

CLINICAL BRIEF: MEDICAL CARE OF THE IDD PATIENT

Ensuring Optimal Outcomes in Patients with Intellectual and Developmental Disabilities

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IDD and Polypharmacy Risks

Individuals with intellectual and developmental disabilities (IDD) have a 2.5 times higher prevalence of chronic comorbid physical health conditions than adults with no limitations. The chronic conditions most associated with IDD include but are not limited to:

- Psychiatric conditions
- Epilepsy
- Asthma
- Dental disease
- Osteoporosis
- Gastrointestinal disorders
- Obesity

And with the increasing life expectancy of the IDD community due to improvements in access to and provision of healthcare and other services, the prevalence of conditions commonly associated with aging also increases, especially diabetes, hypertension, and hypercholesterolemia.

With the prevalence of both behavioral and physical health conditions in this population, the risks associated with polypharmacy rise dramatically. In one study of adults with IDD over age 40, 32% were

found to have polypharmacy (defined as 5-9 medications) and 20% were found to have excessive polypharmacy (10+ medications) based on regular use of both prescription and over-the-counter medications. Individuals with IDD in residential facilities had 4 times the rate of excessive polypharmacy vs. community living (group home/independent living), independent of other factors.

Polypharmacy is directly associated with increased risks for adverse drug events (ADEs). In a well-controlled study comparing the proportion of hospitalizations associated with ADEs for adults with IDD vs adults from the general population in the United States, the rate of admissions for the IDD population was almost 2.5 times that of the general population. In addition to polypharmacy, the relevant variables for this admission include impaired cognition, multiple comorbidities, dependent living situation, and nonadherence to medication regimens. While the overall incidence of ADE admissions is low compared to admissions for other ambulatory care sensitive conditions, these findings have important clinical relevance due to the associated increased prevalence in this population of acute conditions such

as UTI, respiratory, musculoskeletal, and gastrointestinal conditions—the associated challenges of coordination or communications between different groups of providers. Any single clinician should have access to the patient’s complete medication list, and regular medication reconciliation should take place by the primary care team in collaboration with the patient’s care manager.

The 2018 Canadian Consensus Guidelines on primary care of adults with intellectual and developmental disabilities makes the following recommendations:

- Every three-month medication review for indications, dosing, effectiveness, and ADE risk, involving a clinical pharmacist whenever possible, especially for those medications with drug-organ or drug-drug interactions.
- Educate patients and caregivers about appropriate use of medications, interactions with over-the-counter, alternative, and as-needed medications, and to report potential

adverse drug events. Simplify the medication administration routines and recommend appropriate medication administration aids (e.g., dosettes or blister packs) and other needed supports.

- Determine the patient’s capacity and need for supports for both decision making and medication adherence and engage caregivers and care managers whenever possible.

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Team-based Service Coordination in Practice: Working with Care Managers

What is commonly called “team-based care” is well established to improve stability and outcomes for individuals with medical complexity, especially including patients with intellectual and developmental disabilities (IDD). The American College of Physicians, the American Academy of Pediatrics, the American Academy of Family Physicians, and the American College of Obstetrics and Gynecology have all reviewed the evidence and endorsed “team-based care” as an optimal model for such special needs populations.

However, what does “team” mean? The nature of the team structure, the roles and responsibilities of team members, and the relationship among team members who may not all have the same organizational affiliation are always challenging when trying to coordinate care for an individual with multiple, diverse disciplinary needs.

Individuals with IDD often have complex “health resource communities,” meaning those individuals, organizations, entities, and environments (including the patient and their family) that have any

involvement or influence—actual, virtual, or potential—on the variables that influence their health and well-being.

In our current systems of practice, the responsibility for the elements of any patient’s care is often apportioned independently among different professional disciplines (primary care and specialist physicians, nurses, therapists, social workers, etc.) who, based on the mental model of their discipline, contributes insights and any related orders or action items.

Unfortunately, when decisions are made in isolation of other members of the patient’s health resource community, it can lead to fragmented and uncoordinated care, adding risk to the patient and family, especially those with IDD.

Even under an interdisciplinary model, teamwork is really “groupwork”: while all necessary domains may be represented, members actually work in parallel on tasks that match their purview; achievement of

individual goals among the team members is expected to add up to the groups purpose.

