Développement Humain, Handicap et Changement Social
Human Development, Disability, and Social Change

Promoting Self-Determination in Health for People with Intellectual Disabilities through Accessible Surveys of their Healthcare Experiences

Alexa White, Penny Liberatos, David O’Hara, Dan Davies et Steven Stock

Volume 21, numéro 1, avril 2015

Autodétermination et technologies de soutien des personnes ayant des incapacités
Self-determination and Support Technologies for People with Disabilities

URI : https://id.erudit.org/iderudit/1086491ar
DOI : https://doi.org/10.7202/1086491ar

Aller au sommaire du numéro

Éditeur(s)

Réseau International sur le Processus de Production du Handicap

ISSN

1499-5549 (imprimé)
2562-6574 (numérique)

Découvrir la revue

Citer cet article

White, A., Liberatos, P., O’Hara, D., Davies, D. & Stock, S. (2015). Promoting Self-Determination in Health for People with Intellectual Disabilities through Accessible Surveys of their Healthcare Experiences. *Développement Humain, Handicap et Changement Social / Human Development, Disability, and Social Change*, *21*(1), 29–39. https://doi.org/10.7202/1086491ar

Résumé de l'article

Augmenter nos connaissances sur les façons de fournir des services de santé efficaces nécessite de se préoccuper de l’amélioration de la littératie en santé, ainsi que de l’engagement, voire l’autogestion, des patients dans leurs expériences d’utilisation des services de santé. L’atteinte de tels objectifs pour les personnes ayant des incapacités requiert toutefois la mise en place de solutions innovantes. Le Westchester Institute for Human Development (WIHD), centre universitaire d’excellence en éducation, en recherche et en services, propose une offre de services de santé complète à plus de 5 000 personnes ayant des incapacités intellectuelles. Il s’est engagé à ce que la conception et l’utilisation des technologies d’information en santé soient faites de telle sorte qu’elles augmentent l’autodétermination des personnes ayant des incapacités intellectuelles. Dans le cadre de ses travaux, le WIHD soutient un projet de recherche visant la numérisation du sondage du gouvernement fédéral américain sur les expériences des utilisateurs des services de santé dans un format permettant aux personnes ayant des incapacités intellectuelles d’y répondre de manière autonome. Cet article présente le processus de recherche, les résultats et les succès associés à l’utilisation de ce sondage accessible, de même que leurs implications pour les futurs developpements technologiques souhaitant améliorer l’autodétermination des personnes ayant des incapacités intellectuelles dans l’utilisation des services de santé. Le questionnaire employé s’intitule le « US Agency for Health Care Quality and Research Consumer Assessment of Providers and Systems (CAHPSD) patient experience survey ».

Revue Développement humain, handicap et changement social, 2015, **(21)**, 1, p. 29-38.
Journal of Human Development, Disability, and Social Change

Promoting Self-Determination in Health for People with Intellectual Disabilities through Accessible Surveys of their Healthcare Experiences[1]

ALEXA WHITE[1], PENNY LIBERATOS[1], DAVID O'HARA[2], DAN DAVIES[3] AND STEVEN STOCK[3]

[1] New York Medical College, New York, U.S.A.
[2] Westchester Institute for Human Development, New York Medical College, U.S.A.
[3] AbleLink Technologies, Colorado Springs, U.S.A.

Article original • Original Article

Abstract : Increasingly our knowledge of how to provide effective health care finds itself concerned about how to improve health literacy and increase patient engagement in, and self-management of, their health care experience. For people with intellectual and developmental disabilities (IDD) addressing these issues requires some innovative solutions. The Westchester Institute for Human Development (WIHD), a university center of excellence in disability education, research and service, is a comprehensive health care provider to over 5,000 adults with IDD. WIHD is committed to ensuring that health information technologies are designed and used in ways that enhance self-determination in health care for people with IDD. As part of its work in developing accessible health information technologies WIHD supported a research project designed to convert an existing US Federal Government survey of a patient's experience of their health care into an electronic format that enabled direct responses to survey questions by the patient with IDD. This article discusses the research process, findings and success of this accessible patient experience survey technology project and its implications for future technology innovation designed to improve self-determination in health care for people with IDD. The survey in question was the US Agency for Health Care Quality and Research Consumer Assessment of Providers and Systems (CAHPSD) patient experience survey.

