Designing for Teens and Adults with Autism: Busting Myths and Taking Down Barriers

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Quick Bits about Me

• Director of Online and Community Programs at the Interactive Autism Network @ Kennedy Krieger Institute
• Healthcare and technical communicator, UXer, IA, and autism researcher
“Disability is a conflict between someone’s functional capability and the world we have constructed. In this social view of disability, it is the product that creates the barrier, not the person...”

“Ability + Barrier = Disability”

*Horton & Quesenbery, 2013, p. 3*
Eliminate the barriers and you have ability

Franklin D. Roosevelt Four Freedoms Park on Roosevelt Island, NY
Task

• Write down one thing that you as a person involved in technology design might do to make a product more accessible to people with autism?

• Why do you think that will help?
Main Themes
Autism Spectrum Disorder (ASD) is a condition that affects the brain, behavior, understanding, and perception.
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Autism Elevator Speech

• Lifelong
• Prevalence is 1 in 68* (1.1 million children in US)
• Males to females - 4.5:1*
• It’s three-dimensional spectrum
  ✓ Non-verbal to verbal
  ✓ 44% have average or above average intellectual ability*

*CDC, 2016

Images courtesy CDC, 2016.
Autism Elevator Speech

• Core characteristics include*
  – Deficits in social communication and social interaction
  – Restricted, repetitive patterns of behavior, interests, activities
  – Sensory over- or under-reactivity

• Impairments in fine and gross motor skills, gait, and postural control common

*DSM-5, 2013
Deficits with social communication and social interaction affect:

• interacting with others
• understanding nonverbal cues and communicating nonverbally
• creating, sustaining, and interpreting relationships
Language differences

Knowledge of words is often fine (80%), but social aspects may be difficult, including:

• How words are put together
• Initiating or taking turns in conversations, knowing when to stop talking, or asking for help
• Understanding the subtle, contextual meaning of words (jokes, word play, idiom, metaphors, or insinuations)
• Pitch, volume, or rate of speech may not be typical in individuals with ASD. May not understand these aspects of speech in others.
• Prefer non-speech sounds over speech sounds
• Difficulties integrating visual speech cues with auditory speech cues
Think about how these language differences might affect how you:

• Design forms
• Use icons
• Write and structure content
Restricted, repetitive patterns of behavior, interests, activities

• Repetitive motor behaviors
• ‘Odd’ use of objects including lining up and sorting objects
• Different speech patterns including repeating what others say (echolalia)
• Often people with ASD have strong reactions to any changes in routine—small or large—and develop their own inflexible routines.
Think about the consequences of errors and inconsistencies within interfaces and between interfaces.
Visual Processing

• Abilities are uneven: deficits in verbal abilities; relative strengths in visual and spatial processing
• Often detail-focused. For example, people with ASD tend to focus on facial features rather than the whole face, or the details of a scene rather than the whole.
• Difficulties in interpreting the larger meaning of an image or a scene.
• Individuals getting confused or distracted when a lot of information is provided.
• This ‘trees rather than forest’ cognitive style, pertains to all of the senses
Visual Processing

• Some evidence that adults without intellectual disability, can comprehend the gestalt of a complex situation just as quickly if it doesn’t involve social relations
• Problems in control of eye movement in some
• Problems in coordinating auditory and visual cues in some
• Think about the images and videos that you use
• With visual design, **simplify and unify**
Auditory processing & sensitivity

• Approximately 65% sensitive to noise
• With background noise, have problems understanding speech
• Most likely part of the general sensory processing profile in autism in which the filtering mechanisms work differently than in neurotypical population

Photo credit: https://www.youtube.com/watch?v=dOxEes-r584Auditory Processing/Auditory
Motor difficulties

- Fine and gross motor; gait and control of posture
- Translating intention into complex motor action
- Each component of a complex movement is treated separately rather than in a fluid, integrated movement
- Motor planning - may have difficulty using visual information cues to prime movements
- Easier time predicting and understanding machine motion vs. biological motion

Effect the person’s abilities to access educational and social resources
Frequently co-occurring conditions

- Anxiety
- Depression
- Bipolar
- Seizure disorder
- Suicidality
- Attention/focus
- Executive function/planning
• Think about how you design interactions to minimize the amount of complex motor actions involved. Also, allow people plenty of time without time pressure.
Societal barriers

People with autism are not fully included in society. Young adults and their parents reported*:

• In the first years out of high school, more than $\frac{1}{3}$rd in the US had no jobs and were not involved in higher education. Higher than rates for comparison disabilities.

