

## Using Cognitively Accessible Survey Software on a Tablet Computer to Promote Self-Determination among People with Intellectual and Developmental Disabilities

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Volume 21, Number 1, April 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/1086490ar>

DOI: <https://doi.org/10.7202/1086490ar>

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Publisher(s)

Réseau International sur le Processus de Production du Handicap

ISSN

1499-5549 (print)

2562-6574 (digital)

[Explore this journal](#)

Cite this article

Schwartz, A., Bacon, A., O'Hara, D., Davies, D., Stock, S. & Brown, C. (2015). Using Cognitively Accessible Survey Software on a Tablet Computer to Promote Self-Determination among People with Intellectual and Developmental Disabilities. *Développement Humain, Handicap et Changement Social / Human Development, Disability, and Social Change*, 21(1), 17–28.  
<https://doi.org/10.7202/1086490ar>

Article abstract

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## Using Cognitively Accessible Survey Software on a Tablet Computer to Promote Self-Determination among People with Intellectual and Developmental Disabilities<sup>1</sup>

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Article original • Original Article

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**Abstract** : People with intellectual and developmental disabilities (I/DD) identify “speaking for oneself” as a highly salient aspect of self-advocacy and self-determination (SABE, 2011), yet limitations in cognition or language often limit their direct participation in surveys. This study describes a self-administered survey procedure that used supportive software on an iPad to create a survey interface that was easily navigable by respondents with I/DD. A survey based on items from the National Core Indicator (NCI) Adult Consumer Survey (HSRI & NASDDDS, 2001) was developed that included five items on choice-making which have been previously studied by Lakin et al. (2008) and Stancliffe et al. (2011). Cognitively diverse groups of self-advocates were recruited to take the iPad survey at both a national and state self-advocacy conference. The results indicated that the iPad survey platform enabled people with varying degrees of I/DD to respond independently to a self-administered survey with little training or assistance. The resulting iPad-gathered data on the NCI choice items supported the validity of the procedure by conforming to patterns from standard NCI interviews. This self-administered survey technology holds great promise for gathering many types of survey information directly from people with I/DD, allowing them to more actively participate in the design of supports, services, and environments that affect their lives.

**Keywords** : cognitive accessible survey software, self-determination, speaking for oneself, intellectual and developmental disabilities, tablet computer, choice-making

**Résumé** : Les personnes ayant des incapacités intellectuelles et des troubles envahissants du développement (DI-TED) identifient le fait « de parler pour soi-même » comme un aspect central de la défense de leurs droits et de l'autodétermination (SABE, 2011). Leurs incapacités langagières et cognitives limitent toutefois souvent leur participation directe aux différentes enquêtes les concernant. Cette étude décrit une procédure d'enquête auto-administrée ayant utilisé des logiciels de soutien sur un iPad afin de créer une interface de sondage facilement navigable par les répondants ayant une DI-TED. Une enquête basée sur les énoncés de la *National Core Indicator (NCI) Adult Consumer Survey* (HSRI & NASDDDS, 2001) a été développée. Elle incluait également les cinq énoncés faisant référence à la prise de décision étudiés précédemment par Lakin et al. (2008) et Stancliffe et al. (2011). Des personnes ayant des capacités cognitives différentes ont été recrutées lors de conférences nationales et régionales sur la défense des droits afin de participer au sondage proposé sur iPad. Les résultats montrent que la plate-forme de sondage utilisée a permis aux personnes ayant différents niveaux d'incapacités intellectuelles et de troubles envahissants du développement de répondre à un questionnaire auto-administré de manière autonome, et ce, avec une formation et une assistance minimale. Les données recueillies au moyen de l'iPad sur les questions à choix multiples de la NCI soutiennent la validité de la procédure développée puisqu'elles confirment les tendances observées dans le cadre des entrevues standard réalisées dans le cadre de cette même enquête. Cette technologie auto-administrée de sondage semble très prometteuse auprès des personnes DI-TED, lesquelles pourraient les amener à participer plus activement à la conception des mesures de soutien, des services et des environnements qui présentent un impact sur leur vie.

**Mots-clés** : logiciel de sondage accessible, autodétermination, parler pour soi-même, incapacités intellectuelles et troubles envahissants du développement, tablette numérique, prise de décision

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<sup>1</sup> This research was conducted as part of The National Training Initiative in Self-Determination (NTI-SD), a five-year grant funded by the U.S. Department of Health and Human Services, Administration on Intellectual and Developmental Disabilities, Grant No. 09-DD-0659. The project consortium is comprised of five University Centers for Excellence, including the Westchester Institute for Human Development in New York State. Information about the NTI-SD is available at <http://www.aucd.org/ngsd>. The authors would like to thank Mitchell Levitz and Marilyn Vitale of the Westchester Institute for Human Development, George Gotto and Susan Palmer of the UMKC Institute for Human Development, University of Missouri-Kansas City, and Steve Stock of AbleLink Technologies, for their assistance in training and data collection. We also offer our appreciation to the self-advocates who took part in the survey, and their family members and support staff who assisted.

