



# Elevating Voices of People with Disabilities in Health Care



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# Introductions

## FAB Center for Complex Care

- Providing primary care to adolescents and adults with complex childhood onset conditions
- Team approach
  - Medical Doctor
  - Social Work
  - Nursing

## Jefferson Center for Autism and Neurodiversity

- Team of developmental-behavioral specialists works with children and their families to assess potential diagnoses and develop personalized care plans that integrate medical, educational, and therapeutic services
- We also consult with businesses, healthcare organizations and community stakeholders to promote awareness and provide training for neurodiversity and accessibility issues

# The Jefferson Mission

- Values:
  - Put People First
    - Embrace diversity
  - Be Bold and Think Differently
  - Do the Right Thing

# The Current State

## American with Disabilities Act

- Based on civil rights law to prevent discrimination
- Applies to Autism and invisible disabilities
- But there are no guidelines for invisible disabilities
- The care and support that some need but everyone can benefit from



# Benefits of Embracing Diversity

- Welcoming
- Novel ideas
- Intrinsic motivation matters in performance
- The difference between inclusion and belonging
- “If you think diversity doesn’t include disability, you are doing it wrong”

# Neurodiversity

- Processing and communicating differently
- Autism
- Intellectual and Developmental Disorders
- Psychiatric Diagnoses
- Neurological Problems
- Aging
- Anyone with a novel and stressful medical condition or significant life stressor (including supporting a family member with challenges)

# Meet Brandon







# Our Approach

- **People-** Ask what matters to them
  - **Education-** With resources and accommodations
  - **Outcome Measures-** Advocacy
  - **Practice—Supported experiences**
  - **Life Lessons—Create a culture shift**
  - **Built Environment-** always a consideration
- 
- **Jefferson People Model**

## Our Approach

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## Education and Engagement

### Checking In

I might check in on a tablet or at the front desk. If I am not sure of where to check in, or I need help, I can ask

The front desk person will ask to see me and ask for my name, appointment time, insurance card and ID.

She may give you some forms to fill out for the doctor.

After that, I might wait in the waiting room.



# Teaching Opportunities

- Pennsylvania Developmental Disabilities Council - Quality Healthcare Access Grant
  - Provide education to Jefferson and Einstein Family Medicine Residency programs on working with people with disabilities
- HRSA Grant: JET PHILA
  - Expand education to other programs
  - Create an area of concentration for family medicine residents
  - Create a class in the medical school

# Tips for a Smooth Transition to Adult Care

## Be proactive!

- Ask your current providers or community members for recommendations
- You may have to wait to see the new provider and you don't want any gaps in care
- Contact the potential provider's office and gather the information you will need:
  - Do they accept your insurance?
  - Are they accepting new patients?
  - Is there a wait to be seen?
  - Is there criteria to meet to be accepted into the practice?
  - Where are they located?
  - Is the office accessible to your child?
  - Do they have a late or no-show policy?

# Preparing for Your First Visit

- Bring with you, or ask your current provider to send prior to your visit the following information
  - Last visit notes, unless the new provider has requested your entire chart or a summary
  - Vaccine history
  - List of current medications
  - List of durable medical equipment (DME)
  - Copies of Power of Attorney (POA), guardianship, caregiver attestation
  - Contact information for
    - Specialists
    - Supports coordinators
    - Mental health providers
    - School or community based programs
    - Nursing or home health agency
    - Case managers

# The 1<sup>st</sup> Visit – Think of it as a 1<sup>st</sup> Date

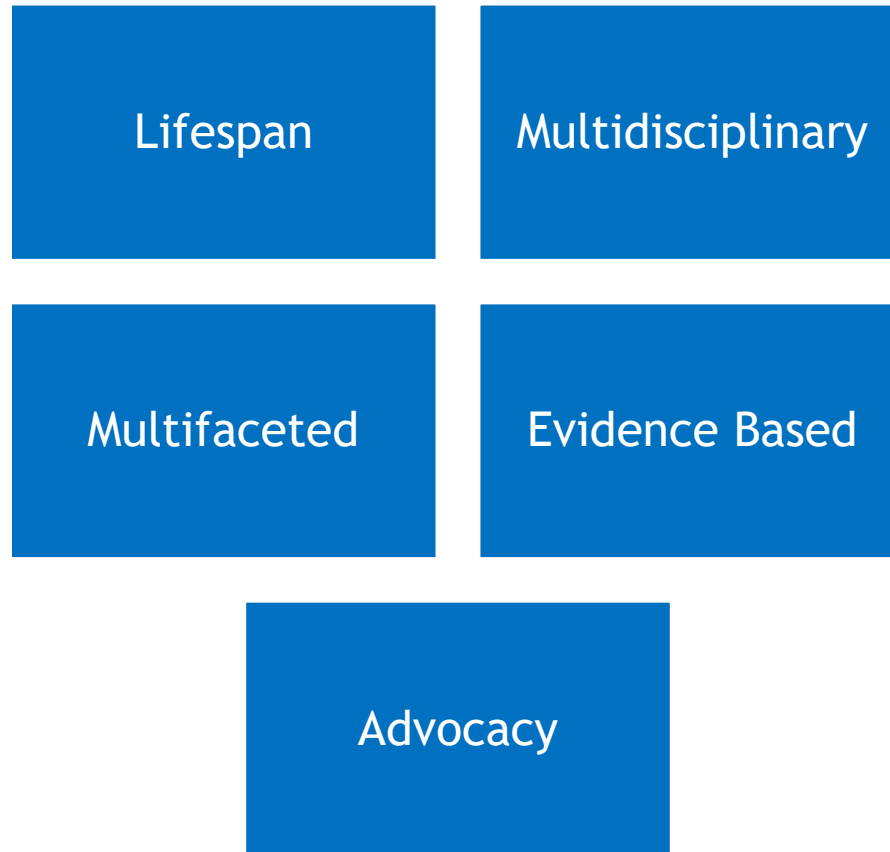
## List of Questions

- What do you want to know about the doctor and their practice?
- What medical questions do you have?

