Technology: A Key to Independence and Inclusion

Using NCI to measure quality outcomes

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1. The context: Science, rights, and the role of technology

   • National Core Indicators – Technology Questions
   • Planning for Quality: Failure Modes and Effects Analysis in design and use of assistive technologies.
Overview of Technology and People with Disabilities: The Good, the Bad... And the Link to Rights
People with Disabilities As Subjects, Participants, and Scientists

• People with disabilities have historically been exploited as unknowing subjects of scientific research (e.g. institutionalized children fed radioactive oatmeal, adults with ID given the flu virus, etc.). Today, people with disabilities are often excluded from population based studies drug testing, longitudinal health studies...

• The views of people with disabilities are rarely solicited regarding priorities for scientific research, the ways in which products can be adapted for their needs, and the extent to which they find scientific advances as enhancing the quality of their lives.

• For members of the scientific community, there is evidence that the types of accommodations necessary for those with physical and sensory disabilities is not routinely available.

• People with disabilities are not routinely consulted in design of research that will have an impact on their lives.
The Digital Divide

• Physical limitations make it difficult for some people to use the internet
• Adaptations to make the web accessible are expensive
• People with disabilities are more likely to be poor and internet connections and other devices such as mobile phones are out of reach
• For people with intellectual disabilities technology may make their lives harder rather than easier
Science and Technology in the Realization of National and International Rights

To be included in civic life, employment, relationships, people with disability need access to science through technology including:

- GPS technology
- Augmentative communications devices
- Adaptive equipment
- Remote monitoring / remote supports
- Smart houses
- Universal design
- Health monitoring and health aids and prompts
- Voice recognition software
- Durable medical equipment (e.g., wheelchairs, walkers, etc.)
While the gap between customized AT and mainstream technology is shrinking, complexity is increasing.

But... COMPLEXITY

- Cross-system alignment
- Updates: limit or change interface
- Added specialists in a person’s life?
- Status and disparities in access
- Privacy protections
In other words...

New iPad...  
I need an app!  

24 hours later...  
I need a nap!
MEASURING AND ASSURING QUALITY

- National Core Indicators
- Planning for Quality
As of 2018-19: 46 states, the District of Columbia and 22 sub-state regions
National Core Indicators provides a unique perspective

- **Individual characteristics** of people receiving services
- Residential setting type
- Activities they engage in during the day including whether they are working
- **The nature of their experiences with the planning and supports that they receive** (e.g., case managers, ability to make choices, self-direction)
- Friends, community involvement, safety
- Health and well-being, access to healthcare
- **Use of communication and mobility technologies**
NCI SURVEY RESULTS – 2017-2018
Living Setting and environment are key considerations in technology use

- 39% - Lives with family/relative
- 31% - Group home
- 18% - Own home or apartment
- 5% - Foster care
- 4% - ICF/IID or other institutional settings
- 2% - Other / Don’t Know

Source: NCI At-a-Glance, 35 states 25,671 respondents to the IPS in 2017-2018
Use of Mobility Aids

- **Moves self around environment without aids**: 77%
- **Moves self around environment with aids or uses wheelchair independently**: 13%
- **Non-ambulatory, always needs assistance to move around environment**: 9%
- **Don't know**: 0%
Use of Communication Technology:

Note: 1% of sample reports using a communication device or technology to communicate.

“Do you need these additional services?”

<table>
<thead>
<tr>
<th>Service</th>
<th>Percentage</th>
</tr>
</thead>
<tbody>
<tr>
<td>Communication technology</td>
<td>5%</td>
</tr>
<tr>
<td>Environmental adaptations</td>
<td>3%</td>
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</tbody>
</table>

Communication technology (technology or other assistance to support the person's communication – e.g., communication board, text speak, Dynavox)

Environmental adaptations/home modifications (changes to the home environment to make it easier for the person to get around and live in the home, includes remote monitoring/call technology)
Additional Services Needed (open-ended responses)

- Assistive tech assessment
- Electric lift from bed to chair
- Smart Drive & Parking
- Would like information on home modification
- Specialized Medical Supplies
- Would like a cellphone
- Wheelchair
- Wants to live on own
- Video monitor if not in house
- Vehicle adaptations
- Training for Aug Com Device
- iPad
- Communication Technology
- Online dating for people with disabilities
- Needs automatic door installation
- Need Wi-Fi at home to Skype with parents.
- Hearing aids
Adult Family Survey
11 States and DC & 5221 Respondents

63% have a legally appointed guardian

36
Average age

43% Female
57% Male

White 77%
Black or African American 13%
Hispanic or Latino 9%
Other* 7%

*Includes Asian, American Indian or Alaska Native, and Pacific Islander
Adult Family Survey data

75% of family members need some or extensive support with personal care activities (for example, bathing, dressing, eating).

2% of family members use a communication aid or device to communicate.

Of those family members who are non-verbal, 32% report that there are always support workers who can communicate with him/her (states range from 21% to 40%).
54% of respondents report that family members **always have access to the special equipment or accommodations that s/he needs** (for example, wheelchair, ramp, communication board, etc.).

11% of respondents report that their family member needs **additional support or training to use assistive technology.**

States range from 3-28%.
2018-19 IPS includes questions:

Do you have a cell phone or smart phone?

If no, do you want a cell phone or smart phone?

If you do not have a cell phone or smart phone but you would like one, why don’t you have one?
State-specific questions can be added:

Ohio’s example

“[Does this person receive] Remote Support Technology….?”

In Community Inclusion Section, OH asks re. barriers to participating as much as wanted.
Response options include:
- **Accessibility** and
- **Transportation challenges**
Some people use technology in their daily lives. I am going to ask you about some things - I’d like to know if you use them, and if so whether you can use them at any time?

Response Options include:

- Computer, ipad, table,
- Uber/Lyft
- Internet
- Home automation…
- Social Media
Ensuring Quality: Avoiding Equipment Abandonment, Failure Modes and Effects Analysis
Assistive Technologies have high rates of “equipment abandonment”

- Reported rates of “abandonment” 50% up to 78%
  - Hearing aids are most likely to be abandoned

- Change in user needs are the strongest predictor for “abandonment”.
  - This may be positive: are there opportunities for AT Re-Use?
  - A portion (aprox.30%) due to mismatch between person and the equipment.

- Interdisciplinary approach to planning reduced equipment abandonment from 37% to 9.5% ⁴

- Individualized assessment, personal support, and follow up to ensure AT meets ongoing needs reduces equipment abandonment.
Risks to consider in the delivery of AT

- Equipment failure
- Human error in use of AT result: dangerous or ineffective use?
- Use of AT results in secondary disability
- AT is not acceptable to user / community
- Inappropriate to environment (e.g. school vs. home, unpaved roads/weather)
- Equipment is not used
Failure Modes and Effects Analysis: Design to Delivery and Beyond

- From engineering and industry design processes
- Increasingly used in health / human services
- Emphasis on prevention

“FMEA is particularly useful in evaluating a new process prior to implementation and in assessing the impact of a proposed change to an existing process.”

(Institute for Healthcare Improvement FMEA tool)
http://www.ihi.org/Workspace/tools/fmea/
Quality in Assistive Technology Planning and Delivery

- Individualized, person-centered planning with interdisciplinary input.
- Consider complexity of technology, personal, environmental, and individual factors.
- System level monitoring: NCI supports this, also attend to rates of ongoing use, equipment non-use and reason for non-use.
- Link to AT re-use programs where available.

https://www.at3center.net/repository/devicereuse
Thank You.
References


