

Developmental personal health libraries: Supporting independence through design

Amelia N. Gibson, Ph.D & Kristen L. Bowen, MSLS, University of North Carolina at Chapel Hill

Introduction

Many autistic [1] people experience limited independence, and rely on support from a family member, social worker, or other caregiver for management of their personal healthcare and wellness planning [2,3]. We are proposing a few considerations for design of a developmental personal health library (D-PHL) – a personal health library that acts as a teaching tool to help individuals build independence in seeking and managing personal health and health data by increasing access to health information, teaching teens and young adults to manage their own health data, supporting health information seeking and providing secure space for storing mobile health devices and fitness data.

This poster describes partial qualitative findings of an ongoing study of the information needs and seeking practices of autistic individuals and applies them to development of a heuristic for evaluating the usability of a personal health record and/or library for people on the spectrum [4].

Methods

The Deconstructing Information Poverty Study: Autism (DIPS Autism) is an ongoing study on information seeking and exchange among autistic people and their families in North Carolina [4]. The researchers conducted thematic analyses of sixteen 60–90 min interviews with autistic teens and adults and parents (dyads, for a total of 32 participants). Participants talked about their information seeking and sharing related to health, education, social interests, money, and independent living. They were asked about their technology use, their use of libraries, and about the ways that they learned to use new technology. Two researchers used inductive content analysis to identify emergent themes related to information seeking, information sharing, and information exchange

DIPS-Autism Research Questions

1. What are the information needs of local ASD communities/community members?
2. How do the information or service needs of members of the local ASD communities differ from other local community members?
3. Where and how do members of the ASD community currently look to fulfill their information, technology, and service needs?
4. How does the library currently fit into the information worlds/horizons of people with ASD and their families?
5. What gaps exist between information resources and ASD community member information needs?

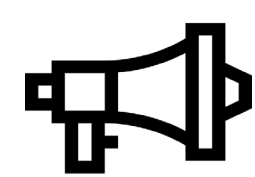
Findings

Trustworthiness and Safety



on websites and mobile phone applications was framed as foundational for exploration and experimentation. Participants relied heavily on opinions of trusted people and institutions (e.g., family members, commercial verification systems). Providing good sources of “trusted” information and highlighting heuristics for “trustworthy” sources could help build seeking skills. Additionally, providing guidance about sharing information online (limits, guidelines for how & when to share) could be helpful.

Supporting Patient-Provider Communications & Patient Rights



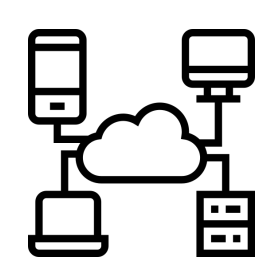
Many participants used text messaging and voice-to-text for everyday mobile communication but did not know how to contact their own doctors to ask questions. Supporting patient communication might include making video, audio, or speech-to-text versions of questions, or live chat (Ask a nurse, or Ask a health librarian for help searching) available in addition to the email-style messages currently used in many popular EMRs. Providing guidelines for effective communication might include providing access to a medical dictionary and/or transcripts for effective self-advocacy around difficult-to-discuss issues (e.g., reproductive health or describing pain).

Formattable Text and Layout



Many participants expressed difficulties with reading written text. The ability to reformat text on the page (including font, font size, and background color), to make all text fully screen-readable, and the ability to add their own images to text was particularly important for these participants. Readability was also a concern as several individuals had limited literacy.

Multimedia & Multimodal Communication



Providing information in multiple modes (e.g., written, visual, and auditory) using multiple media (e.g., pictures, video, podcasts, text) would give users multiple points of access to information/data.

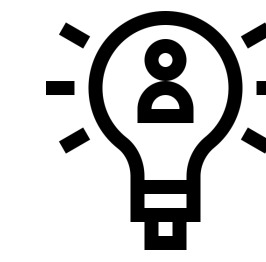
Costs: Time and Money



Many participants had limited income, if any at all. In many cases autistic adults had limited control over their own finances and spending. This meant that they were often unable to access services and web applications that cost money. D-PHLs should provide clear guidelines about cost (e.g. in some cases, emailing a provider will incur a visit charge), and when necessary, provide mechanisms for approval by legal guardians or account holders while maintaining as much privacy possible.

Findings (contd.)

Capitalizing on Special Interests



Most of the participants described a special interest (e.g., basketball, cooking, kinesthesiology) that motivated much of their online information seeking. A PHL that is flexible enough to support connections between special interests and health could help users build a more healthy lifestyle.

Language



Despite the high concentrations of Spanish-speaking people living in the study communities, Spanish-language resources were difficult to find. A D-PHL would ideally help fill language gaps by providing resources and data in a second language.

References

1. Autistic Self-Advocacy Network. n.d. Retrieved July 1, 2019 from <https://autisticadvocacy.org/about-asan/identity-first-language/>
2. Bishop-Fitzpatrick, L., Hong, J., Smith, L. E., Makuch, R. A., Greenberg, J. S., & Mailick, M. R. 2016. Characterizing objective quality of life and normative outcomes in adults with autism spectrum disorder: An exploratory latent class analysis. *Journal of autism and developmental disorders*, 46, 8: 2707-2719.
3. Eaves, L. C., & Ho, H. H. 2008. Young adult outcome of autism spectrum disorders. *Journal of autism and developmental disorders*, 38, 4: 739-747.
4. Gibson, A. N., & Hanson-Baldauf, D. 2019. I want it the way I need it: Modality, readability, and format control for autistic information seekers online. *International Journal on Innovations in Online Education*, 2, 4: 1-12. Doi: 10.1615/IntJInnovOnlineEdu.2019029842
5. Jaeger, P. T., & Burnett, G. 2010. *Information worlds: Behavior, technology, and social context in the age of the Internet*. Routledge.

Image Credits

Icons:
<https://www.flaticon.com/authors/freepik>

Acknowledgments

This project was made possible in part by the Institute of Museum and Library Services grant number RE-07-17-0048-17.

