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EASA Connections: Community-Based Participatory Research to Develop a Peer-Based Early Psychosis Web Resource With Young Adults

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Abstract

Young adults (YA) who have experienced early psychosis (EP) have valuable information about their recovery process yet are often left out of research. We used a community-based participatory research (CBPR) approach in partnership with the Early Assessment and Support Alliance (EASA) EP program and Portland State University to develop a peer-driven, web-based, recovery resource. We used our CBPR process to collaboratively develop the resource and conducted an iterative usability study to test and refine it. The resource was well-received and accessible. YA partners emphasize the importance of being prepared to learn about research and one's self, being open to new experiences, and how being co-researchers can help with processing EP experiences for the benefit of one's self and peers. Peer involvement in intervention development may increase usability. It benefits YA and adult co-researchers. We strongly recommend including YA who have experienced EP as co-researchers.

Introduction

Background

Around 100,000 individuals in the U.S. experience first episode psychosis yearly, typically starting as young adults in their teens or 20s.¹ Over the lifetime, if unaddressed, psychosis can lead to poor outcomes, including in education, employment, interpersonal relationships, health and safety, economic future, and quality offered life.²⁻⁴ Early intervention, particularly near the time of the first episode, can greatly increase the chance of recovery before a young person's life is compromised.¹

A wealth of first-person literature from peers with early psychosis experience is starting to provide deeper insight into how young adults find their way to recovery. Some describe discovering a sense of control and self-efficacy in thought and action, having a positive future, engaging in treatment and community activities, and participating in reciprocal relationships with peers.^{5,6} Others describe focusing on skills for self-reflection, communication, growth, and resilience.⁷ However, early psychosis intervention research rarely includes the voice of young adults who have experienced first episode psychosis.

Incorporating three methods of recovery delivery—1) psychoeducation,^{8,9} 2) computer-based decision support systems¹⁰ and internet-based health information^{11,12} and, 3) peer support and exposure to others with lived experience¹³⁻¹⁵—our project aims to use a

community based participatory research approach^{16,17} to develop a web-based, peer-driven resource for young adults in first episode psychosis recovery. Grounded in self-determination theory, which centers competence, autonomy, and relatedness as the basic psychological needs of self-determination,¹⁸ the resource focuses on supporting: engagement with treatment and recovery, self-efficacy, hopefulness, self-esteem, reduced internalized stigma, and retention of community and interpersonal connections. This paper details the resource development process, usability testing, and lessons learned as our partnership engaged young adult graduates of the Early Assessment and Support Alliance (EASA) early psychosis program, EASA program directors, and academic scientists as co-researchers in all phases of the work.¹⁹

Method

Partnership History and Community Based Participatory Research Approach

EASA is a community-based early intervention program primarily serving young adults ages 15 to 26. It includes a Young Adult Leadership Council (YALC) within its infrastructure.²⁰ YALC is comprised of about 15 graduates of the EASA program who help guide EASA's priorities, language, and programming. In 2014, YALC identified the need for additional support to welcome new people to the program, and to let them know they are not alone in their experiences. This coincided with an opportunity to develop a research project within the Research and Training Center for Pathways to Positive Futures at Portland State University's Regional Research Institute for Human Services, with which EASA had an existing partnership from past collaborations. Thus, this project came about organically when a community need coincided with a new federal funding opportunity through an existing academic-community (non-CBPR) partnership.

Our project took a community based participatory research (CBPR) approach with intention to include the researched community as co-researchers equitably in every phase of the project, and to adhere to the principals of CBPR.^{16,17} We recruited young adult members ages 18–29 for our CBPR team—called the “Design Team”—from YALC, and through outreach by EASA clinicians to young adults nearing completion of the program and who might be looking for new ways to engage with peers, EASA, or their communities. The original Design Team consisted of seven young adults who had experienced first episode psychosis, the Executive and Clinical Directors of the EASA Program, an academic Principal Investigator with experience using CBPR in similar projects,²¹ and an EASA staff member in training as a counselor. Due to the fast pace at which young adults' lives can change due to educational opportunities, career development, and other factors, the young adults on the Design Team changed over time, but they always comprised a majority.

Co-authors for this paper include seven members of the Design Team and/or YALC (four young adults, the EASA directors and a staff member, and the academic PI) who contributed to the work described here as well as to the reflections and lessons learned, and two academic research assistants who contributed substantially to resource content development and manuscript development. All coauthors developed and revised this manuscript.