## Set Expectations

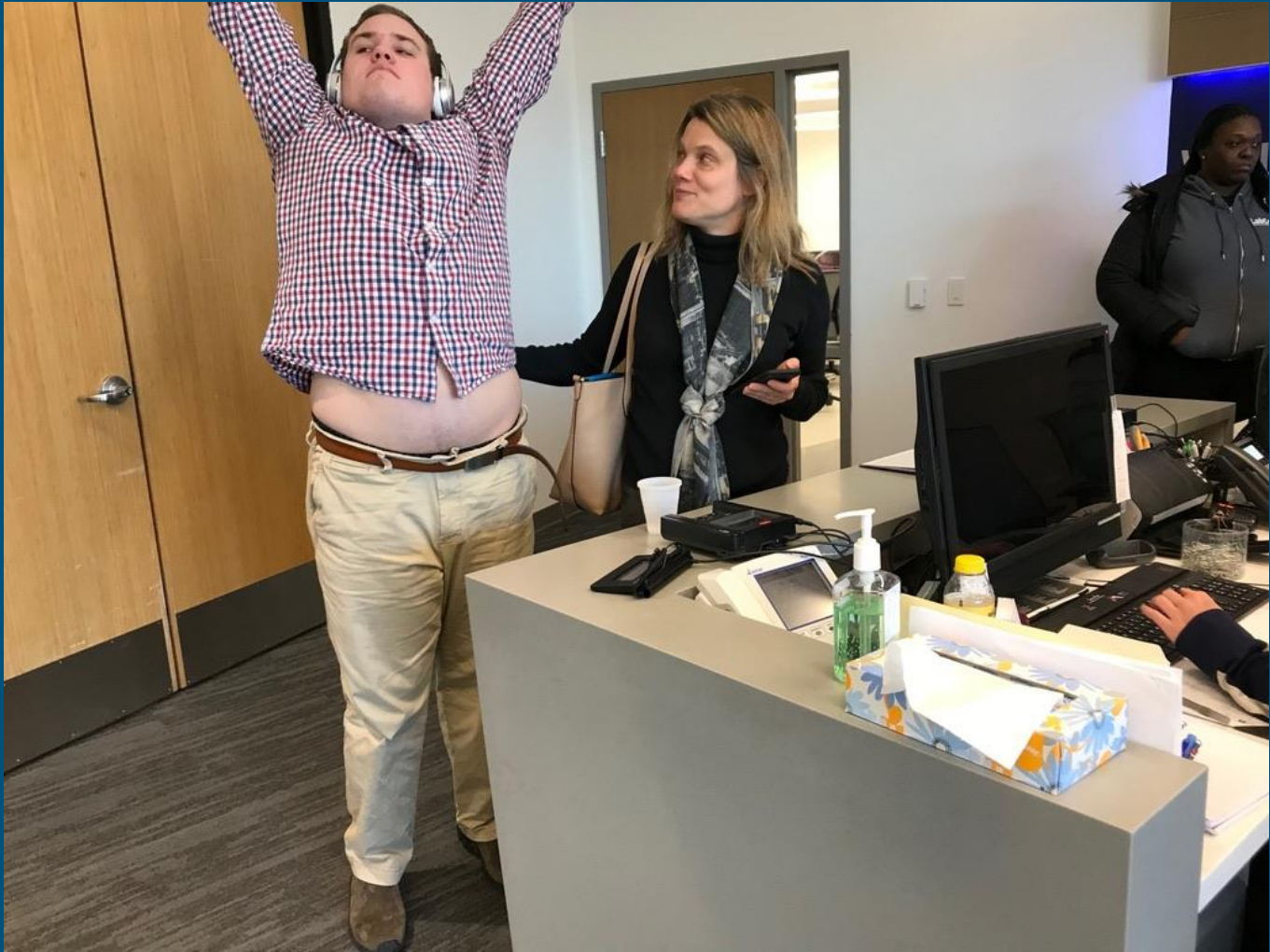
- What do you need from your health care provider?
- What is the best way for them to communicate information to you?
- Do you have a friend/family member/caregiver you would like to be present for appointments and/or to have access to your medical information? Does the office have policies about this?

# Core Differentiators









# Background

**Jefferson Center for Autism and Neurodiversity** has been involved in consultation on the design of Jefferson's forthcoming Specialty Care Pavilion in an effort to help create a healthcare environment conducive to the care of those with neurodiversity and, by extension, even more accessible to typical individuals as well.



# eStablishing Value and Building Capacity

- Better understanding within Jefferson
- Community Interaction
- Courses across disciplines
- Diversity that includes disability
- Health Resume
- Built environment



# Spark Interactive Strategies

- **S**caffolding and sensory environments
- **P**atience
- **A**ttend
- **R**espond, don't react
- **K**ind



# Strategies



- Be Patient
- Don't Judge
- Respond don't react
- Be aware of sensory needs
- Prepare patients
  - Visits and Exams
  - Use visuals
- Coordinate care
- Schedule carefully, consider telehealth
- Involve caretakers thoughtfully
- Presume competence

Thank You!