## Introduction

People with I/DD identify “speaking for oneself” as a highly salient aspect of self-advocacy and self-determination (People First of California, 2010; SA-BE, 2011). The opportunity and capacity for self-expression are at the very heart of self-advocacy and self-determination (Sicilia, 2005) and are embodied in disability law (Developmental Disabilities Act of 2000, PL 106-402). As Wehmeyer and Metzler (1995) stated: “In order to assume control over one’s life, one must have the opportunity to express preferences, indicate choices, and make decisions” (p. 111).

Unfortunately, there are many barriers to self-expression confronting people with intellectual and developmental disabilities (I/DD), including linguistic and cognitive impairments, physical challenges, and social influences. These limitations interfere with the opportunity for people with I/DD to directly participate in surveys. Recent innovations in technology are providing devices, applications, and procedures that offer people with I/DD increased access to unimpeded self-expression. In this article, we describe a novel approach to gathering survey information in a self-administered way using digital technology (i.e., an iPad with cognitively accessible software), which both protects privacy and potentially increases validity.

Many widely used approaches to gathering information from people with I/DD are fraught with challenges to validity. Although routinely done (e.g., National Core Indicators Phase II Technical Report, 2001), collecting information directly from people with I/DD through interviews or written questionnaires presents special difficulties (HSRI & NASDDDS, 2001). For example, directly interviewing people with I/DD can distort findings by unintentionally introducing socially driven biases (e.g., acquiescence, social desirability) that influence the way any group of participants answers questions (Messick & Jackson, 1961; Crowne & Marlowe, 1960). Inaccurate responses can also result from not understanding questions, or embarrassment (HSRI & NASDDDS, 2001).

Self-administered paper and pencil questionnaires provide a greater sense of privacy than verbal interviews. Under these conditions, typical adults show increased openness and a willingness to disclose more about what they think and feel (Tourangeau & Smith, 1996). Several comprehensive reviews (e.g., Lee, 1993, De Leeuw, 1993) have documented that self-administered paper and pencil questionnaires “produce more valid reports of sensitive behavior and less socially desirable answers in general” (De Leeuw et al., 2003, p. 224). However, there are drawbacks to paper and pencil questionnaires for people with I/DD: they require the participant to be able to read; they limit the complexity of questions that may be asked; there is no interviewer feedback to judge response validity; and one cannot probe for a more elaborated response.

Surrogates or proxies – such as parents, staff, or teachers – are often used to answer survey questions on behalf of people with I/DD. The use of proxies is considered an acceptable practice when asking about factual information like services received or the frequency of community participation. However, when posing more subjective and experiential questions, especially those asking about choice, quality of life, or satisfaction, a proxy is often not a valid surrogate for the person with I/DD (Sheppard-Jones, et al., 2005; Shalock, 1997). Recent studies found that parent proxies misrepresent the feelings, experiences, and beliefs of people with I/DD when they attempt to speak about subjective issues (Watkins et al., 2006; Glidden et al., 2011; Rotsika et al., 2011). For example, Shipman et al. (2011) found that self-reports of quality of life by adolescents with Autism Spectrum Disorder were significantly more positive than those of their parents. Therefore, methods that enable people with I/DD to answer questions independently and anonymously (i.e., by private, self-administered survey procedures) may reduce inaccuracies introduced by the use of paper and pencil surveys and distortions from surrogates. Such methods might yield better information about how people with I/DD actually feel.



The rapid development of digital technology (i.e., computers, tablets, mobile devices and cognitively accessible software) has provided new opportunities to promote independent self-expression for individuals with I/DD. Computer-assisted survey techniques fall into two categories: *computerized-assisted self-interviewing* (CASI), and *audio computer-assisted self-interviewing* (A-CASI). These techniques, by which questions and possible answers can be presented to respondents both visually and auditorily, overcome many of the problems associated with paper and pencil surveys, direct interviews, and proxy interviews. Weisband and Keisler (1996) reviewed 39 studies that demonstrated the superiority of computer forms over both traditional paper and pencil data collection and face-to-face interviews. Computer-mediated procedures provide a sense of anonymity and privacy, and are associated with more self-disclosure and a reduction in bias caused by social desirability. In the audio version, a computer can read questions and response options to respondents who need such supports, thereby circumventing literacy issues (Weisband & Kiesler, 1996). In the case of surveying people with physical disabilities, accessibility features like touch screens allow people who cannot operate a mouse to directly respond to survey questions. Also, “intelligence” can be programmed into a sequence of questions using response branches and skip patterns, allowing for more complex surveying.

