How does the Affordable Care Act benefit people on the Autism Spectrum?

Care coordination and client-centered care are promising concepts

by Maayan JAFFE

More than one-third of individuals in Ohio diagnosed with a developmental disability are dually diagnosed with a mental health disorder, according to a report published by the Ohio Coordinating Center of Excellence for Mental Illness and Developmental Disabilities (MIDD CCOE).

Ohio's statistic are in-line with the national average; according to the National Autism Association, there are a number of co-morbid conditions associated with autism, such as Fragile X, allergies, asthma, epilepsy, bowel disease, gastrointestinal/digestive disorders, persistent viral infections, PANDAS, feeding disorders, anxiety disorder, bipolar disorder, ADHD, Tourette Syndrome, OCD, sensory integration dysfunction, sleeping disorders, immune disorders, autoimmune disorders and neuroinflammation.

There is a national thrust for better care coordination, for breaking down ever-existing silos between physical, behavioral and other care providers, according Dennis Morrison, Ph.D., chief clinical officer for Netsmart, one of the longest standing IT companies in the United States. Today might be one of the best eras to be one of the above people.

> "The question is, 'How can we treat this person as a whole person, rather than thinking about this symptom goes in that bucket or this problem goes in that bucket?'" explained Morrison. "When you segregate someone's intellectual or behavioral healthcare from their physical healthcare, no good comes of it."

For starters, by most estimates, America wastes $240 billion per year on uncoordinated care, which often results in dangerous and frightening mistakes. For example, prescription drug complications caused by various forms of uncoordinated care sends 26 million people to the hospital annually, according to a video produced by BlueCross BlueShield.

Signed into law in 2010, The Affordable Care Act includes language promoting a coordinated approach to care, offering incentives through the Centers for Medicare & Medicaid Services (CMS) to assist healthcare providers of all sizes and types to work together to coordinate patient care. While many of these incentives seem focused on physical health, there is much the intellectual and developmental disabilities community can tap into, especially in terms of best practices and use of electronic tools to leverage better communication and coordination among providers.

Morrison explained there are a few ways this coordination can happen. One is there can be an actual physical exchange of providers. For example, a behavioral health or developmental disabilities clinician might join a primary care practice or vice versa. The other option is via sharing clinical data electronically.

> "We call this virtual integration," he said. "Let's say you and I are both providers. We don't ever have to meet to provide good care coordination for someone we both treat as

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> long as the information we need is shared effectively between us. The cornerstone of this process is the electronic health record (EHR) and the electronic data standards outlined in the ACA. ”

Morrison’s employer, Netsmart, offers several EHRs and cutting-edge solutions, such as CareManager™, which aggregates clinical data to provide a broad picture at the population level, facilitates care coordination across providers, tracks clinical quality measures and outcomes, and manages authorizations and claims across care providers.

At Ohio’s MIDD CCOE, the philosophy is for providers to collaborate live with one another to address service gaps between mental health (MH) and developmental disabilities (DD). Formal teams from both specialties meet regularly and have one or more levels of involvement, including coordinating funding and sharing treatment plans. The organization cites many advantages to this coordination and collaboration, including improvements in service delivery for sub-acute cases and more organized access to resources for the organization and its clients.

> “Dual diagnosis teams can help each system maximize the other’s strengths and meet challenges,” reads one slide in a presentation. “A mental health worker might come to a group home and offer training on working with traumatized clients. A DD worker might offer to bring DD clients to their MH sessions, greatly reducing the risk of no-shows and thus improving productivity for that worker.”

Another example of care coordination improving outcomes and exemplifying best practices is through the Autism Treatment Network (ATN), which launched in 2005. The goal of the network was to determine how to raise the bar of medical care of children with autism and to bring forward the medical issues autism spectrum clients might have been facing but were being overlooked.

ATN pulls together a group of multidisciplinary specialists from 15 clinics to concurrently track the medical needs of their clients, creating a think tank so the information generated from the reporting can be tested for efficacy and then shared outside the ATN.