Keywords : experiences of healthcare users, intellectual disabilities, survey, self-determination, health information technologies, United States

Résumé : Augmenter nos connaissances sur les façons de fournir des services de santé efficaces nécessite de se préoccuper de l'amélioration de la littératie en santé, ainsi que de l'engagement, voire l'autogestion, des patients dans leurs expériences d'utilisation des services de santé. L'atteinte de tels objectifs pour les personnes ayant des incapacités requiert toutefois la mise en place de solutions innovantes. Le Westchester Institute for Human Development (WIHD), centre universitaire d'excellence en éducation, en recherche et en services, propose une offre de services de santé complète à plus de 5 000 personnes ayant des incapacités intellectuelles. Il s'est engagé à ce que la conception et l'utilisation des technologies d'information en santé soient faites de telle sorte qu'elles augmentent l'autodétermination des personnes ayant des incapacités intellectuelles. Dans le cadre de ses travaux, le WIHD soutient un projet de recherche visant la numérisation du sondage du gouvernement fédéral américain sur les expériences des utilisateurs des services de santé dans un format permettant aux personnes ayant des incapacités intellectuelles d'y répondre de manière autonome. Cet article présente le processus de recherche, les résultats et les succès associés à l'utilisation de ce sondage accessible, de même que leurs implications pour les futurs developpements technologiques souhaitant améliorer l'autodétermination des personnes ayant des incapacités intellectuelles dans l'utilisation des services de santé. Le questionnaire employé s'intitule le "US Agency for Health Care Quality and Research Consumer Assessment of Providers and Systems (CAHPSD) patient experience survey."

Mots-clés : utilisation des services de santé, incapacités intellectuelles, sondage, autodétermination, technologies de l'information en santé, États-Unis

---

[1] This research was conducted by the first author in partial fulfillment of her MPH degree requirements from the School of Health Sciences and Practice, New York Medical College. She wishes to thank her faculty advisor, Dr. Penny Liberatos and her Westchester Institute for Human Development (WIHD) supervisor, Dr. David O'Hara for their support and advice throughout the course of this research. The authors would like to thank the staff of the adult health care program at WIHD for their support and encouragement during all phases of this research project. Without their advice and feedback the research would not have been possible. But we would especially like to thank the many self-advocates who agreed to take part in the survey and who were so enthusiastic at being given the opportunity to comment on their health care experience at WIHD.

Introduction

Given the recent emphasis on patient-centered healthcare, patient-reported experience evaluations are becoming increasingly important indicators of healthcare quality (Kurpas & Steciwko, 2005; Manary, Boulding, Staelin, & Glickman, 2013). Self-reported health status is recognized as one of 20 core indicators of US population health and healthcare quality (IOM, 2009). Self-report can reflect an individual's subjective experience of their health and health care (Patrick et al., 2007). It is for this purpose that AHRQ developed the Consumer Assessment of Healthcare Providers and Systems (CAHPS) program to assess consumers' experiences with healthcare as a measure of improvement in quality (AHRQ, 2013).

Although the CAHPS written paper and pencil surveys are used widely, they are designed for the general population and targeted to approximately a 7th grade reading level (NCQA, 2011). This poses literacy challenges for many people with intellectual disabilities (ID) who would not be able to complete these surveys independently (Davies & Stock, 2008). Moreover, excluding people with ID from quality of care assessments is not only ethically problematic (Larsson & Larsson, 2001) but also contrary to recent approaches for self-determination, empowerment and choice for this population (Ramcharan & Grant, 2001; Fujiura, 2012).