Cognitively supportive software applications developed by AbleLink Technologies (e.g., *WorkSight*, *Questnet*, *Atlas*) enabled people with I/DD to indicate preferences and answer test questions more accurately and efficiently at computer workstations than through oral or written procedures (Stock et al., 2003; Stock et al., 2004; Davies & Stock, 2010). For example, in an examination of vocational preferences, Stock et al. (2003) reported that working independently on a computer, rating video clips of various jobs, allowed people with I/DD to express their honest preferences, rather than make choices they believed were favored by parents and teachers. These results suggest that anonymous, self-administered digital surveys for people with I/DD could have many

potential benefits, such as reducing error in the measurement of their subjective opinions. By being able to respond independently, in private, without the presence of an interviewer, evaluator, or assistant, people with I/DD may be more inclined to answer truthfully.

In the present study, we first sought to demonstrate the *viability* of a tablet-based self-administered survey procedure specifically designed for people with I/DD. We wanted to determine whether such a methodology could be made accessible to a group of people with I/DD with a varying range of intellectual abilities. Once the viability of the procedure was established, we examined the *validity* of the obtained results. Criterion validity was established by comparing the iPad-based self-survey item and subscale results with comparable data collected through traditional face-to-face interviews.

## Method

Recently, responses to NCI Consumer Survey items on *choice-making* in everyday activities, living arrangements, and supports were studied extensively by Lakin et al. (2008) and Stancliffe et al. (2010). Both reports were based on the analysis of responses to NCI choice-related items from large random samples of participants in the annual NCI surveys conducted in several states. These data were gathered either by interviewing people with I/DD who were capable of answering for themselves, or by interviewing proxies who knew the person well enough to answer for them. We included five of these choice-related questions in our iPad survey, thereby allowing us to compare the findings obtained using the iPad self-survey platform with data from standard NCI interviews.

### - *Patterns in Choice Data*

Studies have repeatedly found that people with I/DD who live in institutions or large group home settings enjoy less choice than people who live more independently (Stancliffe and Abery, 1997). Lakin et al. (2008) found that NCI choice items cluster around two factors: *support-related choice* (such as choice of home, staff, and housemates) and *everyday choice*

(such as choice of free time or spending money). The degree of choice-making was strongly associated with both level of intellectual disability (see also Heller et al., 1999; Stancliffe et al., 2000) and type of living arrangement. They also reported that opportunities for everyday choice-making were more available than for support-related choice-making.

Several reports (Stancliffe, 1997; Stancliffe and Abery, 1997; Wehmeyer and Boulding, 1999) showed a positive relationship between individualized living arrangements (with fewer housemates) and choice-making opportunities. Stancliffe et al. (2011) investigated choice of living arrangements in a large sample of NCI respondents. Most adults with I/DD had little choice about where they lived or their housemates. Choice of living arrangement was again associated with type of residence, with people living more independently (e.g., in supported apartments) expressing more choice in where and with whom to live than those living in institutions and group homes.

To demonstrate the validity of the iPad self-survey procedure, we sought to replicate these relationships among choice opportunities, living arrangement, and level of intellectual disability in the iPad-gathered dataset.

#### - Survey Instrument

As part of a larger project on self-determination, we developed a 33-item survey that included five items on choice-making adapted from the National Core Indicators (NCI) Adult Consumer Survey (HSRI, 2006). The NCI items have established reliability and validity. Minor wording changes were made to questions without changing their meaning so as to make them more accessible to people with I/DD.

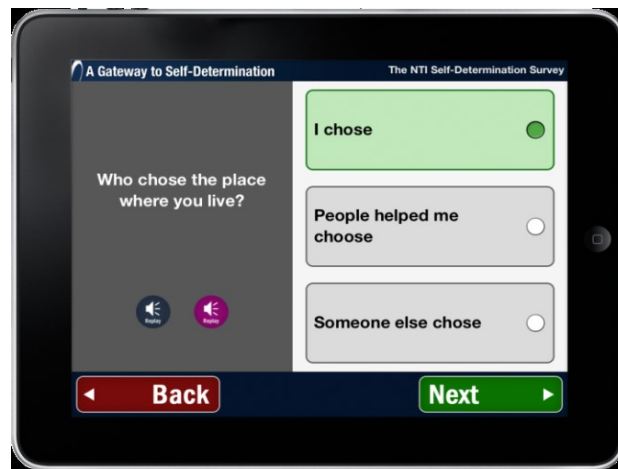
#### - iPad Survey Platform

A digital survey platform was designed to enable people with I/DD to understand and answer these questions by themselves with minimal help (i.e., to self-administer or self-survey).

