VOR
A Voice Of Reason
Speaking out for people with
Intellectual & Developmental Disabilities

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To the members and leadership of the National Council on Disability,

We are writing in response to the National Council on Disability's Request for Information on Disability Clinical Care (issued December 1, 2025, Fed. Reg. Vol. 90, No. 228, page 55181).

We thank you for the opportunity to provide comments on the various enhancements to professional training that would familiarize health care providers with the needs of profoundly disabled patients, thus enabling health care professionals to care for all of their patients with skill and compassion.

For over forty years, VOR has advocated for the rights of individuals with intellectual and developmental disabilities (I/DD), including the right of these individuals to receive high-quality care. Many of the people VOR represents have profound cognitive disabilities which co-occur with serious medical, psychiatric or behavioral challenges. These individuals represent roughly 5% of the I/DD population as a whole. They frequently require continuous around-the-clock care from skilled professionals who can provide the intensive support these patients need.

Some of the people we represent are non-speaking. Some have self-injurious behaviors. Others can be aggressive or have violent outbursts. All of them are beloved members of the families who belong to VOR. All of them deserve individualized care that fully addresses their complex needs.

One of the most common problems we see in the clinical care of our family members is a lack of understanding by health care professionals that our disabled family members are the same as everyone else in some important ways, but very different in other ways. Our family members have the same needs and desires as everyone else. They have feelings, which are hurt by callous or dismissive treatment. Patients with I/DD, however, often present with complicated medical, neurological or psychiatric disorders which require thoughtful expert assessment and a comprehensive treatment plan.

We believe that a strong curriculum in interviewing skills which would prepare clinicians to work effectively with patients with I/DD, and a thorough academic grounding in the kinds of medical, psychiatric and behavioral problems that occur most commonly among patients with I/DD, would be a huge leap forward in providing competent clinical care for our family members.

Enhanced training of this kind would also produce clinicians who are better equipped to care in a wholistic and comprehensive way for every patient they encounter, whether that patient is disabled or not.

A. General Considerations Affecting Clinical Care for All Patients with I/DD

1. Respect for the Patient with I/DD

Our loved ones are people. They deserve to be treated with the same respect and dignity that would be afforded to non-disabled patients in a clinical setting. They have the right to participate in their care (to the extent they are able), and to have their concerns heard and addressed.
How do we achieve this?

a. Clinicians need to have familiarity with patients who have I/DD. Clinicians also need to have actual clinical experience in interviewing them. Ideally, residents in primary care specialties (pediatrics, family medicine, internal medicine and gynecology), as well as residents in fields like gastroenterology, neurology, psychiatry and dentistry, would have mandatory rotations through ambulatory clinics and other settings in which patients with I/DD receive care. For example, the ARC of Massachusetts operates a program called "Operation House Call", which enables patients with I/DD and their families to work with future medical professionals in both home visit settings and classroom teaching settings. The program is designed to increase the comfort level and knowledge base of future medical professionals as they learn how to treat these patients by interacting with them.

b. It takes time to develop rapport with a patient who has cognitive impairments. Residency and other clinical training programs should recognize the need for extra time with patients who may be fearful or non-speaking (or both).

c. Student clinicians should be taught to interact directly with the patient, to the extent the patient is able or willing to interact, and to involve caregivers as historians only as necessary (and hopefully with the patient's assent). All too often, our family members are ignored in clinical conversations as caregivers and providers talk around them as if they weren't there. This is demeaning and humiliating for the disabled patient.

d. Clinicians should be taught to determine, preferably from the patient, how the patient prefers to communicate. Some patients, for example, use AAC (augmentative and alternative communication) devices. Clinicians need to be taught to use plain language, at the patient's level, and to use visual aids or other multisensory input where appropriate. Patients with I/DD should be given time to formulate their responses to clinical questions, as many of them struggle with cognitive processing delays.

e. Standard clinical interview techniques ("rate your pain on a scale of 1 to 10") are often unhelpful for a patient with I/DD. While the patient may indeed be in considerable pain, the patient may not even consciously recognize that fact or be able to communicate accurately where the pain is. Clinicians should be prepared to look for behavioral signs that the patient is in pain (flinching, avoidance, protecting certain areas of the body, behavioral disruption) and to search for clinical problems that may be causing the pain.

f. Clinicians should be aware that conventional treatment spaces may trigger the sensory sensitivities that many patients with I/DD experience. Bright artificial lights, loud noises, unexpected touching, strong smells (e.g., hospital cleaning products) or abrupt changes in environment may cause behavioral disruption in a patient with these sensitivities. The ideal setting for an examination is a calm, private low-stress room with access to calming devices such as stress balls, fidget toys and noise-cancelling headphones.

