

# Partnering with Families and Self-Advocates in Healthcare: Supporting Individuals with Intellectual & Developmental Disabilities

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# Agenda

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Explore key themes identified by families of individuals with IDD and self-advocates in healthcare

Understand core barriers faced by individuals with IDD in the hospital setting

Identify key strategies to improve partnership and communication with self-advocates and families

Gain familiarity with tools that can support patient and family centered care

# Barriers to Safe Care – Intellectual and Developmental Disabilities

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Policies that restrict family member/support person presence

## **Preconceived ideas and bias regarding IDD**

Rounding processes that exclude patient or family member participation

Frequent care team member changes

Lack of education regarding individual communication preferences and strategies

Exclusion from RN change of shift

Family members and Personal Support Workers are NOT visitors. They are key members of the care team.

# Complex Medical Needs =

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More frequent hospitalizations

Long hospitalization & healthcare history

Previous negative & positive experiences that influence current expectations

Relationships with core providers through which new relationships are filtered

Provider tip: Ask about previous experiences: What has worked well? What has been challenging? What can be done differently?

# What patients & families want:

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Family and individual recognized as core team members

- Open acknowledgement of family and individual experience and expertise, particularly when it comes to disability and lived experience
- System to support bedside presence 24/7

Healthcare professional names, roles and contact information shared openly and frequently

- Who are you, what care will provide, and how can I get in contact with you?

# What families want:

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Clear discussion about routines of care

- How will care be given, when are tests discussed, what can we expect each day?

Information presented in a way that is accessible EVERY TIME

- Consistent use of communication devices, language lines, in-person interpreters, AT devices

Pain assessments that account for differences in communication

- Clear explanation of how pain will be accurately assessed and treated

# Roles and Responsibilities: Who does what?

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Care Teams are often large and complex:

- Recognize and acknowledge the critical role that family members and care providers play in bedside rounding
- **FAMILY/SUPPORT PERSON PRESENCE = SAFER CARE**
- Share your name and role often and USE THE WHITE BOARD

How difficult is it for a patient and family to know who is part of their care team and what their role is?

# Care Team Complexity

Charge RN

Patient Advocate

Family

Advanced Practice Nurse

Clergy/Minister

OT/PT/ST

Bedside RN

Patient

Primary Physician

Child Life Specialist

**What member of this team specializes in intellectual and developmental disabilities?**

Medical Social Worker/Case Manager

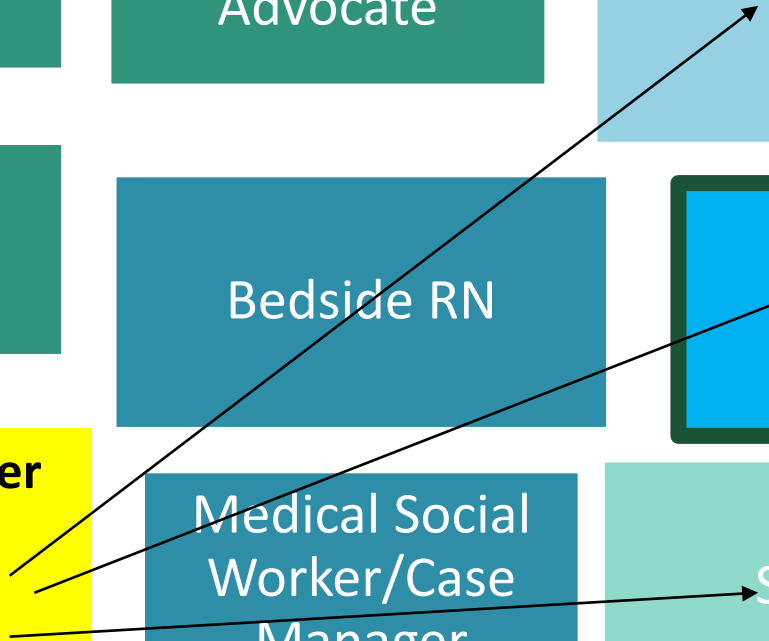
Support Person

Respiratory Therapist

Consulting Physicians

Patient Care Technicians

Counselor





# Roles and Responsibilities: Who does what?

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- Explain the daily rounding process and invite participation daily
- Alter rounding times to accommodate family presence at the bedside
  - Ask permission from patient to discuss medical condition with family or support person present
- Ensure patients and families know how to reach care team members in case of questions