• In college, highest STEM participation rates, but lowest college enrollment rates for comparison disabilities. **

• Only 58% had paying jobs into their 20s. Most jobs were low wage or part time. Lower than rates for comparison disabilities.

• **Vocational skills** most important services needed

*Roux, 2015  ** Wei, 2013
Little research has focused on how people with autism use technology in their day-to-day lives and whether that technology is accessible to them to meet their occupational, economic, entertainment, and information needs.*

*Cohen, 2015
Objectives

To identify the technology barriers by looking at:

• Which teens with autism were using the web and other technologies
• Whether they could use that technology successfully
• What was difficulties
Methods

• Anonymous online 80-question survey
• Administered to parents of children ages 13-17 living in the US with and without autism
• Subjects were recruited:
  – with the assistance of the Interactive Autism Network (IAN) Research Database and Community at the Kennedy Krieger Institute, Baltimore
  – social media
• September – October 2015
• University of Baltimore IRB: Exempt
Participants

• Completed surveys = 347
• Groups:
  – Parents reporting on their teens with ASD – 263 (76%)
  – Parents reporting on their typically-developing teens (TD) – 84 (24%)
• Male-to-female gender ratios
  – ASD (5.9:1) – within expected range
  – TD (1:1)
Analysis groups (n=347):

- **ASD Average** (129/37%) - Teens with ASD and parent-reported average or higher intellectual ability
- **ASD Low** (134/39%) - Teens with ASD and parent-reported below-average intellectual ability
- **TD** (84/24%) - Typically-developing teens with parent-reported average or higher intellectual ability

No statistically significant differences between the groups in demographic characteristics (skewed toward higher SES)

Statistical model used Logistic Regression controlling for age, gender, white (vs. non-white), Hispanic (vs. non-Hispanic)
Does your teen use the internet or the web (go online)?
Which teens are going online?

Almost all teens going online:
• TD – 99%
• ASD Average – 99%
• ASD Low – 89%

Why not?
• No ability (5)
• No interest (5)
• Only watches videos (2)
• Other (2)
Does your teen have problems with common web tasks?
Common web tasks:  
**Filling in web forms**

 Teens with ASD had significantly more difficulty filling in forms, with ASD Low group having the most difficulty.

<table>
<thead>
<tr>
<th></th>
<th>ASD Low n = 117</th>
<th>ASD Average n = 127</th>
<th>TD n = 83</th>
</tr>
</thead>
<tbody>
<tr>
<td>Filling in web forms</td>
<td>57%</td>
<td>20%</td>
<td>4%</td>
</tr>
</tbody>
</table>
Common web tasks:

Finding information on a webpage

Teens with ASD had significantly more difficulty finding information on a webpage, with ASD Low group having the most difficulty.

<table>
<thead>
<tr>
<th>Task</th>
<th>ASD Low n = 117</th>
<th>ASD Average n = 127</th>
<th>TD n = 83</th>
</tr>
</thead>
<tbody>
<tr>
<td>Finding information on a webpage</td>
<td>42%</td>
<td>17%</td>
<td>6%</td>
</tr>
</tbody>
</table>
Common web tasks:

Using search engines

ASD Low group had significantly more difficulty using search engines.

<table>
<thead>
<tr>
<th>Task</th>
<th>ASD Low n = 117</th>
<th>ASD Average n = 127</th>
<th>TD n = 83</th>
</tr>
</thead>
<tbody>
<tr>
<td>Using search engines</td>
<td>28%</td>
<td>10%</td>
<td>4%</td>
</tr>
</tbody>
</table>
Common web tasks:

Switching between websites or webpages

ASD Low group had significantly more difficulty.