g. Clinicians need to take the patient seriously and listen to the concerns the patient is expressing. Not everything is "just" a symptom of I/DD. Patients with I/DD have real medical problems, and real psychiatric disorders, which deserve to be evaluated and treated as they would be in any other patient. Clinicians should be taught to spend the time needed to understand what the patient's typical baseline is, so they can properly interpret and treat new or different symptoms the patient is experiencing.

h. Clinicians should never assume that patients with I/DD will not benefit from and therefore should not be offered treatments routinely offered to patients without cognitive disabilities. It may take more time to work with a patient who has I/DD, and some treatments may need to be adapted for successful use with I/DD patients. Even so, our disabled family members deserve state of the art treatment, just like everyone else.

2. Common Clinical Concerns Affecting Patients with I/DD

As an integral part of their training, all clinical professionals should have some familiarity with the kinds of medical, neurological and psychiatric disorders that commonly occur in patients with I/DD.

a. Patients with I/DD are more likely than other patients to have epilepsy; cardiac disorders; urinary issues; constipation, irritable bowel syndrome or other gastrointestinal disorders; GERD; obesity; sleep disorders; dental problems (often because they have difficulty accessing routine dental care); undiagnosed vision and hearing problems; hypothyroidism and other endocrine disorders, including insulin resistance and diabetes; spinal disorders; osteoporosis; and behavioral and mental health problems (often resulting in problematic polypharmacy). Clinical awareness that these kinds of conditions are more likely in patients with I/DD should result in better screening and prompter treatment of such conditions when they do occur.

b. Especially for patients who are displaying behavioral dysregulation, clinicians should be trained to screen for common medical and dental problems (e.g., urinary tract infections, headaches, constipation, irritable bowel syndrome, celiac disease, dental decay) that may be causing pain or distress. "Behaviors", especially if they are new, could be the patient's way of expressing physical discomfort.

c. On the other hand, behaviors such as self-injury or aggression are not necessarily being "caused" by the underlying I/DD. Patients with I/DD often experience co-occurring mental illness, including anxiety, depression and sometimes psychosis. This issue is discussed in more detail in Section B below.

d. As genomic science advances rapidly, so does our understanding of the genetic anomalies that underlie the symptoms of many patients with I/DD. Clinicians should be generally familiar with genetic syndromes that are linked to I/DD and should understand how to refer patients for appropriate genetic evaluation. Proper and timely diagnosis of an underlying genetic condition will enable treatment of symptoms with the most appropriate regimen of medications.

3. Timely Referrals to Supportive or Protective Services

Health care professionals, especially in primary care specialties, should receive some training in the community-based supports and services (including Early Intervention, Home and Community-Based Waiver services and specialized residential housing) that are available to patients with I/DD. Pediatricians in particular may be the first professionals in a child's life to recognize that the child needs a referral for evaluation of a possible developmental disability.

Patients with I/DD are also likely to experience abuse (including sexual assault) at some point in their lives. Clinicians should be alert to the signs of abuse (which can include behavioral disruption or social withdrawal) and should be trained in the proper procedures for reporting suspected abuse.

B. Special Considerations Affecting Patients with Co-Occurring Diagnoses of I/DD and Mental Illness

Despite the fact that patients with I/DD are disproportionately likely to experience mental illness (such as anxiety and depression), treatment for these patients has historically been split between two different treatment silos. The I/DD clinical and service sector focuses largely on behavioral management techniques, while the psychiatric sector relies heavily on medication management of symptoms such as aggression and self-harm. Splitting care in this way is both ineffective and frequently harmful for patients with I/DD. These patients need coordinated evaluation and management from both clinical silos (or, ideally, a unitary system of care adapted to their needs, which borrows the best from both approaches to the care of these patients).

Psychiatric illnesses can be difficult to diagnose in patients with I/DD, and psychiatry training programs typically do not offer specialty training in best treatment practices for patients with I/DD. General practice psychiatrists may have little exposure to patients with I/DD. There is also a dearth of evidence-based guidance in the use of psychiatric medications in this population.

In the absence of a precise psychiatric diagnosis, treatment tends to be symptom-based. This often leads to a lot of trial and error in medication adjustments, to undesirable polypharmacy, and to the long-term administration of powerful medications which have never been evaluated for use in the I/DD population through the gold standard of randomized controlled trials. Adverse side effects are common with anti-psychotics, mood stabilizers and other medications given to I/DD patients, and yet patients can be on these medications for years without serious in-depth consideration of behavioral supports that could minimize the need for such medications.

