Design Guidelines for Creating Voting Technology for Adults with Aphasia

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Abstract
People with aphasia and other communication disabilities experience a multitude of challenges in everyday life, and experience significant challenges related to interacting with textual information. Voting, and learning about political issues, presents many challenges for this population related to comprehension of text, audio, or video content. Our research is exploring ways to help adults with aphasia learn about voting issues in their area, practice voting, and to apply their knowledge to voting contexts. This paper describes our research to date exploring this issue with SCALE, a local aphasia support center in Baltimore, MD. We have worked for over a year with the members and speech-language pathologists at SCALE. In this report, we briefly describe our interactions with a group of SCALE members who take part in a regular class on news and political issues, and present suggestions for designing accessible information resources for adults with aphasia.

Introduction
The term aphasia describes a medical condition that affects an individual’s ability to process language, including both producing and recognizing language. Thus, aphasia can affect an individual’s ability to read and write, as well as to speak or understand speech. Aphasia is an acquired condition, and is most commonly the result of a stroke, although aphasia may also be caused by traumatic brain injury or other injuries to the brain. Aphasia affects approximately one million Americans, and is more common than Parkinson’s Disease, muscular dystrophy, or cerebral palsy (National Aphasia Association).

Aphasia can vary widely in its severity, based on the extent of the individual’s brain injury. Some people with aphasia may only have occasional difficulty recalling or recognizing a word, while others may be largely or completely unable to recognize or produce language. A diagnosis of aphasia typically does not imply reduced intelligence, only a difficulty in processing language. However, as aphasia is typically caused by brain injury, aphasia may be comorbid with cognitive impairments, and is often comorbid with physical weakness (hemiparesis) or paralysis (hemiplegia). Individuals with aphasia may use a variety of technologies
to support independent activities, and often use some type of augmented and alternative communication (AAC) technology to support their ability to communicate.

As aphasia can vary greatly in its presentation and severity, the impact of aphasia on an individual’s daily life can also vary tremendously. In significant cases, aphasia can negatively impact an individual’s functional independence, quality of life, and mental well-being (Hilari, 2008). Aphasia commonly results in increased social exclusion (Parr, 2007). Being unable to read, write, or speak, can prevent an otherwise cognitively able individual from living and working independently. These challenges can also reduce an individual’s ability to participate generally in public life, including participating in political and community activities.

Our research at the UMBC Prototyping and Design Lab (http://umbcpad.com) focuses on developing novel interactive technologies to support the independence of people with disabilities. Since 2012, we have explored various research projects intended to reduce the challenges experienced by individuals with aphasia in collaboration with the Snyder Center for Aphasia Life Enhancement (SCALE), a private support center for adults with aphasia, located in Baltimore, MD, USA.

Over the past year, we have conducted research to explore the difficulties experienced by adults with aphasia when voting, and when attempting to learn about current events, politics, and other news. This report documents our ongoing research partnership with members and staff of SCALE. We provide an overview of the challenges experienced by individuals with aphasia when learning about news and politics, and identify strategies for presenting content to individuals with aphasia in an accessible manner.

**Background**

In the past year, our research team has participated in on-site research at SCALE. Our research activities have involved a variety of activities, including observations, focus group sessions, interviews, and prototype testing (both paper and electronic) with both staff (speech-language pathologists, personal care assistants) and members.

As of 2013, SCALE has a set of approximately 50 members with adult onset aphasia. Members age from their 30s to their 90s, and vary greatly in the extent and functional effects of their aphasia. SCALE offers a vocational support for moderately impaired individuals, and a comprehensive program for more severely impaired individuals. We have worked primarily with the latter group, who
experience significant communication challenges at a level that makes independent work and living difficult.

SCALE follows a classroom model for its activities. The comprehensive program meets two days per week; members sign up for and attend a series of classes during this time. The class structure provides members with an opportunity to socialize with one another and trained instructors. Classes are taught by speech-language pathologists or subject experts. SCALE’s classes run for 15 weeks, and include topics such as reading, current events, music, photography, and yoga. Our work involving voting accessibility has primarily involved a class called “What’s in the News?”, in which members read and discuss articles on news web sites. These classes are coupled with informal group discussion sessions and one-on-one training sessions with therapists.

