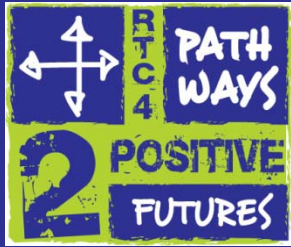


How young adults with mental health conditions use the internet to access mental health information and support

L. Kris Gowen

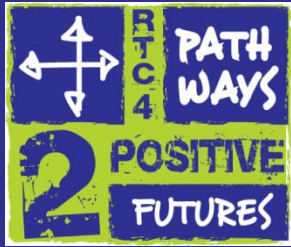
Matthew Deschaine



How to use GoToWebinar

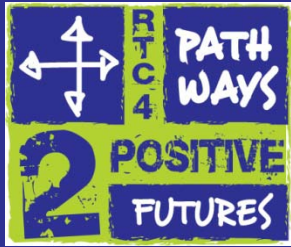
- Move any electronic handheld devices away from your computer and speakers
- We recommend that you close all file sharing applications and streaming music or video
- Check your settings in the audio pane if you are experiencing audio problems
- During the presentation, you can send questions to the webinar organizer, but these will be held until the end
- Audience members will be muted until Q&A
- During Q&A, you can “raise your hand” if you would like to verbally ask a question
- If you are calling in over the phone, remember to enter your unique audio pin so we can un-mute your line

A recording of this webinar will be available online at www.pathwaysrtc.pdx.edu



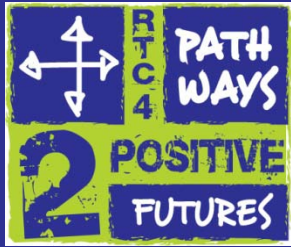
The Overwhelming Majority of Young Adults Use the Internet

- Among young adults, ages 18-29
 - 93% go online
 - 72% use social networking
 - 72% looked for health information online
 - 33% looked up information about mental health
- *“Every day, more people go online for medical advice than actually visit health care professionals”*



People Use the Internet to Guide Their Health Decisions

- 68% of health information seekers state that the information they find online has an impact on their healthcare decisions
- 18% of adults have gone online to diagnose or treat a medical condition on their own, without consulting their doctor
- About half of online adult online health information seekers have read someone else's commentary or experience about health or medical issues
- We hypothesize these numbers are higher for young adults specifically

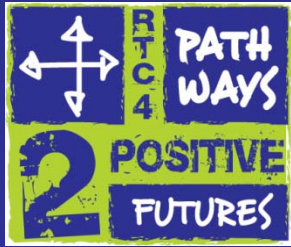


***Problem:
The General Quality of Online Mental
Health Information is Poor***



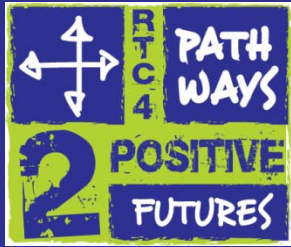
Our Research Questions

- **How do transition-aged youth with serious mental health conditions use the internet for information and support regarding their mental health?**
- When asked questions about mental health, do transition-aged youth with serious mental health conditions find accurate answers online?
- How do transition-aged youth with serious mental health conditions evaluate web sites?
- Can we create a half-day training to improve eHealth literacy in transition-aged youth with serious mental health conditions?



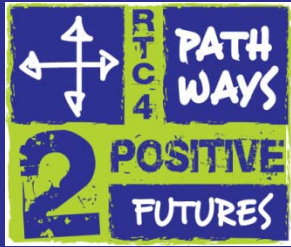
Our Study

- Three focus groups
 - Three different parts of Oregon
 - Three different samples
 - Craigslist (Portland)
 - Youth advocacy group (Eugene)
 - Residential treatment center (Albany)
 - N = 27



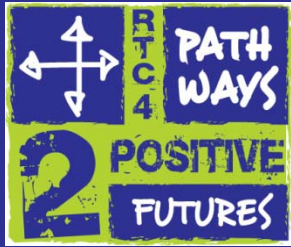
Sample Focus Group Questions

- What sorts of information do you need in order to best manage your mental health?
- Where you like to get information about your mental health?
- What web sites have you gone to in order to get information about mental health?
- How useful have these web sites been in answering your questions?
- What would make these web sites more useful for you?