To date, the most frequently used methods for incorporating the perspectives and experiences of individuals with ID has been either through:

- self-report using simplified questions and answers, simpler vocabulary, easier response formats (e.g., yes/no) and/or visual formats through paper surveys or interviews; or
- proxy reporting in lieu of self-report (Fuijiura, 2012).

Unfortunately, there are difficulties with both approaches.

Response accuracy in individuals with ID has been found to be more likely influenced by the structure and complexity of the questions, response formats and method (Finlay & Lyons, 2001). For example, the issue of social desirability bias (where respondents provide answers that they think the Interviewer "wants to hear") has frequently been cited as a particular problem for individuals with ID in an interview setting (Ramcharan & Grant, 2001; Nota et al., 2006). Additionally, people with ID may have difficulty expressing themselves verbally or in understanding the questions and may be too embarrassed to admit it (Schwartz et al., 2012), 2012). Although use of paper surveys may provide more privacy than an interview, there may be challenges with literacy and fine motor coordination. Also, the complexity of questions and responses that can be used may be limited. Thus this approach is rarely used with individuals with ID (Davies & Stock, 2008).

Although proxy reporting is the most commonly used approach, it can be problematic because responses vary depending on the proxy's relationship to the individual and the domain measured. For example, in one study proxies were found to overestimate impairment and underestimate quality of life and pain (Andresen et al., 2001). Conflicting evidence across studies has led to recommendations that proxies can best be used for objective issues (e.g., frequency of healthcare visits) but not for reporting the subjective experience of others (Fujiura, 2012).

Recommendations for obtaining self-report data for individuals with ID include:

- simplification of questions/answers;
- avoidance of time-based judgments, numerical estimates, and Likert scales;
- use of multiple methods (Fujiura, 2012).

Although many have tried to include individuals with ID in tasks such as CAHPS surveys designed for the general population, Fujiura (2012) has suggested that the task/survey be adapted to better fit the capabilities of the individual rather than the other way around.

Such an adaptation is possible with the use of cognitive support technology (CST) such as the Accessible Testing, Learning and Assessment System (ATLAS) developed by AbleLink Technologies. This software application enables individuals with ID to complete surveys independently (AbleLink Technologies, 2013). A study comparing a traditional written test and one using ATLAS among individuals with mild-moderate ID found participants were able to complete the test with greater accuracy, increased independence, and greater efficiency when using the ATLAS software compared to the traditional written test (Davies and Stock, 2008). Thus, using CST to survey individuals with ID appears to overcome many of the problems associated with current methods. CST negates the need for proxies or interviewers thus enabling more honest self-disclosure and reducing social desirability bias; it provides access for those with limited verbal expression and with fine-motor coordination issues; it addresses literacy issues; and also fosters independence. Lastly, CST-based assessments can allow for more complex testing and surveying (e.g., response branches, skip patterns) which would not be possible with traditional modes of administration for this population (Schwartz et al., 2012).

In collaboration with AbleLink, disability specialists at Westchester Institute for Human Development (WIHD) used the ATLAS software to create a survey to assess self-determination among people with ID using items modified from the National Core Indicator Adult Consumer Survey (NCIACS). The survey was converted into an iPad application thereby allowing for self-administration. Over two hundred and fifty individuals with ID (mostly mild-moderate range of intellectual ability) completed the survey at a national and state conference. With minimal training and assistance, the vast majority of respondents were able to complete the survey independently. The disability specialists at WIHD also shared in the judgment that the responses from the individuals who took the survey were authentic self-expression, thus adding weight to the validity of this method for collecting self-report information from individuals with intellectual disabilities (Schwartz et al., 2012).

This prior experience with the ATLAS survey methodology suggested that it could well serve as the vehicle for obtaining self-reported health care experience information from individuals with intellectual disabilities. So this current study was designed with the following objectives:

- Develop a CST-based, self-administered survey for people with ID to evaluate their experiences with healthcare;
- Describe the efficacy of obtaining self-reported information through CST from this population;
- Assess individuals' experience and satisfaction with this approach;
- Determine individuals' preferences for survey administration.