The *Atlas* software (Davies & Stock, 2010) was used to design the interface. It employed the iPad's accessibility features to "read" questions and answers out loud to self-advocates. Touching the screen on any part of the question initiated *Atlas* to voice that question. There was also a paraphrase button just below each question, which presented an alternative wording of that question, spoken by a different person. Touching any of the response boxes on the right side of the screen voiced that response and temporarily highlighted that box in a different color (thus indicating it was the active choice). Participants could change their response by touching another option box, and they could change their selection as often as they wished. The questions, paraphrases, and responses could be voiced as often as desired.

All questions fell into one of two response types. Some questions ("Who chose the place where you live?") were answered by choosing a response along the 3-point scale represented by, "I chose," "People helped me choose," or "Someone else chose" (see Figure 1). Other questions ("Do you like your home, or where you live?") were answered by selecting "Yes" or "No" on the touch screen. Participants read or listened to the questions, then read or listened to the answers, and then touched the screen to record their answers as described above. Respondents could use "Next" and "Back" buttons to advance through the survey items or go back and change answers.

**FIGURE 1 : EXAMPLE OF A THREE-POINT SCALE ITEM**



After field-testing the survey with local self-advocates and making the few wording changes they suggested, a detailed set of procedures was developed for (a) obtaining informed consent for people who volunteered to take the survey; (b) training each participant to use the *Atlas* application; and (c) insuring that participants took the survey in private and that their answers would remain confidential. We also recruited and trained a small group of self-advocates to assist in coordinating the survey process. The Institutional Review Board of the New York Medical College approved the proposed survey design.

**- Data Collection Procedure**

Data collection consisted of samplings at two self-advocacy conferences. The biannual national conference of Self-Advocates Becoming Empowered (SABE) held in Kansas City in September 2010 provided the first venue to gather data using the self-administered iPad survey. A separate room at the SABE conference was set aside for the survey work using four iPad stations. Students from neighboring universities and volunteers from a local self-advocacy council were recruited and trained to serve as research assistants and mentors. The self-advocate mentors invited people to take the survey, explained its purpose, and helped to obtain informed consent.

A second cohort of individuals was recruited at the annual conference of the Self-Advocacy Association of New York (SANYS), held in Albany in September 2011. Only two iPad stations were used at this venue. In all other respects, the procedures followed were identical to those used at SABE in terms of enlisting self-advocate mentors, recruiting participants, and gaining informed consent.

To begin, the survey participant and a research team member both put on headphones so that the survey could be completed privately. The first ten questions – which asked about age, gender, living arrangement, and other descriptive facts – served as “training” items. Research staff instructed the participant in how to use the *Atlas* interface. These questions also

provided basic demographic information about the individuals taking the survey (see Figure 2).

**FIGURE 2 : A DEMOGRAPHIC ITEM USED FOR TRAINING**



After completing the ten training questions, research staff asked participants if they felt comfortable doing the rest of the survey by themselves. This second part of the survey contained the 27 questions related to self-determination (expanded to 33 questions for the New York State sample). If participants indicated that they could take the rest of the survey on their own, they continued on to complete the survey independently, while research team members were available to provide assistance. If the participant requested additional help, a research team member (or other preferred person – family member, friend or staff) remained with them to assist. Anyone other than a research team member who supported a survey participant was specifically instructed to offer only encouragement, and to refrain from rephrasing or interpreting questions, or influencing responses. Everyone who took the survey was given a *Certificate of Completion* and a small gift for participating.

**- Survey Participants**

This report examines the responses of 208 self-advocates who either volunteered at the SABE 2010 national conference (n=161) or were recruited and screened as group home

residents at the SANYS 2011 state conference (n = 47). Given that our focus was on the choice-related survey items, we followed the procedure of Lakin et al. (2008) by only analyzing the data from individuals living either in supervised (24-hour staffed) or supported (less than 24 hour staffed) living arrangements (i.e., were *not* living at home with family). It is important to note that these samples were not random. The SABE sample was a subgroup of self-described self-advocates who were attending the national conference in Kansas City. They came from all over the country, including thirty-five states, Washington, D. C, and Guam. All SABE conference attendees were invited to participate in the iPad survey, but the sample included only those who volunteered. The impressions of research staff on site, and early analyses of participant responses, confirmed that we had surveyed a highly skilled cohort that expressed high levels of choice.

