CTA Focus Group:

Individuals with an Intellectual and Developmental Disorder and Healthcare Technology

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Abstract

Individuals with an Intellectual and Developmental Disorder (IDD) were invited to participate in a focus group sponsored by the Consumer Technology Association (CTA) Foundation under the direction of CIDE researchers Cathy Bodine, Leslie Emery and Jessica Green. The purpose of the focus group was to help consumer technology healthcare companies better understand the needs and challenges of working-age adults (18-64) with IDD. These adults were diagnosed with a developmental disability before the age of 21 and now, as adults, are seeking more independence and control over their own healthcare. The information gathered in this focus group will be used for the development and market delivery of consumer technology healthcare products.

Individuals with IDD and their caregivers were invited to the University of Colorado Denver campus to participate in a focus group. There was a total of two focus groups held on separate dates to obtain the required number of participants for the study (5). Each focus group consisted of 2-3 participants along with their caregivers and lasted 45-60 minutes.

The data yielded common themes between both focus groups. The top three themes mentioned were ease of use, the importance of learning, and the current use of online portals. These themes reflected an important need for careful consideration in healthcare design to improve usability, learnability, accessibility, and independence for the IDD community.

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Introduction

Purpose

Five individuals living with an intellectual and developmental disorder diagnosed before the age of 21 were invited to participate in a focus group sponsored by the CTA Foundation to help consumer technology health care companies better understand the needs and challenges of working-age adults (18-64). The results of each focus group will be used for the development and market delivery of consumer technology healthcare products.

Methods and Procedures

Procedures

The first focus group was held on July 31st, 2024, and was located in the Commons Building on the University of Colorado Denver campus. This focus group consisted of two participants, participant 1 (33 y/o) and participant 2 (29 y/o), and their respective caregivers. The second group was held on August 29th, 2024, and consisted of three participants, participant 3 (28 y/o), participant 4 (28 y/o), participant 5 (31 y/o), and participant 5's caregiver. Consent forms, provided by the CTA Foundation, were signed prior to beginning the discussions. Each group was asked the same questions prepared by the CTA Foundation and was concluded with an open conversation to facilitate the communication of valuable information in a comfortable environment. The questions pertained to the participants' current usage of health devices, their experience with telehealth visits, and the desired features needed to increase their usage of health devices, apps, and online health monitoring. Both discussions lasted 45-60 minutes. Each participant was given a $75 Visa gift card to compensate for their time.

Both focus groups were recorded using Zoom and an external microphone to capture participant audio. The audio recordings were transcribed via Zoom.

Demographics

A total of five individuals participated in the focus groups. Participant 1 lives with their sister, nephew, and mother. Participant 2 just moved out of their mom's house and now lives with a friend and another roommate. Participant 3 lives with a friend and likes working (currently a dining room server) and hanging out with their friends and family. Participant 4 lives with their mother and likes to build things and do hands-on work. Participant 5 lives in a host home for individuals with IDD and likes to run and compete in races. All the individuals were diagnosed with an IDD before the age of 21.

Participant	Age	Gender
1	33	Female
2	29	Male
3	28	Female
4	28	Male
5	31	Male

Figure 1. Participant Demographics

Data Analysis

The data obtained from the audio recordings and transcriptions during each session were analyzed using qualitative methodology. The researchers listened to the recorded audio to ensure no responses were missed or inaccurately documented in the transcriptions. Participants' responses were notated and used to pull common themes throughout both focus groups. The number of times each theme was mentioned was counted and used to determine the most common and important subjects during discussions. The qualitative data was then used to create graphical data to depict the occurrence of each theme. Researchers also included additional insights and findings in their data participants considered important. Quotes from participants were also included to support findings and results. Researchers wrote example personas for a participant and a caregiver based on the observed data from the focus groups.

Results

A total of 11 themes were discovered through analysis of the data from both focus groups. These themes are listed in order of occurrence (from most to least common) as follows: Ease of Use, Learning, Use of Online Portals, Forgetting to Use Functions, Convenience, Weight and Diet, Disconnection Issues, Preference of Face-to-Face Interactions, Wanting More Independence, Speech Detection, and Lack of Accuracy. The table below depicts the results and occurrence of common themes throughout discussions.

