Establishing Effective Communication with Patients with Intellectual Disabilities:

R.A.F.T. (Respect, Accommodation, Follow-Up, Time) Part 1

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List of Acronyms

- R.A.F.T. = Respect, Accommodation, Follow-Up, Time
- PWID = Patients with intellectual disabilities
- HCP = Health care professional

Understanding Intellectual Disabilities

- **Characteristics:** IQ < 75; limitations in cognitive functioning, communication, and self-care; delayed motor skills development; failure to grow or infant-like behavior; lack of curiosity; failure to adapt to new situations and social cues (NIH 2015; Special Olympics, 2016).
- Limitations in cognitive functioning distinguish intellectual disabilities from other developmental disabilities that cause physical limitations. But they often co-occur so it is not uncommon for individuals to experience both cognitive *and* physical limitations (AAIDD, 2016).
- **Causes:** Injury; disease; or brain abnormality. The most common causes are genetic conditions, complications during pregnancy or birth, and disease or toxic exposure. For 25% of these individuals, the cause is unknown (NIH 2015; Special Olympics, 2016).

Types of Intellectual Disabilities

- Fragile X Syndrome – mutation in gene that connects brain to nervous system
- Down Syndrome – extra copy of chromosome 21 causing delayed development
- Autism – neurological disorder that impacts communication and learning
- Fetal Alcohol Syndrome – alcohol exposure during pregnancy causes disorder
- Cerebral Palsy – neurological disorder that affects movement and muscles
- Apert Syndrome – mutation in gene causing skull bones to close early
- Williams Syndrome – deletion of genetic material from chromosome 7
- Prader-Willi – deletion of chromosome 15 which impacts how genes turn on/off
- Phenylketonuria – inherited disorder where body can't process protein

- While there is no cure for intellectual disabilities, these individuals can still learn to do many things, but may take more time or require different approaches to learning than others (Special Olympics, 2016).

An Introduction to Intellectual Disability

Intellectual Disabilities and Health Care

- Over 6.5 million individuals in the US and approximately 200 million worldwide are diagnosed with an intellectual disability (Special Olympics, 2016).
- These individuals are living longer and moving toward greater social inclusion in all aspects of their lives, including health care (McConkey & Collins, 2010; Wilkinson et al., 2013).
- PWID are 4x more likely to describe their health as poor compared to those without disabilities (Altman & Bernstein, 2008; WHO, 2015).
- PWID struggle to communicate medical information (Blackstone et al., 2015).
- HCPs can deduce inaccurate conclusions from limited information (Iezzoni, 2006).

HCP-PWID Interaction

- Interactions with PWID are inherently different from traditional HCP-patient interactions:
  - Presence of a caregiver (Vrijmoeth et al., 2016)
  - Alternative and augmentative communication strategies (Chew et al., 2009)
  - Require more time and assistance (Wilkinson et al., 2013)
- HCPs cite lack of confidence and awareness in caring for PWID, barriers to communication, and difficulty obtaining the patient's perspective (Dunkley & Sales, 2014).

- HCPs are more likely to segregate PWID, avoid invasive procedures, and spend less time explaining information (Lewis & Stenfert-Kroese, 2010).
- HCPs tend to be more patient-centered with patients perceived to be better communicators, more satisfied, and more compliant (Street et al., 2007).

Opportunities for Improvement

- The overall quality of health care in the US is suffering due to efforts to decrease costs and increase access to care (McClellan & Rivlin, 2014).
- Calls to increase the quality of health care for PWID:
  - Healthy People 2020 (ODPHO, 2016)
  - Interventions for HCPs (Snell et al., 2010; Ryan & Scoir, 2014).
  - Suggested Training Topics: disability and communication; improve attitudes; increase awareness about PWIDs' needs (Hemsley & Balandin, 2014).
- Communication training is not solely about addressing communication problems, but also assisting experienced, high-level communicators to further extend and refine their skills (Keir & Wilkinson, 2013).
- PWID, caregivers, and HCPs' perspectives must be considered in the development of tools and interventions for HCPs (Vrijmoeth et al., 2016).
- Many interventions are developed based on limited data and are not well informed about the influences on their target audiences (Kreps, 2014).

