Consumer Advisory Council
Meeting
January 28, 2020

MISSION: The mission of The Ohio State University Nisonger Center is to improve the lives of people with developmental disabilities and their families.

VISION: To develop and provide the highest quality interdisciplinary care, education, and research to support the inclusion of people with developmental disabilities in all aspects of community life.

VALUES: The Nisonger Center values are the commitments made by our faculty, staff, and students regarding how we will carry out our work. Our values include:
- Person/Family-centered
- Compassion
- Self-determination
- Excellence
- Cultural Competence
- Innovation
- Hope

CAC Agenda

- 3:00 - 3:10 Welcome and Introductions
  Jed Morison
  > Welcome everyone around the table
  > Approval of Minutes (4/23/2019)

- 3:10 - 3:25 Nisonger Center Update
  Marc J. Tassé
  Program Presentations
  - 3:25 - 3:40 National Core Indicators
    Annamarie Sigman
  - 3:40 - 3:55 Next Chapter Book Club
    Stacie Klein
  - 3:55 - 4:10 RRTC and the Role of the Disability Experience Expert Panel (DEEP)
    Christine Brown & Andrew Buck

- 4:10-4:25 Legislative Update
  Michael Kirkman

- 4:25 - 4:30 New Business
  Jed Morison
  Wrap-up & Reminder: Next meeting
  Tuesday, 28 April 2020
  Call for Agenda Items

General Information

- DSACO Dancing with Our Stars 2020
  Honoring Nisonger Center!
  February 1, 2020: 6:00pm > Ohio State Union - Archie Griffin Ballroom

- Nisonger Center 2020 In"Sights" Photo Contest.
  Theme: "Sports & Play Activities"
  Submission deadline: March 31, 2020
  1st Prize: $500
  2nd Prize: $300
  3rd Prize: $100

- Upcoming events:
  - Smart Home Discovery Place "Open House":
    March 30th, 2020 ~ 4:00 – 7:00pm > McCampbell Hall.
General Information

- DSACO Dancing with Our Stars 2020
- Nisonger Center 2020 In’Sights’ Photo Contest.

Upcoming events:
- Screening of "Hearts of Glass" & Panel Discussion: April 15th, 2020 – 6:00 – 9:00pm > Gateway Film Center.

Cutting-edge food production meets social good in an ambitious experiment to provide year-round produce to a mountain town, while creating meaningful employment for community members with disabilities.

https://vimeo.com/278406491

Trailer: 2 minutes

General Information

- DSACO Dancing with Our Stars 2020
- Nisonger Center 2020 In’Sights’ Photo Contest.

Upcoming events:
- TechSummit 2020:
  June 26th, 2020 – 9:00am – 4:00pm > Renaissance Hotel Polaris-Westerville

General Information

- DSACO Dancing with Our Stars 2020
- Nisonger Center 2020 In’Sights’ Photo Contest.

Upcoming events:
- Charting the LifeCourse Ohio Showcase
  August 27th, 2020
  9:00am – 3:00pm
  Renaissance Hotel Polaris-Westerville

General Information

- DSACO Dancing with Our Stars 2020
- Nisonger Center 2020 In’Sights’ Photo Contest.

Upcoming events:
- New Grant Funding:
  - Columbus Foundation => $75,000 (Smart Home Discovery Place)

University News:
- Retirement of President Michael Drake
- Departure of Dean Craig Kent (COM)
- Visit of Chancellor Harold Paz (2/5/2020)
General Information

- DSACO Dancing with Our Stars 2020
- Nisonger Center 2020 In"Sights" Photo Contest.
- Upcoming events.
- New Grant Funding.
- University News.

Other News (since our last CAC meeting in October):
- Dr. Solis names "Best Dentist" for the 4th year in a row.
- Search for Director of the Dental Program - Update.
- 2020 Nisonger Champion Award:
  - Honor an individual who has made significant contributions to the
    quality of life for persons with developmental disabilities and their
    families. The recipient shall not only demonstrate a strong
    commitment to providing the skills and resources needed to
    succeed in the advancement of science, but has also displayed a
    sincere interest in the well-being of persons with developmental
    disabilities. See below and attached for nomination process.

