

## **Community Organization Spotlight: An Interview with Joan Carney**

By Arin Jayes

As part of our exclusive weekly membership content, we will be releasing the “Community Organization Spotlight” series highlighting professionals in the brain injury field who will discuss their work and the programs they are a part of.

This week, I am highlighting a veteran in the field of pediatric brain injury –Joan Carney, Ed. D., Director of the Fairmount Rehabilitation Programs within Kennedy Krieger’s Pediatric Rehabilitation System. Dr. Carney also directs the Inpatient Educational Services Unit and a training grant working with parents and professionals in the community, the Specialized Health Needs Interagency Collaboration project. She also currently serves on BIAMD’s board of directors and the Governor’s Advisory Board for TBI.

After starting her career as a special education teacher, Kennedy Krieger brought Dr. Carney on in 1986 as an Educational Specialist to coach families through navigating the special education process after their child left the hospital. Dr. Carney explains that this process, which was built to accommodate children with developmental disabilities, is cumbersome for families and not always TBI-friendly. “Children with TBI who had been developing normally suddenly had this change in their performance and are returning to school a very different student,” Dr. Carney explains. “Families are left to navigate a process that isn’t good at accommodating these sudden changes.”

Medical care is only the beginning of the continuum of services needed to support a child’s long-term needs after a brain injury. When children are deemed medically stable, insurance limitations often force children to be sent home long before they are ready to return to school. Many of these children are still in need of outpatient therapy, with a schedule and a routine that can help them transition back to a full day of school. In response to this, in 1995 Kennedy Krieger developed their intensive day rehabilitation programs. These programs include the Specialized Transition Program, the Constraint-induced and Bimanual Movement Therapy Program, and the Community Rehabilitation Program.

Within Kennedy Krieger’s Pediatric Rehabilitation continuum, children have long-term follow up throughout their recovery; for many, as long as ten- or fifteen-years post-injury. As the child ages and moves through life’s transitions – new schools, friend groups, and body changes – they are supported through specialized interventions geared toward their unique needs. “You don’t leave here until you move on to adulthood and connect with adult services.”

What also makes Kennedy Krieger’s continuum of care unique is their incorporation of the interdisciplinary team throughout the child’s recovery. Support plans require the effective communication of the psychiatrist, physical therapist, occupational therapist, special educator, psychologist, social worker, and anyone else tied to the child’s recovery plan. “Each time a family comes back for follow-up care, they may have a different need. So, the interdisciplinary

team helps [the family] be able to say to other people, “that’s going well, but today, this is the issue we’re facing right now in recovery.”

Dr. Carney completed her doctorate in education from the Johns Hopkins University in 2012 with her dissertation studying the functional outcomes of children with hemiparesis who participated in Constraint-induced Movement Therapy (CIMT). Her ongoing research focus is on the efficacy and best practice protocols for CIMT and other therapy practices being provided in the clinical programs under her direction. Hemiparesis, or unilateral paresis, is weakness of one side of the body. Through casting the child’s stronger arm, use of the less effective arm is strengthened through functional tasks like feeding, dressing, and play. “We cast them 24/7 for a month. After the first day, the kids get used to it and really start to use their less-functional arm more routinely. It’s about getting used to doing things two-handed again.” When the cast is removed, children practice integrated, bimanual tasks. While a child may still have long-term effects of hemiparesis, incremental improvements are able to be made through these specialized therapeutic techniques. Kennedy Krieger practices CIMT with children as young as 8 months. “Once the child is old enough, we like to talk to them about what it is they would like to do that’s two-handed. We had a boy who walked his dog every day and was having trouble hooking the leash and zipping his hoodie, which were the two most important things that he wanted to do. When the child is old enough, you need to make sure they explain to you why they need to do it.”

Dr. Carney explains that parents often assume that their child will recover better from their brain injury than an adult would, but this is not always the case. “Families tend to think that they’ll have this initial acute recovery period, and that as time goes on, maybe their child will “catch up,” or link right back into the developmental process at the same pace as their peers. And depending on the severity of the injury, that may or may not happen.” The key though, she continues, is to keep looking for improvement.