R.A.F.T. Training

Sometimes we find ourselves in uncharted territory and need a RAFT to help us find our way…

Development of R.A.F.T.

- Formative research with Special Olympics, TX
- Interviews with PWID, Caregivers, and HCPs
- Interview data coded for themes

Acronym Comprised of 4 Themes:

- Respect
- Accommodation
- Follow-Up
- Time

How R.A.F.T. is different:

- Evidence-based and theoretically grounded
- Specific population of patients
- Communication is a core outcome
- Continuum of the patient experience
- Facilitates higher levels of learning

Who Can Use R.A.F.T.?

- R.A.F.T. was designed for all HCPs who provide care to PWID – from physicians and nurses, to pharmacists, psychologists and social workers, to lab technicians, reception staff, and beyond.
- Today you will be introduced to the R.A.F.T. model. We will discuss what the acronym means, when to use it, and specific strategies for implementing it into clinical interactions with PWID.
- Part 2 of this webinar series (August 10, 2017) will utilize case studies that follow the continuum of the patient experience and explain how HCPs can implement R.A.F.T. at all stages of the patient's experience.
  - Admission and Intake
  - Initial Assessment
  - Examination
  - Clarification Before Leaving

R = RESPECT

- PWID can understand more than might seem apparent from their expressive ability. PWID should be acknowledged first and included in all decisions about their health and health care.

"My biggest thing that I've learned is …they are a lot more interactive than I thought they would be. I thought there might be a communication barrier or it might be difficult to have a conversation with them, but most [PWID] are super open and they talk about everything…" ~HCP

"I could tell the way he was acting, I guess, the reactions." ~PWID

Key RESPECT Behaviors:

- Know the patient's name and acknowledge him/her first
- Shift eye contact between the patient and caregiver
- Direct any follow-up questions to the patient directly
- Demonstrate nonverbal immediacy (wave, smile, positive tone of voice)
- Maintain an open body posture – no physical barriers between HCP and patient
- Explain procedures before performing them and use simple, short sentences
- Trust the caregiver's insights and knowledge
- Listen to understand rather than to respond

A = ACCOMMODATION

- PWID have varying levels of need. HCPs can accommodate their behaviors to maximize patient understanding. HCPs must solicit the patient's perspective or experience of health and listen/ask questions to fully understand the patient's unique needs.

"I try to prep my son before we get there so he knows what to expect, like when we are in the waiting room, or when we are waiting for the doctor to come in." ~Caregiver

"Even though I'm trying to speak as simple as I can, they still may not understand what I am saying. And so that's definitely challenging." ~HCP

Key ACCOMMODATION Behaviors:

- Ask open ended questions and allow patients to tell their own story
- Refrain from interrupting the patient and using a traditional interview script
- Ask about special requests and use these to personalize care
- Provide clear, detailed instructions prior to the visit
- Notify other HCPs about noteworthy information
- If the patient does not understand, change your explanation
- Use multiple modalities to explain health information

F = FOLLOW-UP

- Establishing sustained relationships with patients is fundamental in providing high-quality health care and achieving long-term quality of care. Following-up with PWID more often should also decrease feelings of uncertainty and anxiety for all.

"We can't do this again. The switching of doctors on any family is hard. To go through the history, have to explain everything. It's the hardest thing." ~Caregiver

"A lot of time it's communicating with the actual individual [that is most difficult], especially when we don't know them." ~HCP

Key FOLLOW-UP Behaviors:

- Refer to a past story/experience that the patient has shared previously
- Check on patients in the waiting room
- State expectations for the visit when the patient arrives
- Review patient charts to avoid redundant questions
- Use the teach-back technique to check for patient/caregiver understanding
- Find common ground
- Address remaining concerns before leaving
- Distribute opinion/satisfaction surveys to patients

T = TIME

- Time is a limited resource that can be maximized by providing complete and simple explanations to patients/caregivers throughout their visit. This should limit the amount of time needed to re-explain information.