SCALE’s Instructional Approach

Communicating with a person with aphasia can be difficult even in one-on-one settings. Interacting with a group of people with aphasia can present additional challenges. SCALE instructors are trained in interaction with people with aphasia in a classroom setting, and use a variety of strategies to make content accessible, and to ensure that everyone is included in discussion.

Here we briefly describe some of the strategies and techniques used by SCALE instructors and staff to support accessible conversation in and around the classroom. These are general strategies used across all activities at SCALE; we discuss strategies specific to understanding news and politics in a subsequent section.

- **Present content using multiple formats.** Whenever possible, SCALE instructors present content redundantly. Each classroom features a whiteboard or easel that is used to write down key terms. When preparing course materials, instructors combine written content with photographs to enhance understanding.

- **Extract key content.** Long or complex texts can often be confusing to individuals with aphasia. At SCALE, instructors often excerpt text into smaller chunks that can be more easily parsed. For example, when discussing web pages in the “What’s in the News?” class, the instructor will often copy a single paragraph from a web page, and hide the rest, in order to focus on that specific content and reduce distraction.

- **Rephrase for verification.** Rephrasing content, and inverting questions, is an essential tool for determining whether a conversation partner with aphasia
correctly understands the discussion topic. Because aphasia can affect both comprehension and production of language, it is easy for misunderstandings to go undetected. SCALE staff confirm understanding using rephrased or inverted questions – for example, when discussing a tax issue, the instructor might ask both “So you support lowering taxes?” and “You don’t want taxes to stay at this level?” to check for consistent understanding and response.

• **Provide easy feedback mechanisms.** Some individuals with aphasia find it difficult to express that they need further explanation, or that they do not understand. This can be especially difficult in a group discussion setting, in which individuals may have varying levels of ability. SCALE provides a number of physical artifacts that members can refer to during conversation. For example, SCALE provides its members with an accessible volunteer feedback form in which participants can rate their volunteer’s skill at core communication skills: speaking clearly, making eye contact, repeating information when needed, and using writing to support conversation. Classrooms at SCALE also feature signs that can be used to indicate agreement or confusion; pointing at the sign enables the individual to provide feedback even when he or she is unable to articulate this feedback vocally or in writing. Examples of these accessible materials are shown in Figure 1 below. SCALE also ensures that paper and pen are always available to support conversation as needed.
**Volunteer Feedback**

<table>
<thead>
<tr>
<th>My volunteer:</th>
<th></th>
<th></th>
<th></th>
</tr>
</thead>
<tbody>
<tr>
<td>Speaks slowly</td>
<td>Too fast or too slow</td>
<td>OK</td>
<td>Great</td>
</tr>
<tr>
<td>Repeats when needed</td>
<td>Never repeats</td>
<td>Sometimes</td>
<td>Repeats when needed</td>
</tr>
<tr>
<td>Has good eye contact</td>
<td>Poor</td>
<td>OK</td>
<td>Great</td>
</tr>
<tr>
<td>Uses writing</td>
<td>Never</td>
<td>Sometimes</td>
<td>All the time</td>
</tr>
</tbody>
</table>

**Figure 1.** Communication tools used to facilitate communication at SCALE. Top: Volunteer feedback form uses pictographs alongside text to clarify concepts such as “speaks slowly” and “has good eye contact”, and uses cartoon faces to clarify positive, neutral, and negative responses. Bottom: Aphasia-friendly response scale, developed by Kagan et al. (2008), used at SCALE to provide general feedback.

**Participatory Design Research**

Our research group has conducted on-site, participatory research at SCALE for over one year. In general, our research follows a participatory design (PD) approach, in which members of the SCALE community provide guidance and direction for the technology that we are collaboratively developing.
Conducting PD with individuals with aphasia presents additional challenges beyond those found when engaging in PD in the general population. We use a variety of techniques to elicit design ideas and design feedback from our user group:

- **Focus groups and design teams.** We often recruit small design teams of 2-6 individuals in order to focus on specific issues or technologies. These teams will meet approximately once a week to iteratively design and test a design feature.

