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Visioning the future of residential treatment: Creating care communities

Interview with Rita M. Gardner, M.P.H., LABA, BCBA, CDE® by Mary Jane Weiss, PhD, BCBA-D

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In this interview, I had the fortunate opportunity to speak with Rita Gardner, MPH, LABA, BCBA. Rita serves as the President and CEO of Melmark. In this interview we highlight this non-profit organization's expansion of residential options, an area of tremendous need for adults with autism. The vision for a comprehensive residential model that supports each individual in a familiar, responsive, and compassionate care context is truly compelling. As providers face caring for individuals with complex needs, such as those with severe behavioral challenges or who are aging, this model stands out as a creative and beneficial solution. Rita also shares some advice for persevering, for continuing to innovate, and for keeping our focus on the outcomes that matter for those we serve.

Mary Jane: Hello and thank you for taking the time to speak with us about your vision for a novel residential model for autism intervention. Melmark has been known as an innovative service provider for decades. You have successful models for addressing comprehensive care needs throughout the lifespan of the individuals you serve. We have heard people talking about the crisis in adult services, and about the cliff phenomenon (specifically, how services literally drop off and eligibility to quality care is reduced in adulthood). First, can you tell us a little bit about the current landscape of adult services and about the challenges that exist in providing quality care to adults in residential settings?

Rita: The landscape of adult services has chronically been underfunded and, as you stated, often called "the cliff" that individuals fall off as they turn 22. An individual's 22nd birthday ends all educational entitlements and begins the process of trying to find adult services placements. Unfortunately, the condition of Adult Home and Community-Based Service (HCBS) providers in the United States was a significant challenge before, during, and after the COVID-19 pandemic. Post-COVID-19, challenges were significantly worse. We saw increased demand for HCBS services, workforce shortages, and the pandemic created significant financial strain on many human services providers. In 2023, we saw the most significant workforce crisis in the history of the United States. While workforce challenges for direct support professionals (DSPs) in the disability sector were a concern before, the situation has worsened, due to factors like increased demand due to the aging population of individuals in the United States, inadequate compensation, and the increasing complex nature of the work. In today's adult services environment, improving health for these individuals largely falls outside of healthcare facilities. DSPs are no longer just providing basic care but are often providing complex medical supports. We know individuals with I/DD as they are aging experience age-related healthcare conditions earlier than the general population. This leads to a negative impact on the quality of life. Programs must anticipate age-related needs to facilitate appropriate physical environments, provide supportive healthcare services, and ensure skills training to DSPs that will allow individuals to age in place.

Mary Jane: Thank you for providing us with so much context about workforce challenges. The challenges posed seem to be largely systemic, and there seem to be many components that create obstacles. These include regulatory entitlements, funding streams, industry standards, and availability of a qualified workforce.

Rita: Currently, there are not enough financial resources in the HCBS system to address the systematic care needs, and almost 750,000 aging individuals with I/DD sit on waitlists for adult services across the United States.

Mary Jane: Those are some sobering statistics and really illustrate the ways in which inadequate resources hamper our ability to serve this population adequately. Melmark has recently addressed these challenges in a novel way. Can you describe the new model for us? How did you develop this vision?

Rita: We started by evaluating some of the public health research on aging issues in the United States. Our Pennsylvania campus has a significant aging population, and we've learned much over the years about the types of care that are required to ensure best outcomes. We searched the research literature where there are current care systems in place being used with elderly populations. Then, we sought to innovate them with the I/DD aging population, hopefully creating an innovative new adult services model.

It is modeled after the high-end continuing care retirement communities (CCRCs) for elders, where independence at different levels can be maintained with appropriate supports built in. The National Investment Center for Seniors Housing & Care (NIC) provides compelling evidence for the benefits of residing in CCRCs. As revealed in public health research, seniors living in CCRCs not only live longer, but also enjoy a better quality of life compared to those who choose to stay alone at home.

One of the standout findings from the NIC study is that mortality rates for CCRC residents are significantly lower than for the general population. This data aligns with the research highlighted in NIC's recent article, underscoring the social determinants of health benefits of community living for seniors. Residents of CCRCs live longer than those in other senior living settings, including standalone assisted living and independent living environments. Residents also had fewer hospital visits and rehabilitative needs.

