Social Distancing: Thoughts from a Ligas Family Advocate

Well, that escalated quickly… what initially felt relatively manageable has suddenly become deeply isolating. Information is not in short supply, but sourcing it is challenging. Families across the state who are parenting a child or young adult with developmental disabilities are navigating new and murky waters. We are not unfamiliar with social distancing. As a matter of fact, unintended and unwanted social distancing has been a large part of our lives for years. From schools that are poorly resourced, community programs that are built around rigid rules and standards, inaccessible social spaces, outings that lead to sensory overload – being “apart” from the crowd is not new to us. But, this larger sense of vulnerability brings with it so many new concerns.

For our children, regardless of age, who rely so deeply on the school system for relationships, social interaction, and routine – what now? How do students who have worked to make so many gains avoid regression and skill loss amidst this shut down? Parents have reached out to us feeling overwhelmed and unprepared to provide effective academic support. Teachers have provided an excellent framework, hands-on learning tools, and online resource, but the reality for parents is that this is unchartered territory. Most of us are not natural home schoolers, and this new reality around academic support brings real concern and a sense of ineptness. How do we help our children understand the changes that we are facing in a way that doesn’t increase anxiety?

For working parents, the nurses and doctors, janitors and postal workers, the police officers and firefighters who will not be able to miss a beat during this shutdown – how are they to navigate? For these workers who are parenting children and adults with complex medical needs, intellectual disabilities, and mental health challenges that make day-to-day life more challenging, how can we serve them? All of a sudden, the lack of community day programming, school and transition programs, consistent mental health programming and reliable child care has produced real concerns about employment security and basic safety. It is hard to care for others in a professional capacity when you aren’t certain that your own child is safe.

Families have shared their fears regarding the isolation that their adult child living in a CILA may be feeling during a time of strict visiting limitations. They question whether to temporarily remove them from the CILA, upending their routine and daily relationships for likely two months or more, or leave them in the CILA, knowing that they will certainly struggle with the lack of regular in-person connections with their family and friends. For families trying to navigate Home-Based supports, the challenges are different, but not easier. How do you find PSW’s to care for your adult son or daughter who has gone to community day programming for years? Do you set aside your own work to take on a full-time PSW role, knowing that puts your employment at risk? Home-based families are challenged with managing medical needs, emotional and social support, and recreation with little to no planning time or outside support for what is likely weeks of isolation.

Today, at our house, we will navigate it – with some humor, a puzzle or two, and lots of movies. We will remember that we have done this in many different ways through the years, and we will let go of expectations (another area of expertise for each of us!), eat some junk food, and try not to allow ourselves to get sucked into watching the numbers and the closings ramp up. We will remember that this is simply a necessary season. Check in with one another, share your struggles and worries, ask for help, and know that we are with you in this.

Written by Megan Mutti Poole, Mom and Arc Ligas Family Advocate