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How the Internet Supports the Lives of Young Adults with Mental Health Challenges

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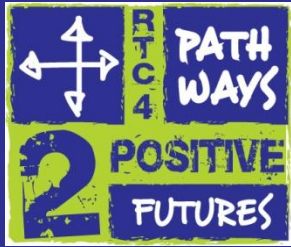
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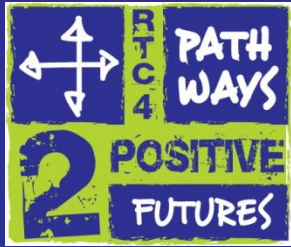
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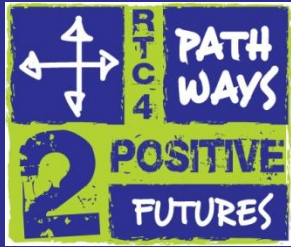
How the Internet Supports the Lives of Young Adults with Mental Health Challenges

L. Kris Gowen
Martin Rafferty



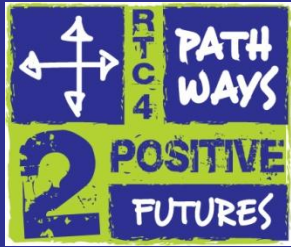
Using Online Resources

- Among online young adults, ages 18-24 who reported mental health challenges
 - **94%** use social networking
- *“Every day, more people go online for medical advice than actually visit health care professionals”*
 - 33% of young adults look up information on mental health.

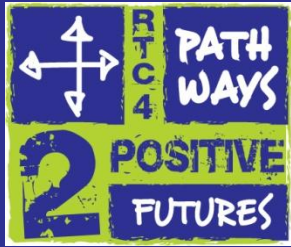


People Use the Internet to Guide Their Health Decisions

- Over 2/3 of health information seekers state that the information they find online has an impact on their healthcare decisions
- About 1 in 5 adults have gone online to diagnose or treat a medical condition on their own, without consulting their doctor
- About ½ of online adult health information seekers have read someone else's commentary or experience about health or medical issues
- We believe these numbers are higher for young adults specifically

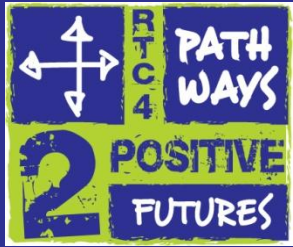


***Problem:
The General Quality of Online Mental
Health Information is Poor***



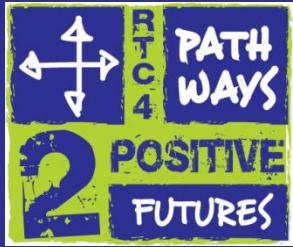
Question

How do think young adults with serious mental health conditions use the internet for information and support regarding their mental health?

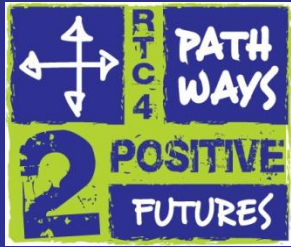


Our Studies

- Three focus groups in Oregon
- NAMI survey of young adults

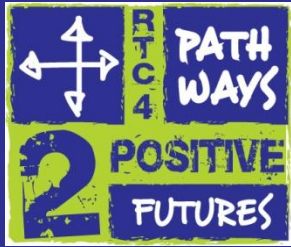


What Sorts of Mental Health Information Do You Look Up Online?



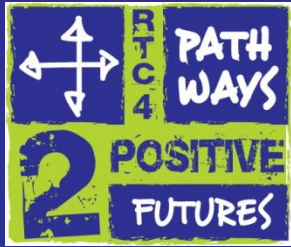
Results: Topics

- 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)



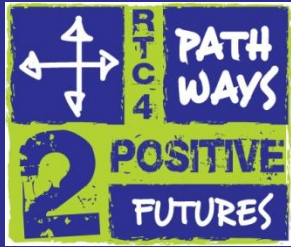
Results: Topics

- 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.”



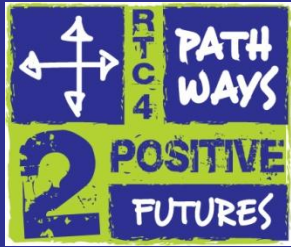
Results: Topics

- 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.



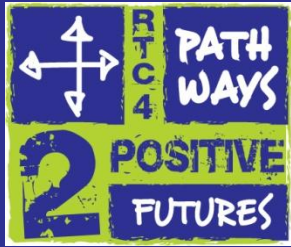
Results: Topics

- 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.



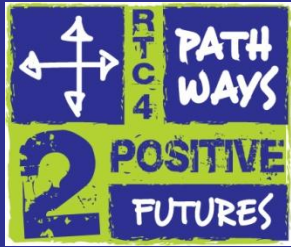
Results: Topics

- 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

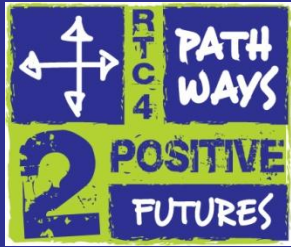
- Support and Resources: *How can I manage on my own?*
- Young people look up strategies for living more independently – everything from how to develop good coping skills to where to get food stamps. To them, the internet provides information on how to successfully transition to adulthood and meet the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



Survey Results

Young people report wanting information on:

1. Independent living skills (88%)
2. Skills to overcome social isolation
3. Relationships
4. Peer Support/Services
5. College
6. Employment
7. How to support a loved one
8. Info on diagnosing and treating mental health condition
9. Advocacy
10. Connection to community activities
11. Housing
12. Social Security (48%)

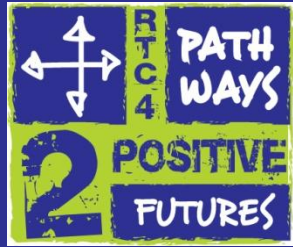


Why Go Online for Mental Health?



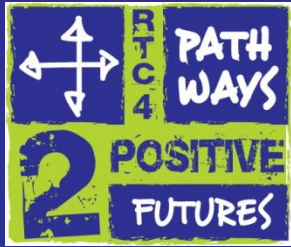
Results: Motivations

- 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: Survey

- From the NAMI survey we know that young adults with mental health challenges are more likely see social networking as a place to:
 - Make new friends
 - Blog
 - Plan social activities
 - Find people with shared interests
 - Connect and socialize



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?"*



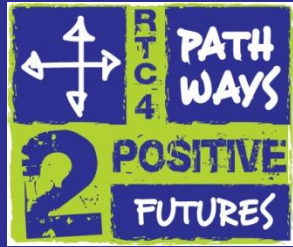
Results: Motivations

- 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.*



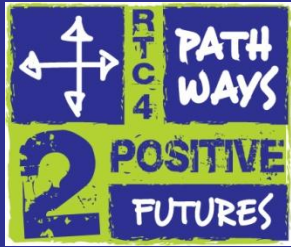
Results: Motivations

- 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.*



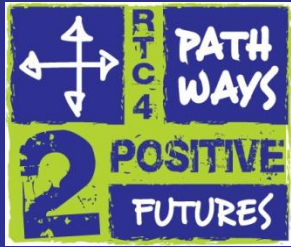
Results: Motivations

- 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.*



Survey Results

- From our survey, we learned young adults want:
 1. The ability to connect and socialize (87%)
 2. Resources on transitioning to adulthood
 3. Opportunities to help others
 4. To post blogs and links
 5. Chat with experts
 6. Discussion groups
 7. To plan local activities and meet others in person (60%)



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Acknowledgments/Funders



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