Resource Development Methods

The Design Team met bi-monthly 32 times in person for between one-and-a-half and two hours between July 2015 and March 2017 to develop the resource. Drawing from lessons learned from the academic PI's previous CBPR collaborations with the autistic and developmental disabilities communities,^{17,22-24} our first meetings focused on internal structure and process. The group agreed to the bi-monthly schedule, and adopted a policy of confidentiality. We also agreed to try the "five finger method" of consensus for decision-making. In this iterative process everyone indicates their level of approval of a decision, if they have more questions first, or their level of disapproval along with why. Discussion follows, the decision is refined, and the process repeated; this is described in detail in Nicolaidis, Raymaker, McDonald, Dern, Ashkenazy, Boisclair, Robertson, Baggs.²⁵ We decided to open meetings with an icebreaker question, which would be provided by different team members each time. We adopted a "keep / change" process at the end of each meeting, asking, "what from this meeting would you like to keep doing next time and what would you like to do differently next time?" This allowed us to refine and improve our communication and power-sharing. Because many of the Design Team members already knew each other from YALC, the group was eager to get to work immediately, and process discussions to further develop the partnership developed organically over time and concurrently with rest of the project development.

We then collaboratively developed the resource (see Figure 1). First, we discussed and refined which constructs we hoped to impact with the resource. Those constructs were: self-determination, hopefulness, self-acceptance, stigma and discrimination, community living, community participation, social connection and support, self-directed treatment and shared decision-making, and symptom mastery. Young adults spoke about their own experiences and co-wrote and approved the final construct definitions. We conducted several brainstorming sessions, writing ideas for resource content topics based on the constructs, and website format and functionality, on post-its. As a group, we organized and narrowed the brainstormed content based on if and how we felt it fit into the constructs we previously defined.

We identified five sections and organized the content within them: 1) introductory materials on EASA and self-determination; 2) psychosis as a common experience that people get through successfully; 3) identifying strengths, challenges, and goals; 4) tools for shared decision-making (including around medicine, treatment, and relapse planning, as well as for self-advocacy and legal rights); 5) staying connected to supportive people and activities that have meaning. Staff and the academic PI then created a first draft of the resource content based on the outline from the brainstorming sessions and brought it back to the Design Team for review. The young adults on the Design Team discussed changes to the wording, and made additional content recommendations. The EASA Clinical (RM) and Executive (TS) Directors, both part of the design team, helped ensure that the content was consistent with both evidence-based practice for early psychosis recovery, and the EASA program's values and programming.

The young adults also developed videos based on their own stories and the messaging they most wanted peers to know. They selected key content topics for the videos (e.g., self-

determination, experiences with the hospital, setting goals, etc.), and talked, along with input from TS, about what they most wanted to tell others at the start of recovery. The academic PI (DMR) facilitated the creation of formal scripts by pulling the verbal discussions into written text and working with young adults to divide the labor of recording. We worked with PSU's media department to film and edit the clips. DMR made final edits, and then the Design Team reviewed the videos and DMR made the final revisions and transcripts.

Concurrently, DMR and the staff created the website to support the identified format and functionality and worked iteratively with the young adults on the Design Team to refine the site.

Lastly, we used the resulting website in a usability study to further test and refine it. The Design Team co-created the study materials during meetings, including selecting which aspects of the resource to highlight in testing, and developing the recruitment script and study consent. We obtained approval from Portland State University's institutional review board prior to starting the usability study.

Usability Study Methods

We conducted a usability study to test the resource. For the website, we used typical procedures for usability testing, asking participants to perform tasks (e.g., navigating to a specified page) and observing participant actions.²⁶ As per typical usability analysis methods (see, for example, US Department of Health and Human Services),²⁷ we recorded and plotted verbal information and behavior in matrices to assess usability issues, and prioritized based on severity (how badly the issue impacted the user's ability to complete the task) and pervasiveness (how many users had the same issue).²⁶

For the content, we used cognitive interviewing,²⁸ which involved selecting the sections we felt might be difficult to understand, and asking participants what they meant. Per the method, discrepancies between response and intended meaning indicate the material needs to be revised. Participants were able to give any other feedback they wished through the semi-structured nature of the interview and were asked to reflect more generally on what they liked best and least.

We recruited participants by word-of-mouth from YALC and through clinicians at one EASA program site. Participants needed to be age 18–25 and a current or former participant in the EASA program (to be eligible for enrollment in the program, one must be aged 15–25, live in Oregon, have experienced first episode psychosis within the past 12 months, and have a diagnosis consistent with a schizophrenia spectrum disorder not better explained by a differential condition).