To increase the diversity of respondents with respect to intellectual disability, we attended a second self-advocacy conference (SANYS). The SANYS conference draws a large group of self-advocates who receive services in 24-hour supervised group-home settings. Therefore, at the SANYS convention we specifically recruited only people with I/DD who lived in such group homes. This strategy diversified the overall sample, allowed us to better test the limits of the self-administered software, and made it possible make comparisons that paralleled those of Lakin et al. (2008) and Stancliffe et al. (2011). Finally, we should note that that all individuals in our analysis were judged by research staff to be capable of understanding all survey questions.

#### - Choice Measurement

The NCI Adult Consumer Survey has nine choice-related questions. These items have well-established inter-rater agreement statistics and one successful examination of test-retest reliability (Smith and Ashbaugh, 2001). As noted earlier, a factor analysis of these items by Lakin et al. (2008) yielded two subscales, which were named *support-related choice* and *everyday choice*. Averaging across the consti-

uent items formed two scales, which gave both scales a similar metric to permit better comparisons. These scales had high factor loadings and high levels of internal consistency reliability (Chronbach's  $\alpha \approx 0.8$ ).

In our analysis of choice, we only used the five NCI choice items that were responded to by all SABE and SANYS participants. We followed Lakin et al. (2008) and calculated the average *support* choice score, based on three items (home choice, home staff choice, and day program choice), and the average *everyday* choice score, based on two items (free time choice and spending choice). To be included in the analysis, these choice scores had to be based on valid answers to at least two of the support choice and everyday choice items. Lakin et al. (2008) used a similar standard. Given this requirement, all 208 respondents had valid choice scores.

## Results

### - Participants

Table 1 shows basic participant characteristics by sample (SABE and SANYS) and in total. The two samples were indistinguishable in nearly every respect (gender, age, ethnicity, physical challenges, and mobility). Indeed, the measures of association, which vary between 0 (no association) and 1 ("perfect" association), were nearly always very modest. Two differences stand out: type of living arrangement ( $\phi=0.8$ ) and level of assistance needed to complete the survey ( $\phi=0.36$ ). With respect to type of residence, the samples were purposely structured to create this distinction. Following Lakin et al. (2008) we eliminated those in the SABE cohort who lived with their families, since for this group the degree of actual choice that one has over home, staff, and housemates is unclear. As a result, the SABE cohort was largely composed (88.8%) of people living in their own homes or apartments. The SANYS cohort was limited to people who lived in 24 hour supervised group homes. Thus, the two groups intentionally represented cohorts with different living arrangements.



**TABLE 1 : IPAD SURVEY PARTICIPANT CHARACTERISTICS BY SAMPLE**

Participant Characteristics	Sample			Association Measure*
	SABE (n=161)	SANYS (n=47)	Total (n=208)	
Women participants	52.2%	55.3%	52.9%	0.03
Mean age of participants	41.7	44.2	42.3	0.09
Latino participants	5.0%	6.4%	5.3%	0.03
Non-white participants	19.9%	21.3%	20.2%	0.02
Participants living in own apt/home	<b>88.8%</b>	<b>0.0%</b>	68.7%	<b>0.80</b>
Participant needing assistance with survey	<b>26.1%</b>	<b>62.8%</b>	34.6%	<b>0.36</b>
Participants with difficulty using hands	17.4%	19.1%	17.8%	0.03
Participants who have difficulty talking	1.2%	2.1%	1.4%	0.17
Participants with problems seeing/hearing	30.4%	12.8%	26.4%	0.02
Participants using a wheelchair	11.8%	8.5%	11.1%	0.04

\*For the association between age and sample (SABE vs. SANYS), the analysis of variance based eta ( $\eta$ ) is reported. For all other associations, the chi-square based phi ( $\phi$ ) is given.

The difference in living arrangements was in turn reflected in the difference between the two groups in the level of assistance required to complete the survey – a moderate association ( $\phi=0.36$ ). As we noted earlier, past research has consistently found cognitive ability to be strongly associated with type of living arrangement. Since the SABE group lived much more independently, we anticipated it would be less intellectually disabled and require less assistance than the SANYS sample. In another way of looking at it, this association validated using living arrangement as a proxy measure of intellectual disability.

**- Choice Items**

The three support choice items had a mean inter-item correlation of 0.474, translating into a Chronbach’s  $\alpha=0.73$ . This level of internal consistency reliability is not quite as high as Lakin et al. (2008), but is acceptable, particularly in such an abbreviated scale (i.e., three items as opposed to six in Laken et al., 2008). The single inter-item correlation between the two everyday choice items was a moderate 0.34, translating into a Chronbach’s  $\alpha=0.51$ . This is a

moderate level of internal consistency at best, but we believe that with the full complement of NCI choice items, and with larger and more diverse samples, this level would be higher. However, our empirical claims do not rest exclusively on these subscales, since all findings are replicated for each individual choice item.