Results

- Categories of analysis
 - Topics searched for
 - Motivations for information seeking
 - Characteristics of desirable mental health websites
 - Barriers to successful searching



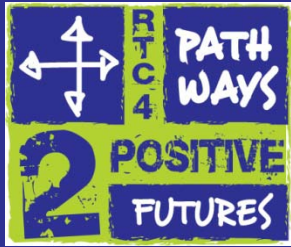
Results: Topics

- Medications
- Diagnosis
- Treatment Options
- Access to health care (i.e., insurance information, places to go)
- Transition to adulthood support/resources (e.g., coping skills, food stamps)



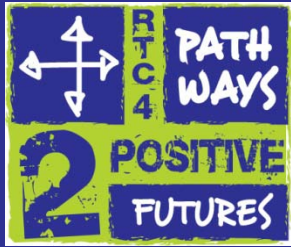
Results: Topics

- Diagnosis: *“What is wrong with me?”*
- Young people will sometimes self diagnose online by looking up the symptoms they are experiencing and finding a diagnosis that fits their experience. They sometimes do this because they feel like they have nowhere else to turn when they aren’t feeling “right.”



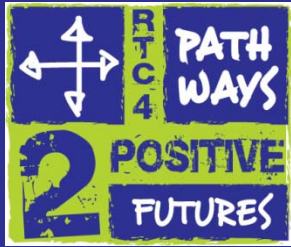
Results: Topics

- Access to health care: *“Where can I go to get care?”*
- Young people use the internet to look for places that they can go that accept clients without insurance or are low-cost. They will also look up doctor ratings or backgrounds. They will also look things up in order to prepare for a health visit.



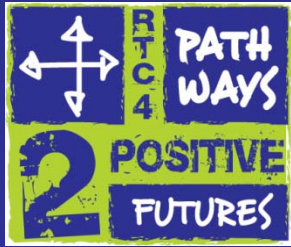
Results: Topics

- Medication: *“What does this medication do?”*
- Young people are very concerned about the medications they are prescribed. They want to know about the side effects, the symptoms they are supposed to treat, and even the diagnosis associated with the medication. They often look up medication information after a trip to a healthcare professional to get their own “second opinion,” challenging the HCP’s suggestion for a particular treatment.



Results: Topics

- Treatment Options: *What is the best treatment for me?*
- Young people want to be in charge of their health and treatment and want to know all the options. They look up information on different approaches to treatment, often outside of medication options.



Results: Topics

- Support and Resources: *How can I manage on my own?*
- Young people look up strategies for living more independently – everything from how to develop good coping skills to where to get food stamps. To them, the internet provides information on how to successfully transition to adulthood and meet the challenges associated with living more independently.



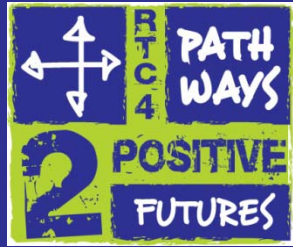
Results: Motivations

- Finding out more: Looking up terms or something else not understood from another source/ Challenging/confirming information heard elsewhere
- Community: Opinions/POVs/personal experience
- *Nowhere else to go: lack of insurance*
- *To prepare for a mental health visit*
- *Anonymity*



Results: Motivations

- Community:
 - *I trust the people who I have met who have had similar experiences. I had never met anyone who was bipolar before I met them on the internet and they told me their experiences personally.*



Results: Motivations

- Finding out more:
 - *I like that you can look up the prescription that your psychiatrist is writing you. Because when you get a new psychiatrist or you have a new one or a crazy one, you can't trust. They are just like "take this, this is what you need." So I just like that you can look it up and it will tell you all the side-effects and then you can go back to him and say "why do you think that I am psychotic?"*



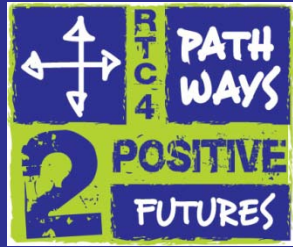
Results: Motivations

- Nowhere else to go:
 - *When I turned 18 I stopped [getting mental health care] and went to one therapy session because I didn't have my mom's insurance anymore. So suddenly it became about what resources I had access to myself, so from the medical field of mental health to the internet field of mental health – that was my transition.*



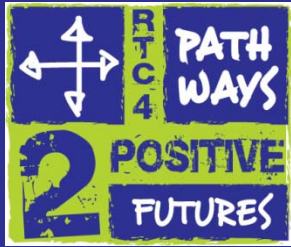
Results: Motivations

- To prepare for a mental health visit:
 - *[Online] I can learn about the breadth of information [about my mental health] at least so when I see a doctor and someone tells me what I have I at least have a basis of foundation for what is going on. So I think that for young people are getting diagnosed these days I bet that 50 percent or 75 percent of them already have some information about what is going on with themselves.*