Methods

- Study Design and Participants

This study consisted of modifications to an existing national survey by the authors and a panel of disability experts, conversion of the survey into an iPad ATLAS application to facilitate independent response by individuals with ID, and testing of the survey and the iPad modality. Adults with ID classified as mild-moderate in severity based on ICD-9-CM codes (an indicator of intellectual functioning) (AAIDD, 2013) were recruited to participate from the adult health services department (HSD) at WIHD, a University Center for Excellence in Developmental Disabilities. Eligibility for participation included: age 18 years or older, mild-moderate ID (ICD-9-CM codes 317, 318.0, or 319 (unspecified)); and completion of a doctor's visit prior to participation. Participation was voluntary and anonymous (except for self-report of first name to facilitate interpersonal interaction).

Procedures

- Development of Survey

The survey was adapted from the CAHPS Clinician and Group Survey Adult Primary Care Questionnaire 1.0 (AHRQ, 2013) by the authors in consultation with a panel of WIHD disability specialists who had participated in an earlier adaptation of the NCIACS on self-determination (Schwartz et al., 2012). CAHPS questions that focused on the process, content and satisfaction with healthcare provider visits were selected for inclusion in this study. Specifically, while still retaining the integrity of the original survey, question/response wording and format were simplified to be more understandable and accessible to people with ID. For example, the timeframe used in questions was changed from the previous 12 months to their most recent doctor's visit, and the question/answer format was changed from a four-point response scale to a yes/no format or three-point scale whenever the former was not possible. For example, the CAHPS question: *In the last 12 months, how often did this doctor seem to know the important information about your medical history? (never/sometimes/usually/always).* Was changed to: *Did the doctor seem to know a lot about you and your health? (yes/no)*.

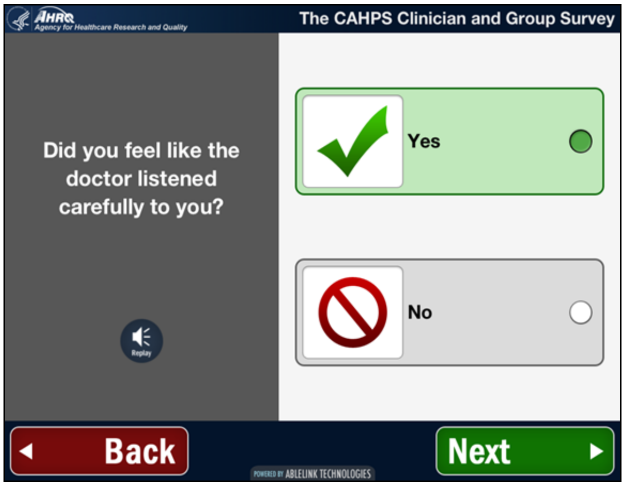
The adapted survey was organized into two parts: Part One contained demographic/background questions (age, gender, race/ethnicity, daytime activity, living arrangements) and Part Two contained healthcare experience questions (e.g., wait time to see doctor, if doctor knew about their health or, conversely, interrupted the patient). In addition, a consent statement describing the content and purpose of the survey and its voluntary and anonymous nature was also created to be read to participants prior to beginning the actual survey. This study was approved by the Institutional Review Board of New York Medical College.

In order to determine whether the content/wording of the survey was appropriate for the target population, a pilot test was conducted with 10 individuals at WIHD over a two-week time period during Summer 2011. The survey was administered by individual interview, wherein questions/answer choices were read to participants who would then verbally indicate their response. While administering the survey to each participant, potential "problem" questions were identified (i.e., those that required multiple prompts, needed to be paraphrased, repeated often, were frequently misunderstood or difficult to answer), then revised and tested with subsequent participants. Utilizing the results of this pilot test, a final version of the adapted survey was created, consisting of seven questions in Part One and 27 questions in Part Two.