Table 2 presents the distribution of choice items for all survey participants (both SABE and SANYS). These items are grouped by choice scale: *support-related* choice items and *everyday* choice items. The means were quite high, ranging from 1.35 for choice of home staff to 1.80 for decisions about free time. Nevertheless, we observed the same pattern in the iPad-derived data that was reported by Lakin et al. (2008) and others: choice levels, despite being concentrated at the upper limits of choice, were higher for everyday choice than for support choice. Note that with the exception of the choice of home staff item, all respondents provided an answer to these questions. Some respondents in the SABE sample reported that they had no home staff, thus reducing the number of non-missing responses to this item to 156.





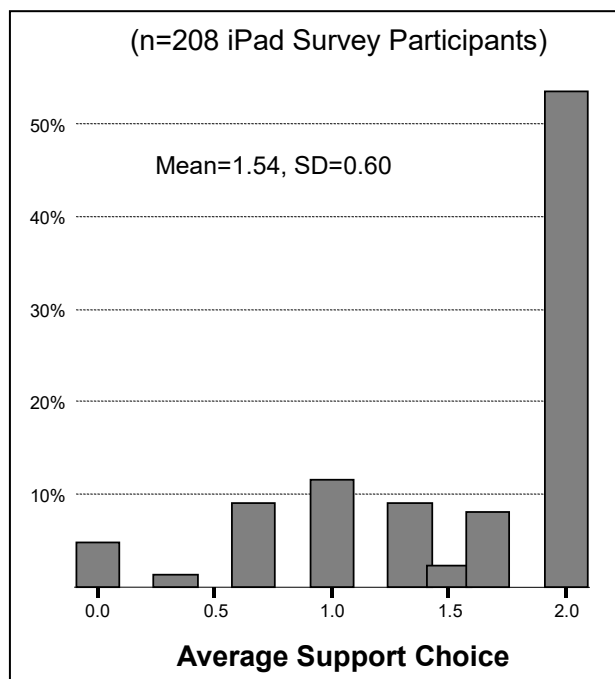
**TABLE 2 : IPAD SURVEY CHOICE ITEM FREQUENCIES, PERCENTAGES, AND MEANS**

Choice Dimension	Choice Items	Who chose/decided?			Total	Mean
		Someone else (0)	People helped (1)	I chose/decided (2)		
Support	Chose where you live?	26 (12.5%)	35 (16.8%)	147 (70.7%)	208 (100%)	1.58
	Chose home staff?	38 (24.4%)	25 (16.0%)	93 (59.6%)	156 (100%)	1.35
	Chose work/day program?	24 (11.7%)	36 (17.5%)	146 (70.9%)	206 (100%)	1.57
Everyday	Decide free time?	13 (6.3%)	15 (7.2%)	180 (86.5%)	208 (100%)	1.80
	Decide what you buy?	8 (3.8%)	27 (13.0%)	173 (83.2%)	208 (100%)	1.79

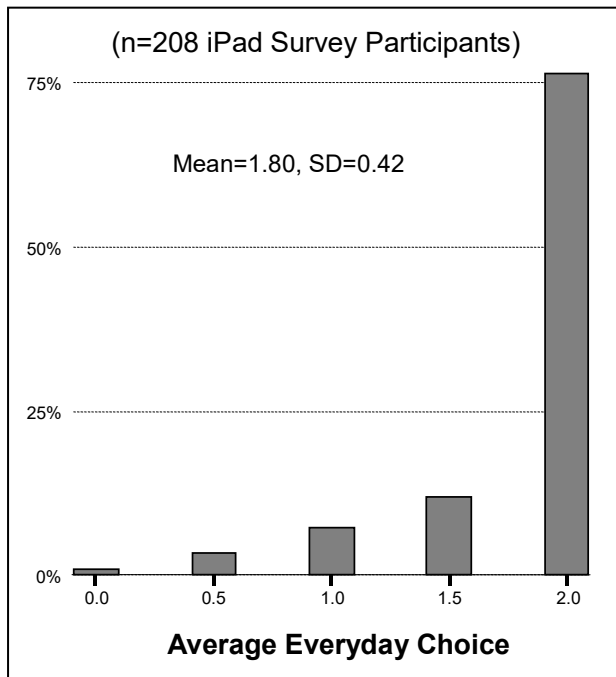
*- Choice Summary Scores*

Figures 3 and 4 show the distribution of support-related and everyday choice scores for all survey participants. With three support choice items and two everyday choice items, the scales in the graphs are somewhat different. Nonetheless, both summary scales showed a left skew, with scores concentrated at the highest value of 2 (full choice) and tailing toward the lower scores. The support choice mean was 1.54, and the everyday choice mean was 1.8, again replicating the common pattern (i.e., higher everyday choice scores) and demonstrating overall elevated choice levels among self-advocates. Everyday choice was more concentrated (less variable), with over three in four respondents telling us they decide about both free time and what they buy with their money. However, at around six in ten, support-related choice was also quite high. The standard deviation (sd) for everyday choice was 0.42 compared to 0.60 for support choice. Therefore, most self-advocate survey participants described themselves as in charge of these areas of their lives.

