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Presidential Address 2024—Achieving Health Outcomes Across the Lifespan

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It is my great honor and privilege to speak with all of you today to help open the 148th annual meeting of the American Association on Intellectual and Developmental Disabilities (AAIDD) and welcome you to this great city of Louisville. I would like to thank members of the Planning Committee, the Local Arrangements Committee, Dr. Maggie Nygren, and the superior AAIDD staff who have worked tirelessly over the course of the last year to ensure an engaging, interactive, and interesting conference where we can all learn from each other, network, and leave feeling inspired about the work that we do. Please take this time away from your daily jobs to immerse yourself, reconnect with old friends and colleagues, and meet new ones.

I may not be able to rap like Dr. Liz Perkins, cite research like Dr. Karrie Shogren, or author and edit books like Dr. Mike Wehmeyer, but what I do know well is how to support the community health care needs of individuals with intellectual and developmental disabilities (IDD) and/or autism. For almost 30 years now, this has been my role in Southeast Pennsylvania, just completing my 25th year at my current organization, Philadelphia Coordinated Health Care (PCHC), which is also known as the Southeast Region Health Care Quality Unit.

Healthcare in a Post-COVID World

As I reflected on my work related to this year's conference theme, Achieving Health Outcomes Across the Lifespan, I realized that we haven't hosted an annual meeting with a healthcare focus since 2017, which also means since pre-COVID. So, as much as we feel like things are relatively back-to-normal now, I would be remiss if I did not mention how access to healthcare has changed in general and for the IDD population since that time. I recently read an article that indicated that this generation would all remember where we were on Friday, March 13, 2020 when the world stopped due to COVID. I'm sure if you all take a minute, you can remember exactly where you were or exactly what you were doing in the days leading up to it. That day is now monumental and etched in our brains like the day some of us heard that John F. Kennedy was assassinated or the space shuttle Challenger exploded. For me, I was hastily trying to complete the work-from-home approval forms that my staff would need to telecommute for the "2 weeks" COVID was supposed to last. Little did we know then that it would last much longer.

Living and working in Pennsylvania's Southeast Region, with Philadelphia as our lead county, one would think that we had lots of resources and support at our fingertips. After all, we have the Jefferson Health System, Pennsylvania Hospital, and the University of Pennsylvania and Temple Hospitals all within close proximity. Well, nothing was further from the truth, especially for folks with intellectual and developmental disabilities. The calls and emails started fast and furious that very first evening from provider agencies trying to navigate the crisis with the following questions: How do we get personal protective equipment? How do we teach staff about COVID? Where do we get resources and support? What do we do if individuals and/or staff became infected? How do we get medications? For the community provider world, this was your worst nightmare—it was New Year's Eve, Mother's Day, and a massive snowstorm all rolled into one, and it wasn't going away.

In fact, it was worse in our region because we were so densely populated, much more than our other counterparts around the state. I remember being on a program director's call in which the others only reported a few COVID cases each. I was quiet on the call and spoke last. I reported the triage work that my community nurses were handling while participating in at least two to three provider calls a day. Our nurses completed approximately 135 community provider engagement calls during the first year of COVID.

I liken it to feeling like the old TV show *MASH*. The other health care quality units around Pennsylvania could not comprehend what we were experiencing in the Southeast Region. Even though we were working remotely, we still felt the pressure and responsibility of being a resource and providing answers to the teams of staff and individuals that were alone working in the community. This was all new to everyone. How was the system supposed to provide access to quality healthcare in the community during a pandemic?

But the Southeast Region of Pennsylvania did what we do best—we rallied together and faced COVID like Rocky running up the Philadelphia Museum of Art steps. We were in Philadelphia after all. Community nurses, provider agency staff, supports coordinators, county administrators, and even regional state staff ensured that individuals with IDD were safe, had adequate staffing, could get their medications, and could access COVID vaccination shots and boosters as needed. They did all this work while telecommuting, I might add. But then, as COVID lingered, it impacted routine medical appointments and quality of life issues for the folks we supported, which we all learned to endure as "the new normal," and changed the service delivery system for everyone.

