FINDINGS

Importance of Problem

Researchers are beginning to acknowledge the importance of including perspectives of individuals with disabilities in research studies. The Office for Human Research Protections (OHRP) stresses the need to be inclusive of all persons in research studies. A more diverse participant group increases the credibility and generalizability of the findings.

Objectives

Understand issues in recruiting youth aged 14-25, who receive Social Security (SS) Disability benefits due to their own disabilities.

Identify strategies to recruit youth with disabilities, 14-25, to increase the up-take rate for a random-assignment study.

Methods

86 names were selected randomly from a list of SS Disability Recipients, aged 14-25, who live in three study areas in Colorado. Recruitment letters were sent to the youth and their representative payee (for the SS Disability Benefits).

19 Families who made a decision to be or not be in the study were interviewed about their decision.

3 Payee Agencies who made the decision for their client to be involved in the study were also interviewed about their decision.

Logs that recorded the number of contact efforts to recruit clients were analyzed.

Findings

Findings—Cont.

Unity/Marketing is Key to Reduce Confusion

There was inconsistency in information about who is conducting the study. Recruitment letters referred to the UCDHSC, the Workforce Centers (where the treatment is being implemented), and the name of the project. Staff referred to UCDHSC (grant recipients) and Social Security (granting agency) when talking about the study.

In follow-up interviews there were several instances where the youth: (1) enrolled in the study (2) mailed in the consent form, (3) received their incentive, and (4) provided data but still did not recall that they took part in the study.

Because this group is often asked to sign forms (for medical and benefit reasons) and some may have short-term memory loss due to disability (e.g. Traumatic Brain Injury), it is important to be consistent and repetitive so the youth are aware of the study and are aware of their rights as study participants. All study personnel now are identified under the project name and have business cards, stationary, etc. with the project name.

Marketing to Service Providers is Important

Service providers often act as gatekeepers. In 1/3 of cases where the decision was NOT to join the study, the service providers were somehow involved.

Need to get buy-in of service providers. We had our treatment staff establish a local consortium with the providers in their areas. Staff meet face-to-face with managers and direct service staff to educate them about the study.

Conclusion

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