**FIGURE 3 : SUPPORT-RELATED CHOICE**



**FIGURE 4 : EVERYDAY CHOICE**



**- Comparisons to Other Choice Studies**

Tables 3 and 4 report how the iPad data compared to choice studies based on NCI interview data. These comparisons were approximations, because the “self-advocates” (i.e., those least intellectually disabled) among the respondents in other studies could not be formally identified in the samples and thus separated out for comparison. We also *expected* the self-advocate choice scores in our samples to exceed those of more normalized comparison groups of people with I/DD. Nonetheless, two recent studies (Lakin et al., 2008; Stancliffe et al., 2010) employed NCI data, used similar measurement protocols, and produced variables scaled in the same way as ours. Therefore, we can see if the *patterns* in our data, if not the *absolute levels*, paralleled those in these studies. If so, confidence in our data collection platform should be increased. In Table 3 we compare choice *items*. In Table 4 we compare choice *summary or scale scores*.

In Table 3, iPad choice item means were compared across residential situations. Stancliffe et al. (2011) employed only one of our NCI choice items (choice of where you live), but the same

sample comparison was made: people living in apartments or their own homes vs. group homes. In Lakin et al. (2008) a slightly different residential comparison was made: newer residential living arrangements in the Home & Community Based Services (HCBS) waiver vs. the traditional Intermediate Care Facilities (ICF) model. However, in Lakin et al. (2008) choice score means are available by intellectual level, allowing for a better comparison with our self-advocate respondents.

As expected, Table 3 shows that the choice *item* scores of our self-advocate samples were elevated. Compared to Stancliffe et al. (2011), the apartment vs. group home difference was in the same direction, though larger in our self-advocate sample. Similarly, the residential difference in Lakin et al. (2008) was in the same direction but was even more pronounced in the self-advocate data. Interestingly, for the everyday choice items, the iPad data and the results from Lakin et al. converged somewhat, both overall and in setting differences.

Table 3 also shows that the iPad survey data followed the same pattern for *means* as Lakin et al. (2008): higher everyday choice means compared to the support-related choice means. Further, this pattern held true *within* different living arrangements as well. Everyday choice item means were higher than support choice item means irrespective of whether one lived in an apartment, group home, the HCBS service environment, or a traditional ICF/MR service environment.

Table 4 compares how mean everyday and support choice *summary or scale scores* for the iPad dataset lined up with identical data reported by Lakin et al. (2008). Because Lakin and colleagues reported choice scale score means by intellectual level, we were able to select their most intellectually capable cohort (those with mild and moderate I/DD levels) and compare them with the self-advocate data from our iPad study. The same patterns were repeated. While the mean choice scores for the combined SABE/SANYS samples were higher than the Lakin et al. (2008) levels, the *pattern* of choice differences between residential types

**TABLE 3 : CHOICE ITEM MEANS BY SETTING**

Choice Items	iPad Survey Means			Stancliffe et al. Means			Lakin et al. Means		
	Apartment/ Own Home	Group Home	Total	Apartment/ Own Home	Group Home	Total	HCBS	ICF	Total
Chose where you live?	1.79	1.12	1.58	0.93	0.55	0.71	0.72	0.46	0.66
Chose your house staff?	1.73	0.83	1.35	...	...	...	0.84	0.64	0.79
Chose work/day program?	1.75	1.25	1.59	...	...	...	0.80	0.62	0.76
Decide free time?	1.92	1.54	1.80	...	...	...	1.56	1.20	1.47
Decides what you buy?	1.85	1.68	1.79	...	...	...	1.42	1.23	1.37

**TABLE 4 : SUPPORT AND EVERYDAY CHOICE SCALE MEANS BY SETTING**

Choice Summary Scores	iPad Survey Means			Lakin et al. Means*		
	Apartment/ Own Home	Group Home	Total	HCBS	ICF	Total
Support Choice	1.79	1.12	1.58	.93	.88	.92
Everyday Choice	1.88	1.61	1.80	1.64	1.50	1.61

\*Respondents with mild or moderate ID.

was consistent across both studies: people who lived in apartments or their own homes expressed more living arrangement choice than people in group homes. Furthermore, the everyday choice means were higher than support choice means in every setting for both samples. Finally, the bottom row of Table 4 shows that the everyday choice means and differences were similar across the two studies.

