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Pilot scheme of hospital based link workers to help address non-medical needs of children with neurodisability and their families

Submission date
20/07/2022

Recruitment status
No longer recruiting

Registration date
02/08/2022

Overall study status
Completed

Last Edited
31/01/2025

Condition category
Nervous System Diseases

[_] Prospectively registered
[X] Protocol
[_] Statistical analysis plan
[X] Results
[_] Individual participant data

Plain English summary of protocol

Background and study aims
Children and young people (CYP) often have unmet health and social needs. These could be addressed through social prescribing (SP). SP is supported in the NHS Long Term Plan. It involves link workers (LW) helping those with health and social care needs to engage with supportive community resources.

The aim of this study is to identify the components of effective SP for CYP. More specifically, the study team will:
1. Obtain in-depth understanding of SP for CYP using a range of methods including interviews with those taking part and observation of SP sessions
2. Identify and share recommendations for optimal SP service provision
3. Understand how policy can support wider adoption of SP for CYP

It is hoped that the results of this study will provide practical recommendations for best practice based on key active ingredients and any setting-specific requirements, to inform LW training, service provision and policy.

Who can participate?
Participants will be invited to join this study either as part of the hospital-based project, Great North Children's Hospital (in collaboration with Ways to Wellness) that will include children and young people (aged under 16).

What does the study involve?
LWs will sit with the children and families in the study, and map out their areas of need. They will help identify relevant services to meet those needs, and support families to access those services. LWs will review at 3 and 6 months.

The study team will:
1. Gather data summarising the profiles of need and the demographics of those using the service, as well as uptake of services offered

2. Undertake observations of interactions between LW and participants, and engagement of participants with services
3. Undertake interviews with participants and with link workers to discuss their experience of the service

Questionnaires will capture specific types of outcome separately.

Steering groups and stakeholder workshops will guide the process.

What are the possible benefits and risks of participating?
Participant confidentiality will be respected and strict data security measures followed. Link workers on the project have honorary contracts with the Great North Childrens Hospital.

Participants may find it distressing to talk about issues such as non-medical needs and disability. However, taking part in the study could be beneficial in that the link workers will provide a listening ear and help the participants find potential solutions to their difficulties. Signposting to services such as counselling is part of the LW role.

LWs will be referring participants to community services. There is a responsibility within these community services to be of good quality and to be safe, and LWs can not take responsibility for the quality of community services provided. However, they can aim to have an overview of and keep in touch with a range of service providers, which will help them to identify and refer to high quality services.

We anticipate a mixture of face to face and virtual (telephone or Teams) interviews, factoring in flexibility in relation to potential developments with the COVID-19 pandemic and also convenience and resources available to families. COVID may restrict the nature of services and support which can be made available to families.

We will try to minimise the time burden to families for taking part in the study. Also it is important for families to know that no aspect of taking part in the study or withdrawing from it would have any adverse effect on their clinical care.

Where is the study run from?
The Newcastle upon Tyne Hospitals NHS Foundation Trust (UK)

When is the study starting and how long is it expected to run for?
From May 2020 to November 2023

Who is funding the study?
The National Institute for Health and Care Research (NIHR) Applied Research Collaboration North East and North Cumbria (UK)

Who is the main contact?
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Additional identifiers

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309038

Central Portfolio Management System (CPMS)
52488

Protocol serial number
Grant Codes: OFC2021-24 / GNCH7647

Study information

Scientific Title
Social Prescribing And Community rEsources for Children and Young People: "SPACE CYP" Pilot

Acronym
SPACE CYP Pilot

Study objectives
We hypothesise that introduction of a hospital based link worker scheme for children with neurodisability and their families will lead to a reduction in unmet non-medical needs for those taking part

Ethics approval required
Old ethics approval format

Ethics approval(s)
Approved 31/05/2022, North West - Greater Manchester Central Research Ethics Committee (3rd Floor, Barlow House 4 Minshull Street Manchester M1 3DZ; +44 (0)207 1048 007; gmcentral.rec@hra.nhs.uk), ref: 22/NW/0110

Primary study design
Interventional

Study design
Non-randomized trial

Study type(s)
Treatment

Health condition(s) or problem(s) studied
Children and young people with neurodisability

Interventions
This is a “mixed methods” study, as it uses a range of methods both numerical (“quantitative”) and non-numerical (“qualitative”). Our study will involve the use of questionnaires, but also observations of link workers interacting with participants, and observations of participants engaging with services. A key component of the study will be an in-depth interview with participants to understand their experience of the service. These observations and interviews will provide insights about the service that could not be captured by numerical methods alone. We will undertake in-depth interviews in around 15 children and families in total, which should be adequate to reach “data saturation”, i.e. to have captured a very wide range of views and experiences, especially as we will choose families to interview based on this aim. We will also be recruiting four link workers to the study, as we want to capture their views about the service too.