Dr. Carney highlights the transition from elementary school to middle school as particularly challenging for children living with brain injuries. Elementary school, which is usually very structured and taught by one instructor, is a stark contrast to middle school – which involves multiple teachers, differing classroom routines, and many extracurricular activities. This adolescent transition period – when children are asked to become more independent and take risks – is when Kennedy Krieger’s continuum of care becomes critically important. “The whole overlap of recovery and development are tricky... Just when you think a kid is doing really well in school, what we are asking them to do changes and all of the sudden they don’t look as good as they did. But that means we just have to adjust what we are doing for them.”

When asked what she would say for discouraged parents reading this article, Dr. Carney stated that parents of children with brain injuries rarely think about their own needs. She recommends support groups for caregivers, which provide a sounding board for parents to share their struggles and gain support from others with similar experiences. For parents less willing to attend a large group setting, talking to another parent who has gone through it is also an option. These types of networks often happen organically in Kennedy Krieger’s waiting rooms and can develop into lifelong friendships.

In addition to seeking support from other parents, Dr. Carney recommends that parents adjust their expectations. “Choose your priorities,” she says. “What do you want to accomplish this year?” With the help of a multidisciplinary treatment team, families can map out realistic goals with their child’s long-term wellness in mind. “We use the word recovery a lot, which implies that this child is going to get back to where they were. There is a kind of totality in the word recovery rather than just improvement... Some of these children are going to be different and there are going to be adjustments that they and their family will have to make.”

Dr. Carney also calls for increased pediatric TBI screening to raise legislative awareness of the issue. This past year the Maryland TBI Advisory Board, with Dr. Carney as a board member, proposed [legislation](#) designed to study and report the under identification of brain injuries among school-age children, and make recommendations for a process to identify these children. It was introduced in the Maryland House of Delegates, where it passed unanimously. However, the proposed [legislation](#) was voted down in the Senate. The TBI Advisory Board is currently drafting new legislation for this upcoming year to help identify students affected by brain injury.

Noting that education supports developed for children with developmental disabilities are often utilized in working with children with TBI, Dr. Carney stresses that these two group’s needs are overlapping but also very different. “I think the biggest thing that we’re struggling with right now is really finding out how many children have experienced TBI, because if the schools knew how many students they serve with TBI, then they would maybe be putting more resources towards educating teachers and raising awareness... And then recognize how they’re different from other students with disabilities, both along the developmental continuum and in the patterns of needs that they have in an educational environment.”

While pediatric brain injury is difficult field to be in, Dr. Carney finds motivation in witnessing the strength that children and families draw upon every day. While attending a Christmas party last year, a guest asked what she did for a living and remarked “that work must be so sad!” She disagreed. “For me, it’s a very optimistic field to be in. There is always that incentive – that you’re going to meet another family and another child that needs the help of myself and all the colleagues around me. In the end, they’re so much more improved when they leave, so there’s always that optimism that comes with watching them change. The onus is never on one person to make things happen. It’s a group effort.”

HB 708

<http://mgaleg.maryland.gov/webmga/frmMain.aspx?pid=billpage&stab=02&id=hb0708&tab=subject3&ys=2019RS>

SB 778

<http://mgaleg.maryland.gov/webmga/frmMain.aspx?pid=billpage&stab=02&id=sb0778&tab=subject3&ys=2019RS>

## REFERENCES

- Joan Carney, EdD (n.d.). Retrieved from <https://www.kennedykrieger.org/patient-care/centers-and-programs/specialized-transition-program-neurorehabilitation-day-hospital>
- Specialized Transition Program (n.d.). Retrieved from <https://www.kennedykrieger.org/sites/default/files/library/documents/patient-care/centers-and-programs/brain-injury/specialized-transition-program-factsheet-11-28-2016.pdf>
- Center for Brain Injury Recovery (2016) Retrieved from [http://kki-copy.centreteksolutions.net/sites/default/files/patient-care-related-brochures/center-for-brain-injury-recovery-brochure-october-2016\\_0.pdf](http://kki-copy.centreteksolutions.net/sites/default/files/patient-care-related-brochures/center-for-brain-injury-recovery-brochure-october-2016_0.pdf)
- Reyst, H. (Ed.). (2016). *The Essential Brain Injury Guide*. Vienna, VA: The Brain Injury Association of America. Print.