- **Sketches and play-acting.** We use drawings and play-acting extensively to introduce and demonstrate new ideas to the group (Figure 2). As many of the technical features we are exploring are difficult to express verbally, sketches and acting can help explore ideas and elicit feedback before prototyping.

*Figure 2. Example of low-fidelity participatory designs used with SCALE members and staff. This drawing illustrates the concept of a location-aware communication tool.*
• **Low-fidelity prototypes on tablets.** The majority of SCALE’s members regularly use a touch screen-based tablet device, such as the Apple iPad. We have observed that such devices are often quite desirable to adults with aphasia, in part do to their simplified user interface (simple on-screen layout and touch interaction). We leverage this familiarity in design whenever possible, such as conducting our low-fidelity “paper prototyping” activities using images on the tablet screen.

• **Use existing communication artifacts.** Whenever possible, we use SCALE’s existing feedback tools and artifacts (such as those shown in Figure 1) to enable participants to provide feedback during the process.

Our PD approach for individuals with aphasia has been documented in a recent publication (Kane et al., 2012).

**Relevant Prior Research**

Prior research has shown that a diagnosis of aphasia can reduce social participation, and has even been shown to reduce ability to vote in informal settings (Dalemans et al., 2010). To our knowledge, no comprehensive study of the impact of aphasia on voting participation has been conducted.

In general, little research has examined how information technology, and in particular accessible user interfaces, can improve the lives of people with aphasia. Most prior research in this area has focused on AAC tools and devices to enable people with aphasia to more easily generate speech (e.g., Beukelman and Mirenda, 2006). Within the human-computer interaction community, researchers have designed technology to support people with aphasia in writing email (Al Mahmoud and Martens, 2010), planning daily activities (Moffatt et al., 2004), and managing recipes (Tee et al., 2005). To our knowledge, our current research is the first to examine accessible user interfaces for improving access to voting information for individuals with aphasia.

**Understanding Current Voting Behaviors and Challenges**

To understand the challenges faced by adults with aphasia, and their current strategies for overcoming these challenges, we continue to conduct fieldwork at SCALE around the topics of voting and learning about current events. The current document describes research conducted between September 2012 and July 2013. Our research has included focus group discussions, classroom observations, and one-on-one interviews with SCALE members (adults with aphasia) and speech-
language pathologists. We have particularly focused our research on a class titled “What’s in the News?”, in which members and staff review and discuss current events. Our research also draws from training materials developed by the SCALE.

This section describes the techniques implemented at SCALE to improve access to news and current events, provides an overview of the challenges experienced by adults at SCALE when voting (and learning about voting issues), and describes their current voting behaviors.

**What’s in the News?**
SCALE offers a revolving set of classes on a variety of topics, with a 15-week “semester.” While some classes, such as a recent class on exotic animals, are only offered once, some classes are offered each semester. Examples of these current classes are a class on reading comprehension, and a class covering current events, called “What’s in the News?”

The News class typically features about 10 students, and is led by a single instructor, typically a speech-language pathologist from the SCALE staff. Student volunteers sometimes provide additional classroom support. The class meets for 1-2 hours each week. The purpose of this class is to learn about, and discuss, news and current events.

In this class, the instructor typically leads the group in reading about and discussing current news topics. She typically drives the discussion by loading news-related Web pages on a computer, and displaying them on a projection screen. She will ask class members if they are familiar with the subject being discussed, and will often ask them about their opinions on the current subject (either positive or negative). Discussion is guided by the interests and responses of the

The content of the News class is not limited to political or voting information, but often focuses on this topic when elections are near. The instructor also assists members of the class in preparing for voting activities, by viewing news articles on upcoming election issues, and by printing out and reading through practice ballots. SCALE does not directly assist members in voting at a polling place, although many members receive assistance from family members when voting.