- Development of iPad Application

The adapted survey was then converted into an iPad application by the authors and Able-Link Technologies utilizing ATLAS software. The software allows the iPad to "read" text to users and record their responses, while enabling them to navigate through the survey by touching the screen at appropriate places. The application was designed so that one question and its responses appear on each screen at a time. The questions appear in large print on the left and the responses are arranged vertically on the right. Each question is read automatically upon advancing to a new screen. When the user touches each response, it is highlighted in a different color and the response is read to them. The questions/responses can be repeated as often as desired until a final response is selected. To move to the next question, the user touches the green "Next" button at the bottom right corner of the screen, which only appears after a response has been selected to prevent accidental non-response.

FIGURE 1 : A SCREEN SHOT OF MODIFIED QUESTION FROM THE AHRQ CAHPS PATIENT-CENTERED MEDICAL HOME PATIENT EXPERIENCE SURVEY ACCESSED ON AN IPAD



Did you feel like the doctor listened carefully to you?

● Yes

○ No

Before beginning the survey, the first screen read to the user presents the consent statement. If the respondent selects the “No, I do not want to take the survey” response, the application stops. Selection of “Yes, start the survey” leads to the beginning of the survey. When the survey is completed, the user is congratulated on their accomplishment. Each completed survey is stored on the iPad which can be exported into an Excel spreadsheet for analysis.

In order to test the viability of this alternative survey modality with the target population, a second pilot test with 10 WIHD participants was conducted over a one-week time period during Summer 2011. The study purpose was explained and the iPad was described and demonstrated. One of the investigators then assisted each participant in the completion of the demographic questions (Part One) in order to accustom respondents to navigating the questions on the iPad. Respondents were then asked if they felt comfortable taking Part Two independently and if so, were given headphones (to provide a sense of privacy and independence while the investigator remained in the room but at a distance). If not, respondents were assisted as for Part One. Eight of ten participants were able to complete the second part of the survey independently, with an average of one request for assistance per participant across all questions. All participants responded that they enjoyed using the iPad to take the survey.

- Testing the Survey Application

Encouraged by the results of the pretest, a larger study was conducted in early 2013. Nurses in the WIHD adult health care program identified individuals who met the study criteria and recruited them for study participation. Individuals were told that their participation was voluntary and anonymous and if they agreed, they were introduced to one of the study investigators. The procedures were then the same as for the second pilot test. The investigator also recorded: the presence/absence of caregiver, number of requests for assistance, length of time to complete Parts One and Two, whether Part Two was completed independently and prior experience with an iPad.

After completion of the iPad survey, a post survey was conducted where respondents were read seven questions and their possible response choices. The post survey consisted of: prior experience in taking surveys, preference of modality for taking future surveys, and the modality (i.e., questionnaire, interview, iPad) with which they felt that they could be most honest and understand the survey questions/ give their answers most easily.

Data Analysis

Frequency distributions were computed for all questions (iPad and post survey), ID level, presence of caregiver, completion of Part Two (independently or with assistance), and prior iPad use. An average value was calculated for the requests for assistance (of those completing Part Two independently) and time to completion.

Results

Seventy-nine adults with ID participated in the study; however, eight individuals were dropped due to: caregiver interference during survey completion (n=3), non-understanding of survey questions/completion issues (n=3), response bias (n=1), or frustration/loss of interest (n=1). Table 1 depicts the demographic characteristics of the 71 participants included in analysis as well as those of the entire HSD patient population for purposes of comparison. There is a similar age and gender distribution among both populations, although there are slightly more males than females within the HSD population. Approximately one-half of the study and HSD groups identify as White, non-Hispanic; however, race/ethnicity is not available for roughly 30% of the HSD population. Lastly, while 73.2% of study participants were classified as having mild-moderate ID, approximately 40% of HSD patients have multiple ID levels listed with nearly half (45.9%) having unspecified listed as a level. Thus, with the exception of ID level, the study population appears to be demographically similar to the HSD patient population.