The cure for many of these professional ills lies in cross-disciplinary training and collaboration in clinical practice.

a. Psychiatrists and psychiatric nurse practitioners should all receive basic training in accurate diagnosis and evaluation of psychiatric disorders in patients with I/DD.

   Before prescribing medication, psychiatric professionals should be trained to do an in-depth analysis of environmental and historical factors that may be contributing to psychiatric symptoms in patients with I/DD, such as trauma from abuse, bullying or other adverse circumstances. Patients with I/DD are more likely than their neurotypical peers to have experienced social rejection, exclusion, confinement to restrictive clinical settings and incidents of seclusion and restraint in such settings. While these conditions would likely be traumatic for anyone, including those without I/DD, they can be especially damaging for patients with I/DD who lack the social and verbal skills needed to cope with them. Recognizing and addressing the stressors in the patient's environment may reduce the need for medication. A detailed social history may also aid the practitioner in arriving at a more accurate diagnosis and better-targeted medication where medication is necessary.

b. Psychiatric professionals need to learn in training to consider the need for specialized genetic testing to determine whether the patient has a recognized genetic syndrome. Once a particular syndrome has been identified, that data may guide optimized treatment.

c. Psychiatric professionals should receive specialized training in the most effective and evidence-based psychopharmacology for treating anxiety, depression and other forms of mental illness in patients with I/DD. Many patients with I/DD do not respond to psychiatric medications in standard or expected ways.

d. Psychiatric professionals should receive training in the adaptation of commonly used clinical tools, such as mindfulness training, for patients with I/DD and mental illness. Patients with I/DD who are experiencing emotional dysregulation are frequently told that they are not eligible for therapies such as cognitive behavioral therapy, mindfulness training or dialectical behavior therapy. Groundbreaking work being done by Dr. Carla Mazefsky and colleagues at the University of Pittsburgh's REAACT Research Program demonstrates that patients with autism can benefit from these treatment modalities. See *Susan White, Ph.D. et al, "Efficacy of the Emotion Awareness and Skills Enhancement (EASE) Program in Autism: A Randomized*

Controlled Trial", Journal of the American Academy of Child & Adolescent Psychiatry, published July 31, 2025.[1]

e. In addition, psychiatric professionals need training in the use of positive behavioral supports, behavioral management techniques and sensory-friendly environmental modifications. These interventions can reduce the need for psychiatric medication and can help to minimize the use of restraint and seclusion.

f. Clinical psychologists, neuropsychologists, social workers and other clinical professionals who evaluate and manage patients with I/DD should receive some general cross-training in psychiatric methods of assessment and treatment. These professionals should work closely with psychiatrists or psychiatric nurse practitioners where necessary to co-manage patients who would benefit from medication or psychiatric therapy.

Ideally, patients who present with both I/DD and mental illness would be treated collaboratively by clinicians who have a deep understanding of both kinds of disorders, and how those disorders interact. Only that kind of collaboration can produce truly integrated care for the whole person. University Hospitals Cleveland Medical Center (a hospital affiliate of Case Western Reserve University School of Medicine) has an innovative IDD psychiatry program which trains residents and fellows in the specialized field of dual diagnosis (I/DD and mental illness) psychiatry. Programs of this kind, which provide better-integrated treatment, are badly needed everywhere.

For further reading in the complex field of treatment for patients with co-occurring I/DD and mental illness, you may wish to consider as a starting point this helpful summary article: *John N. Constantino, et al., "Toward Actionable Practice Parameters for "Dual Diagnosis": Principles of Assessment and Management for Co-Occurring Psychiatric and Intellectual/Developmental Disability", Current Psychiatry Reports Volume 22, Issue 2 (February 1, 2020).*[2] We would be glad to provide further background informational resources should you wish them.

We thank you again for the opportunity to submit comments in response to the National Council on Disability's Request for Information. We would welcome the opportunity to work more closely with NCD or with individual training programs to develop policies and practices that better meet the needs of our developmentally disabled loved ones.

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[1] Efficacy of the Emotion Awareness and Skills Enhancement (EASE) Program in Autism: A Randomized Controlled Trial", Journal of the American Academy of Child & Adolescent Psychiatry, published July 31, 2025 https://pubmed.ncbi.nlm.nih.gov/40750084

[2] "Toward Actionable Practice Parameters for "Dual Diagnosis": Principles of Assessment and Management for Co-Occurring Psychiatric and Intellectual/Developmental Disability", Current Psychiatry Reports Volume 22, Issue 2 (February 1, 2020) https://pmc.ncbi.nlm.nih.gov/articles/PMC6995447