Recruitment:
Potential participants will be identified by hospital staff who are part of the existing care team and provided with a flyer giving information about the link worker service and study. If they are interested in taking part, information sheets will be given and their contact details will be passed on to a member of the research team to undertake fully informed consent. It will be made clear that participation is voluntary and that not taking part will not adversely affect care.

Intervention:
Link Workers (LW) at the Community site and the Hospital site will establish peoples’ individual profiles of need, identify and support clients to engage with relevant services, reviewing progress at 3 and 6 months. In practice, this will mean:
1. Person identified as potentially eligible
2. Consent for referral to LW (through standardised pathway) and study participation

3. LW meets participant, builds relationship, records demographic data; documents profile of need (guided by parents as proxy where necessary). For the hospital-based project, related needs of close family members will be similarly captured.
4. LW identifies and discusses relevant resources with participant
5. Participant accesses resources in the community, with support if needed (e.g. after discharge from hospital)
6. LW follows up with tailored support (e.g. regular phone calls for updates) and reviews at 3 and 6 months.

Methods Of Data Collection And Data Analysis
Three interrelated approaches will be used:
1. Qualitative data to understand features of optimal service (both settings)
1.1 Qualitative observations of interactions between link workers and children/families, and of engagement with services, using audio recordings where consent is provided. In practice this means that a researcher would sit in on a meeting between the link worker and the family, to observe and take notes; or the researcher would go to a community service and observe the child engaging with that service.
1.2. In-depth interviews with families (parents, and children including siblings where appropriate /possible) will be undertaken. We will use purposive sampling to explore experiences of families /children with differing needs and backgrounds, to start to establish what works, for whom, when and how. This means that we will select which families to offer interviews to, so that we cover a broad range of needs and backgrounds. We will encourage them to bring photos of meaningful moments captured during community engagement sessions to aid in expression of what they found beneficial. These interviews will be taken around 3 and 6 months after onset of the intervention, or at the end of the intervention if sooner.
1.3. Short, informal debriefs between the research team and the LW every two weeks to understand service issues (This part does not involve the recruited children and their families). We anticipate a mixture of face to face and virtual (telephone or Teams) interviews, factoring in flexibility in relation to potential developments with the COVID-19 pandemic and also convenience and resources available to families. A topic guide, developed by the research team including parent advisors, will be used to guide the interviews but will not be restrictive.
2. Quantitative process data to understand pathways and throughput. We will use routinely collected data on the number of referrals, uptake rate, continued engagement rate and numbers declining or deemed inappropriate for referral; demographics; number and nature of community groups referred to and engagement with these; and time spent by LW per person, and nature of work
3. Quantitative pre- and post-intervention data (at start and end). Baseline data collection including demographics and contact details for families will be collected and forms part of standard care for link worker interventions.

Pre and post-intervention data will be collected at each setting, covering the domains of:
1. Profile of needs
2. Quality of life and wellbeing
3. Specific data relevant to the population under study

We have aimed to minimise the burden of data collection on families whilst also ensuring we have enough data to undertake a sound evaluation. The data being collected is as follows:
1. The Support Star will be used by the link worker as part of the assessment of needs. This does not form part of usual NHS care but is the method by which a link worker will gather information to guide the intervention and to record progress. The Support Star was designed for young people facing serious illness, with both young person and parent/carer versions available). It is quite quick to complete but will likely prompt discussions about how to address any needs

identified. It will be used at the start, at 3 months and at the end (6 months).
2. The following questionnaires will be administered by the research team (or LW) and are not part of routine data collection by link workers, but are gathered for the purposes of this study
2.1. Wellbeing (Outcomes Rating scales including age <5y with proxy scoring). This takes around 30 s to complete and looks at how things have been going overall in the past week, marking this on a scale.
2.2. Quality of life (EQ-5D for adults; CHU-9D for children including proxy version). This takes <5 min to complete.
2.3. Warwick-Edinburgh Mental Wellbeing Scale (parents). This takes <5 min to complete.
2.4. Three questions to gauge financial strain on the family. This takes <5 min to complete.

