The text-based tool consists of three separate sections, each consisting of a series of

questions designed to help the service user think about their support and how it should be structured to meet their specific needs and preferences. Each of the three sections explores a theme:
1. Personal aspects and preferences (e.g., style of communication, stressful situations, what type of initiatives the service user wants the support worker to take, and daily routines).
2. How the service user prefers the support to be structured within different support areas (e.g., remote, in-person, or blended).
3. Productive ways of communicating remotely (e.g., agreements about how to communicate on the phone or through text messages).
The service user will be asked to review and think about the questions in advance, and then continue the discussion with their support worker. Based on these questions, the service user and their support worker jointly will decide how they should continue with the support.

Intervention Type
Behavioural

Primary outcome(s)
Feasibility/acceptability:
1. Recruitment rate, uptake, and retention will be measured using information collected continuously over the course of the study
2. Characteristics of the included and retained samples (e.g., diagnoses, age, gender, housing /residence) and current needs, and preferences related to daily living support will be measured using information collected at pre-intervention
3. Usefulness and relevance of the tool will be measured using an evaluation form post-intervention
4. Participation/involvement will be measured using the Patient Participation and Rehabilitation Questionnaire pre-and post-intervention
5. Overall feasibility/acceptability will be measured using in-depth interviews with participating service users and their support workers post-intervention

Key secondary outcome(s))
Preliminary effects:
1. Quality of life measured using the Assessment of Quality of Life (AQoL-8D) tool pre- and post-intervention
2. Self-efficacy measured using the Generalized Self-Efficacy Scale (GSE) pre- and post-intervention

Completion date
30/09/2024

Eligibility

Key inclusion criteria
1. Aged 18 to 29 years old
2. Autism spectrum condition or attention deficit hyperactivity disorder
3. Currently accessing housing support
4. Sufficient proficiency in Swedish

Participant type(s)
Service user

Healthy volunteers allowed
No

Age group
Adult

Lower age limit
18 years

Upper age limit
29 years

Sex
All

Total final enrolment
15

Key exclusion criteria
Not meeting the participant inclusion criteria

Date of first enrolment
01/11/2023

Date of final enrolment
30/06/2024

Locations

Countries of recruitment
Sweden

Study participating centre
Karolinska Institutet, Center of Neurodevelopmental Disorders (KIND)
Gävlegatan 22
Stockholm
Sweden
SE-113 30

Sponsor information

Organisation
Karolinska Institutet

ROR

https://ror.org/056d84691

Funder(s)

Funder type
Research council

Funder Name
Forskningsrådet om Hälsa, Arbetsliv och Välfärd

Alternative Name(s)
Swedish Research Council for Health, Working Life and Welfare, Forskningsrådet om Hälsa, Arbetsliv och Välfärd, FORTE

Funding Body Type
Government organisation

Funding Body Subtype
Local government

Location
Sweden

Results and Publications

Individual participant data (IPD) sharing plan
The datasets generated during the current study are not expected to be made available, to ensure the anonymity of the participants. The datasets will be stored in a non-publicly available repository at Karolinska Institutet.

IPD sharing plan summary
Stored in non-publicly available repository, Not expected to be made available

Study outputs

Output type	Details	Date created	Date added	Peer reviewed?	Patient-facing?
Participant information sheet	Participant information sheet	11/11/2025	11/11/2025	No	Yes
Study website	Study website	11/11/2025	11/11/2025	No	Yes