However, interdisciplinary is not the same as integrated. And the diverse, often complex needs of the IDD community can often stress the capacity of individual providers. As noted in the 2018 National Academy of Medicine discussion paper “Optimal Team-Based Care to Reduce Clinician Burnout,” well-defined team-based care presents a unique opportunity to improve patient outcomes, the efficiency of care, and the satisfaction and well-being of health care clinicians.

High performance goal achievement in environments characterized by complexity and diverse human factors requires sharing responsibility, authority, and accountability among team members. To be successful, this model of collaboration must be based on a belief that the benefits of collaboration will offset perceived costs such as loss of autonomy and territorial control. Then, care delivery becomes a collective enterprise as opposed to a departmental, command and control phenomenon, with active coordination of goals and activities to effectively resolve complex problems that could have dire consequences in the face of failure.

In the symphony, performers use their instruments in collective effort to create a harmonious and moving experience for the audience. Extraordinary collective performance—whether in technology, special forces, or healthcare—is also symphonic: dozens of technical and interpretive experts, each of whom has invested in mastering their specific instrument or craft, come together, subsume their individual identities, and, in a shared effort, are able to create a concordant, goal-directed experience.

The conductor is not the leader, but serves an essential integrating role, holding the vision for the performance as a whole. Even the most virtuoso players understand they cannot conduct and sit first chair; they respect, trust, and defer to the conductor and listen carefully—not for reaction, but for connection—to their fellow players, because they understand that a solo may be in their hands, but the symphony only exists in the collective effort.

In our current systems of care, a well-trained and comprehensive Care Manager is the ideal “conductor,” serving an essential integrating role, holding the vision

for “whole-person” outcomes. Their expertise is orchestrating collaboration and a single focus on facilitating the goal-directed activities of team members.

However, it’s important to understand that there are many different forms of care management. Knowing the specifics of an organization’s care management model will help you make better decisions as to who is on your team for specific patients. For medically complex patients, such as those with IDD, Care Managers should be open to augmenting your staff and engaging in activities that promote access to care. They will also help patients and families navigate the healthcare system, identify, and engage referrals, coordinate and support the management of transitions of care (home/residence to hospital, hospital to skilled nursing facility or SNF, SNF to home/residence), follow-up on emergent or urgent care needs and provide linkages to social and government services, community supports and long-term care, and hold interdisciplinary team meetings. They can also conduct or refer for specialized functional and risk assessments, which can add to the data used in your practice for decision making and quality improvement. That data will be useful to create integrated patient-centered plans of care based on IDD best practices to ensure appropriate access to resources and services, including preventive interventions, safety plans, and necessary equipment.

For example, New York State (NYS) has developed a care management model for the IDD community that is used in the IDD-focused Care Coordination Organizations/Heath Homes (CCO/HHs). The CCO/HH model offers a unique, well-defined and predictable level of service that can offer great value to healthcare services organizations. Care Managers at CCO/HHs and CCO-associated health plans have extensive experience working with individuals with IDD; some are Qualified Intellectual Disabilities Professionals (QIDP). As the primary relationship managers for patients and families eligible for services under NYS Office of People With Developmental Disabilities (OPWDD), Care Managers can serve an “essential integrating function” in your practice. While most health plans offer their own form of care management, some health plans choose to partner with CCO/Health Homes for IDD patients because of their model of care and disciplined performance.

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Advance Care Planning and IDD

Adults with IDD have made significant gains in longevity in the last twenty years. Between 2008 and 2017, the average lifespan for adults living with these disabilities (which include intellectual disabilities, Down syndrome, and cerebral palsy) rose more than for adults without IDD. However, there remain disparities in lifespan from other non-disabled adults, with variation by type of disability: individuals with cerebral palsy have a significantly shorter lifespan (23 years fewer than non-disabled adults) than those with primary intellectual disabilities (12 years fewer).

In addition, racial and ethnic minorities with IDD have additional risks: a wide gap exists in the average age at death between non-Hispanic white adults with IDD and their peers in other racial/ethnic groups. By way of example, non-Hispanic white adults with IDD live nine years longer, on average, than Black and Native American adults with IDD and 12 years longer than Hispanic/Latino adults with IDD.