**Current Voting Participation and Accessibility**
The members of the News class comprise the majority of SCALE members who are actively interested in news and politics. While we have not collected individual
data on who has voted and when due to confidentiality reasons, we have identified general trends and issues related to voting and learning about voting.

In general, the act of voting, and especially informed voting, was considered to be quite challenging by many of the individuals with aphasia. Most of the individuals that we spoke to brought a companion to help them vote. Due to the difficulty in voting, some individuals focused only on major elections and issues, or voted by political party only, and did not pay attention to minor issues. Many individuals who had experienced aphasia many years reported that they no longer followed news and politics due to the difficulty of doing so.

SCALE staff and members reported a variety of accessibility challenges when voting:

- **Lack of accessible and unbiased voting information.** When researching voting issues, SCALE members often experienced challenges finding accessible and unbiased information. Large media outlets such as CNN and Fox News often provide the most accessible online information, and are more likely to feature multimedia content. However, some individuals expressed concern about the biases of such large media outlets. Furthermore, these large organizations typically focus on national issues; consequently, it is often more difficult to find accessible information about local issues.

- **Lack of physical access.** Many individuals who have had a stroke experience weakness or paralysis in parts of their body, and may use a cane, walker, or wheelchair. Physical accessibility of the polling place and voting technology was frequently reported as a barrier to participating in voting. Some individuals reported specific challenges regarding getting to the polling place, and waiting to vote, especially if they were required to stand.

- **Difficulty understanding instructions.** Our participants with aphasia often experienced difficulty understanding, following, and remembering instructions, both those provided by staff at the polling place as well as those on the ballot itself. This problem was exacerbated by electronic voting systems, which may require learning to use a new computer interface.

- **Concerns about making incorrect choices.** Many of the adults at SCALE who had voted were concerned about accidentally making an incorrect choice, and voting against their own interests. When faced with an unclear question,
individuals sometimes preferred to leave their response blank rather than risk making an incorrect choice.

- **Complex ballot initiatives.** People with aphasia often do well with simplified statements and content. However, many issues that individuals are called to vote upon are inherently complex, and cannot be reduced to a simple statement. This is especially true for ballot initiatives, which often have complex structures. For example, Maryland’s 2012 state ballot featured an initiative involving whether the state should allow undocumented immigrants to pay in-state tuition rates. The text of the ballot question was 125 words long; as measured by Microsoft Word 2011, the initiative text presents a Flesch Reading Ease Score of 13.3 (“best understood by university graduates”), and a Flesch-Kincaid Reading Level of 12th grade (Kincaid et al., 1975).

- **Difficulty processing numbers.** Many of the adults at SCALE have difficulty understanding numbers and accurately gauging the relationships between them, whether represented as numerals or text. Thus, ballot initiatives involving complex numbers could be quite difficult to understand. Some SCALE members understand numerical content better when presented with charts or graphs, though this content is typically not available on actual ballots.

- **Effect of phrasing on comprehension.** While adults with aphasia typically understand their own opinion on an issue, the phrasing of questions about that issue may distort their response. If the individual is expecting a question or topic to be phrased in a certain way, encountering that issue in a different context may cause them to misunderstand the content, or even to adopt an opinion opposite their own beliefs.

- **Differences between sample and real ballots.** SCALE members often prepared to vote by reading and practicing with a sample ballots. However, they sometimes found that the actual ballot differed in presentation from the practice ballot, and experienced difficulty connecting the two.

- **Misunderstandings when working with an aide.** When voting, SCALE members typically brought along a companion, such as a family member, to provide assistance. However, the aide did not always fully understand the individual with aphasia’s plan or preferences. Accurately learning these preferences requires time and patience from both the individual and his or her aide, and often one party or the other was resistant to doing so. Furthermore, if
the individual with aphasia encountered a problem while voting, he or she would not always choose to seek help.

**Making Voting Accessible to People with Aphasia**

Through our observations during the News class, and through interviews with the instructor and students, we identified a number of strategies used at SCALE to increase the accessibility of news and voting topics during the class.