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  - Tuesday, 28 April 2020

5 THING TO KNOW: NCI

What is NCI

- NCI is a voluntary effort by public developmental disabilities agencies to measure and track their own performance.
- Collaboration coordinated by the Human Services Research Institute (HSRI) and The National Association of State Directors of Developmental Disabilities Services (NASDDDS) which began in 1997
NCI PARTICIPATING STATES

NCI SURVEYS

- Adult in-Person Survey (formerly the Adult Consumer Survey)
- Adult Family Survey
- Family/Guardian Survey
- Child Family Survey
- Staff Stability Survey

OHIO AND NCI

- Participating since 2008-2009 survey cycle
- Adult in-person survey
- Staff stability survey
- Family & Family/Guardian Survey – resuming this upcoming survey cycle

WHY IS OHIO PARTICIPATING

- Monitor services and supports
- Track progress
- Inform policy change
- Set benchmarks
- Allocate resources
- Quality assurance
- Improvements and initiatives

THE NCI IPS

- The survey is completely voluntary
- Survey information is kept confidential; unique survey codes are used instead of individual’s name
- Services are not directly affected by participation

IPS – DOMAINS/SUB-DOMAINS

- Individual Outcomes
  - Work, community inclusion, participation and leisure, choices, decisions, self-determination, relationships, satisfaction
- Health, welfare, and Rights
  - Safety, health, medications, wellness, respecting rights
- System Performance
  - Service coordination, access
WHO WILL BE SURVEYED?
- Approximately 600 randomly selected adults receiving services from the state and a separate group of approximately 400 adults who live in ICFs.

PARTS OF THE SURVEY
- Four Parts to the Survey
  - Pre-Survey Information
  - Background Information
  - Section I
  - Section II

PRE-SURVEY
- Obtained before the meeting
- Used for arranging the meeting
- Any needed accommodations
- Collects familiar names and terms to prepare surveyor for a more personalized conversation.
- Completed by service coordinator

IPS – BACKGROUND SECTION
- Also completed by service coordinator
- Obtained through administrative records
- Some information can be collected directly from person/guardian
- Questions include demographics, residence, health, employment status, and services and supports

IPS – SECTION I (SUBJECTIVE QUESTIONS)
- Questions only answered in face-to-face conversation
- Person receiving services only allowed to answer
- Determines the individual level of satisfaction
  - Relationships
  - Service coordination
  - Access
  - Respect/rights
  - Safety
  - Work
  - Community inclusion

IPS – SECTION II (OBJECTIVE QUESTIONS)
- Questions can be answered by a proxy
- Family, friends or staff
- No Case managers

Indicators covered in section II:
- Community inclusion
- Choices
- Respect & rights
- Access to needed services
- Technology use
HOW CAN YOU ACCESS NCI DATA?

NCI data can be accessed by anyone from anywhere, just visit www.nationalcoreindicators.org and view data summaries, presentations, generate a chart, and much more! 😊

INFORMATION

• NCI website: https://www.nationalcoreindicators.org/
• Nisonger NCI Website: www.Nisonger.osu.edu/NCI
• Ohio’s website/data Page: http://dodd.ohio.gov/IntheNews/Pages/Data.aspx

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Next Chapter Book Club

Helping People with Disabilities Enjoy Books, Friends, and Community

Why start a book club?

In a book club, "people can read a book and then have someone else to talk about it with. Then [book club members] see that a book can lead to the pleasure of conversation, that… reading can actually be a part of the path to communion [relationships] and community."

-Bell Hooks
Next Chapter Book Club (NCBC) offers supported opportunities to continue reading and learning after school ends.

NCBC offers dependable opportunities to socialize and build friendships.

NCBC offers weekly opportunities to be part of community life.

What is different about Next Chapter Book Club?

Who can be a member?

Next Chapter Book Clubs welcome members with any reading level.

What do NCBC members do?

Even though NCBC does not teach reading, NCBC members often learn new skills and vocabulary just by coming to book club each week.

What do NCBC members read?

Adapted Classics
- Black Beauty
- Little Women
- The Call of the Wild
- The Secret Garden
- The Wind in the Willows
- Treasure Island

Popular Fiction
- Because of Winn-Dixie
- Bridge to Terabithia
- Charlotte's Web
- Harry Potter series
- A Wrinkle in Time
- Percy Jackson series

Short Stories, Plays and Poems
- Lucky Dogs, Lost Hats, and Dating Don'ts
- New Love, Spilt Milk, and Patbelled Pigs

What do NCBC members do?