Telehealth and Online Supports

I think we can all agree that one of the most positive changes to come out of the COVID experience in regard to access to healthcare for people with IDD is the increased use of telehealth and the continuity of care it brought for the folks that we support in the community or at home with families. Suddenly, managed care, health insurance, and medical practitioners were finding a way to use telehealth with our population. Community providers, families, and direct support professionals (DSPs) began supporting individuals to use it. It became a necessity for healthcare maintenance and preventative care access. With telehealth, individuals with IDD could continue a much-needed medication regimen, receive a quick COVID test, confirm a diagnosis, or simply ask a question or try to alleviate a pain issue. Zoom, or your favorite virtual platform, was your new best friend and used as an alternative form of communication for many health assessments, team meetings, or reviews. And, finally, the field was forced to transition to electronic health records and electronic forms to comply with the requirements of many funding entities, which also eased some administrative burdens.

I can remember when our organization had to pivot from hosting integrated heath clinical reviews (IHCRs) from in-person to Zoom. The IHCR is a team approach in which physical health concerns are evaluated by a community nurse before a behavioral health team makes an assessment. In some situations, a psychiatrist will conduct a medication review and attend the team meeting to provide their recommendations. It's a lengthy process that involves a lot of support members from the person's team. We quickly realized that it was much easier on the whole team, especially for the individual, to meet virtually via Zoom. Let's face it, no one wants to drive into center city Philadelphia and navigate traffic and parking. But, most importantly, it was much less stressful for the individuals themselves and we could easily accommodate many more people's schedules virtually than in-person. Once we switched to Zoom, we have not gone back to providing in-person IHCRs and we have actually increased the number of these types of clinical reviews we perform in a month and on a yearly basis since COVID. This provides an increased support to the individuals we support with a dual diagnosis in Southeast Pennsylvania.

Some other positive outcomes to come out of COVID were an increase in online services and supports. People began to rely on the internet to provide healthcare online training, supports, and resources for individuals, families, and DSPs without ever having to leave the house. If necessity is the mother of invention, then COVID opened the doorway for more advanced and interactive virtual healthcare learning. Although online training existed before COVID, during COVID, it became the only means of education for DSPs that felt isolated while in homes with individuals who still needed ongoing education and information. YouTube and Pinterest provided creative ways for not only entertainment but also creative recreational, communication, and physical behavioral health ideas. Due to the increase and widened use of Zoom and telehealth, many states changed their policies to incorporate both platforms into their regulations and procedures.

Achieving Health Outcomes Through Training

Enhancing Advocacy in Physicians

Although there were some positive things that affected healthcare access for folks with IDD during COVID, there remained some challenging issues as well. Unfortunately, there is still a lack of physicians who are willing to treat this population, especially in the areas of dental care and behavioral health. I can't tell you how many calls I receive asking for a list of a larger number of dentists, psychiatrists, and behavior specialists that serve with people with IDD in our region, and we are in an urban city. But we all know what happens as soon as a new physician is found that treats individuals with IDD—we refer everyone to them rather than expecting all physicians to treat patients with IDD in their caseload. This is where physician education is vital!

Dr. Rick Rader from the Orange Grove Center in Tennessee recently presented to the United Nations as part of Down Syndrome International's 2024 World Down Syndrome Day Conference. In his presentation, he stated, "There are 1.4 million medical students in the world, attending 3,800 medical schools in 186 countries. Training to become a doctor, depending on the country and specialty can take from 8 to 15 years of intense education" (Rader, 2024). Rader indicated that, on average, a physician will see close to 40,000 patients in their lifetime and stressed three main points to include in physician education: how to be an advocate, examine negative bias towards disabilities, and to avoid diagnostic overshadowing (Rader, 2024). I think we can collectively agree that these points should be included in all education for both medical school students and practicing physicians.

