

#IDefineMyWellness

Twitter Chat to Learn About Wellness and Disability Resource Summary

Background

In May 2019, the Association of University Centers on Disabilities National Center on Disability in Public Health hosted a Twitter chat, in collaboration with its Wellness and Mental Health Learning Group, to engage the overall disability community in a conversation on what wellness means and encourage the sharing of helpful resources. The hashtag used was #IDefineMyWellness.

Twitter chat discussion guests included:

- Cari Cho, [@CornerstoneMoCo](#), CEO, Cornerstone Montgomery
- Mark Crenshaw, [@mccrenshaw](#), Director of Interdisciplinary Training at the Center for Leadership in Disability (UCEDD/LEND) at Georgia State University
- Andy Imparato, [@AndyAUCD](#), Executive Director of the Association of University Centers on Disabilities (AUCD)

Discussion guests were invited 4-6 weeks in advance and were provided with the chat questions at that time.

Chat Questions were:

- Q1. Do you have a #disability? How do you define #wellness? #IDefineMyWellness
- Q2. How does your definition of #wellness differ from others' definitions? #IDefineMyWellness
- Q3. Does culture/ethnicity guide your definition of #wellness? How? Please share from your perspective. #IDefineMyWellness
- Q4. How are people with #disabilities represented within #wellness communities? Why is it important that people with #disabilities are accurately represented? Share examples. #IDefineMyWellness
- Q5. What resources do you need to make #wellness a priority in your life? #IDefineMyWellness
- Q6. What #wellness resources (community programs, websites, self-help groups) have you utilized that have positively impacted your life? #IDefineMyWellness
- Q7. In what ways has your #disability impacted your ability to access #wellness resources in your community? #IDefineMyWellness
- Q8. What do you want #wellness professionals to know about #wellness and #disability? #IDefineMyWellness

A timed agenda was created and shared with the Discussion guests to support the flow of the virtual conversation. Discussion guests were encouraged to create content in advance as well as share spontaneously during the chat.

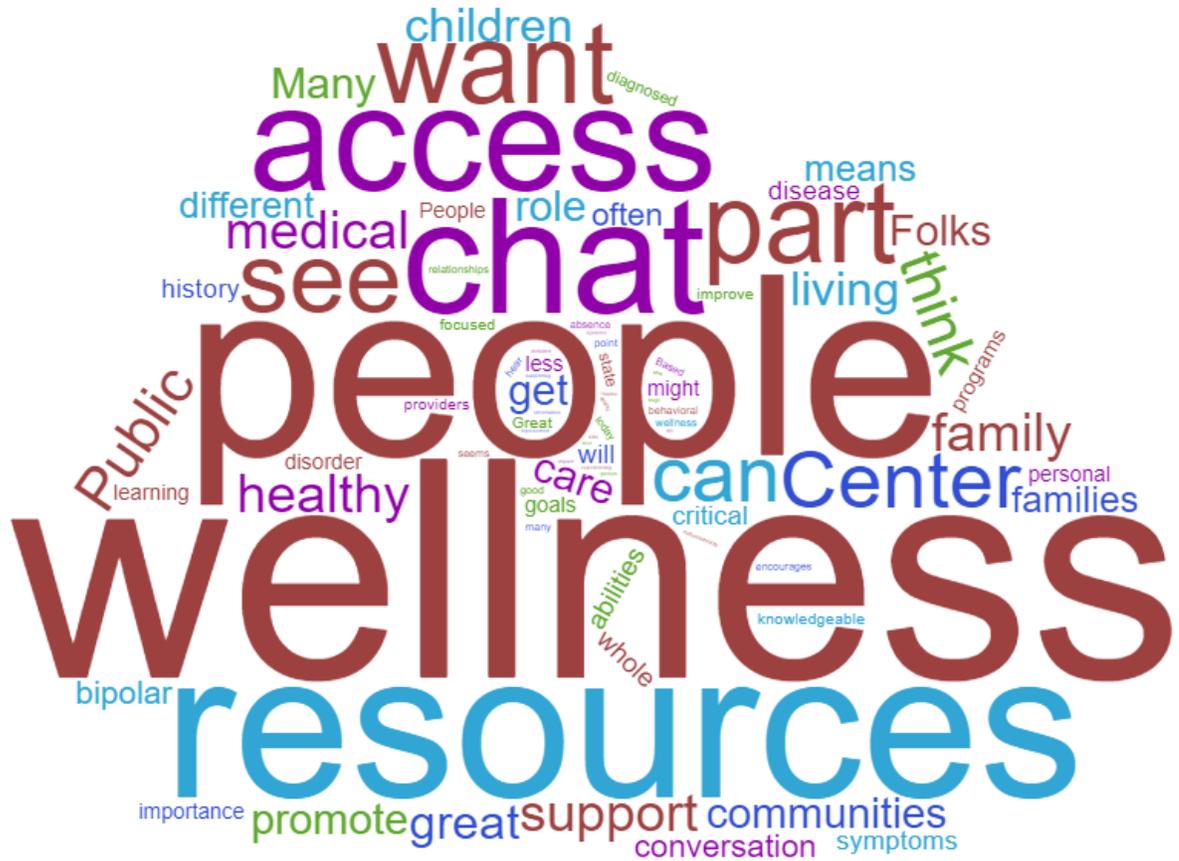
Social media promotions on Twitter for the chat were shared with organizations in the wellness, mental health and disability areas 2 weeks prior to the chat. Organizations of the Wellness and Mental Health Learning Group and Discussion guests also shared the chat promotions.