## What happens in daily care team rounds?

- Review care plan/make needed changes
- Review and discuss tests/procedures/medications
- Assess pain management plan & effectiveness
- Discuss dietary plan - what to eat/drink?
- Discuss discharge plan and necessary steps to discharge
- Talk through patient and family concerns and questions

# Communication

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Families identify several basic communication issues:

- Failure to accurately assess how an individual communicates
- Inconsistently using communication devices at the bedside
- Directing communication to family members instead of the individual receiving care

**Support Person Tip:**  
Ask when daily rounds occur and plan to be bedside. If that is not possible, request a call during rounds and participate via phone

# Communication

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- Failure to share communication preferences with the entire care team
- Providing care and updates, including daily rounds, without family member presence
- See Stonybrook form (*Ballan, M. & Perri, C. (2020). COVID-19 Disability Form. StonyBrook, NY: NY.*) Our appreciation to Michelle Ballan, PhD for generously sharing.
  - The form can be filled out online and printed at: [https://cpb-us-e1.wpmucdn.com/you.stonybrook.edu/dist/a/4436/files/2020/04/COVID-19-Form\\_IL\\_Fill.pdf](https://cpb-us-e1.wpmucdn.com/you.stonybrook.edu/dist/a/4436/files/2020/04/COVID-19-Form_IL_Fill.pdf)

# Sensory Needs

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Avoid underestimating the sensory challenges present in the healthcare setting

Build in time to accommodate sensory needs

Partner with family/support people to accurately identify sensory needs

**Ask for Child Life participation**

# Sensory Needs

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## Alter the environment

- Turn down/off florescent lighting
- Limit number of medical caregivers in room
- Adequately educate individual on what to expect with procedures and allow encourage questions and practice (Child Life)
- Spread out interventions and procedures; consider completing in separate room

# Patient Centeredness

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Patient and Family Centered Care is not a “buzzword”

Concrete set of actions that improve safety, family commitment to treatment plan, and patient satisfaction\*

- **Transparency** in care and decision-making; access to medical records
- **Dignity and respect**; perspective sharing – respect for choices; Valuing of patient and family culture and backgrounds
- Patients and families as **full partners** in care
- **Collaboration** with patients and families in system design, education to medical professionals, policy development
  - *The Institute for Patient and Family Centered Care, [www.ipfcc.org](http://www.ipfcc.org)*

# Family and Support Person Presence

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24/7 family/support person access supports safe, patient centered care

Bedside presence is often necessary to support communication

Individuals with IDD in Illinois who are hospitalized have the right to have a support person present

Hospitals need to have a clear plan for how that need will be accommodated in **all healthcare areas**

For individuals with high support needs, bedside respite services may be needed

**Family Tip: Find out the CURRENT (COVID updated) policies and procedure around Family/support person presence before you need them**

# What can families do?

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Bring appropriate documentation:

- Guardianship and Power of Attorney paperwork
- Insurance cards/Medical Cards
- Any paperwork that documents legal role/responsibility

Take photos on your phone of key documents so that you have access in an emergency



# Healthcare Policies & Supports: What works for everyone?

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Patient Advocacy Programs

24/7 Support Person Access

Medical Chart accessibility

Case Management & Discharge Planning

Volunteer Services

Child Life Specialist Programs

Interpreter Services

Ask for documentation in the medical chart that clearly documents - communication needs, ways in which distress/pain is shown, comfort strategies, key contact numbers for support people.