Categories	
Ease of Use	12
Learning	6
Online Portals	5
Forgetting to use functions	4
Convenience	3
Weight and Diet	3
Disconnection Issues	2

Figure 2. Session 1: Frequency of common discussion topics

Categories	
Ease of Use	13
Learning	7
Online Portals	3
Forgetting to use functions	2
Prefers face to face interactions	2
Wanting more independence	2
Speech Detection	2
Weight and Diet	1
Lack of Accuracy	1

Figure 3. Session 2: Frequency of common discussion topics

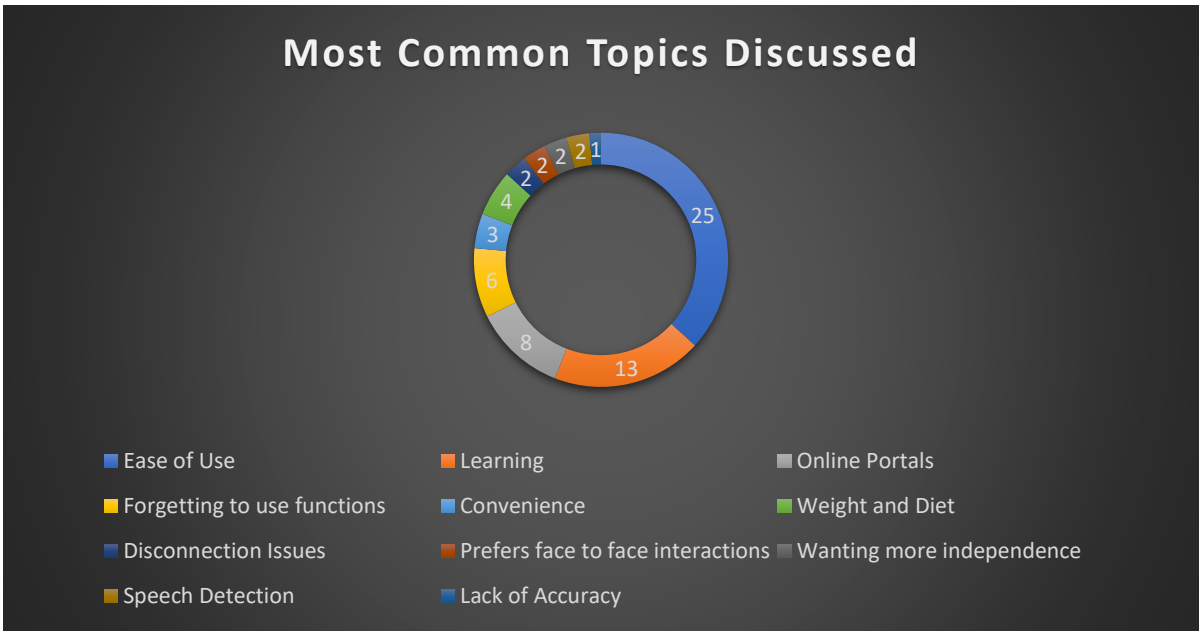

Figure 4. Compiled frequency of common discussion topics for both focus groups

Ease of use was brought up multiple times during each focus group. Participants disclosed they have difficulty trying to use online portals and some healthcare devices to manage their health. They stated their parents typically manage their online health portals due to it being too difficult for them to navigate the portal websites themselves.

The second most frequently mentioned topic was methods of learning. Four out of five participants expressed interest in learning how to use medical health devices and online portals. They stated that they would like the ability to perform tasks such as scheduling their own doctor appointments and checking their online health notes. All participants stated that they would prefer to learn from in-person demonstrations or by watching video instructions. All participants disclosed they currently use YouTube as a resource for learning how to do tasks on their own. This discussion also correlated with the participants' desire for more independence. Participant 3 stated they always try to do tasks on their own and google information if needed before they call their parent for help. They explained they prefer to do things on their own and try to do tasks without help whenever possible.

