

Question & Answer (Q&A): Supporting Individuals With Intellectual and Developmental Disabilities (I/DD) as They Age

Webinar participants asked these questions during the December 2019 Supporting Individuals with Intellectual and Developmental Disabilities (I/DD) As They Age webinar. We have edited speakers' responses for clarity. The webinar recording, slides, and transcript can be found on the Resources for Integrated Care website:

https://www.resourcesforintegratedcare.com/IntellectualandDevelopmentalDisabilities/2019_IDD_Webinar/Supporting_Individuals_with_IDD_as_they_Age

Featured Speakers:

- Gerard Kerins, MPA, FACP, MD, Yale University School of Medicine
- Sheli Reynolds, PhD, University of Missouri Kansas City, Director of Individual Advocacy and Family Support, UMKC Institute for Human Development
- Debbie Pfeifer, Intellectual and Developmental Disabilities Administrator, Aetna Better Health of Kansas
- Callie Simmons, Service Coordinator, Aetna Better Health of Kansas
- Sharon Spurlock, Director of Family Supports, St. Louis Arc

Clinical Concerns for Older Adults with Intellectual or Developmental Disabilities (I/DD)

Q1: Dr. Kerins, what recommendations do you have for providers for supporting older adults with intellectual or developmental disabilities (I/DD) who also have anxiety or depression?

Dr. Gerard Kerins: It is important to first determine if the person has anxiety, depression, or both diagnoses. In my opinion, we should approach treatment the same way as we do any older adult. There are some good, safe, effective treatments for depression. We want to follow the principle of starting low and going slow, but certainly they should have every opportunity, through counseling, medication and other supports, to have their depression treated.

At times, medications for anxiety are indicated and can be helpful. One thing to bear in mind is that a patient may “pre-medicate” provider appointments due to their anxiety – I caution against this, as I prefer to see the patient in their day-to-day routine, without additional medication.

In sum, I think we should use the same approaches as the general population – our approach should be interdisciplinary, and we should also try to find, if we can, ways to modify the environment to reduce what might be adding to their anxiety or depression.

Q2: Dr. Kerins, what strategies would you recommend to screen individuals with I/DD for common comorbidities, such as thyroid disease and Alzheimer’s disease?

Dr. Gerard Kerins: We recommend that thyroid function be checked every six months in our patients with Down syndrome, even though in the general older population it might be done once a year or once every two years. We recommend this because subtle changes in thyroid function can present more dramatically in people with Down syndrome than in the general population.

I think in those conditions where there is a higher incidence and prevalence among older adults with I/DD, providers may want to do routine screenings. This can help them pick up subtle changes that might indicate the development of these conditions before they become more problematic and affect function.

We also recommend consistent cognitive screening, which we think everyone should undergo routinely. We recommend for those common conditions that more proactive screening be done instead of just waiting until actual symptoms develop.

Q3: What screening tools do you recommend for Activities of Daily Living (ADLs) in adults with I/DD, with the purpose of looking at cognitive function over time?

Dr. Gerard Kerins: Various tools exist to assess function in older adults, including the Katz ADL scale, the Lawton-Brody Instrumental Activities of Daily Living (IADL) scale, the “Get Up and Go” Test and the Clock Drawing Test. Unfortunately, no screening tool has been validated for use among older adults with I/DD. I would propose a more narrative-style screening and evaluation of function. Examples would include asking patients and caregivers questions like “What is your typical day like, and how has this changed recently?” and “Tell me what you have difficulty doing now, that was not an issue in the past?” Following responses to questions like these, over time, may give insight into functional decline.

[Charting the LifeCourse – Providers and Plans](#)

Q4: Sharon, how is the Arc working to extend Charting the LifeCourse training to additional staff, and why are you making that an organizational priority?

