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I/DD and Heart Disease: 8 Tips to Manage Risks, Reduce Complications

People with I/DD often have an increased risk of early-onset heart disease, especially conditions such as congenital heart disease, valve problems, and electrical conduction abnormalities. If providers understand the risks and special needs related to heart disease and I/DD, they can help keep individuals safe and prevent complications that can result in hospitalizations or contribute to mortality.

William Mills, MD, executive vice president of medical affairs and innovation for BrightSpring Health Services, offers some key points to help shape protocols and care planning:

- 1. Congenital heart issues are common in this population. These conditions include structural defects, heart valve abnormalities, and electrical conduction problems. About 40% of children with Down syndrome have congenital heart disease, so all individuals with Down syndrome should be screened for it.
- 2. Even if they don't have a congenital heart condition, people with I/DD are at risk for developing heart disease in adolescence or later in life. Risk factors include obesity, diabetes, high blood pressure, and/or high cholesterol.
- 3. The care team, as well as family members, need to watch for signs and symptoms of heart problems in this population. These may include shortness of breath (especially on exertion), difficulty catching breath when lying flat, discomfort or pain in the chest, dizziness, and/or swelling or edema in the feet or legs. It also is important to conduct regular blood pressure checks, screening for diabetes, and lipid screens.
- 4. It is important to encourage healthy lifestyles. Smoking cessation is first and foremost for anyone who smokes. It is also valuable to do Body Mass Index (BMI) screenings and to coach the individuals you serve (as well as caregivers and families) about the importance of healthy diets and eating sensibly. Don't expect these efforts to be one and done. It may take multiple conversations or different approaches to get people to change habits and lifestyles.
- 5. It is important to create awareness of the value of preventive screenings among providers, caregivers, and families. Make sure everyone is aware of what to watch for regarding condition changes and how and to whom they should report them. Provide access to regular care and follow up.
- 6. The consultant pharmacist plays a significant role in addressing heart disease in those with I/DD. For instance, pharmacists can send evidence-based medication recommendations to prescribing physicians. They also can supply preventive care guides to prescribers and other care team members. If someone is on a drug for high cholesterol, the pharmacist can promote regular re-screenings to ensure appropriate lipid levels are reached. The pharmacist also can offer updates on promising new treatments such GLP-1 agonist drugs that are showing tremendous effects in managing heart disease risks in patients with or without diabetes. These drugs also have an indication for weight loss and can help address obesity.



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I/DD and Heart Disease: 8 Tips to Manage Risks, Reduce Complications, Cont.

- 7. Alternatives can be key to improve access to care. People with I/DD may face barriers when accessing care and interventions. For instance, they may have issues with transportation, so it may be harder for them to get to an appointment. At the same time, some may resist going to routine physician visits. Dr. Mills said, "We have seen onsite care at I/DD living centers work well. It also may be useful to arrange for a nurse or other clinician to come into individuals' homes to provide regular care."
- 8. Person-centered care is essential. Knowing people's preferences, likes, and dislikes can help providers target strategies to improve adherence to interventions and encourage necessary lifestyle changes. For example, someone who loves pets may be motivated to exercise more by walking a dog. Those who like sports can be encouraged and enabled to play basketball, volleyball, or other games they enjoy to get more exercise and manage weight.

