

State of Washington
**Certified Professional Guardianship
and Conservatorship Board**

Presentation by
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Good morning everyone. My name is Tina Baldwin. I am the director of The Mental Health Project of Spectrum Institute.

I truly appreciate the opportunity to speak to you today. Thank you.

There are two other people here that I would like to introduce. Tom Coleman is here to speak after me. He is the executive director and legal director of Spectrum Institute and legal director of the Mental Health Project.

Emmi Deckard, who is the author of the report I am about to comment on, is also here and said she is willing to answer questions in the Q & A session following Tom's presentation.

It is Spectrum Institute's intention to stimulate the adoption and implementation of long overdue improvements in the delivery of mental health services to adults with developmental disabilities.

To this end, Spectrum Institute published a report in May written by Emmi titled *Consequences of Delayed or Denied Mental Health Care for Individuals with Developmental Disabilities*. It not only looks at the origins and frequency of delayed or denied mental health services to adults with developmental disabilities but also highlights the complexity of the situation and the significant adverse consequences that can impact an individual's overall well-being and quality of life.

This is a vulnerable population in which there is a greater prevalence of mental illness and behavior difficulties than in the general population.

Although psychological disorders commonly occur alongside developmental disabilities, these disorders are chronically underdiagnosed, misdiagnosed, or poorly managed. Emmi writes in the report and I quote "Diagnostic overshadowing, in which symptoms of mental or physical illness are misinterpreted as symptoms of one's IDD, is a likely contributor to suboptimal care which results in less likely diagnoses of psychiatric disorders in this group despite higher occurrence."

“She goes on to say that "Individuals with developmental disabilities are less likely to have developed coping skills and, as a result of potentially limited verbal skills, may resort to physical aggression in order to express their discomfort or stress. Alternatively, physical aggression could be rooted in a mental illness or be an expression of pain resulting from a medical issue.

“There are numerous explanations for this single behavior; however, clinicians are quick to assume the behavior is attributed to the developmental disability rather than exploring alternate causes as would be done for individuals without developmental disabilities. Hence, the diagnosis of an developmental disability can overshadow any other diagnosis. If clinicians don't maintain a high index of suspicion for alternate causes of their behavior, people with developmental disabilities or mental health disorders can be denied appropriate screenings, treatments, and investigations necessary for making alternate diagnoses.”

I repeat "Clinicians are quick to assume the behavior is attributed to the developmental disability." Obviously, this assumes that the individual has gotten into see a clinician in the first place.

So, then we have to ask whose responsibility is it to see that an individual with developmental disabilities receives accurate evaluations for causes beyond the development disability.

Whose responsibility is it to see that the individual receives access to the same therapy options available to people in the general population and to see that they are appropriately received in a timely manner.

What if the responsible person says they don't have the time to deal with any of it?

Or what if they say "there is no one within 10 miles so we are just going to let go of it" when, in fact, there is somebody who can do it by Zoom regardless of distance?

Should these rationales exempt CPGCs from the responsibility to ensure prompt and appropriate care for an individual who must depend on them for such care?

I'm excited to have you read the report to learn more about

- * the myriad adverse consequences of denial or delay of mental health services,
- * how they impact the life of an individual with a developmental disability
- * and, how pervasive, insidious, and complicated they are.

We are asking you, the Certified Professional Guardianship and Conservatorship Board to review your existing policies and procedures in order to

- * improve access and delivery to mental health services especially considering the adverse consequences to the individual when that access is delayed or denied and
- * to help CPGCs comply with the Americans with Disabilities Act and other state and federal laws.

In addition to *Consequences of Delayed or Denied Mental Health Care for Individuals with Developmental Disabilities*, we believe there should be three more reports that address the following:

1. the consequences to an individual's family and others in their network of support when mental health services are denied or delayed.
2. the potential legal consequences that willful or negligent delay or denial for such services can have for those who are gatekeepers, for example, primary care physicians, professional or lay guardians, and court-appointed attorneys in guardianship.
3. the potential financial consequences that the deprivation or delay of mental health therapy places on state and local resources, for example, entitlement programs, law enforcement services, and judicial proceedings.

We believe the CPGC Board is a key player in Washington in efforts to improve the delivery and access of mental health services to adults with developmental disabilities and, therefore, we truly look forward to continuing this conversation with you.

Thank you.



Christina Ann Baldwin in the Director of the Mental Health Project of Spectrum Institute and the Chairperson of the Board of Trustees.

The purpose of the Mental Health Project of Spectrum Institute is to promote improved access to a full range of mental health therapies for adults with intellectual and developmental disabilities. The project focuses on the role of guardians, conservators, and others who have assumed primary caregiving responsibilities for this special needs population. These individuals are mental health therapy fiduciaries. The mission of the project is to educate these fiduciaries about their duty to take the necessary steps to implement the right of adults with intellectual and developmental disabilities to have prompt access to the necessary and appropriate mental health therapies they need. The mission also includes the education of self-advocates and family advocates on the right to mental health therapy and how to ensure that court-appointed agents and those who have assumed caregiving responsibilities fulfill their fiduciary duties. The project accomplishes its mission through research, education, and advocacy. In addition to working with advocates and mental health fiduciaries, it also reaches out to primary care physicians who are often the gatekeepers to mental health services, and to psychologists, psychiatrists, social workers, and other licensed mental health professionals.

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