Chat Themes

A Word Cloud and key quotes from the participants highlight the themes of the chat. Key chat themes are: belonging, caring for body and mind, disability being part of being well, visible and invisible disabilities, and access to healthcare and services.

Word Clouds were created with <https://www.wordclouds.com/> and www.wordle.net/create, using a transcript of the Twitter chat. The word cloud created with the wordclouds.com tool did not include Tweets that were shared nine times or less. This was done to share the top replies in a visually accessible picture. The word cloud created with the wordle.net tool only included original Tweets in an effort to stay true to the content shared by the original Tweeters.

Both word clouds identified an alignment of key terms of people, wellness, resources, chat, and access.



Created with Word Clouds



Created with Wordle

Selected Chat Highlights from Participants

Q1. Do you have a #disability? How do you define #wellness? #IDefineMyWellness

A1:

 **Emily Starnes** @ecstarnes · May 30

A1 I am autistic, have a rare genetic condition called Sotos Syndrome, and am a sibling. #Wellness is caring for your body, mind, and soul. It's physical, social, spiritual, and emotional! #IDefineMyWellness

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Q2. How does your definition of #wellness differ from others' definitions? #IDefineMyWellness

A2:

 **Edmund Asiedu** @AsieduEdmund · May 30

My definition of #wellness differs from other definitions because I've customized it to my #disability and health needs. #IDefineMyWellness

 **AUCD** @AUCDNews · May 30

Q2 How does your definition of #wellness differ from others' definitions? #IDefineMyWellness

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Q3. Does culture/ethnicity guide your definition of #wellness? How? Please share from your perspective. #IDefineMyWellness

A3:



Luis Valdez @Lu3_1 · May 30

A3 As a Latino, culture played a huge role in how I perceived #Wellness. Growing up, I'd see barriers such as fear due to status, lack of access, lack of qualified Spanish-speaking professionals, and budget limitations factor into my family seeking healthcare. #IDefineMyWellness



AUCD @AUCDNews · May 30

Q3 Does culture/ethnicity guide your definition of #wellness? How? Please share from your perspective. #IDefineMyWellness



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Q4. How are people with #disabilities represented within #wellness communities? Why is it important that people with #disabilities are accurately represented? Share examples. #IDefineMyWellness

A4:



Destiny @destinyjxox · May 30

A4: People with #disabilities are represented as being 'different' or 'lesser than'. They are often isolated into their own groups or have specific day programs in which only individuals with these needs are welcome to take part in. #IDefineMyWellness



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Q5. What resources do you need to make #wellness a priority in your life? #IDefineMyWellness

A5:



Cornerstone @CornerstoneMoCo · May 30

A5 I am no different from those I serve...I need the support of family and friends. I need to be able to find other resources in the community. Access to behavioral health treatment is a huge issue and barrier to people getting the help that they need. [#IDefineMyWellness](#)



AUCD @AUCDNews · May 30

Q5 What resources do you need to make #wellness a priority in your life? #IDefineMyWellness



Q6. What #wellness resources (community programs, websites, self-help groups) have you utilized that have positively impacted your life? #IDefineMyWellness

A6:



Linda H Starnes @Linda_PEART_FL · May 30

A6 Back in my parenting days of our children, we sought family wellness through recreational and outdoor activities, and time in our faith community, in lieu of yet another round of therapy (when possible), or the ease of just staying home.

[#IDefineMyWellness](#)



AUCD @AUCDNews · May 30

Q6 What #wellness resources (community programs, websites, self-help groups) have you utilized that have positively impacted your life? #IDefineMyWellness



**Linda H Starnes** @Linda_PEART_FL · May 30

A6 (cont) We fervently pursued these activities, in hopes that our children would know and feel "wellness" & how to maintain it in their lives going forward.