Intervention Type
Other

Primary outcome(s)
Qualitative measures:
1. Participant and link worker views on the social prescribing scheme including service provision and the link worker role measured using in-depth interviews at 6 months
2. Engagement with the scheme measured using in-depth interviews at 6 months and qualitative observations throughout the study

All qualitative analyses will be conducted according to the standard procedures of rigorous qualitative analysis. We will use procedures from first-generation grounded theory (coding, constant comparison, memoing), analytic induction (deviant case analysis), and constructionist grounded theory (mapping). We will undertake independent coding and cross-checking and a proportion of data will be analysed collectively in data clinics (with the core research team) and workshops with stakeholders where people share and exchange interpretations of key issues emerging from the data.

Key secondary outcome(s)
1. Non-medical needs assessment measured using the Support Star questionnaire at baseline, end of the intervention, and 6 months
2. Wellbeing measured using Outcomes Rating scales including age <5 years with proxy scoring (takes <1 min to complete) at baseline, end of the intervention, and 6 months
3. Quality of life measured using the EQ-5D for adults or CHU-9D for children including proxy version (takes<5 min) at baseline, end of the intervention, and 6 months
4. Mental wellbeing measured using the Warwick-Edinburgh Mental Wellbeing Scale for parents (takes <5 min) at baseline, end of the intervention, and 6 months
5. The financial strain on the family measured using three questions to participants (takes <1 min to complete) at baseline, end of the intervention, and 6 months
6. Process evaluation using numbers referred, throughput to other services, and retention throughout the study

Completion date
30/11/2023

Eligibility

Key inclusion criteria
1. Children aged <16 years, and their families
2. Complex chronic needs related to neurodisability (e.g. cerebral palsy, epilepsy)

3. Hospital in-patients (admitted under any paediatric team)
4. Living within the North of Tyne/Gateshead ICP region
5. Parental consent to both the intervention and the evaluation

Participant type(s)
Patient

Healthy volunteers allowed
No

Age group
Adult

Sex
All

Key exclusion criteria
1. Considered too medically unwell for SP intervention to be appropriate at this time;
2. Index case aged ≥16 years
3. Does not have a condition leading to neurodisability
4. Out of region
5. Unwilling to give consent to take part
6. If the potential participant is already involved in a research study, and taking part in our study would interfere with the findings of one or both studies, then we would not recruit them. If they are taking part in, or have taken part in, another research study that does not conflict with the current study, we would be happy for them to take part in this one, provided they would not be, or feel, overburdened by research commitments.

Date of first enrolment
11/07/2022

Date of final enrolment
30/05/2023

Locations

Countries of recruitment
United Kingdom

Study participating centre
Great North Children's Hospital
Queen Victoria Road
Newcastle upon Tyne
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Sponsor information

Organisation
Newcastle upon Tyne Hospitals NHS Foundation Trust

ROR
https://ror.org/05p40t847

Funder(s)

Funder type
Government

Funder Name
National Institute for Health and Care Research

Alternative Name(s)
National Institute for Health Research, NIHR Research, NIHRresearch, NIHR - National Institute for Health Research, NIHR (The National Institute for Health and Care Research), NIHR

Funding Body Type
Government organisation

Funding Body Subtype
National government

Location
United Kingdom

Funder Name
NIHR Applied Research Collaboration North East and North Cumbria

Results and Publications

Individual participant data (IPD) sharing plan
The datasets generated and/or analysed during the current study will be published as a supplement to the results publication. The datasets generated during and/or analysed during the current study are not expected to be made available due to the risk of a confidentiality breach given the population under study and sample size.

IPD sharing plan summary
Published as a supplement to the results publication, Not expected to be made available

Study outputs

Output type	Details	Date created	Date added	Peer reviewed?	Patient-facing?
Results article		30/01/2025	31/01/2025	Yes	No
HRA research summary			28/06/2023	No	No
Protocol file	version 1	25/08/2022	26/08/2022	No	No