“We are finding what co-existing conditions are most being seen with children with autism and then what are the best ways to treat them. That is how we collect the data, for outcomes,” said Donna Murray, senior director of medical research, noting they also look at what treating the co-morbidity has on one’s autism symptoms. Murray said already the team has found gastrointestinal issues, for example, tend to be prevalent among children on the spectrum. Currently, there is data from nearly 7,000 children in the ATN registry, which is accessible to external researchers, too.

In Ohio, the Ohio Department of Developmental Disabilities, a state agency, oversees the Autism Diagnosis Education Project, ADEP. This program builds partnerships between physicians and early intervention specialists. Currently, 47 of 88 counties are involved in the program, and their collaborative work has enabled the state to lower the average age of diagnosis from 4 years old to 30 months.

> “We have identified these partnering physicians and the teams work together on the diagnostic process. This ensures families don’t get bumped from one entity to another when they first suspect their child has autism. The families have a local connection and a solution to get the answers they are looking for,” said Jody Fisher, a former autism project manager for the Ohio department.

CLIENT-DRIVEN CARE

Another shift in the healthcare landscape is one toward greater client engagement. In a whitepaper recently co-published by Morrison and Roy Starks, M.A., vice president of Rehabilitation Services and Reaching Recovery, Mental Health Center of Denver, the authors state the traditional model of healthcare was paternalistic, driven by professionals in a hierarchical model in which clinicians believed they and

the staff knew what was best for the patient. Treatment planning and charting activities were usually done behind closed doors and with no patient involvement. It was common for clinicians to communicate using professional jargon, especially around diagnostics. Decision-making was largely the purview of the clinical professionals.

> "The model of the all-knowing clinician and the passive patient is coming to an end," wrote Morrison and Starks, noting the ACA expressly calls for giving patients more control over their lives.

This stands to benefit the intellectual/developmental disabilities community, too.

> "Treatment is different for every single person [on the autism spectrum]," said Tom Hess, autism project manager for the Ohio Department of Developmental Disabilities. "The treatment goals are as varied as the people who have autism."

According to a 2012 ONC policy brief, Individuals who engage in their healthcare treatments achieve better health outcomes and benefit from lower health care costs.

The Grafton Integrated Health Network in Virginia is at the forefront with its use of Applied Behavior Analysis (ABA) to increase useful or desired behaviors and reduce behaviors that may be harmful or interfere with learning. ABA therapy is used to increase language and communication skills or improve attention, focus, social skills, memory and academics. ABA can be used to help decrease problem behaviors.

Grafton ABA services are provided by a Board Certified Behavior Analyst (BCBA) or a highly-trained paraprofessional under the supervision of the BCBA. Services can be provided in the child's home, school, or at one of the Grafton clinic locations. Once clients learn in a structured teaching setting, the focus is placed on incorporating the skills into everyday life. The ability to apply learned skills to various environments, settings and situations such as school, home and the community is imperative, and the end goal of Grafton's ABA program.

> "Grafton emphasizes a person-centered approach which embraces the preferences, goals and choices of the consumers we serve," said Jason Craig, Grafton's director of ABA services.

The organization is piloting a technology it calls Reboot, which enables clinicians to take the goals they set with and for their clients and make them accessible via a user-friendly web portal. This way, explained Scott Zeiter, Grafton executive vice president, families "see the goals in real time, can communicate their successes and challenges to the treatment team [and vice versa] and the family can be engaged more in the treatment."

Tracking it all through a web-based portal allows Grafton clinicians to use the outcomes of these treatment plans as "big data" to help drive which types of interventions are best for which types of children with autism. This approach can also take geography, age and a multitude of other factors into account to personalize the care provided.

ATN's Murray said while it has always believed patient engagement was a high priority, the team is starting to rethink the definition of engagement with the greater push for (and evidence of success through) utilization of electronic tools.

> "We used to think having patients come to the clinic was the best for their treatment over time. What we are learning from families is when you do need face time versus when you could use technology more effectively," she said, noting the network is in the market now for patient portals and interactive apps so they can stay better in touch with clients on their own terms.

> "The prevalence of autism appears to be increasing. …I think the market is trying to find solutions that are more community focused and better integrate the family and community into the treatment," said Zeiter. "We are working to develop best practices so we can do that in the most effective way."

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