With their growing life expectancy, the numbers of older adults with IDD continues to expand, and community agencies and families now face the challenge of providing supports as these adults experience age-related changes. In comparison with adults without long-term disabilities, adults with IDD are more likely to experience earlier age-related health changes, limited access to quality health care, and fewer financial resources. In addition, they are more likely to be living with parents into adulthood and have more limited social supports and friendships outside the family.

This all speaks to the need for Advance Care Planning (ACP) in early adulthood for individuals with IDD. Getting started early sets the foundation for the individual's future, especially because the ACP is not a

singular act, but an ongoing process that best practices say should be reviewed at least annually and/or with any significant change in status.

The overarching goal of the ACP is to improve the quality of the end-of-life experience for both the person who is dying and their caregivers by increasing the likelihood of adherence to the person's wishes when they become seriously ill and reach life's end. The outcomes in these situations are significantly better when the ACP process is carried out effectively.

Many barriers to ACP exist, enhanced by the presence of IDD. There is a tendency to think that individuals with IDD lack the capacity to understand the issues at hand and to be more reactive than proactive when it comes to ACP for these individuals, thus often delaying conversations until the final stages of an advance illness in response to worsening prognosis and/or a change in care needs. Caregivers, including both ageing parents and adult siblings, are often reluctant to engage in future planning because they fear it may affect the care their loved one receives, lack an understanding of the process, and have fears related to their own mortality. This is validated by a study that found people with intellectual and developmental disabilities to be less self-determined in the domain of end-of-life planning when compared to people without disabilities.

Despite these barriers, opportunities for meaningful ACP exist for people with intellectual and developmental disabilities and those who support them. Fostering effective relationships between people with intellectual and developmental disabilities, their caregivers, and healthcare providers can ensure the wishes of the person as central to the decision-making process.

The two concepts that drive the ACP process are the capacity and competency of the individual involved; capacity can be supported with assistance. While many people with IDD are inaccurately presumed to lack capacity, a 2014 Institute of Medicine report noted that while some people with IDD may lack decision-making capacity for certain medical decisions, they may retain capacity for other decisions, including the selection of a proxy or healthcare agent.

Competency is more complex, grounded in the question: Is this person 18 years of age or older and considered legally competent under the law to make their own medical decisions? If not, surrogate decision makers can be appointed; surrogates can be relatives, friends, caregivers, or healthcare providers.

The facilitator of the ACP does not need to be the primary care physician, and the role can be assigned by them to other, non-clinical personnel, such as a social worker, nurse, or care manager who is knowledgeable of, and comfortable with conversations related to death and dying, and skilled at communicating about these subjects with people who have intellectual and developmental disabilities and their relatives. The facilitator must also thoughtfully and intentionally engage the person and their relatives so that they have the information needed to make informed decisions, understand their roles in the process, and ultimately have a positive experience.

People with intellectual and developmental disabilities can and should be engaged in the ACP

process. Recent research has found these individuals to have the capacity and interest to participate in ACP, especially when person-centered accommodations are made, and shared decision-making is facilitated by healthcare staff. Person-centered planning assumes that people are authorities in their own lives and, as such, deserve agency in deciding what services they receive and how they are provided. This imperative extends to ACP.

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Behavior Management in Practice: Practical Considerations

Individuals with intellectual and developmental disabilities (IDD) may demonstrate behaviors that vary from your neurotypical patients. These can manifest themselves on a spectrum ranging from differences in:

- Cognitive, communication, social, emotional, adaptive functioning, to
- Hyperactivity, impulsivity, routines or stereotypy, mood liability, vocalizations, to
- Physical aggression, self-harm.

Identifying, differentiating, and adapting the response of the practice to what is normative for the patient versus what may require therapeutic intervention is essential to ensuring a non-disruptive encounter. Some patients with autism, for example, use self-stimulation such as rocking, finger flicking or other hand movement, or even pacing to help them concentrate during social encounters that may otherwise be overwhelming. Other patients may regularly spontaneously vocalize in a way that might

be associated with pain in another person. The practice needs to accept these behaviors as part of the patient’s person-hood. At the same time, behaviors that are barriers to well-being such as self-harm or impulsive elopement may require assessment and associated interventions.