There was a total of three caregivers who were present during the two focus groups. Each of the caregivers uses an online portal to manage their son or daughter's health. They all said online portals were very convenient and helped them communicate with healthcare providers more easily than calling the doctor's office. They also stated they enjoyed being able to print health information for new providers without having to contact the doctor's office to release records.

During the discussions, the majority of the participants said they frequently forgot to utilize specific functions on the devices they currently use. Participant 2 said they used their Fitbit to track steps and sleep but often forgot to look at the data tracking in the Fitbit app on their phone. Participant 1 stated they sometimes forgot if they have taken their medication and would like a reminder system to help them keep track of their medication schedule. While this could be done with their phone's calendar and alarm clock, they reported not remembering to use these features. Most of the participants agreed with each other during the focus group discussions that they often forgot to go into the apps that are linked to their smartwatches to view the data being tracked and would like reminders to do so.

Each of the caregivers mentioned the convenience of using online health portals and/or telehealth visits. Participant 1's caregiver stated a preference for telehealth visits because it is easier to attend appointments without worrying about transportation. Other caregivers stated that online health portals are very convenient for managing their child's health because all the health information is stored in one easily accessible place. Some of the caregivers also expressed a desire to track their child's weight and diet. Most of the participants with IDD wore smartwatches with capabilities for health tracking. The caregivers said they would like a program to actively track their child's weight and give customized dietary advice. They think it would

help their children stay healthier if they could access meals, exercise, and habit suggestions from an app.

Participant 4 wears a Fitbit watch to track their steps during the day and sleep at night. They stated that they have issues with their watch disconnecting from their phone multiple times per day. When this happens, they have to restart their watch to re-connect it to their phone and continue tracking data. Because they have to constantly re-connect their Fitbit to their phone, they tend to not trust the accuracy of the data being tracked. This comment sparked an additional conversation from another participant. Participant 5 said they like to record a map of their runs and have found their Apple watch is not as accurate as they would expect, which makes it difficult for them to trust the data.

During discussion, each of the participants expressed their preference for face-to-face interactions. Participant 1 had done a few telehealth visits but said that they prefer to see their doctor in person. All the other participants said that they have not done telehealth visits because they prefer face-to-face interactions with their providers. While the caregivers felt that telehealth visits were convenient for transportation purposes, the participants all preferred to see their providers in person.

Finally, Participant 3 said they liked to use speech-to-text on their phone. They often have difficulty writing and spelling correctly, so they use speech-to-text to receive an accurate transcription to then copy/paste into their text messages. Participant 5 stated that they also use speech-to-text when texting on their phone because it is easier than typing.

Additional Findings and Preferences

At the end of each focus group, we opened it up for free discussions about anything the participants and caregivers wanted to discuss. To kick off the open discussion, Participant 5's

caregiver said their online health portal is too complicated for their child to use. They said their child does not know how to make an appointment and would not know where their doctor's office is located well enough to get to an appointment on their own. They said that it would be nice to have a simpler portal for individuals with IDD so they could manage their own health. They also stated that they would like to see an online portal that allows for speech-to-text instructions they are able to follow. For example, the portal is able to respond appropriately when told "message my doctor that I have a cold and am not feeling well." Similarly, if the individual wanted to schedule an appointment, they would say "make appointment" and the program would take them to the correct page and walk them through the necessary steps for making the appointment.

The participants also mentioned doctors' appointments and how they typically need their parents to drive them. Participant 3 stated they sometimes go to doctor appointments on their own and use Uber for transportation. The researchers then asked the participants if they have used the Uber app to schedule their own rides and, if so, what they like and dislike about it. Participant 3 said that they are able to use the Uber app on their own and they feel like it is really easy to use. They said the app walks them step-by-step through the tasks needed to schedule a ride. They think the app is simple to use and allows them to have an independent method of transportation.

At the end of each focus group, the discussion prompted a realization for the caregivers. Multiple caregivers admitted they automatically take care of their children and do most tasks for them. The focus group discussion made them realize they could teach their children how to use tools like online portals to help them become more independent. They all stated they worry about what their children will do once they are no longer around and would like support in making

their children more independent. They do not want their children to rely on non-family caregivers, who might not know their entire health history, to manage their health.