- **Modifying existing sources to make them more accessible.** The instructor used a variety of techniques to simplify existing material, such as web pages and sample ballots. The instructor carefully reads through material with the group, highlighting important phrases by circling them, underlining them, or writing them down on a whiteboard. The instructor often copies a small section of text from a document and pastes it into a separate document to isolate it, reducing information overload. The instructor also frequently relies upon repetition to emphasize points and increase comprehensibility.

- **Combine speech, text, and image.** When covering news articles in class, the instructor presents the text alongside representative images. She also reads along with the text, or uses web sites that can read their own content automatically, such as The New York Times and The Wall Street Journal.

- **Rephrasing content.** The instructor will often read text from an original source, and then rephrase it to increase comprehensibility. Many of the adults with aphasia at SCALE have difficulty understanding speech, but benefit from hearing the same content phrased multiple ways.

- **Practice sample ballot.** Before elections, the instructor prints out sample ballots and leads the class through the ballot. She highlights and underlines important terms in the ballot. As the class goes through the sample ballot, she polls the class for their opinions on each of the issues, and writes down their opinions so that they can be revisited and double-checked later.

- **Frequent polling.** The instructor ensures that class members are following along through frequent verbal polling. She will typically ask a question about the current content, and ask class members to indicate whether they agree or disagree. She will often ask about the same topic from multiple perspectives, to test whether the class members’ responses are consistent, or whether they may be experiencing difficulty in understanding the topic.
• **Verifying answers.** Adults with aphasia may sometimes respond to multiple questions about the same topic inconsistently, if they have difficulty understanding a question or articulating the response. The instructor of the News class stated that she is always careful to restate and verify class members’ opinions to be sure that the instructor was not speaking for the member.

In addition to the aforementioned strategies, the News class instructor relies upon a set of reliable and accessible online sources for course content. The instructor typically begins with mainstream information sources, and modifies them to be more accessible class members. Large, mainstream news sites such as CNN, The New York Times, and The Wall Street Journal are often most useful, as they were likely to feature supplemental audio or video content.

SCALE members also enjoy sites that feature charts, graphs, timelines, and other information visualizations. Figure 3 illustrates some examples of sites that have been successfully used in the News class: the US Debt Clock, which shows a real-time count of debt in the United States; iCasualties, which charts casualties in war over time; Politifact’s Truth-or-Meter, which visualizes promises made by politicians, and their actions to keep or break these promises; and the Voice of America, which features videos on news topics presented in simple English, along with text captions.
Guidelines for Making Information Accessible

Based on our ongoing work, we identify the following guidelines for improving accessibility of written and electronic content for presentation to adults with aphasia. These guidelines are not intended to be comprehensive, but provide initial steps for producing accessible documents.

1. **Present simple text, in small chunks.** Text should be written in plain language. It should be possible to break long passages into small phrases. When possible, provide alternative phrasings as ancillary content.

2. **Provide redundant multimedia content.** Many people with aphasia benefit from multimedia information. Present supplementary multimedia information whenever possible; combine text with pictures, captioned videos, and audio.

3. **Provide audio controllable feedback.** When providing audio content, allow the user to control the speed of the audio feedback, and make it easy to skip back and repeat content.

4. **Provide alternatives to numerical content.** Numbers, whether presented as text or numerals, can be difficult for people with aphasia to understand. When possible, provide alternative representations to numerical content, such as charts and graphs.

5. **Make instructions simple and omnipresent.** Make instructions as simple as possible. People with aphasia may benefit from direct manipulation-based interactions. Present instructions at all times to reduce the likelihood that the individual will become confused.

6. **Request user feedback via simple inputs.** When soliciting user feedback, ask simple questions and provide visual guidance when possible. The feedback tools used by SCALE, as shown in Figure 1, serve as examples of effective methods for collecting positive or negative feedback.