DMR administered the usability study in a series of one-hour sessions. Participants took part in three sessions of testing, reviewing either new or new and revised material each time. Each session included both usability tasks on the website (e.g., navigate to a specific page), if applicable, and cognitive interview questions on the content (e.g., read the section on what is psychosis; what do you think it is saying?). At the end of each iteration, the academic PI and staff updated the website and content based on Design Team discussion and participant

feedback. We checked with participants to see if we had corrected the more major issues in the following session. The details of what we included in each iteration are shown in Figure 2.

Results

Resource Development Results

Young adults recommended multimedia content including video, written word and graphics. They also recommended a variety of formats for conveying key information in addition to exposition: personal stories, activities and worksheets, tip sheets and instruction sheets, links to external resources, and printable content. We had lengthy discussion within the Design Team about how to present the information. The original idea was as a structured slide presentation that needed to be viewed in a specific order; however, young adults strongly felt that individuals should have their choice of what to view and when. Therefore, we designed the website give users control over whether to view the content in order or to use a menu to skip around inside the content. We incorporated all of the recommendations of the young adults into the website.

In addition, young adults on the Design Team, in collaboration with YALC, scripted and participated in a series of fifteen live videos to go with the five sections. Through connections to the broader EASA program through the Executive and Clinical Directors, we were able to create several videos with EASA clinicians that supported messaging guided by the young adults. Figure 3 shows samples of the completed interactive website.

Usability Study Results

Four diverse individuals participated in the usability study: 50% female; 50% white, 50% multiracial; one Latino; ages 19–24. Two had a BA, one was in college, and one was in high school. All self-identified as comfortable using the web and enjoyed receiving information online. Three of the four participated in all three iterations. Participants' experiences converged quickly during testing.

The majority of issues with the website and presentation arose in the first iteration. Originally, content was broken into small subsections, one per page. Participants universally wanted all content for each main section present on the same page to minimize clicking and to keep the ideas in context with each other. Several participants really liked a page that used bolded topic sentences to focus the important ideas in longer blocks of text and requested more. The second version of the web site simplified the navigation, placed all content for each section on a single page, and used bolded topic sentences throughout. The second round of testing showed that the serious issues were addressed, and only fine-tuning was needed from that point on. Table 1 summarizes the website changes.

In general, the cognitive interviews did not reveal serious issues with content accessibility, although some pointed to places that were unclear or potentially triggering. While participants were initially skeptical of the content, they quickly became excited when they realized it was written by and for people similar to themselves and noted its accessibility. Participants were eager to skim through the whole resource and offered unsolicited

comments beyond the formal interview questions. One participant remarked, “Oh my gosh I really wish I would’ve had this [when I was new to the EASA program].” Table 2 gives typical examples of the kinds of issues and comments that arose regarding the website content.

Conclusions

Web Accessibility Recommendations

Based on our findings, we recommend the following when designing web-based psychoeducation for young adults experiencing early psychosis, in addition to following general accessibility standards (e.g., W3C 29 which includes, for example, providing alternate text for images, transcripts or subtitles for audio media, page navigation via keyboard, etc.):

- Keep the user interface simple. Only use images where necessary and pare down site functionality to essential features.
- Use whitespace and icons to sort information visually.
- Provide information in multiple ways for different learning styles (written, video, graphically, etc.).
- Bold topic sentences to show what’s most important, even if the rest goes unread.
- Use plain language³⁰—language suited for the audience—but do not “dumb-down” or oversimplify the ideas being presented. Consultations with young adults are helpful to ensure accessible language.

Design Team Reflections and Lessons Learned

The material presented in Lessons Learned comes from reflection and discussion among this paper’s co-authors, of which four are young adults who have experienced early psychosis, seven are affiliated with EASA, and three are academics from Portland State University. We discussed these reflections during the preparation of a presentation on these findings,³¹ and during the preparation of this manuscript. Quotes are from these discussions, as recorded by DMR during the conversation.

The initial process and structure choices of the Design Team facilitated early success in collaboratively accomplishing work, while being flexible enough to make changes to meet challenges. Through the feedback of the keep/change exercise, we found at various times we needed to implement additional processes for turn-taking and communication. Techniques to support turn taking and communication involved using a “talking stick” (whoever holds the designated object is the only person allowed to talk) to give individuals uninterrupted time to make their point, going “round robin” (going around the room in consecutive order) to ensure everyone had a chance to speak. The Design team members would know when their turn was coming up, encouraging people to write down their thoughts so that they would keep until it was their turn. Finally, allowing people to attend meetings via video conference when they moved for work or school. Young adults said the flexibility to meet with the team on their own terms was important both to their ability to attend meetings, and to feel valued.