# Improve Family Experience?

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Understand the family experience by utilizing core tools consistently:

- Patient and Family Interviews in real time (protect confidentiality)
- Choose particular care practices to improve (see quick improvement)
- Develop a **robust** Patient & Family Advisory Board
- Family Care Team Meetings
- Patient Centered Rounding
- Family Participation in RN change of shift

# Transitions in Care: Hotspots for Problems

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Pediatric to Adult Care

Floor to floor within hospital

Hospital to Home

Home to Group Home

Hospital to Home Health Care

## Provider Tips:

- Allow adequate planning time
- Plan & Practice: Avoid surprise moves/changes
- Check in often in early days
- Assess understanding: Why are we making this change?
- Ensure presence of support person

# LEND – Connect the Dots Transition Advocacy Tool

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[https://www.illinoislifespan.org/wp-content/uploads/2020/07/Connect-the-Dots-Tool\\_FINAL-MMEH2020.pdf](https://www.illinoislifespan.org/wp-content/uploads/2020/07/Connect-the-Dots-Tool_FINAL-MMEH2020.pdf)

Family tip: utilizing  
preplanning documents  
to  
Assist with core  
transition topics can be  
useful

# Medical Passports

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- [http://flfcic.fmhi.usf.edu/docs/FCIC\\_Health\\_Passport\\_Form\\_Typeable\\_English.pdf](http://flfcic.fmhi.usf.edu/docs/FCIC_Health_Passport_Form_Typeable_English.pdf) (English)
- [http://flfcic.fmhi.usf.edu/docs/FCIC\\_Health\\_Passport\\_Form\\_Typeable\\_Spanish.pdf](http://flfcic.fmhi.usf.edu/docs/FCIC_Health_Passport_Form_Typeable_Spanish.pdf) (Spanish version)

**Ensure patient and family permission for information that  
Is displayed publicly (For example, on wall near patient bed)**

- *E.A. (2011). My Health Passport for Hospital/Clinic Visits. Florida Center for Inclusive Communities, [http://flfcic.fmhi.usf.edu/docs/FCIC\\_Health\\_Passport\\_Form\\_Typeable\\_English.pdf](http://flfcic.fmhi.usf.edu/docs/FCIC_Health_Passport_Form_Typeable_English.pdf). Development of this material was supported by the Administration on Developmental Disabilities (#90-DD-0668, Fox and Kincaid). For more information visit [www.flcic.org](http://www.flcic.org) For further information contact Dr. Elizabeth Perkins at [eperkins@usf.edu](mailto:eperkins@usf.edu).*

# What can healthcare providers do?

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Learn about disability and disability culture

Talk to disability self-advocates

Avoid assumptions about disability

Reject disability framed as inspiration

Understand and ensure access – in information, in physical structure, in care provision

**\*Understand the disability support system in the state in which you practice\***

# Pandemic Resources: Disability Planning

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## **Joint Commission Roadmap:**

- <https://www.jointcommission.org/-/media/tjc/documents/resources/patient-safety-topics/health-equity/roadmapforhospitalsfinalversion727pdf.pdf?db=web&hash=AC3AC4BED1D973713C2CA6B2E5ACD01B>

## **Adults with Communication Disabilities Face Health Care Obstacles**

- <https://leader.pubs.asha.org/doi/full/10.1044/leader.FTR1.24032019.46>; [Michelle L. Stransky](#), PhD and [Megan A. Morris](#), PhD, MPH, CCC-SLP

# Pandemic Resources: Disability Planning

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## **Pandemic Planning:**

- [https://www.ipfcc.org/resources/Pandemic Planning and PFCC.pdf](https://www.ipfcc.org/resources/Pandemic%20Planning%20and%20PFCC.pdf)

## **Advocate Andrew Pulrang in Forbes:**

- <https://www.forbes.com/sites/andrewpulrang/2020/03/08/5-things-to-know-about-coronavirus-and-people-with-disabilities/#5cc210191d21>

## **Respectability - Covid 19 and Mental Health:**

- <https://www.respectability.org/2020/03/webinar-covid-19-disability-mental-health>



# Contact Information

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