Enhancing Disability Competence Among Healthcare Practitioners

We do have some examples that are providing physician and student education about IDD. Intellect Ability has developed a curriculum for physicians, physician assistants, nurses, nurse practitioners, and other clinicians. The Curriculum in IDD Healthcare (IntellectAbility, n.d.) consists of 6 modules that teach practical skills that improve clinical competence in the provision of healthcare to people with IDD:

- DD Basics: Then, Now, and Next
- Healthcare Basics in IDD
- Common Behavioral Presentations of Medical Conditions in People With IDD
- Dual Diagnosis in IDD
- Effective Communications for IDD Healthcare
- Bringing it All Together: Case Studies in IDD Healthcare

IntellectAbility has already partnered with a few medical and nursing schools to train students using this curriculum. The curriculum is also being used to train practicing physicians to further their working knowledge and education.

Promoting People With Lived Experience as Teachers

Besides IntellectAbility, the Nisonger Center University Center of Excellence in Developmental Disabilities (UCEDD) at The Ohio State University (OSU) has been collaborating with the OSU College of Medicine since 2017 to incorporate IDD into their medical school curriculum. Individuals with IDD are paid contributors in the healthcare training practicum. The program embeds people with IDD into each year of medical school through lectures, patient panels, and an intensive curriculum. People with IDD pretend to be patients and have 1:1 interviews with the students. This curriculum helps the students become more comfortable treating individuals with IDD and reduce their biases toward treating people with disabilities.

Promoting Integrated Health and Wellness

Another innovative health access/education program has been initiated by Mr. David Ervin from Makom in the Washington D.C. metropolitan area. Makom hosted a health summit in May 2022 with self-advocates; local, regional, and national health policy experts; healthcare providers; and practitioners with experience delivering healthcare to people with IDD. The group met over 2 days to conceptualize a healthcare delivery system that provides comprehensive healthcare (including integrated dental care, mental and behavioral health, and specialty care) and wellness to people with IDD, design a national center of excellence in clinical training for health profession students and other practitioners in developmental medicine and dentistry, and develop a workplan to build such a system. The result of this summit is a blueprint for a healthcare collaborative clinic in which multiple stakeholders such as physicians, dentists and other health professionals, hospitals, academic medicine and dentistry, research institutions, and government can come together with a common purpose to identify gaps in healthcare for people with IDD and develop solutions to improve their care (Ervin et al., 2023a, 2023b; Ervin, 2024).

So, I think it's safe to say that we have some examples of successful models of physician education and medical school training even within this great state of Kentucky. The Lee Specialty Clinic led by Dr. Matt Holder is right here in Louisville. In fact, the last time we held the AAIDD annual conference here, the association's Health and Wellness Interest Network toured the facility. The Lee Specialty Clinic provides a wide range of comprehensive and general healthcare services for the IDD population, including physical health, behavior health, therapies, crisis intervention, and nutrition. It has "teamed up with accredited medical, dental, nursing and dental hygiene schools across the USA and the world" (Lee Specialty Clinic, n.d.) to create disability curriculum enriching educational programs for undergraduate, predoctoral, and postgraduate students. The Lee Specialty Clinic is ensuring that the next generation of healthcare professionals are better equipped to care for patients with IDD.

Educating Individuals About Their Healthcare

Besides educating medical students and physicians, we must also remember how important it is to educate individuals themselves about their own healthcare. PCHC has developed and presented plain language healthcare training (in person and online) and created resources on a variety of both physical and behavioral health topics. There are also many outreach topics that lend themselves to personal protection in the community, including internet safety, summer and winter safety issues, emergency preparedness, and, of course, COVID. In Pennsylvania, we have a statewide initiative to educate individuals, staff, caregivers, and families on the symptoms and treatment of a grouping of conditions that are known as the Fatal Five: aspiration/dysphagia, dehydration, constipation, seizures, and infection/sepsis. These health conditions can directly result in preventable incidents and deaths, and all of the health care quality units in Pennsylvania have made education on the Fatal Five a priority for the folks that we support.