The study also noted that CCRC residents spend less time in hospitals and require fewer home health visits, indicating not only fewer medical issues but also a faster recovery from any health events that do occur. Furthermore, CCRC residents are less likely to need rehabilitative services, suggesting a lower incidence of severe health events that require intensive post-care. This study has been replicated in public health research and published in peer review journals.

Mary Jane: Sounds like these findings are not only compelling—they're instructive. How will you adapt the CCRC model to meet the unique needs of young adults with intellectual and developmental disabilities. Tell us about the most important elements of the program…

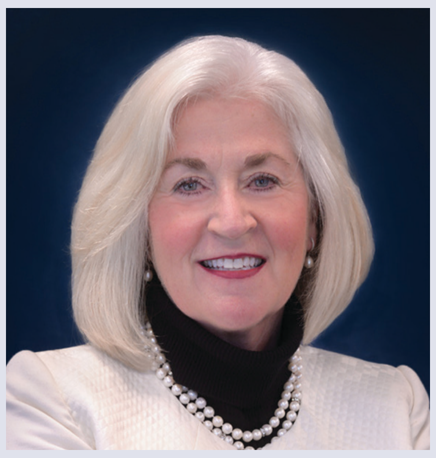
Rita: We plan to provide our young adults with a supportive environment that enhances their lives, while stabilizing the staffing population that this acute population absolutely requires.

We will offer comprehensive care offerings and robust wellness programs to ensure that every resident can maintain their health in a community that cares deeply about their well-being and knows how to provide medical care through thorough assessment and evaluation. We plan to tailor our health care services to meet the individual needs of each resident, ranging from minimal support to advanced medical care, contributing to fewer hospital stays and a significantly enhanced quality of life. The studies on CCRCs are clear: Living in a CCRC leads to a life characterized by better health outcomes, less medical intervention, and more positive, active, and social years while individuals age in place.

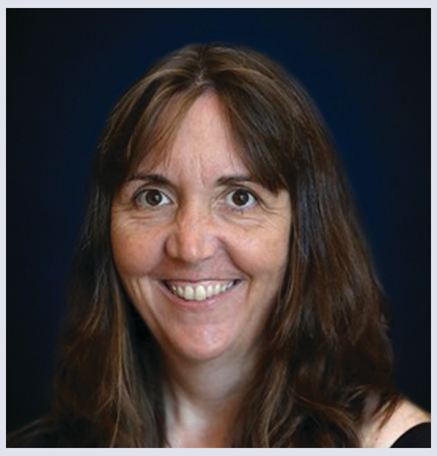
The project will address an ever-growing need in the state of Massachusetts for adult services that are evidence-based and instructional for individuals with autism, intellectual disabilities, and developmental disabilities. The three-acre site in Tewksbury, MA will include four residences housing a total of 20 adults, an instructional and vocational day program for 50+ individuals, a vocational coffee shop social enterprise, daily living activities, supports, community engagement, recreational opportunities, and affordable staff housing.

Mary Jane: That sounds like a wonderfully engaging environment! It is heartening to hear about all the details that have been considered and all of the elements that will provide diverse and high-quality experiences for clients. Given the challenges to funding and effective service delivery, we need to consider what families of consumers and service provision organizations can do to advance the goal of providing quality care to individuals with disabilities, especially as adults. And we need to consider these questions in the context of reduced resources.

Rita: Medicaid cuts are a reality that all nonprofits and advocates must accept is coming. Working with policymakers to create new ways to reduce waste, consolidating and sharing resources across programs, and developing more efficient systems will serve our community more effectively. While specialized housing may seem expensive initially, the long-term cost benefits are compelling. Research shows that individuals with ASD incur average annual healthcare costs of $22,653 through Medicaid, with frequent hospitalizations and emergency interventions driving up these expenses. The lifetime societal cost of supporting an individual with autism can reach $3.2 million, with adult care being one of the largest components. Studies have consistently shown that individuals with autism have higher healthcare utilization and costs compared to the general population, but these costs can be significantly reduced through appropriate specialized care and skilled direct care staff that prevent crises rather than simply responding to them. By investing in proper housing and support systems now, we can improve outcomes, reduce long-term societal costs, and allow our individuals to age in place.