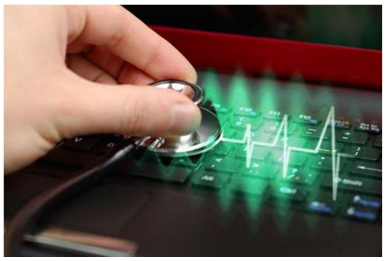
"Just slow down, we know you are busy, we know you've got tons of patients to look at, we've waited in the waiting room for that hour, hour and a half, so we want more than just 10 minutes to get a proper diagnosis…" ~Caregiver

"They may take a little more time to understand and a lot more patience and a little bit more of your time but they are just people. Just like you and me. They are just slower." ~Caregiver

Key TIME Behaviors:

- Allow additional time for the appointment if possible
- Be respectful of time – notify patients of increased wait times
- Summarize information and provide comparisons
- Answer questions fully when they are asked
- Check for understanding before moving on to minimize confusion
- Utilize alternative and augmentative forms of communication
- Slow down and think carefully about referrals
- Follow-up with patients after they return home

Troubleshooting



There are some instances where HCPs may experience difficulty implementing the R.A.F.T. model due to others' behaviors that are outside of your control.

The section is designed to help you navigate those instances, providing you with strategies to still improve communication even when the environment is not ideal for doing so.

Troubleshooting

1. You know that it is important to address the patient directly and ask for his/her response before turning to the caregiver for additional information. However, the caregiver is at times overbearing. He/she dominates the conversation, answers questions before the patient has a chance to respond, and does not allow the patient to get a word in.

2. Although you direct your questions to the patient directly, the patient seems uncomfortable speaking up for him/herself and continually looks to the caregiver to respond. The caregiver seems to know what he/she is talking about but you have no way of knowing if it is accurately describing how the patient feels.

3. You allow the patient some time to tell his/her own story, but they do not stop talking and you are running out of time to complete the tasks you need to. You want to be considerate and not interrupt them, but you also want to maximize the time that you have.

Troubleshooting

④ You use verbal and nonverbal immediacy to set a positive tone. But the patient and/or caregiver does not seem to reciprocate. It makes you feel uncomfortable and perhaps a bit anxious. You question whether you should stop being so immediate.

④ The patient arrives with an alternative/augmentative communication device that you are not familiar with. You want to accommodate them but you are afraid that your message will get lost in translation so you would rather stick to traditional communication strategies that you are most familiar with.

⑤ You are implementing R.A.F.T. behaviors as best you can, but the other HCPs that you work with are not interested in changing how they do things to better accommodate PWID. It seems like the model is not effective unless everyone is onboard and that is not going to happen. You are considering going back to the old model to keep the peace.

Key Takeaways

- Interactions with PWID are inherently different from traditional HCP-patient interactions so it is normal to feel a bit more uncertain or anxious about them. Establishing relationships with PWID will help the patient like and trust you, and be more likely to open up about his/her experiences.
- PWID have varying abilities and levels of need. HCPs should make efforts to learn about accommodations they need and would like and ones that they do not need.
- Caregivers are valuable resources but they are secondary to the patient. PWID should be treated with respect and addressed directly.
- Time is a limited resource that should be maximized wherever possible. Preparing ahead of time and communicating with other HCPs will help avoid redundant questions, save time, and improve continuity of care for the patient.
- The R.A.F.T. model is not a one-stop solution for all problems associated with HCP-PWID communication.

We have about 10-15 minutes remaining. Please use this time to ask any additional questions about anything that we have covered (or not covered) today. You may type your questions into the comment box.

Thank You.

Part 2: August 10, 2017 (1-2pm EDT)

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