Multiple Workforce Challenges Present Barriers to Achieving Healthcare Outcomes

Nurses

COVID has also affected the nursing workforce in this field. We seem to have seen a wave of developmental disabilities nurses retire or transition to other jobs once the COVID crisis was over. Because the demand for nursing was so high in hospitals, many nurses left the community provider sector for higher paying and more flexible positions. This has resulted in increased vacancy rates in nonprofit organizations that cannot compete with salaries being offered in other sectors. The Developmental Disabilities Nurses Association (DDNA) does extraordinary work to help recruit nurses to our field, providing ongoing education, and highlighting the importance of their role. However, more work could be done in nursing schools to provide an introduction to IDD content, specialty diagnoses, and hands-on experiences. The Jefferson Hospital System in Philadelphia recently partnered with the City of Philadelphia Department of Behavioral Health and Intellectual disAbility Services to provide nursing students with a hands-on education through their capstone project. The program's goal is to provide nursing students with IDD experiences and mentorship by provider community nurses while learning and working with area physical and mental health providers.

Support Coordinators

So, although all COVID restrictions have been lifted and it feels like we are back to normal in our daily work, we are still not totally back yet. Some parts of Pennsylvania and some provider agencies are not as fully open as they were pre-COVID. As I am sure you are all well aware, there is a massive amount of turnover, especially for the DSP and supports coordinator roles. This could be due to post-COVID residual feelings, lack of knowledge of IDD, health-related issues or just a sense of wanting a different career choice. The collective "we" haven't figured it out yet, but we are still working hard by caring for the folks that we have made a commitment to and running up those steps every day like Rocky.

My Story: Thrown in the Deep End

Everyone in this room has their own unique story of how they started working in this field. Whether it's a family member, close friend, volunteer, special interest, or, like me, you kind of fell into it and stayed, our unique stories are woven together like a fine tapestry or a beautiful blanket of diverse supports and services. One of the greatest assets of joining an association like AAIDD is having such a strong, multidisciplinary membership that enables us to ask each other for assistance, resources, or ideas throughout our careers.

In reviewing past presidential addresses, many include their story, so, if you would indulge me for a moment, I would like to tell you mine and how it led me to community healthcare for IDD and how I am standing before you today.

It all begins with three women of Ryan's Run, the provider home in the community in which they lived. The oldest was in her 70s and the two younger ones were in their 40s, each with their own diagnosis. The reason they lived together was due to their discharge from, and related litigation to, Pennhurst State School. I was new to the system and a freshman in the field. Every 90 days, it was my responsibility to take these three, along with a DSP, from a suburb of Philadelphia to center city Philadelphia during rush hour, in person (with parking), so that their medical records could be reviewed by court-ordered contracted physicians. I had no idea what I was doing. I had no experience with seizures, let alone psychotropic medications. What was Tardive Dyskinesia? Dysphagia? Did the medications treat the target symptoms? I had absolutely no idea, but here I was. That was also the year Pennsylvania's IDD Medicaid coverage pivoted from a single state plan to multiple managed care organization (MCO) plans. I was charged with deciding which Medicaid MCO would best benefit each woman and transferring their primary care physicians, durable medical equipment, pharmacies, etc. Besides your usual mandatory required training like Fire Safety, First Aid/CPR, and Crisis Intervention, there wasn't any training about healthcare, the internet was limited at the time, and we used pagers or beepers, not cell phones. I can remember being on the group home's landline "house phone" to help transition the women's health insurance plans and calling their primary care physicians to make sure they were included in their plans. There was no checking plans on the internet. I held a huge amount of responsibility for the lives and health of others, with no real training. I felt very overwhelmed and liken it to the feeling that I had when I had my first child many years later, but, of course, with children I had the support of friends and family.

DSPs Are an Aging Workforce

According to a recent report by the University of Minnesota and The National Alliance for Direct Support Professionals (NADSP), the average age of DSPs is 45 to 47 years old (Pettingell et al., 2023). This age range may seem high, but I spoke at length with Mr. Joe Macbeth of NADSP about the situation and he clarified to me that, in general, one-half of DSP hires leave or turn over, so the workforce is aging as the half of hires that stay grow ever closer to retirement age. His belief was that the newly hired DSPs were "significantly younger and that that they tend to turn over faster" (personal communication).