Rita M. Gardner, M.P.H., LABA, BCBA, CDE®
Melmark President and CEO



Mary Jane Weiss, Ph.D., BCBA-D
Melmark Senior Director of Research

- Importantly, for behavior analysts to help address critical public policy issues, there are several things they can do to be part of the solution:
- Preventing costly crisis interventions and hospitalizations through proactive care;
- Reducing medication needs through better environmental and behavioral supports;
- Reducing quantity of medical and therapeutic visits by adopting an on-site interdisciplinary co-treating model;
- Lowering staff turnover and training costs by providing specialized career paths, supporting team environments, and allocating additional and consolidated resources during a behavioral crisis or crises;
- Minimizing property damage through appropriate physical facility and environmental design; and
- Decreasing family caregiver burden and associated lost productivity.

Mary Jane: That information is so crucial. And I think you are so right; we need to highlight these financial realities as we advocate for service models that deliver meaningful outcomes and solve significant challenges in service delivery. What suggestions might you have for how innovation might inspire us to create new solutions? How can we "think outside the box" to develop innovative models of care?

Rita: We must think outside the box and consider innovative approaches. We can learn and borrow from what is known from other disciplines and other populations, and then tailor supports that are needed for individuals with autism. This model is compelling because it supports Quality of Life, leverages the expertise of autism service professionals in a long-term care context, and ensures that clients continue to thrive in an environment defined by humane and compassionate care.

Mary Jane: What suggestions do you have for mobilizing our community to work toward solutions to these shared challenges?

Rita: It has been very hard to be resilient in a time of such rapid changes and post an exhausting pandemic. We all must realize that without our voices nothing really ever changes. Our work starts by engaging in individual advocacy. This means educating stakeholders about the needs of adults as they turn 22 and how we can develop resources to ensure there are safeguards available so that the work done in under 22 programs is not wasted. Individual advocacy must focus on extending programs past an individual's 22nd birthday and ensuring that adult services and HCBS programs across the US have a range of models that build in individuals' choices, and that are built to meet a range of needs. The burden to mobilize truly is on all of us.

We cannot benefit from employment in the field of autism services without also using our voice to change public policy. It is critical that we move from individual to systematic advocacy to look at remedying the underlying causes of practices such as lack of funding and the unavailability of supports and programs for individuals to live healthy and safe lives. Behavior Analysts, and many other professionals, are in positions to engage in both types of advocacy (individual and systemic). They can offer support from the research and from the front lines of clinical care, and they can demonstrate success in programs that can be modelled. Public policy work takes time and significant behavior shaping. There are no better professionals to do that advocacy than Behavior Analysts.

Mary Jane: This last question is broad but reflects the reality of these times. Perhaps more than ever, it can be difficult to sustain hope as funding challenges intensify, and it can be difficult to discern solution-oriented paths forward. What propels you to continue in your work and in your mission? What advice can you offer to the community about perseverance and persistence?

Rita: I like to say I was built for this work by my Mother's modeling while she raised fourteen children. She helped shape my values, and the mission is something that is personal to me. It reflects my heartfelt beliefs about community and what we should all embrace. I am incredibly lucky to work with colleagues, particularly over the last 30 years, where success becomes the foundation for added success. I am often thinking the next mountain is too big or the goal or vision is too bold, but we reach it! I love complex problems and will never give up on resolving them or on designing good organizational interventions to address and elevate our work. We have found in working together, opening over 100 programs, that we have been able to reach and achieve more than we had ever imagined. So, when there are difficult times and perseverance and persistence are required, we remind ourselves that for 40 years, the sector has had its ups and downs, and the only way to move forward is to continue to focus on the mission of serving individuals with the highest quality services possible. At the end of the day walking down to a classroom and seeing a new student being incredibly successful, or a student graduating back to a less restrictive environment, or an adult socializing with peers in the community, is all I need to wake up every day and persevere to continue to achieve those best outcomes. When the path feels steep, remember that it's the quiet triumphs (the smile of a thriving resident, the dignity of an adult living their best life) that make climbing that mountain worthwhile. Let those moments guide you, and never lose sight of why you started this important work in the first place.

Mary Jane: Rita, I am not sure how to thank you for the model that you are to all of us. While your innovation has been inspiring to so many for decades, I think it is your perseverance and persistence that I most admire. Thank you for continuing to be the role model of resilience, focus, and mission-driven action that we all need to emulate. It has been exciting to learn about how Melmark is envisioning this supportive and integrated care community. Thank you for leading the way with your vision and example.