## Discussion

The present study was intended to be exploratory. Our primary objective was to determine if self-report opinion data could be gathered from people with mild to moderate I/DD using a self-administered survey platform that provided cognitive support. Our fieldwork strongly suggested that the iPad hardware and software were accessible, popular and efficient. Nearly nine in ten (88.5%) of the self-advocate respondents successfully navigated the software

on the iPad and, in the judgment of the research team, provided authentic survey responses. Virtually all participants said they enjoyed the experience, liked using the iPads and the interface, and found the survey questions important and interesting. Many said using the iPad was “fun,” perhaps not surprising given the popularity of the device. Only a handful of the respondents dropped out because they became frustrated or lost interest before completing the survey.

Two days of surveying, with at most four iPads in use, produced over 250 authentic surveys, making this approach an extremely efficient method for capturing self-report data. As an added efficiency bonus, the *Atlas* software automatically saves surveys in digital files that can be downloaded to a spreadsheet for analysis. No data entry is required.



However, we also wanted to demonstrate, if possible, that this survey methodology produced valid data, where our validity test was to see if patterns in the data conformed to patterns in comparable datasets collected through standard interview, keeping in mind that our self-advocate respondents are less intellectually disabled than other normally-distributed survey samples, and operate in choice-rich environments. Our analyses indicate that we were largely successful in replicating those patterns. In this respect, our project was a successful proof of concept.

Nonetheless, our data have many limitations. Most significant are limitations that stem from the small and non-random nature of our samples, and the lack of a direct measurement of intellectual disability. Since we had no individual measure of intelligence we used *type of living arrangement* as a proxy for level of I/DD. This assumption was confirmed in that the levels of assistance needed to complete the survey, and levels of choice expressed by groups identified by type of living arrangement, followed the expected patterns. Without a direct measurement of intellectual disability, it is also impossible to state with any certainty the utility of this survey platform for people with more severe levels of intellectual disability. This should be an important focus of future research.

The SABE and SANYS self-advocates who participated in this survey were unique cohorts of people with I/DD. The absolute values of their choice scores, both on individual items and summary/scale scores, were exceedingly high. To some extent these high scores may reflect the nature of these self-advocacy groups, whose members see themselves as highly self-determined and independent. Stancliffe (1995) has observed that people with I/DD may in fact over estimate their choice of living arrangement as compared to estimates of their choice offered by proxies, a tendency that could have further raised the choice scores of the less intellectually disabled self-advocates in our samples. Nevertheless, even though choice item and scale scores were heavily skewed upward for our samples, we were able

to find the very same differences between choice scales (everyday vs. support) and between choice levels by residential type (apartment vs. group home/ICF) that have been observed for NCI interview data gathered by interview from random samples.

Broader research should be conducted to determine if the elevated choice scores of these self-advocates is an artifact of the self-report procedures and technology that we employed. One obvious way to explore this question, as well as the overall validity and reliability of self-administered survey data, would be to compare responses to identical NCI items from groups of randomly selected self-advocate respondents using both digital and interview data gathering strategies.

As a practical matter, the term “choice” is not strictly defined for NCI respondents. Participants are asked if they “make choices themselves,” or if they “have input” into how decisions are made. This is often not an easy distinction. In our survey, the middle point of the response set was to ask if “others helped make decisions.” Perhaps the expression of choice is highly sensitive to slight changes in wording or emphasis. Future research attempting to validate observed levels of choice would do well to consider incorporating a more precise and concrete method for describing choice levels, and standardizing the anchors and mid-points of choice scales, presented to people with I/DD.

There are two primary benefits to using self-administered surveys for people with I/DD. Collecting survey data from people with I/DD through direct interviews is time-consuming and costly. A viable self-administered procedure using tablet-based digital technology would reduce costs and improve efficiency. Secondly, interviews, questionnaires, and proxy respondents present challenges to validity. Allowing people with I/DD to “speak for themselves” by completing a self-survey under conditions that maximize privacy and anonymity should result in more valid and authentic opinion data. Considering the growing importance of self-determination, consumer satisfaction, and outcome measurement, relative straightforward and in-

expensive self-administered survey procedures have the potential to allow people with I/DD to provide feedback about the supports and services they receive. One can readily employ this technology to capture information about quality of life, satisfaction with services, health status, general knowledge, social judgment, and so forth. Most importantly, the approach will allow people with I/DD to express themselves directly, thereby more actively participating in the design of the supports, services, and environments that affect their lives.

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