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IntellectAbility – Identifying and Reducing Health Risks for People with Intellectual and Developmental Disabilities



Craig Escudé MD FAAFP. President

IntellectAbility https://replacingrisk.com/

Health Risk Screening Tool – <u>https://replacingrisk.com/health-risk-screening-tool/</u> Person Centered Services – <u>https://replacingrisk.com/person-centered-services</u> Curriculum in IDD Healthcare – <u>https://replacingrisk.com/curriculum-in-idd-healthcare-elearn/</u>

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"When people learn who we are and the impact our products can have on the lives of so many, it's much easier to become part of the conversation and a part of the solution." Craig Escudé MD FAAFP.



Interview conducted by: Lynn Fosse, Senior Editor, CEOCFO Magazine

CEOCFO: Dr. Escudé, the tagline on your site is, "Replacing Risk with Health and Wellness." What is the approach to doing so at IntellectAbility?

Dr. Escude': Our company focuses on reducing health risks often missed in people with intellectual and developmental disabilities. The idea behind that statement is that our products aid in identifying health risks that people may not recognize and reducing those risks. We help supporters address those risks allowing the person to have better health and quality of life. We replace health risk with health and wellness.

CEOCFO: Are there common health risks that go unidentified in this group of people, or is it really as varied as it might be with any other population?

Dr. Escudé: There are some very particular risks that people are unaware of. Aspiration pneumonia is much more prevalent in people with disabilities for a few reasons. One is that sometimes people have swallowing issues that allow material to get into the lungs instead of going down into the stomach where it should be.

Other issues include a higher incidence of constipation and bowel obstruction, seizures, gastroesophageal reflux disease, and dehydration. These health issues are part of the "Fatal Five," meaning these are the top causes of preventable morbidity and mortality in people with intellectual and developmental disabilities.

Such conditions often go unrecognized because many providers and people who work with people with disabilities, including nurses and physicians, receive little training in recognizing and identifying these issues in people with IDD. In addition, people with IDD often use alternative means of communication rather than words, such as "adverse" behaviors, to communicate pain or other signs of illness. These signs may go unrecognized or are attributed to the person's disability rather than a potentially treatable health condition. This phenomenon is called "diagnostic overshadowing."

CEOCFO: *Does the medical community not know this is a problem, or do they just not know how to recognize it?*

Dr. Escudé: The answer is both. It stems from how the medical community perceives people with intellectual and developmental disabilities, where people with IDD are not necessarily seen to have a valuable quality of life. Many times, especially in the past, the availability of effective treatments for many conditions was limited. Still, there was also an attitude that maybe we would not aggressively treat these conditions because the perception was that people with IDD did not have a good quality of life. Not much effort was put into providing healthcare, preventative healthcare, and identifying treatable health issues.

Lack of recognition is also an issue that stems primarily from differences in how people with IDD might communicate. For example, a typical patient/clinician interaction involves a person describing their symptoms verbally. They might say, "Hey Doc, I am coming in because every once in a while, I have this terrible burning sensation in my throat. It makes me cough, I feel very uncomfortable, and I am not sure what is going on." The physician can take those symptoms and say, "That sounds like gastroesophageal reflux disease." However, a person who does not use words to communicate with the same condition might become very agitated because they are experiencing this pain in their chest. They may be in pain and do not know how to communicate that to anyone. This might cause them to become aggressive. They might hit themselves. They might hit other people. They might become withdrawn. And might even begin to refuse meals because they associate eating with the occurrence of reflux symptoms. Most clinicians and not taught that gastroesophageal reflux disease might present this way for people with IDD.

CEOCFO: What have you developed to address the problem?

Dr. Escudé: We have several tools and training courses that we have developed. The primary tool of <u>IntellectAbility</u> is called the <u>Health Risk</u> <u>Screening Tool</u>. It is a web-based tool that helps to identify many of these health issues that often go unrecognized. Once it identifies areas of increased health risk, it provides action steps to supporters to help them mitigate those risks. For instance, it might identify a person is at

increased risk for aspiration pneumonia, constipation, or gastroesophageal reflux disease. Then it supplies supporters with specific steps that they can take to help lower those risks.

In addition, we have also developed several online training courses that teach people who work with people with disabilities about many of these conditions that I described, such as the Fatal Five. We have courses that teach people about the increased risk of choking and how to reduce those risks. We also have a course specifically developed for physicians and other clinicians, like nurses, nurse practitioners, and physician assistants, that teaches the fundamentals of healthcare for people with intellectual and developmental disabilities. That course is called the *Curriculum in IDD Healthcare*, and it is currently being utilized by clinicians in practice, as well as by nursing schools, nurse practitioner schools, and medical schools to teach clinicians about this area of healthcare.

CEOCFO: Are people with these types of disabilities seeing a family practitioner or someone who specializes in the area?

Dr. Escudé: Most people are seeing some type of primary care physician, whether it be a family physician, an internist, or a nurse practitioner. Additionally, many people end up in the emergency room for various issues because they are not necessarily sure where to go or because it often serves as the catch-all place for people.