TABLE 1: DEMOGRAPHIC CHARACTERISTICS: STUDY SAMPLE VS. WIHD HSD POPULATION

	Study Sample		WIHD HSD	
Variable	**N**	**%**	**N**	**%**
Total Respondents	71	100	724	100
Age (in years)				
18-29	13	18.3	129	17.8
30-39	16	22.5	136	18.8
40-49	19	26.8	157	21.7
50-59	14	19.7	192	26.5
Over 60	9	12.7	110	15.2
Gender				
Male	35	49.3	428	59.1
Female	36	50.7	296	40.9
Race/Ethnicity[a]				
White (non-Hispanic)	38	53.5	246	48.7
Black/African American (non-Hispanic)	19	26.8	128	25.3
Latino (any race)	12	16.9	119	23.6
Other (non-Hispanic)[b]	2	2.8	12	2.4
I/DD Level				
Mild (ICD-9-CM = 317)	38	53.5	2	0.28
Moderate (ICD-9-CM = 318.0)	14	19.7	138	19.1
Severe (ICD-9-CM = 318.1)	0	0	141	19.48
Unspecified (ICD-9-CM = 319)	7	9.9	160	22.1
Multiple codes listed	12	16.9	283	39.1

[a] Race/Ethnicity calculations for WIHD HSD based off of those with available data (N=505).

[b] Other includes American Indian/Alaska Native and Asian.

The majority of participants (52.1%) reported attending a day habilitation program (see Table 2). Seven individuals reported doing two or more of the listed activities (e.g., day program and paid job) while five reported not doing any. Also, approximately 70% of study participants reported living in a group home (a community-based residence for up to 10 people with ID) (U.S. Census Bureau, 2010).

Table 2: Daytime Activities and Living Arrangement

Variable	N	%
Daytime Activity(ies)		
School	4	5.6
Day program	37	52.1
Paid job	18	25.4
Two or more	7	9.9
None	5	7.0
Housing		
Own house or apartment	14	19.7
With family	7	9.9
Group home	50	70.4

Table 3 describes aspects of survey administration. Over half of participants (54.9%) elected to complete Part Two of the survey independently, with only 4.2% requiring assistance. Overall, there was an average of only 1.5 requests for assistance per participant. Interestingly, of those who requested continuing assistance with Part Two, 14.1% ended up completing it independently.

Table 3 : Aspects of Survey Administration

Variable	N	%
Total Respondents	71	100
Preference For/Actual Survey Completion (Part Two)[a]		
Independent/Independent	36	50.7
Assistance[b]/Assistance[b]	22	31.0
Independent/Assistance[b]	3	4.2
Assistance[b]/Independent	10	14.1
Presence of Caregiver		
Yes	21	29.6
No	50	70.4
Prior iPad Use		
Yes	21	29.6
No	50	70.4

	Mean	Range
Average Requests for Assistance (Part Two)[a]	1.5	0-7
Average Time to Complete (in minutes)		
Part One	3.8	1-8
Part Two	6.3	2-13

[a] Only computed for Part Two as Part One of the survey was treated as the training session and hence was completed with the participants.

[b] Assistance includes help provided by a participant's caregiver (if present) or by a survey team member.

Table 4 depicts results from the post survey. All participants reported that they enjoyed using the iPad to take the survey. Of those who had taken a survey before (52.9%), over half (52.8%) reported that they took it with the help of another person or had someone take it for them. When asked about their survey preferences, almost three-quarters (73.7%, 14/19) of individuals reported that they would rather take surveys independently. An overwhelming majority of participants responded in favor of the iPad across four key aspects of survey administration:

- taking a future survey (95.5%);
- being most honest (83.6%);
- understanding the questions (88%);
- giving one's answers (91%).