Sharon Spurlock: We have engaged with Charting the LifeCourse for about five years, using it in different capacities across various departments in our organization. We serve almost 4,000 individuals a year, so there are many different opportunities to use these principles, but we have not always made it a systematic effort. When we did our strategic planning 18 months ago, we used the Charting the LifeCourse tools to create our own vision. Through that process, we determined that the framework would be really important for our organization.

So, our strategic plan includes adopting Charting the LifeCourse as our framework for planning and problem-solving. In conjunction with that, we are now doing an internal Ambassador

Series, where 15 employees are going through the training so that they can be the experts and champions for these principles across different service delivery areas to support everybody's engagement in those activities. We also continue to provide training and support to individuals and families, both through traditional training and by embedding the tools and the activities into all of our family support groups and a lot of our workshops. I anticipate that Charting the LifeCourse concepts and tools will eventually be used both programmatically and across our administrative departments (HR, Finance, IT, and Communications/Marketing).

Q5: Why should health plans adopt strategies for supporting individuals with I/DD that extend beyond the medical model or traditional long-term services and supports? What benefit does the plan see from your commitment to implementing Charting the LifeCourse?

Debbie Pfeifer: For Aetna, we believe it is better for our members. Our members are at the center of what we do, so finding ways for them to guide their services and supports is vital. As a plan, we benefit from using Charting the LifeCourse because we are always striving to improve our quality and member experience, and this helps us in that endeavor.

[Charting the LifeCourse – Tools and Strategies](#)

Q6: Can you elaborate on ways to work with individuals who communicate non-verbally to ensure their preferences and goals are addressed?

Sheli Reynolds: I recommend that people remember that communicating well with individuals who do not talk or use words to communicate has nothing to do with the specific Charting the LifeCourse tools. It has to do with really figuring out the best way to get the information you need about their goals and preferences from the person and the people who know them the best. For example, a direct support professional or a teacher may know this information, or a parent may know there is a special twinkle in their eye or particular behavior if they like something and are indicating their preferences. Whether a person has declining health, does not speak, or uses behavior to communicate, the LifeCourse tools become the way to collect information from the whole team and capture the essence of the person.

Q7: Can the Charting the LifeCourse framework be applied to other populations such as individuals with acquired brain injury?

Sheli Reynolds: The Charting the LifeCourse framework and tools can be used for any target audience or any type of planning or problem-solving. We believe that they are universal and human-centric, allowing a person to use them for any situation or need that they have. They are not based on a diagnosis or life stage.

Q8: How can you work with the individual, their family, friends, and loved ones to focus on the individual's preferences and goals? Sometimes, family may want to answer or speak for the member, or even provide answers that contradict what the member really wants.

Sharon Spurlock: Charting the LifeCourse offers tools for each stakeholder so that everyone can have a voice. Sometimes, I meet with individuals with disabilities and work through a LifeCourse form with them while I have the family members write their ideas on their own form so they can contribute after I have had an initial conversation. Sometimes, we bring people with I/DD and their families together and then provide separate visioning or problem solving activities, in separate rooms. We then bring everyone together to share what they learned. Family members often have needed to advocate for their children to get better quality services. We need to recognize this and teach family members how to shift their focus from advocating to supporting their children to advocate for themselves.

Q9: What additional considerations and strategies are needed to ensure work with this framework is culturally competent, for example, to reflect members' and families' ethnic, racial, or religious identity, gender identity or sexual orientation?

Sheli Reynolds: The Charting the LifeCourse framework and tools are designed as an organizing framework that allows for problem-solving, planning and capturing the needs, wants, and visions of a person and their family or support team. The tools are designed to be open-ended and written in user-friendly language, allowing the person's identity and specific experiences to come through based on their responses. In addition, the Charting the LifeCourse team works with an array of stakeholders from around the country to continue to evolve and refine the tools and resources to meet different target audience needs. We have partnered with Latino and Chinese families in California to adapt the tools and address other differences. We are also working with the National Center on Deaf-Blindness to develop tools that are accessible for different communication needs.