Including individuals with learning disability as research participants: the journey from consent to interview

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Recruitment

- Bilingual (Welsh/English) easy read participant information.
- Researcher attended team meetings in each locality to present information about the study.
- A purposive sample of adults with learning disability were recruited through a NHS Community Learning Disability Nursing Service.
- Community Learning Disability Nurses (CLDN) used their professional knowledge and skills to complete an Initial assessment of capacity to consent of individuals who are known to them, or on their caseload, that also met the inclusion criteria for the study.

Consent

Stage 1
- The CLDN responsible for the nursing service that the potential participants receive is given information about the study.
- The service user is given the choice to involve a regular carer/advocate for support at this stage.

Stage 2
- The CLDN facilitates a contact/introduction between the service user and researcher at a mutually convenient time and place.
- Information about the study is conveyed to the service user verbally, supported with an easy read version of the information sheet.
- The service user is given the choice to involve a regular carer/advocate for support at this stage.
- The researcher arranges to visit the service user within a minimum of 3 days maximum 2 weeks to allow the service user sufficient time to consider the information presented.
- Following the initial information giving meeting with the service user, the researcher may suggest that the service user does not have the capacity to consent or does not meet the inclusion criteria of the study. In this event, the researcher will discuss the individual case with the CLDN and a bespoke exit strategy will be agreed in the best interest of the service user. This may or may not involve a return visit by the researcher and or CLDN.

Stage 3
- The researcher will return after a minimum of three days, maximum of 2 weeks at a mutually convenient time and place for the service user.
- If interested in participating in the study the service user’s capacity to consent in the specific context of the study will be assessed with a regular carer present using a protocol (Form: Assessment of capacity to consent) based on the work of Arscott et al (1999).
- The information sheet will be read with the service user twice, the service user will be encouraged to ask questions of the researcher. The researcher will ask the service user questions to assess – as far as possible – whether the person understands, retains and uses the information to arrive at a decision.
- If the protocol indicates that the service user has the capacity to consent to participation in the study, and is willing to do so, stage 4 of the consent process is implemented.

Stage 4
- If the service user has the capacity to consent to participate in this study, and is willing to do so, the researcher will then re-read the information sheet, and ask for the participant’s verbal and or written consent witnessed by both the researcher and a regular carer (Form: Participant Consent).
- The regular carer will be asked to sign as witness on the Consent form. Consent to interview and audio record will be sought, and recorded at the beginning of the data collecting interview.
- This procedure draws on the advice from public bodies such as the Welsh Assembly Government, for instance the “Good Practice in Consent Implementation Guide” (WAG 2002) and other published research such as Goldsmith, Saxton & Webb 2008, Cameron, Murphy 2007, Dye, Hardy & Hendy 2007, Webb 2008, Dagnan & Krosse 1999, Arscott, Dagnan & Krosse 1998.

Interview

Inclusion criteria

Adults with learning disability who:
1) have the ability to consent to participate in the specific research study;
2) are currently receiving a learning disability nursing (LDN) service or has received a LDN service within the last 12 months;
3) have received a LDN service for a minimum period of 2 months with a minimum of 4 contact visits from a CLDN;
4) are not currently receiving treatment/intervention for mental health difficulties and or challenging behaviour;
5) have a supportive social network, given that Northway (2000) suggests that people with limited social networks may find ending research difficult;
6) are willing to communicate their views and experience of the LDN service;
7) are available to engage in three meetings with the researcher: an introduction to project meeting, data collecting interview, and the end meeting of project meeting.

References