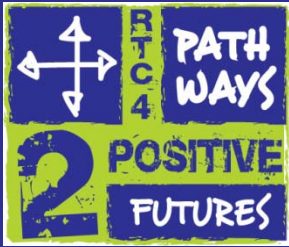
Results: Motivations

- Anonymity
 - *The internet is private, there is no one there questioning me or what I'm looking up. Its personal and totally under my control.*



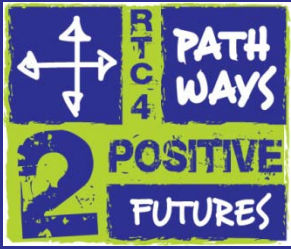
Results: Desirable website

- Specific features (message board, interactive diagnoses assessment)
- Ease of navigation
- Accessible, youth-friendly language
- Targeted audience (youth, dx specific)
- Presentation “look and feel”
- Quality indicators (cited sources, research, credible)



Results: Desirable website

- Specific features
 - *It has a mixture of mediums not just video and text but an availability of live chat with other people: that shows real dedication.*



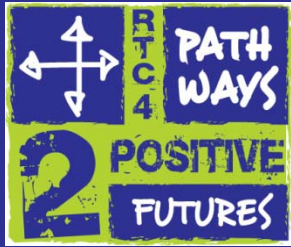
Results: Desirable website

- Ease of navigation
 - *I just won't use Web MD because I cannot navigate that site. It is not user friendly. It is all blue and green and I just don't know what to push. So, I'm like f_____ this.*



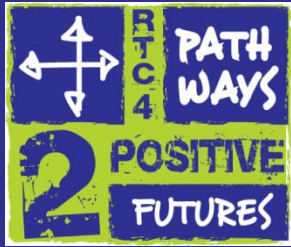
Results: Desirable website

- Accessible language
 - *KG: What would make some of these websites more useful to you?*
 - *Definitely youth friendly terms. I feel like in the search engines if I want to type in something, like, oh I don't know, I just can't take acronyms. Just youth friendly terms. I can't take those 13-syllable medical terms.*



Results: Barriers

- *Accuracy of information*
- *Too much information: overwhelmed/irrelevant*
- *Personal struggles vs. abstract possibility*



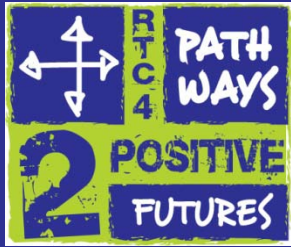
Results: Barriers

- Accuracy of information
 - *I don't really trust those things [message boards]...people would say irrelevant things. They contradict. They are putting their two cents in and its only worth a half cent.*



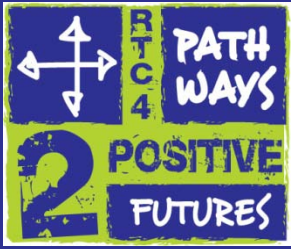
Results: Barriers

- Too much information
 - *if you have a search engine like google or something like that you type one thing in say “schizophrenia” to see what the symptoms are and you got to that it might show a bunch of things with schizophrenia in the title and it might have a whole paper on what the symptoms of schizophrenia are and then you click on another and it might bring up a you-tube video of a dude freaking out. It gets really hard to make it specific, and that’s for anything on the internet and its what frustrates me so much about it when I use the computer.*



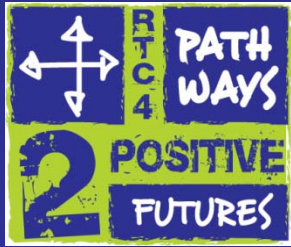
Next Steps

- Phase 2 data collection on information searching strategies and quality of websites accessed (underway);
- Develop a workshop to teach how to search for accurate mental health information online.



Stay in Touch!

- Website: <http://www.pathwaysrtc.pdx.edu/>
- Facebook:
<http://www.facebook.com/pathwaysrtc>
- Twitter: pathwaysrtc



Acknowledgments/Funders



The development of the contents of this presentation were supported by funding from the National Institute of Disability and Rehabilitation Research, United States Department of Education, and the Center for Mental Health Services Substance Abuse and Mental Health Services Administration, United States Department of Health and Human Services (NIDRR grant H133B090019). The content does not represent the views or policies of the funding agencies. In addition, you should not assume endorsement by the Federal Government.