Table 4: Post Survey Results

Question	N	%
Liked using iPad to take survey		
Yes	71	100
No	0	0
Not sure	0	0
Ever taken survey before		
Yes	36	52.9
No	31	45.6
Not sure	1	1.5
How was survey taken[a]		
Paper/Pencil	12	33.3
Interview	5	13.9
Someone helped me/Took it for me	19	52.8
Preference: Take survey on own or with assistance[b]		
On own	14	73.7
With assistance	5	26.3
How most like to take survey		
Paper/Pencil	2	3.0
Interview	1	1.5
iPad	64	95.5
Be most honest		
Paper/Pencil	4	6.0
Interview	7	10.4
iPad	56	83.6
Easiest to understand the questions		
Paper/Pencil	2	3.0
Interview	6	9.0
iPad	59	88.0
Easiest to give your answers		
Paper/Pencil	3	4.5
Interview	3	4.5
iPad	61	91.0

[a] Only asked if participant answered "Yes" to previous question.

[b] Only asked if participant answered "Someone helped me/Took it for me" to previous question.

Lastly, virtually all participants had a positive experience and were very satisfied with this survey approach (see Table 5).

Table 5: Participant Experience and Satisfaction

"I like how fast I learned to use the iPad."

"That was really fun!"

"I liked that a lot."

"That was easy!"

"I liked taking it by myself."

"It made me feel happy."

"I want an iPad now!"

"I like how it spoke to me."

"It's so much fun using the iPad."

"I loved it."

"The iPad is much better."

"That was great."

Discussion

The current study provides evidence that individuals with mild-moderate intellectual disability can independently complete a CST-based, self-administered survey with minimal training and assistance. It also is an efficient method for capturing self-report data without requiring individual interviews and ATLAS enables immediate access to results (AbleLink Technologies, 2013). Thus, this approach can be used to effectively obtain self-reported healthcare evaluations from this population. Moreover, all participants enjoyed using the iPad to take the survey and virtually all chose it as their preferred mode of survey administration.

These results are significant for several reasons. First, this CST-based approach may provide a mechanism to improve the quality of care for individuals with ID which ultimately may lead to better health outcomes for this population. Second, this approach is likely applicable to the ID population overall since 96% of all ID individuals in the US fall in the mild-moderate range (Davies & Stock, 2008). Third, use of this method potentially opens the door to other groups who also face communication challenges (e.g., those with: aphasia, low levels of health literacy, limited English proficiency). Fourth, CST provides a way to increase self-determination, self-esteem and empowerment in this population (Schwartz et al., 2012). This project also addresses a Healthy People 2020 objective to “connect with hard-to-reach populations” (DHHS, 2010, p.1). Lastly, CST has the potential to help enhance communication between healthcare providers and individuals with ID, making the patient-provider relationship more effective.

There are also other ways in which CST can be used to increase the independence, self-determination, and social participation of individuals with intellectual disabilities. For example AbleLink Technologies has also developed a GPS-based software application – Wayfinder – that can be downloaded to a hand-held device to support independent travel.

As with all studies, this study has some limitations. First, the small, non-random nature of the study sample drawn from one center limits generalizability of the findings until this approach is used more widely. However, this was planned as a pilot study and as such has shown great promise.

Second is the use of ICD-9-CM codes as a proxy for measuring intellectual disability. Although ICD-9-CM codes incorporate a measure of intellectual functioning, they do not incorporate a measure of adaptive functioning (AAIDD, 2013). This likely affects the generalizability of study findings to individuals with more severe levels of ID.

Third, some may be reluctant to adopt this survey approach since many people with ID have not been exposed to technology in general and staff members and caregivers may assume that it is too complex for individuals with ID. It is therefore important for CST developers to discuss the benefits of this approach and to provide an opportunity to experience its accessibility firsthand.

Overall, this study provides substantial evidence to support the use of this approach to improve the quality of care for individuals with ID and ultimately their health outcomes. It also adds to the growing body of research demonstrating that CST can increase the independence and self-determination of people with ID by allowing them to report their thoughts, opinions, and experiences without dependence on others. CST holds great promise for gathering many types of self-reported information directly from individuals with ID as well as those with other communication challenges, and potentially assisting them in other aspects of their lives.