<table>
<thead>
<tr>
<th></th>
<th>ASD Low n = 117</th>
<th>ASD Average n = 127</th>
<th>TD n = 83</th>
</tr>
</thead>
<tbody>
<tr>
<td>Switching between websites or webpages</td>
<td>15%</td>
<td>5%</td>
<td>1%</td>
</tr>
</tbody>
</table>
Which applications and programs is your child using and how difficult are they to use?
Office/Productivity Applications

Teens were using a wide variety of applications, with ASD Low teens using fewer office/productivity applications and having more difficulty when using them than ASD Average and TD groups.

<table>
<thead>
<tr>
<th>Application</th>
<th>ASD Low</th>
<th>ASD Average</th>
<th>TD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Word processor use</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Had difficulty</td>
<td>59%</td>
<td>82%</td>
<td>79%</td>
</tr>
<tr>
<td></td>
<td>36%</td>
<td>11%</td>
<td>5%</td>
</tr>
<tr>
<td>Spread sheet use</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Had difficulty</td>
<td>30%</td>
<td>51%</td>
<td>68%</td>
</tr>
<tr>
<td></td>
<td>82%</td>
<td>23%</td>
<td>7%</td>
</tr>
<tr>
<td>Graphics, drawing, or video editing use</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Had difficulty</td>
<td>39%</td>
<td>62%</td>
<td>81%</td>
</tr>
<tr>
<td></td>
<td>45%</td>
<td>14%</td>
<td>5%</td>
</tr>
<tr>
<td>Calendar/scheduling use</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Had difficulty</td>
<td>31%</td>
<td>43%</td>
<td>66%</td>
</tr>
<tr>
<td></td>
<td>54%</td>
<td>22%</td>
<td>7%</td>
</tr>
<tr>
<td>Calculator on device use</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Had difficulty</td>
<td>62%</td>
<td>78%</td>
<td>95%</td>
</tr>
<tr>
<td></td>
<td>16%</td>
<td>1%</td>
<td>1%</td>
</tr>
</tbody>
</table>
Entertainment Applications

The ASD Low teens were using entertainment applications less and having greater difficulty than the other groups.

<table>
<thead>
<tr>
<th></th>
<th>ASD Low</th>
<th>ASD Average</th>
<th>TD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Video/movie use</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Had difficulty</td>
<td>75%</td>
<td>82%</td>
<td>95%</td>
</tr>
<tr>
<td></td>
<td>8%</td>
<td>0%</td>
<td>3%</td>
</tr>
<tr>
<td>Games use</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Had difficulty</td>
<td>84%</td>
<td>91%</td>
<td>96%</td>
</tr>
<tr>
<td></td>
<td>6%</td>
<td>0%</td>
<td>0%</td>
</tr>
<tr>
<td>Books/magazines/web on device use</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Had difficulty</td>
<td>55%</td>
<td>88%</td>
<td>88%</td>
</tr>
<tr>
<td></td>
<td>19%</td>
<td>6%</td>
<td>0%</td>
</tr>
<tr>
<td>Camera on device use</td>
<td></td>
<td></td>
<td></td>
</tr>
<tr>
<td>Had difficulty</td>
<td>74%</td>
<td>81%</td>
<td>98%</td>
</tr>
<tr>
<td></td>
<td>12%</td>
<td>1%</td>
<td>1%</td>
</tr>
</tbody>
</table>
Educational Applications

There was no significant difference between the groups in the use or difficulty of educational applications, which tend to be tailored for different skill levels.