Most behavior management does not take place in the primary care or medical specialists office, but there are some behavioral techniques that can help practices manage the variations in behavior of the IDD patients.

These techniques are generally called the “common factors” because they are not specific to any one condition but are elements of effective communication skills that positively affect outcome, regardless of diagnosis. They are grounded in three key principles focused on managing complex care and

enabling acceptance and commitment to plans of care (including self-management):

- Fostering relationships to improve therapeutic alliances,
- Improving information exchange to support better informed, shared decision making, and
- Increasing patient/family participation in care by responding to emotions through listening and offering acknowledgment, legitimation, empathy, and support.

The “common factors” techniques to be used in practice are grounded in the mnemonic HELP (Figure 1). There is significant evidence that medical generalists can readily apply these techniques in practice with limited training.

Figure 1. HELP Mnemonic

H	Hope	Increase the family’s hopefulness by describing your realistic expectations for improvement and reinforcing the strengths and assets you see in the patient and family.
E	Empathy	Communicate empathy by listening attentively.
L²	Language	Use the patient or family’s own language to reflect your understanding of the problem as they see it and to give the patient and family an opportunity to correct any misperceptions.
	Loyalty	Communicate loyalty to the family by expressing your support and your commitment to help.
P³	Permission	Ask the family’s permission for you to ask more in-depth questions or make suggestions for further evaluation or management.
	Partnership	Partner with the patient and family to identify any barriers or resistance to addressing the problem, find strategies to bypass or overcome barriers, and agree on achievable steps aligned with the family’s motivation.
	Plan	Establish a plan (or incremental first step) through which the patient and family will take some action(s), work toward greater readiness to take action, or monitor the problem, then follow up with you based on the patient and family’s preferences and sense of urgency.

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WHY JOIN THE PHP PROVIDER NETWORK?

Partners Health Plan (PHP) is a specialized health care organization exclusively committed to understanding and supporting the quality of health and well-being of adults 21+ with Intellectual and Developmental Disabilities (IDD) in nine (9) downstate New York counties.



Partners Health Plan...

- ✓ **will work with you** to coordinate, allocate, and manage a portfolio of resources designed for the special needs of patients with IDD.
- ✓ **is highly collaborative and dedicated to providing integrated care** with its healthcare professional partners with whom we share the responsibility for caring for this special needs IDD population.



WHY WORK WITH PARTNERS HEALTH PLAN?

KEY BENEFITS

- ✓ **A Qualified Intellectual Disabilities Professional (QIDP) will be assigned** to work with your practice. This Care Manager will coordinate care and augment your staff to support access, scheduling, and transportation to healthcare sites and other resources required for the patient's care (e.g., community programs and OPWDD waiver services).
- ✓ **A clinically licensed professional (Nurse, Social Worker, Psychologist) will be assigned to serve as Clinical Team Leader for the QIDP staff.** They will oversee the stratification of high-risk patients, provide guidance to patients and families, and support the management of transitions in care, including discharge planning with full accountability to the medical team.
- ✓ **24/7 access** to specialized IDD care management services.
- ✓ **Claims-based data sharing** including comprehensive diagnosis and medication lists with clinical pharmacists' review/insights into utilization data.
- ✓ **Access to functional and psychosocial assessments** to support comprehensive care planning.
- ✓ **Support** to meet your quality health care goals.
- ✓ **A dedicated and IDD experienced Provider Relations team** with competitive market rates and 24/7 provider portal access.
- ✓ **Integrated relationships with:**
 - Developmental Disability Services Providers
 - Rehab (OT/PT/Speech)
 - Community resources (including social needs, adult day care, and vocational programs)
 - Broad network of specialist physicians, pharmacy services, hearing, vision, and preventive care services, urgent care, emergency room and hospital networks
 - Urgent/non-emergent telemedicine and tele- psychiatry services
 - IDD-specialized dental services
 - Home health and nursing services, including personal aides, and nursing home care

TO LEARN MORE ABOUT THE PHP PROVIDER NETWORK PLEASE CONTACT:

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