Although there was a lot of turnover, young adults who had been around longer mentored newcomers and we did not experience substantial challenges beyond additional time for orientation and trustbuilding. The Design team acknowledged fresh perspectives were at times valuable.

Both young adults and adult members of the Design Team appreciated the sense of community fostered during the process and looked forward to meeting with their “Design Team family.” The icebreakers at the start of meetings, while at times fun or silly, became poignant as team members got to know and trust each other and feel they were in a safe environment for expressing diversity, and for disclosing cross-cultural connections and personal challenges. One young adult said that coming to the meetings made them realize they weren’t alone in living with psychosis and appreciated the opportunity to build friendships with the other young adults on the team, some of which persisted outside the project. Many young adults came to the project with a desire to give back to the EASA program and make a connection with or help others, and, in keeping with the original idea YALC had for welcoming new EASA participants, and they felt accomplished in those goals.

Throughout the project, we tried to remain actively aware of the importance of power.³²⁻³⁴ One young adult reflected, “[there was a] really nice power balance, I was in a room with amazing people but wasn’t intimidated by it either, I felt like my voice was as valuable as [the Clinical Director’s] for example, I really felt heard and CBPR is important to do it in a way that the young people feel like their opinions matter and they don’t feel intimidated.” Attention to process helped us with balancing power; the young adult continued, “There is no weight to the votes [using the five-finger consensus process²⁵]; they are all equal. That allows confidence that [lived] experience is important and can make a difference.”

Young adults emphasized that peers interested in doing this kind of work should be prepared to learn both about research and about themselves, and to be open to new and potentially challenging experiences. For some, their participation brought up difficult memories and unresolved feelings. However, they also felt their participation helped to process those difficult experiences for the benefit of themselves, other young adults, and the broader community.

The work was also challenging to adult members, some of whom had experience living with a mental health diagnosis and/or were family members of those who had experienced psychosis. The academic PI DMR entered the project having been, at times, both a non-academic Autistic community partner and an academic investigator on autism-focused CBPR projects.³⁵ However, they were uncertain if and how to transfer that intersectional experience into a setting where they are an adult with a different diagnosis and considerably more power, and initially held back their own experiences. Over time, the young adults—who knew about DMR’s neurodiversity activism—encouraged them to share, and DMR realized that sharing lived experience could be valuable and helps build trust and connections, as long as they framed their experiences as adjacent and not exact, and made sure to hold space and be aware of power. This led to rich conversations about intersecting experiences between autism and psychosis. For example, the section on stigma and

discrimination emerged through a frank conversation in which DMR and the young adults discussed the similar (and also different) realities of what it's like to live in a society that discriminates against atypical behavior. Through this partnership, DMR learned new ways to navigate power and vulnerability in a community adjacent to, but not precisely, their own.

For the EASA Executive Director and Community PI TS, CBPR modeled a new collaboration dynamic with young adults, adults, and scientists where different voices and types of knowledge were given equal weight. TS described it as “an experience of what a true peer-to-peer relationship with young adults is like” in a collaboration. She has since taken CBPR's model of power-sharing and the facilitation tools, and a new conceptualization of the psychosis experience, from this project to other meetings. She has identified EASA Connections as a template for future EASA program development.

Finally, the young adults appreciated the amount of impact they could have by co-developing the project. One Design Team member summarized it as, “Being part of the research [team] instead of a research subject can reach a larger audience on a more personal level.” Foremost, the young people on the Design Team wish to share and promote a message of hope, recovery, and success.

Discussion

We were able to use a CBPR approach with the early psychosis community to collaboratively develop a multi-media web-based resource for young adults experiencing first episode psychosis. Attention to structure, process, communication, and power-sharing helped facilitate productive and fulfilling team meetings with young adults, adult program directors, and academic scientists. The results of our usability study indicate that young adult participation in the process can help create a product that is accessible to peers with a minimum amount of revision. Moreover, we found that the process of working together had a positive impact on the young adult members of the research team.