CEOCFO: How did you get involved in this arena?

Dr. Escudé: When I completed my residency program in family medicine in the 1990s, I was trying to figure out which area of practice I wanted to be in. I started in traditional family medicine and found that it was not necessarily where I wanted to be. I then began working at a large state mental hospital in Mississippi. That particular hospital had several people with mental health issues, but also some with intellectual and developmental disabilities, which is how I got introduced to this field. There was a neighboring Intermediate Care Facility for Individuals with Developmental Disabilities (ICF/IID) that needed additional medical assistance, so I decided I would begin to work part-time there. That was the first time I had significant exposure to people with severe and profound levels of intellectual and developmental disabilities, and very quickly, I learned how ill-prepared I was to provide healthcare to this group of people.

Over the next several years, I learned a tremendous amount working there. As time passed, there was a movement to have people with disabilities be more integrated into community life, which meant less reliance on larger institutions like where I was working. I immediately recognized that if people moved out into community settings, they would seek healthcare from community-based physicians who had the same level of training in this field as I did. I knew that the outcomes would be poor. It was then that I made it my mission to do what I could to provide education and training to healthcare providers and other supporters of people with intellectual and developmental disabilities.

CEOCFO: How does the Health Risk Screening Tool work?

Dr. Escudé: The <u>Health Risk Screening Tool</u> (HRST) asses risk in 22 different areas. Examples of some areas assessed include eating,

ambulation, and transferring risk, and behavioral areas such as aggressive and self-abusive behavior. Risks associated with bowel issues, seizures, and certain medications are also included. The tool asks very simple "yes or no" questions related to these 22 different areas of risk. The tool is designed to be administered by anyone who knows the person well, not necessarily a nurse or other clinician.

The HRST processes information from the answers into a risk score in each of the 22 areas. Once a person is fully screened, they are assigned an overall Health Care Level, which has been proven to correlate directly with an increasing risk of death. The higher the healthcare level, the more chance a person has of dying. That is the risk identification part of the tool.

The next part of it, which is the most exciting to me, is that the tool then actually provides specific steps that can be taken to reduce the identified risks. For example, if a person is identified as having a high risk for aspiration, steps to lower that risk will be provided. In addition, it also includes training recommendations for supporters to help them understand what areas of increased risk this person might have and what role they can play in reducing that risk.

CEOCFO: *Would you tell us about where telemedicine comes in now for IntellectAbility?*

Dr. Escudé: One of the more recent advances in healthcare is the ability to receive care through telemedicine services. As I mentioned earlier, many clinicians have not received training about how to meet the healthcare needs of people with IDD. IntellectAbility has partnered with StationMD to create <u>Health Risk Informed Telemedicine</u> (HRIT). HRIT consists of three components; training clinicians about IDD Healthcare, providing telemedicine access for patients and making the HRST risk profile data available to physicians in real-time to help inform their clinical decision-making. This innovative partnership has been developed to help improve health equity for people with IDD.

CEOCFO: What are your person-centered training services?

Dr. Escudé: <u>Person-centered training</u> means that the person is at the center of their life decisions. The field of providing supports and services for people with intellectual and developmental disabilities has always been very heavily weighted on what people think is best FOR that person. They might say, "I think it is best for this person to have X, Y, or Z," or, "I think they should be able to do this, but they should not be able to do that." What happens is that people without disabilities are making decisions for people with disabilities about the way they think their lives should go. Person-centeredness is about bringing that control, or that decision-making ability, back to the person themselves so that they can have positive control and influence over their lives to the greatest extent possible while still ensuring safety and health.

We all want autonomy in our lives. With that, we also all need support in some areas of life. Person-centered training helps teach people who work with intellectual and developmental disabilities how to incorporate both what is important FOR the person with what is important TO the person, restoring balance to the person's life.

CEOCFO: How are you reaching out to people in the medical community, perhaps organizations that are focusing on this arena, to patients, caregivers, and so on?

Dr. Escudé: As a company, our primary focus is to reach out to state agencies and provider organizations who work in the field of supports and services for people with intellectual and developmental disabilities. We meet many people in this field at the numerous conferences we attend relating to supports and services for people with IDD. We are also expanding our outreach to healthcare training programs, including medical schools, nurse practitioner schools, nursing schools, and dental schools, as we have expanded the types of offerings that we have, mainly the training programs for clinicians to teach them how to provide healthcare for people with IDD. It's all about building relationships and educating supporters on the importance of addressing the health needs of the people they support.

CEOCFO: What have you learned at IntellectAbility about getting a foot in the door when you are talking to providers or training organizations? What have you learned about how to stand out at a conference when there are often many people with many ideas, products, and services, and they may all be good, but you are still competing for time?

Dr. Escudé: Trust and Value. First and foremost, it's about being personable and building a trusting relationship with people. Secondly, we must help people understand the value of what we do. We always talk about our company's origins and the challenges faced in this field. When people learn who we are and the impact our products can have on the lives of so many, it's much easier to become part of the conversation and a part of the solution.