Discussion

After analyzing the data from each focus group, several key points emerged. It was found that most participants prefer simple user interfaces that have the ability to walk them through the steps necessary to complete a task. It was also found that most participants prefer face-to-face interactions and in-person training methods for learning how to use new devices/programs. Because the participants preferred face-to-face interactions, they reported they were unlikely to utilize remote technologies like telehealth visits to interact with their providers. It was also found that participants would prefer to have features including facial recognition, speech-to-text, and the ability for smart speech-to-text that helps them accomplish a communicated task.

Most of the participants expressed their desire to complete tasks independently and said they are actively trying to do so in their everyday lives. The discussion about the participants' ability to use devices, apps, and online portals facilitated the caregivers' realization that the participants could be taught how to use these technologies to increase their independence. It was determined that if a user interface is simple and prompts them through certain tasks, the participants would be more likely to learn how to use the interface on their own.

Example Personas

Healthcare Technology User with IDD Persona

Dave is a 30-year-old male who works at a coffee shop and likes to run. He spends a few days a week working in the coffee shop where he is on his feet the entire shift and walks a lot. In his spare time, Dave likes to train for long-distance races. Dave uses a smart watch to track his fitness, which links to the fitness app on his phone. He is a healthy male, so he does not go to the doctor often. Because Dave has an IDD, he has his father schedule doctor appointments and manage all his health information using an online portal. Dave would like to use the online portal himself and be able to track more health information using other apps on his phone, but he gets

overwhelmed when he tries to use them. Dave often has trouble knowing which options to select to perform the task he wants. He also struggles with spelling and has a tough time typing the correct words into online portals to manage his health.

Caregiver of Individual with IDD Persona

Mary is a 65-year-old female who likes to have brunch with her friends once per week and spend time with her daughter. Mary's daughter has an IDD, so Mary manages her daughter's health information when she needs to take her to doctor appointments. She uses an online portal through the hospital that allows her to have all her daughter's health information in one place. Mary feels this is convenient because she can send health records to multiple physicians, request appointments, and communicate with physicians in one place. Mary's daughter has asked if she can make her own appointments, but Mary knows that the online portal is too complicated and worries that it will overwhelm her daughter and feels that it is easier if she just manages everything on her own. While she wants her daughter to manage her own health, she feels that health apps and online portals do not have the correct functions and support for individuals with IDD.

Appendix

1. Information Given by CTA Foundation

1.1 Parameters and Questions for Participants

Parameters

1. Timing
    a. To be conducted before July 31st, 2024 (note: the researchers were given permission to operate outside this deadline)
    b. Each partner can set their own date and time for the event.
    c. Each partner is responsible for the invites to their focus group session.
2. Length
    a. 45-60 minutes
3. Participants
    a. 5-7 individuals in the IDD community. Additionally, if needed, the participants may have a caregiver attend with them.
    b. Each participant will receive a $75 VISA gift card.
    c. Each participant will sign a waiver to participate in this market focus group and allow their comments to be audio recorded for use in product development.
4. Partner Support
    a. The CTA Foundation will make a $5,575 grant to each participating organization to offset their time and the cost of the gift cards.

Questions for IDD Community

- What technology do you think would help you take care of your health?
- What information would you like to track about your health on your phone?
- What healthcare technology have you interacted with before? What did you like? What did you not like?
- Have you participated in telehealth visits?
    - On a computer, tablet or phone?
    - What did you like?
    - What did you not like?
- What technology would help you communicate better with your healthcare provider?
- What are some challenges or concerns you have when using a mobile app technology to manage your health?
- Describe any preferences you might have in using technology to manage your health.
- What type of technology do you currently have access to?

Questions for Caretakers

- Describe any preferences they might have in using technology to manage their health.
- What are some challenges or concerns you have about the patient using technology to manage their health?
- What technology would help the patient communicate better with their healthcare provider?