Engagement in research as both study participants and co-researchers is an important aspect of community participation,³⁶ and may help empower people who are disengaged from broader communities,^{37,38} such as young adults who have experienced psychosis. While CBPR has grown in popularity since its inception, including with young adults around mental health,³⁹⁻⁴¹ there remain few examples of it with individuals experiencing psychosis—and those are limited to adults and/or to bi-polar disorder (e.g., a Delphi study to understand self-management for bi-polar which included adults 19+ and claimed a CBPR approach⁴² or a well-documented CBPR project with young adults regarding online resources for self-management but focused solely on bi-polar⁴³). To our knowledge, we are first in the U.S. to use CBPR with young adults who have experienced first episode psychosis, broadly.

Young adult involvement in intervention development may increase the chance of an intervention that is usable and acceptable to young adults, as it has for other populations.^{21,22,44-46} It also benefits young adults, providing new experiences, connections, and a unique opportunity for personal growth. Some of these experiences may further engage

known facilitators of recovery, such as increasing self-efficacy, enabling empowered decision-making, and providing opportunities for supportive and reciprocal peer connection and personal growth.⁵⁻⁷ We hope that our lessons learned and our success will inspire others to take a similar approach of equitably including young adults who have experienced early psychosis to co-conduct their research and intervention work.

We acknowledge that this work has limitations. It was conducted in the Portland, Oregon Metro area, and may exclude important perspectives from young adults who live in other regions, rural areas, or who identify as African American or Native American. It was developed within the context of the EASA program, and some content (e.g., EASA's philosophy) is not applicable to other programs. Although some may feel the small number of participants in the usability study is limiting, it is commonly accepted that an N of around 5 is sufficient to catch most usability issues,⁴⁷ and, given the convergence of experiences, we do not feel the N is a limitation of our usability study. Lastly, this resource is developmental in nature; its integration into a broader intervention, and rigorous pilot and efficacy testing is still required. We are currently conducting that work and will report on it once we have completed our analysis. We feel, however, that despite these limitations there is a substantial amount of transferrable process and lessons learned from our work that can be useful to others.

There is still much work to be done in intervention development for early psychosis recovery, particularly in understanding how to integrate peer expertise into programming. In addition to completing the analysis of our intervention which uses this resource and making the resource available to the public, we hope to continue our CBPR collaborative despite a recent change in federal priorities that compromised our ongoing funding. The EASA program has started using CBPR as a model throughout their program development and intends to use it in future projects. We also hope that our work opens a new avenue of approach, using our facilitation methods as a foundation, for other peer-engaged and peer-directed research in collaboration with scientific and clinical experts. Young and emerging adults who have experienced first episode psychosis have valuable perspectives regarding their recovery process. The recovery and scientific communities have much to learn from them about what has facilitated their recovery, and how to work beside them to translate their wisdom into practice.

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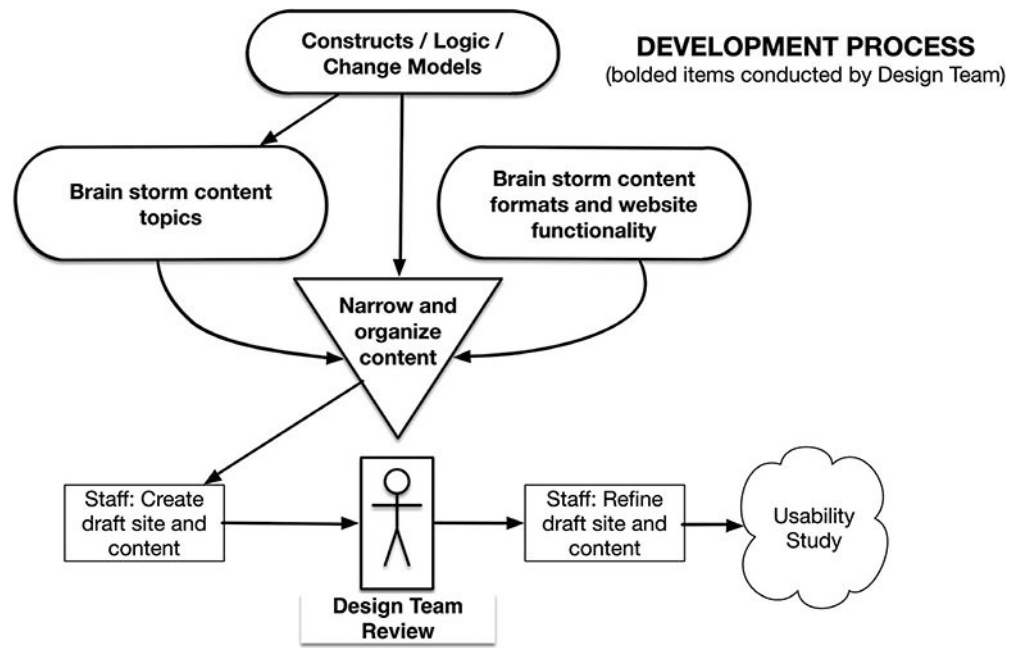