So, to think about that for a moment: if the most experienced DSPs are nearing retirement age and newly hired DSPs are turning over faster, all the healthcare training in the world will not suffice to support the aging population of our field. This topic is so imperative, especially related to healthcare as our population ages. How can we guarantee that today's DSPs' family members are ready to care for the long-term effects of aging and dementia in conjunction with IDD and autism? A vast array of education and continued supports is needed as we strive to enable individuals to age in place and participate in their own end-of-life planning (Velardo, 2021).

For the past 30 years, the DSP workforce has, in a sense, worked and aged right alongside the IDD population. Now, due to medical advances, medications, and more attention to their overall daily quality of healthcare, individuals with IDD are living longer than ever before. That means they are acquiring the same aging symptoms and diagnoses as the general population, and we desperately need staff, family, and caregivers to be educated to understand how aging effects IDD, dementia, and even end-of-life issues.

All this being said, I would not change my initial experience for the world. It provided me with a strong foundation and deeper understanding of supporting different individuals with different diagnoses in the community together. I have found since working at Ryan's Run that whenever I present training to DSPs and share my experiences, they appreciate my background and common understanding of their experiences and they trust my knowledge base more.

Health Outcomes Approaches

Perspectives Explored in Conference Plenaries

At this conference we are lucky enough to have a spectacular panel moderated by past president Dr. Susan Havercamp addressing the "Social Determinants of Health" with Dr. Kara Ayers, Dr. Emily Hotez, and Dr. Yolanda Suarez-Balcazar, who will each discuss different aspects of how their work helps to achieve better health outcomes for people with IDD. Kara will explore ableism, health equity, and the environment. Emily will relate the social determinants of health to the neurodivergent population, including bias and the need for physician training.

Yolanda will discuss her research, which includes intersectionality, race and ethnic issues, family and community engagement, and the importance of engaging individuals in research. The closing plenary will feature Dr. Gloria Krahn, who will show us how to interpret health outcomes for people with IDD from public health datasets and provide us with some future trends.

Everyday Lives Standards

In thinking about this year's theme, I was reflecting on the lessons still to be learned from those who lived at Pennhurst. Even though the initial litigation occurred almost 40 years ago in 1985, there are still ongoing court monitoring and compliance issues. The parties involved in a 1993 settlement shifted the focus of evaluation of compliance issues toward examining outcomes for class members and created the Quality Enhancement Support Team (QEST).

> One of the major steps in this plan was to develop a set of standards that could be used in the design, implementation, and outcome measurements of both existing and new supports and services. These standards became known as the Everyday Lives Standards. (Greusel, 2003)

The Everyday Lives Standards became the blueprint or gold standard for Pennsylvania's Office of Developmental Programs (ODP) and implemented by QEST. QEST developed a framework of domains for quality of life outcomes, many of which correspond with the categories of social determinants of health categories and are very beneficial in evaluating the person's overall quality of life and well-being.

The Pennhurst class is also aging. QEST has been able to evaluate their quality of life outcomes by domains, but has also been able to monitor their changing healthcare status as they age. At last count, there are 360 class members in the Southeast Region of Pennsylvania and 375 statewide, and the average age of the class members is in the mid- to late-60s. The court order will continue until the last member is deceased.

Looking Ahead

Supporting Students and Early Career Professionals

I would like to bring your attention to a priority for my presidential term and a topic that has been discussed by the board. The data shows that our membership has been steadily declining over the years. Retirement, social media, free online resources, and, of course, COVID have all played a role. AAIDD is not out of the norm in comparison to other national membership associations; in fact, we are quite the same. We have to constantly think of new and creative ways to entice new members to join and retain their memberships while reinventing our most coveted products and publications for students and professionals.