#IDefineMyWellness

**AUCD** @AUCDNews · May 30Q6 What #wellness resources (community programs, websites, self-help groups) have you utilized that have positively impacted your life?
#IDefineMyWellness

Q7. In what ways has your #disability impacted your ability to access #wellness resources in your community? #IDefineMyWellness

A7:

**Héctor M. Ramírez** @CROWDREAM · May 30

A7: My disabilities can be non-apparent/invisible. Folks often times don't think I am worthy of #wellness For some I don't look disabled enough and for others I dont act to normal. It's exhausting having to disclose over & over. Not to forget folks bias. #IDefineMyWellness

**AUCD** @AUCDNews · May 30

Q7 In what ways has your #disability impacted your ability to access #wellness resources in your community? #IDefineMyWellness



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Q8. What do you want #wellness professionals to know about #wellness and #disability?
#IDefineMyWellness

A8:



Andy Imparato @AndyAUCD · May 30

A8 I want #wellness professionals to know that #IDefineMyWellness and they don't, and that my disability is part of my wellness



AUCD @AUCDNews · May 30

Q8 What do you want #wellness professionals to know about #wellness and #disability? #IDefineMyWellness



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ADA National Network @ADANational · May 30

We love this answer so much! Accessibility for all ❤️
"#WellnessIs4Everyone and looks different for each person"
#IDefineMyWellness



Morgan Lerdahl @MorganLerdahl · May 30

A8. I want wellness professionals to know that #WellnessIs4Everyone and looks different for each person. Make modifications, think outside the box, and ask a person with a disability to help you in making your #wellness resources accessible to all! #idefinemywellness



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Wellness Resources

Wellness resources were shared by the Twitter chat participants. A summary of resources on diet, exercise, mental health, self-help, and self-advocacy are highlighted in this brief. Many helpful resources were shared by the Twitter chat participants. Highlights include:

- Diet
 - Academy of Nutrition and Dietetics
 - [Find a Registered Dietitian Nutritionist \(RDN\) : Academy of Nutrition and Dietetics](#)
 - [Eatright.org](#)
 - Association of University Centers on Disabilities
 - [Nutrition and Healthy Weight: Focus Area of National Center on Disability in Public Health](#)
- Exercise
 - [14 Weeks to a Healthier You](#) - free, personalized, web-based physical activity and nutrition program targeted to people with mobility limitations, chronic health conditions and physical disabilities. Created by National Center for Health, Physical Activity and Disability (NCHPAD), the program can help you get moving and make healthy nutrition choices.
 - [Balanced Body Pilates](#) offers an [online search tool](#) to locate Pilates facilities, instructors and studios throughout the U.S. Referrals may also be obtained by phone
 - [United States Pilates Association](#) (USPA) offers an [online search tool](#) to locate Pilates instructors and studios throughout the U.S. Search by zip code or city/state. Instructors in the search tool are certified under the New York Pilates Studio Teacher Certification Program.
 - [IDEA Health & Fitness Association](#) With more than 22,000 members, IDEA Health & Fitness Association is the world's leading membership organization for fitness and wellness professionals. IDEA offers the [FitnessConnect Directory](#), the largest national industry-wide directory of fitness professionals. The online directory connects more than 16 million consumers to more than 250,000 fitness professionals, with credentials verified by the top 100 fitness certification and training bodies.
- Cognition
 - CogniFit- [Home : CogniFit](#)
- Mental Health
 - [MentalHealth.gov](#)
 - [Center for Mindfulness](#)
 - [UCLA Mindful Awareness Research Center](#) — Offers free mindfulness meditation exercises online.
- Complementary and Alternative Treatments
 - National Center for Complementary and Integrative Health (NCCIH)
 - [Be an Informed Consumer : National Center for Complementary and Integrative Health](#)
 - [Mental Health](#)

- [Meditation : National Center for Complementary and Integrative Health](#)
- Meditation Society of America- [Meditation Station : The Meditation Society of America](#)
- Self-help
 - Patients Like Me- Online patient network and real-time research platform for people affected by a variety of medical conditions <https://www.patientslikeme.com/>
 - Find help - A confidential Behavioral Health Treatment Services Locator <https://findtreatment.samhsa.gov/>
 - Improving Access to Children's Mental Health Care- Information for families <https://www.cdc.gov/childrensmentalhealth/access.html>
 - Family Interaction Training (FIT) - behavioral training program designed to help parents of young children with disruptive behavior <https://www.aucd.org/template/page.cfm?id=1023>
 - Mental Health & Developmental Disabilities National Training Center (mhddcenter.org) - resources for people with intellectual and developmental disabilities who have mental health concerns
- Self-Advocacy
 - AUCD webinar "[Hearing our Voices: Treatment Needs of Young Adults with IDD and Mental Health Conditions](#)" - Self-advocates reminded us that listening to all voices in our community is the key to learning.
 - Consumer advocate information - <https://findtreatment.samhsa.gov/locator/link-AG#.XXEKX3dFyUk>

Acknowledgements

The #IDefineMyWellness Twitter chat and summary brief were developed by: AUCD's National Center on Disability in Public Health Wellness and Mental Health Learning Group: Cassie Call, Salena Hill, Morgan Lerdahl, Héctor Manuel Ramírez, and Erin Vinoski. AUCD Staff: Adriane Griffen.

Questions?

Please email NationalCenterDPH@aucd.org.

Please note: These resources are not endorsed by AUCD, AUCD's National Center on Disability in Public Health or the Wellness and Mental Health Learning Group. These resources were highlighted in the May Twitter chat and are not substitutes for mental health and wellness care.