

Being Brave

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ABCT Autism SIG Virtual Seminar Series

*Unity is Strength: Cultivating Harmony and Camaraderie in Partnerships with
Neurodivergent Colleagues to Enhance Research*

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Introduction

- Neurodiverse collaboration
- Arriving at collaborations via different routes
- Barriers we can anticipate... and some we cannot!

Who Are We?



Dena

- Senior Research Scientist, AJ Drexel Autism Institute
- National Board of Directors, Institute for Exceptional Care
- She is a wife, mother, grandmother



Lauren

- Professor, Psychology Department, St. John's University
- Leadership Board of Home & Community Positive Behavior Support Network
- She is a wife and mother

Nontraditional Mentorship

- We're colleagues, equals, each bringing different areas of expertise



Access check-in

- **For everyone** - not just disability-related needs
- Builds **understanding**
- Allows for **more time, patience, and support**



Social Relational Model

Social Relational Model

- Disability is the experience of the dual effects of *impairments and social oppression*.
- Respect must be paid to all forms of communication as a means to self-advocacy for self-actualization. In other words, *MAXIMIZING supports*, not by trying to outgrow them.
- We must *celebrate* this diversity in all its forms.
- It is demonstrated in *language, identity and accountability*.

Four Questions

1. What have we learned from each other?
2. What has been hardest for you about collaborating with neurotypical researchers and practitioners?
3. If I were to ask you for one wisdom that you would want people to take away from our working relationship and personal relationship, what would you want people to know?
4. What are you still working on?

1. What we have learned from working with one another?

Humility

- Acknowledging that we are coming into our relationship with different backgrounds and lived experience
- *Explicitly* honoring lived *and* learned expertise
- Actionable changes reflecting growth
- Willingness to change practices

Changing Environment vs. Person

- Changing the environment *vs* changing the person (or both)
- Examining options *prior* to changing the person
 - *e.g., fear of blackout vs. storm → give flashlight*
 - *e.g., headphones*
 - *e.g., early arrival, or early departure, or eliminating the event altogether*

Questioning Goals/Outcomes

- Whose quality of life is this improving? And is there an alternative?
- Question *what* behaviors need to be changed & *how*
- **Values and function**
 - e.g., Questioning when to use exposure to face fears versus accommodate
 - e.g., snake phobia

**2. What has been hardest for you
about collaborating with
neurotypical researchers and
practitioners?**

Our Access Needs & Levels of Support Change from Moment to Moment

- “My expression of autism creates a cognitive dichotomy – no matter how many stories I tell, people still can’t conceptualize that I have autism”
 - e.g., confused by hyperlexia
- “All the responsibility is falling on me”

Being Direct and Transparent

- “I don’t have an option about being transparent – that’s hard-wired”
- Lessons:
 - Be explicit and open in discussion about professional/personal boundaries
 - Be direct with family, friends, colleagues, clients, acquaintances
 - *e.g., preface it with our key phrase “The rule is...”*

3. If I were to ask you for one wisdom that you would want people to take away from our working relationship and personal relationship, what would you want people to know?

Openness in All Things

- Be open to change, willing to change → growth is exciting!
- Open your mind to envision different possibilities for what constitutes a good “quality of life”
- Approach the relationship with **openness** and **humility** and a **willingness** to learn and see issues from a different perspective

Be Brave – Take Professional Chances

- If panel does not include an autistic person, have the courage to say, “Where are all the disabled people?”
- We’re talking to our allies who have the privilege of being asked to the panel
- Women are often socialized in research to just be grateful for whatever they can get – they’re afraid to speak up and ask the conference to pay for someone else

4. What are you still working on?

Accommodating Other People

- Not everyone thinks and processes information the way I do
- Communicate to people that you are sincerely interested in joint success

Take Home Messages

- Unity and partnership take time and care
- Find joy in what you're doing!

Discussion Questions

- How to identify someone who *could* be a good collaborator/partner?
- How to initiate a potential partnership?
- How to build trust?
- How to address and support when one is distressed?
- How to maintain an active dialogue about the relationship?
 - What is working well?
 - What is not?
- How to make it sustainable?

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