7. **Verify the user’s understanding.** Adults with aphasia may become confused by inaccessible content, and may provide inconsistent or incorrect feedback. For people with aphasia, it is important not only to verify the user’s input, but to verify their understanding of the topic being discussed. Verify the user’s understanding through repeated polls and verification steps. Use alternative
phrasings of the same question to verify that the user understands and is responding consistently.

**Future Work**

Our research team is developing new technology to support people with aphasia in becoming informed voters and learning about critical issues. Our ongoing research project, VotingVoice, will allow people with aphasia and their supporters to annotate existing voter materials with accessible information.

Here we identify some remaining challenges in making voting tools and materials accessible to people with aphasia, and opportunities for transferring insights from this research to address other populations.

**Remaining Challenges**

Designing user interfaces to support people with aphasia presents the designer with a number of significant challenges. When designing technology to support participation in voting, additional restrictions on how information can be altered may conflict with what is best for improving accessibility. Some notable design challenges include:

- **Use of images and alternative representations.** Many adults with aphasia comprehend information best when it is paired with information in alternative formats, including images and video. However, we must explore ways to identify which supplemental media will improve accessibility for a given piece of content. Furthermore, adding additional content can impart bias to the source material. We must therefore explore methods for examining potential supplemental information and measuring its impact on the source material.

- **Rephrasing and isolation of content.** Rephrasing content, or isolating specific segments of content, can increase comprehensibility of information for adults with aphasia. However, altering source materials can introduce bias. The research community should consider how existing materials can be rephrased and altered while minimizing the effects of bias.

- **Supporting effective voting activities with personal assistants.** Many of the adults with aphasia at SCALE can only vote with the assistance of another person. However, the assistant may not be completely aware of the individual’s preferences, or may have misunderstood some preference. When the assistant is a friend or family member, the individual with aphasia may not wish to share every detail about his or her voting plans. The research community should
explore methods to enable individuals with aphasia to work better with an aide, sharing information accurately while maintaining privacy and independence.

- **Measuring and tracking comprehension.** Individuals with aphasia often experience difficulties in comprehending information, and may also experience difficulties indicating that they do not understand. As a result, measuring and tracking the user’s understanding is key to developing interactive systems for people with aphasia. Speech-language pathologists often confirm the individual’s comprehension by rephrasing or inverting the information; thus, a simple confirmation screen may be insufficient for verifying the individual’s choices.

**Opportunities for Translational Research**
Many of the problems experienced by adults with aphasia when voting are similar in character to problems experienced by other user groups. Thus, design techniques that are effective with one such group may be transferable to another. Table 1 lists some challenges faced by our user group, and connections to other user groups that may experience similar challenges.

<table>
<thead>
<tr>
<th>Accessibility challenge</th>
<th>Related user groups</th>
</tr>
</thead>
<tbody>
<tr>
<td>Difficulty in comprehending written text</td>
<td>Older adults; individuals with cognitive impairments; non-native speakers</td>
</tr>
<tr>
<td>Benefit from text-to-speech, captions, and multiple communication modes</td>
<td>Individuals with vision impairments; individuals with hearing impairments</td>
</tr>
<tr>
<td>Need for increased verification of choices made</td>
<td>Individuals with cognitive impairments</td>
</tr>
<tr>
<td>Difficulty understanding numerical information</td>
<td>Individuals with cognitive impairments</td>
</tr>
</tbody>
</table>

*Table 1. Accessibility challenges experienced by adults with aphasia, and other user groups that may experience similar challenges.*

**Conclusion**
Individuals with aphasia still experience significant accessibility challenges surrounding voting, including the act of voting itself, but also in learning the appropriate background knowledge required to vote in an informed manner. The adults with aphasia who have participated in our research currently rely upon a
significant amount of external assistance to learn about voting issues, prepare to vote, and to vote. Many of these challenges extend beyond text complexity, and cannot be resolved through simplifying language alone.

Understanding the current challenges to voting accessibility, and identifying strategies developed both by individuals with aphasia and subject experts to address these challenges, provide useful design guidelines for developing more accessible information resources and future access technologies.

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