In reviewing past presidential addresses, one that stood out for me references the importance of supporting and promoting the students and early career professionals within AAIDD. I vividly remember Dr. Marc Tassé's 2012 presidential address as an early career professional, sitting in the audience like many of you here. At one point in his address, he began reviewing his priorities and, although I could relate to all of them, this one stood out for me. Although it is now 12 years ago, I think this priority still rings true and is worth repeating. So, if he will allow me to indulge you to share what I believe is a great reminder of how to support and promote students and early career professionals:

- if you are an AAIDD Fellow, become a guide;
- help support them by making a contribution to the Student Scholarship Fund;
- take extra time to chat with them at the annual meeting;
- go to their panel presentations and poster presentations;
- support a student's membership to AAIDD;
- support a student's conference registration and/or travel expenses to attend the annual meeting. (Tassé, 2012, p. 522)

I hope I can speak for the entire membership in saying how much we value the attendance and participation of the Student and Early Career Professionals (SECP) members. Your continued involvement is vital to the association's longevity. We look forward to your continued contributions.

Growing Our Professional Home

Time and time again, I have heard from numerous members and read in many of the past presidential addresses that a great deal of us feel that AAIDD is our professional home. Although I agree with you 100%, I also believe we are so much more.

Personally, for me, that was clearly demonstrated during the recent unexpected passing of my mother. I was so grateful and, frankly, overwhelmed by the outpouring of support from current and past board members, past presidents, colleagues, and members I like to call some of my "best" professional friends from all over the country. Many of you called; sent texts, emails, or cards with beautifully handwritten notes; and even sent food. I don't know too many other national professional organizations that support each other like we do. I believe Liz Perkins said it best at the end of her presidential address: "we are your AAIDD family, and we are here with you, and we are here for you" (Perkins, 2018).

Embracing the Value of Networking

My experience is only one example of how truly powerful and strong our AAIDD network is and how important it is both professionally AND personally for all of us to maintain and continue to strengthen our membership association. We all understand the importance of interpersonal relationships, especially post-COVID. Every year when the board reviews the annual conference survey, one of the most noted favorable comments is: "Networking"! When we had to pivot and provide a virtual conference platform, the thing missed most and commented on the surveys was the lack of "social interaction and networking," although Michael Bloom and I tried very hard with a virtual happy hour.

As we move towards celebrating AAIDD's sesquicentennial in 2 short years, it is our obligation as members to ensure our future for not only members yet to be, but to continue the vital work our association has produced in support IDD for close to 150 years.

My Agenda Items

As I conclude my presidential address, I would like to leave you with my agenda items to think about over the course of the conference and the next year:

1. *What will we do differently to make sure that individuals with IDD and DSPs are educated about healthcare?* My experience has been that educating individuals with IDD and DSPs together has been a very successful strategy. Utilizing plain language training material and creating curriculums to help people with IDD learn about their own physical and behavioral health diagnoses, and especially preventative health, can be advantageous to their overall well-being and quality of life.
2. *How can we better educate students and health care professionals about IDD?* Although we have some unique programs and champions within the IDD field, in this area, we could always use more. This is where the power of networking comes in. It only takes that one connection, personal relationship, or creative idea to start the ripple effect. Let's keep the momentum going.
3. *How can we ensure the continued stability and growth of our organization past the Association's 150-year mark?*

Think of one person, be it a new member, a student or early career professional, or a mid-career professional, that you can gently champion, mentor, and support within AAIDD. Encourage or join them in a proposal, support a SECP scholarship or just invite them to attend next year's conference in Washington, DC. I can guarantee we are all here as members now because, at one time or another, someone gave us that gentle nudge and encouraged us to attend a conference, submit a proposal, or join an Interest Network. I'm asking for all of us to continue that tradition and pay it forward to help sustain the membership of our association and the great work it produces. I'm excited to see what the future holds for AAIDD and the creative services and supports we have yet to develop for IDD.

At this time, I would like to thank you for this amazing opportunity and your trust to lead this wonderful association. I look forward to serving as the 147th President of the Board for AAIDD.

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