References

AbleLink Technologies. *About AbleLink ATLAS reports.* Retrieved September 22, 2013 from http://atlas.ablelinktech.com/about

Agency for Healthcare Research and Quality (AHRQ). *About CAHPS*. Retrieved September 22, 2013 from http://cahps.ahrq.gov/about.htm

Agency for Healthcare Research and Quality (AHRQ). *CAHPS Clinician & Group Surveys.* Retrieved September 22, 2013 from https://cahps.ahrq.gov/clinician_group/

American Association on Intellectual and Developmental Disabilities (AAIDD) (2013). *FAQ on intellectual disability.* Retrieved September 22, 2013 from http://aamr.org/content_104.cfm

Andresen, E. M., Vahle, V. J., & Lollar, D. (2001). Proxy reliability: health-related quality of life (HRQoL) measures for people with disability (Abstract). *Quality of Life Research*, *10*(7), 609-619.

Davies, D. K., & Stock, S. E. (2008). *ATLAS: An accessible testing, learning and assessment system for individuals with intellectual disabilities to facilitate inclusion and access to the general curriculum.* Phase I Final Project Report submitted to the U.S. Dept. of Education.

Finlay, W., & Lyons, E. (2001). Methodological issues in interviewing and using self-report questionnaires with people with mental retardation. *Psychological Assessment*, *13*, 319-335.

Fujiura, G. T., & RRTC Expert Panel on Health Measurement (2012). Self-reported health of people with intellectual disability. *Intellectual and Developmental Disabilities, 50*(4), 352-369.

INSTITUTE OF MEDICINE (IOM) (2009). *State of the USA health indicators: Letter report.* Washington, DC: National Academies Press.

KURPAS, D., & STECIWKO, A. (2005). Patient satisfaction as the main indicator of primary care quality (Abstract). *Przegląd Lekarski, 62*(12), 1546-1551.

LARSSON, G., & LARSSON, B. W. (2001). Quality of care and service as perceived by adults with developmental disabilities, their parents, and primary caregivers. *Mental retardation, 39*(4), 249-258.

MANARY, M. P., BOULDING, W., STAELIN, R., & GLICKMAN, S. W. (2013). The patient experience and health outcomes. *New England Journal of Medicine, 368*(3), 201-203.

NATIONAL COMMITTEE FOR QUALITY ASSURANCE (NCQA) (2011). *Implementation of the CAHPS PCMH survey.* Retrieved September 22, 2013 from http://www.ncqa.org/portals/0/HEDISQM/Programs/SVC/CAHPS_PCMH_Survey_RFP_2012_FINAL_-_9-9-11.pdf

NOTA, L., SORESI, S., & PERRY, J. (2006). Quality of life in adults with an intellectual disability: the Evaluation of the Quality of Life Instrument. *Journal of Intellectual Disability Research*, *50*(5), 371-385.

PATRICK, D., BURKE, L., POWERS, J., SCOTT, J., ROCK, E., DAWISHA, S., O'NEILL, R., & KENNEDY, L. (2007). Patient-reported outcomes to support medical product labeling claims: FDA perspective. *Value Health*, Suppl 2,125-137.

RAMCHARAN, P. & GRANT, G. (2001) Views and experiences of people with learning disabilities and their families: the user perspective. *Journal of Applied Research in Intellectual Disability, 14*(4), 364-380.

SCHWARTZ, A., BACON, A., O'HARA, D., DAVIES, D., & STOCK, S. (2012). *Using iPads with cognitively accessible software to directly survey people with developmental disabilities.* Unpublished manuscript.

U.S. CENSUS BUREAU (2010). *2010 American Community Survey/Puerto Rico Community Survey group quarters definitions.* Retrieved September 22, 2013 from http://www.census.gov/acs/www/Downloads/data_documentation/GroupDefinitions/2010GQ_Definitions.pdf

U.S. DEPARTMENT OF HEALTH AND HUMAN SERVICES (DHHS) (2010). *Healthy People 2020.* Washington, DC: U.S. Government Printing Office.