Figure 1:
Development Process

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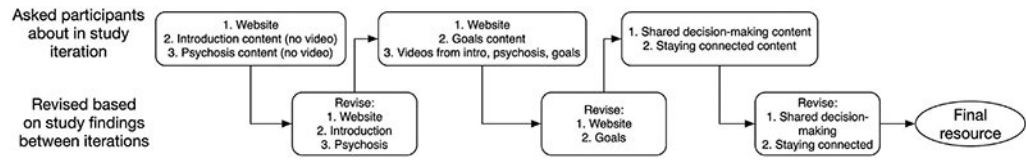


Figure 2:
Usability Study Iterations

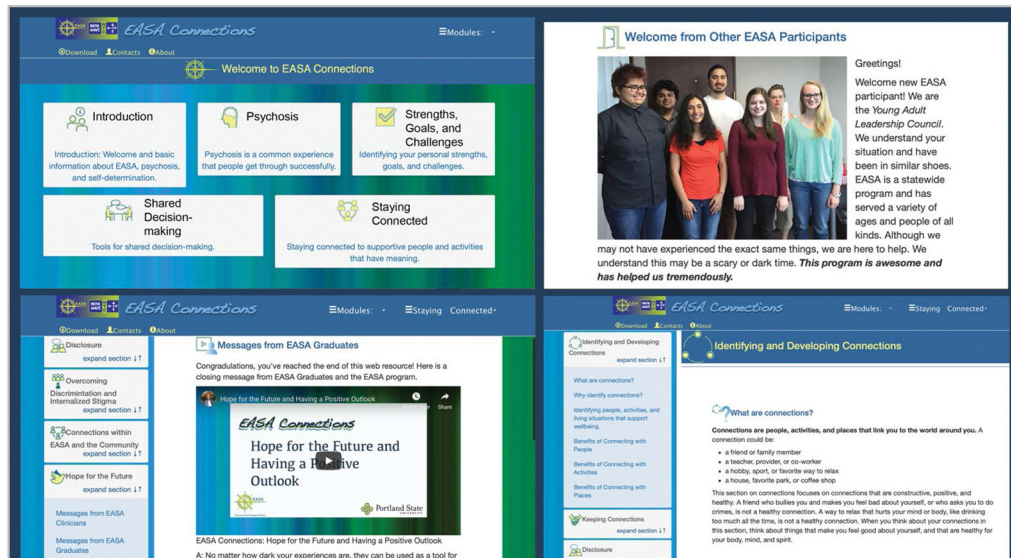


Figure 3:
EASA Connections Interactive Website

Summary of Website Changes

Table 1:

Version	Description	#Issues	#Severe Issues	Example Issues
1.0	interactive slide show, one topic per page, navigation to go in order or skip around sections	10	4	unusable number of clicks, many issues related to single-slide presentation
2.0	TOTAL REDO! menu for each section on left with all section content on right, lots of white space	7	0	unexpected behavior on clicking home link
2.1	minor refinements	3	0	buggy logo, put a "back to top" link at the end of each page

Table 2:

Example Results From Usability Testing of Content

Content Topic	Issues With the Content	Positive Reactions to the Content	Severity of the Issues
<i>brain chemistry background</i>	a bit hard (N=1), should be with the brain chemistry idea (N=3)	better than the textbooks	medium
<i>brain chemistry idea</i>	should be with the brain chemistry background (N=3)	better than the textbooks	medium
<i>how does EASA work</i>	“builds on that” spell out what “that” is referring to		medium
<i>what is self-determination</i>	understood but concerned about “self-determination” as a scary word – synonyms?	“empowering”	medium
<i>stages of adjustment</i>	a few typos; possibly add that the stages can come in small steps	“oh my gosh I really wish I would’ve had this”	low
<i>what is [redacted]</i>	“Problems” has negative connotation; would be better as “obstacles”		low
<i>radical acceptance</i>	make explicit “you can use this with symptoms”	“everyone should know this!” “this needs to be written in the sky!” thought the example was great, said the serenity prayer	low
<i>neurodiversity</i>	“biodiversity” needs explanation (N=2)		high
<i>what’s happening in the brain</i>	“much the same way” hard to parse; didn’t know word “kaleidoscope”		high