- Vote for the book they want to read
- Take turns reading with or without support
- Ask questions/start conversations about the book and everyday life
- Pay for any drink or small snack they want
- Behave respectfully and safely at all times
- Support and encourage others in book club

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- New Love, Spilt Milk, and Patbelled Pigs
NCBC Meetings

- Clubs meet for 1 hour each week, at the same time and location
- 4 to 8 members, 1 to 3 facilitators per club

NCBC Meetings

- Members take turns reading aloud, receiving as much support as they need
- Members also spend time socializing with each other

NCBC, 2002 – 2020

NCBC was started in 2002 in Columbus, Ohio.
Now, there are over 300 Next Chapter Book Clubs across the world!

www.nextchapterbookclub.org

Becoming a Facilitator

NCBC facilitators are volunteers from all walks of life
- Students
- Retirees
- Professionals
- People with disabilities
- Family members

NCBC facilitators join members at book club to foster an environment that is safe, supportive and fun

Get Involved

To join an NCBC in Franklin County, contact Program Coordinator **Stacie Klein** at
- (614) 293-6945
- Stacie.Klein@osumc.edu

To learn about NCBC’s outside Franklin County, contact **Tom Fish** at
- TFish@nextchapterbookclub.org

Acknowledgements

In Franklin County OH, NCBC is operated by The Ohio State University Nisonger Center and receives support from:
- Franklin County Board of Developmental Disabilities
- The Columbus Foundation
Thank you

The Ohio State University
Nisonger Center
Rehabilitation Research and Training Center
- Christine Brown: Clinical Research Assistant
- Andrew Buck: Learning & Development Consultant

The Need for Inclusive Health Research
- Proxy reporting
  - Health professionals often rely on opinions and observations of someone close to the patient
  - Improving health care requires getting answers directly from patients

The OSU Nisonger Rehabilitation Research and Training Center (RRTC)
Nisonger Center won a grant to:
- Adapt health surveys
- Study rates of comorbidity
- Advance mental health treatment

The Need for Inclusive Health Research
- We do not have accurate data on the health care needs of people with intellectual disabilities (ID), especially mental health needs
- Mental health issues are hard to diagnose
The OSU Nisonger RRTC

- The Rehabilitation Research and Training Center (RRTC) grant is funded by the National Institute on Disability, Independent Living, and Rehabilitation Research
- Susan Havercamp, Ph.D., is the Principal Investigator of the 5-year project

Our Goal

Improve health and quality of life outcomes for people with ID (Intellectual Disabilities)

Our Commitment Statement

The RRTC at Nisonger Center is committed to including individuals with lived experience with intellectual disability in every aspect of our research.

What are we trying to do?

- Learn how adults with ID can speak up about their own health
- Make health surveys easier to understand for self-report

What are we trying to do?

- Find the prevalence rate of adults with ID and mental health issues
- Understand best practices in treating mental health issues for adults with ID

What are we trying to do?

- Construct and share guidelines for clinical care and mental health therapy
- Conduct research that includes people with lived experience
**Study 1: Health Surveys**
- Make health surveys more accessible
  - Reduce reading level
  - Simplify vocabulary
  - Add images and icons
  - Improve technology access

**Study 1: Health Surveys**
- Increase self-report in adults with ID (Intellectual Disabilities)
  - Survey 1 Draft
  - Survey 2 Draft

**Study 2: Rate of ID and Mental Health Conditions**
- Find the rate of mental health conditions & health outcomes among adults with ID
- National Core Indicators (NCI): Random sample from different states

**Study 3: Best Practice Guidelines**
- Make best practice guidelines for health professionals to support adults with ID
- Improve health care and mental health treatment for adults with ID

**Learning Collaborative**
We recruited researchers and community members to form a “Learning Collaborative:”
- Research Experiences Expert Panel (REEP)
- Disability Experiences Expert Panel (DEEP)
Learning Collaborative
DEEP: Disability Experiences Expert Panel
- Community Members with ID
- Inform and Support Research Process
- Give Feedback, Ideas, and Perspective
- Share Project Information

Next Steps: Study 1
We are actively recruiting more people to participate in the process:
- 50 community members with ID in Central Ohio to complete the adapted surveys

Next Steps: Study 3
- 56 community members with ID to conduct focus groups on accessible therapy
  - 32 (Central Ohio)
  - 24 (Nationally)

HELP US HEAR YOUR VOICE!

YOUR VOICE MATTERS.
To Learn More:
- Visit our website: [http://go.osu.edu/RRTC](http://go.osu.edu/RRTC)
- Send us an email: rrtnisonger@osumc.edu
- Give us a call: 1-833-678-7782
Thank You!

Christine Brown: Christine.Brown@osumc.edu
Andrew Buck: Andrew.Buck@osumc.edu

References
