

Research Paper

# Development of an audio-computer assisted self-interview to investigate violence and health in the lives of adults with developmental disabilities

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## Abstract

**Background:** Audio computer-assisted self-interviews (ACASIs) have safely and effectively obtained sensitive research data from the general public and have been recommended for use with people with disabilities. However, few studies have used ACASIs with people with disabilities and ACASIs have not been used to investigate the relationship between disability, interpersonal violence (IPV), and physical and psychological health among people with developmental disabilities (PWDD).

**Objective:** We developed an accessible ACASI specifically designed to allow PWDD to answer questions independently, while privately and securely collecting anonymous data related to their disability, IPV experiences, and physical and psychological health.

**Methods:** We used a safety protocol to apply community based participatory research (CBPR) principles and an iterative process to create, test, and administer a cross-sectional ACASI survey to 350 adults with developmental disabilities in urban and rural locales.

**Results:** Most participants completed the ACASI independently and reported that its accessibility features allowed them to do so. Most also agreed that the ACASI was easy to use, its questions were easy to understand, and that they would prefer using an ACASI to answer IPV and health-related questions rather than in a face-to-face interview. The majority agreed that health and safety were critical issues to address.

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**Conclusions:** ACASI technology has the potential to maximize the independent and private participation of PWDD in research on sensitive topics. We recommend further exploration into accessibility options for ACASI technology, including hardware and Internet applications. © 2014 Elsevier Inc. All rights reserved.

**Keywords:** Audio computer-assisted self-interview (ACASI); Disability; Violence; Community-based participatory research (CBPR)

People with developmental disabilities (PWDD) have historically been underrepresented in research.<sup>1,2</sup> Overly-restrictive, paternalistic interpretations of human subject protections, assumptions about decision-making capacity, misconceptions of PWDD as unreliable sources of information, and inaccessible data collection approaches have encouraged the use of proxy respondents. Increasingly critical of these barriers, academic researchers and PWDD are advocating for more direct inclusion in research.<sup>3</sup>

Inclusion can be challenging with research on interpersonal violence (IPV), which demands privacy and adherence to mandatory reporting requirements.<sup>4–6</sup> In participating in IPV-related research, PWDD may risk perpetrator retaliation or the loss of services<sup>7</sup>; thus, few IPV studies have collected data directly from PWDD. In this paper we discuss the design, use, and evaluation of an ACASI approach to anonymously and effectively obtain self-report data of IPV experiences of PWDD.

An ACASI program allows self-administration of a questionnaire. Utilizing ACASI technology in social science research has become a common method for collecting health data perceived as sensitive or stigmatizing, such as drug use,<sup>8,9</sup> HIV-risk behaviors,<sup>10–12</sup> IPV,<sup>13–16</sup> and elder abuse.<sup>17</sup> Compared to paper-pencil questionnaires and face-to-face interviews, ACASIs provide higher rates of disclosure of sensitive information and are typically well received by participants.<sup>16,18–21</sup>

ACASIs can address disability-specific barriers to research by enhancing accessibility.<sup>22</sup> An ACASI developed for a prior study allowed participants to: change font size; self-pace with visual tracking cues; and use enhanced keyboards, headphones, screen-reader software, and embedded audio/visual media.<sup>18</sup> These features helped remove participation barriers, increased privacy and anonymity, and decreased proxy reporting.<sup>18</sup> Participants reported that ACASI was easy to use.<sup>18</sup> Over half agreed that knowing their answers related to IPV would remain anonymous and not reported to Adult Protective Services or the police contributed to their willingness to honestly answer questions using the ACASI.<sup>18</sup> Although ACASI technology is recommended to increase participation of people with disabilities in research,<sup>23</sup> only a few studies have used ACASIs with participants with disabilities.<sup>18,24,25</sup>

We developed the ACASI as part of a larger CBPR project. Found to be effective for conducting research with people from marginalized groups,<sup>26</sup> CBPR allows community members equitable inclusion as full members of the research team in all phases of the research process. Academic and

community partners are expected to share power, learn from each other, and contribute to the benefit of scientific progress and the welfare of the community.

This paper includes a review of the development, utilization, and evaluation of the ACASI, which was designed to increase participation of PWDD in a CBPR study examining the associations of IPV exposure and health status. Information on the psychometric properties of the adapted measures incorporated within the ACASI and the study findings are presented in Nicolaidis et al.<sup>27</sup> and Hughes et al.<sup>28</sup> Our work serves as a model for others' efforts to incorporate ACASIs and thereby increase research participation of underrepresented groups.

## Methods

### *Community based participatory research (CBPR)*

CBPR is effective for conducting research with underrepresented groups.<sup>26</sup> We applied CBPR principles to develop, refine, and administer an ACASI to collect data on IPV, health, and disability in populations of PWDD at rural and urban sites. Each site included academic and community researchers who served as project leaders and worked closely and equitably throughout the study's development and implementation. At each site, community advisory boards (CABs) included individuals with DD, at least one DD services professional, and parent of a person with DD.

### *Overview of the development and refinement of the ACASI*

We used a three-phase iterative process to refine a prior ACASI used by people with diverse disabilities<sup>18</sup> to specifically adopt the ACASI for PWDD through: 1) review by project leaders, who included academic investigators and community partners with DD; 2) review by CAB members; and 3) target population usability testing. In each phase, stakeholders reviewed the ACASI and provided feedback used by computer programmers to refine the ACASI prior to the next phase.

### *Project leaders' and CAB members' review of the ACASI*

The academic investigators and community partners with DD reviewed the prior ACASI, making recommendations to improve accessibility such as including a more

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