<table>
<thead>
<tr>
<th></th>
<th>ASD Low</th>
<th>ASD Average</th>
<th>TD</th>
</tr>
</thead>
<tbody>
<tr>
<td>Educational application use Had difficulty</td>
<td>83%</td>
<td>77%</td>
<td>83%</td>
</tr>
<tr>
<td></td>
<td>33%</td>
<td>18%</td>
<td>10%</td>
</tr>
</tbody>
</table>
**Apps for Autism**

**Apps with autism are being used mostly by the ASD Low teens.** Despite the large amount of attention and development effort going into autism apps, only 29% of the teens, mostly those with ASD and below average intellectual ability, were using them. Most of the apps listed by parents were mainstream picture-based communication programs.
Advice from Parents to Us

What advice do you have for people who design computers and other digital devices, computer applications, and web pages so that they could improve these technologies for your child?

Six related high-level themes emerged. These themes are very much in line with the recommendations and guidelines for people with cognitive and physical disabilities.
Recommendations from parents with teens with autism

- Simple and predictable
- Error free
- Safe
- Multi-sensory
- Accommodate motor differences
- Respect your users

These recommendations line up well with current accessibility standards and guidelines.
Simple and predictable

Parents wanted:
• use of clear, simple, concrete language
• clean design
• predictable navigation
• clear instructions

Stop making everything take a million unnecessary steps.

Make them more intuitive and less symbolic in terms - be literal

Make the apps easier to navigate for the lower functioning people. Some of the icons are confusing. There is sometimes too much stuff on the pages -- easily distracting to some people.
Error free

Make them so nothing ever goes wrong and they always do what they are supposed to do! Ha ha ha...
Safe

Parents wanted:
• Safe spaces for the teens to explore
• Better ways to monitor and control their teens’ activities
• The outside world to help foster a safe environment

It would be fantastic if parental controls vis-à-vis time and content were more user-friendly.
Parents wanted:
• Spaces that accommodate a variety of learning and perceptual differences
• More visual, language, and auditory

Though there is a strong popular perception that people with autism are mostly visual thinkers, this may be an overgeneralization.

Make symbols also come with a description. The "trash" can could say "delete things" - that is a concrete concept.

My daughter is an auditory learner. If there would be an option for the instructions to be auditory as well as in print, that would be very helpful!

make them more visual - require less reading
Parents commented that:

- Despite cognitive differences, their teens appreciate games and information with sophisticated, age-appropriate material.

Be sure to design fun and interesting spaces for older people with lower cognitive abilities. They are not children.

Make graphics age appropriate. A 13yo may read at a 7yo level but doesn't want to read about first graders.
Accommodate motor differences

Fifty-nine percent of the teens with ASD in this study had fine motor difficulties and 41% had gross motor problems.

Parents reported that:

• ASD teens are having more difficulty with device use, but using all devices

  Touch screen is the best.
  Mouse use is difficult, double clicking is difficult.

  Touch only, not dragging or swiping or anything more complex.
Summary

• The ASD teens in this study are devoted users of technology.

• For many, technology is a special talent and interest, a career goal, as well as a lifeline.

• Yet technology in its growing complexity poses many barriers to this population.
General accessibility standards and those specifically for cognitive differences are **good for people with autism** and are **good for everybody**.

Make it easier for others and it will benefit autism.
• If you are doing user testing, don’t forget to recruit users on the autism spectrum.
• If you are doing QA, don’t forget to hire people on the autism spectrum.
Books

A Web for Everyone,
Horton and Quesenbery

Letting Go of the Words,
Janice (Ginny) Redish
For further reading

**Plain Language.gov** (plainlanguage.gov/)

**Cognitive Accessibility User Research**
(w3.org/TR/coga-user-research/)

**Web Accessibility Initiative**
(w3.org/WAI/intro/wcag)
Your elevator task!

• Write down one thing that you as a technology designer might do to make a product more accessible to people with autism?

• SHARE!
Additional questions about autism?

IANCommunity.org

cohenc@kennedykrieger.org
Acknowledgements

- Individuals with autism and their parents and guardians for their generous contribution of time and effort
- Subjects were recruited with the assistance of the Interactive Autism Network (IAN) Research Database at the Kennedy Krieger Institute, Baltimore
- My thesis advisor, Kathryn Summers, PhD
- My stats mentor, Alison Marvin, PhD
- You!