1.2 Information for Participants

Purpose

You have been invited to participate in a focus group sponsored by CTA Foundation under the direction of [name of responsible partner]. The purpose of this focus group is to help consumer technology healthcare companies understand the challenges and needs of working age adults (18-64) who developed a developmental disability before the age of 21 and are seeking more independence and control in their healthcare. The information learned in this focus group will be used in the development and market delivery of consumer technology healthcare products.

Procedure

As part of this focus group, you will be placed in a group of 5 – 7 individuals. A moderator will ask you several questions while facilitating the discussion. This focus group will be audio-recorded, and a note-taker will be present. However, your responses will remain confidential, and no names will be included in the final report.

You can choose whether or not to participate in the focus group, and you may stop at any time during the course of the study.

Please note that there are no right or wrong answers to focus group questions. CTA Foundation wants to hear the many varying viewpoints and would like everyone to contribute their thoughts. Out of respect, please refrain from interrupting others. However, feel free to be honest even when your responses counter those of other group members.

Benefits and Risks

You will receive a $75 gift card as a benefit for your time - the focus group is estimated to last 45 - 60 minutes. However, no risks are anticipated beyond those experienced during an average conversation.

Confidentiality

Should you choose to participate, you will be asked to respect the privacy of other focus group members by not disclosing any content discussed during the study. The CTA Foundation will analyze the data, but—as stated above—your responses will remain confidential, and no names will be included in any reports.

2. Raw Data

2.1 Participant Findings

- The age range of participants was 28-33. All participants were generally healthy and did not need many medications or visit their health care providers very often. Most participants visit their providers once per year and then only when needed for sickness or concerns that arise.
- Most of the participants' caregivers schedule appointments and manage online portals for them.
- All participants stated that most apps and online portals are too complicated for them to use.
- A computer is preferred over a phone or tablet. This is due to the larger screen size to read text and the ability to click on boxes where you must input information instead of a touch screen.

- Devices that are currently being used by participants include:
    - Phones
    - Computers
    - Tablets
    - Smart watches
    - Apps that link smart watches to phones
- Health information currently being tracked by participants includes:
    - Steps and/or distance walked
    - Heart rate (EKG)
    - Calories
    - How well they slept
- Dislikes about using technology by participants include:
    - Watches disconnecting from their phone constantly
    - Feeling skeptical about the validity of the results from a smart watch
- 2 out of 5 participants have used telehealth before. One liked it and felt like it was easy to use. The other participants did not like it because they felt like in-person was better for them.
- Weight is the most common answer for what the participants would like to track.
- Neither the participants nor their caregivers had thought about having the participant learn how to use apps or online portals. Depending on the complexity, they both felt that the participants would be able to use apps, online portals, or health devices if given proper training.
- Most participants expressed interest in learning how to use apps and online portals if given in person training or training videos.
- Some preferred features include:
    - Facial recognition
    - Allowing voice commands for navigation
    - Speak to text
    - Tracking food health and giving suggestions on food/portions based on current health (weight, exercise, calorie intake, etc.)
- Most participants use YouTube to learn how to do something. The visual and audio of the video helps them learn. In-person training is also preferred for learning styles.

2.2 Caretaker Findings

- Many of the caretakers stated that they manage the participants' healthcare for them. They stated that apps and online portals are too complicated for the participants to navigate so they do it for them.
- Many of the caretakers use an online portal to manage the health of the participants. Overall, they enjoy how it functions and find it to be a very convenient way to keep track of everything and communicate with providers.

- They said having a phone number for IT support was preferred if they could talk to a person.
- Many of the caretakers expressed their concerns about the complexity of apps and online portals. They currently take care of everything and feel that if they were not around anymore, their child would not be able to manage their health on their own. They stated that the participants do have support through the state and in some group homes, but it would be difficult to have all the correct information if the caretaker were not there.
- After the focus group discussions, many of the caretakers stated that they now realized that the participants may be capable of navigating healthcare on their own or more independently if given the proper training. They felt that if the apps, online portals, or health devices were easier to use and had proper support for individuals with an IDD, then the participants would be able to use them.