

Presidential Address: The Next Generation Workforce, A Call to Action

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It is my great honor to close the 145th meeting of the American Association on Intellectual and Developmental Disabilities (AAIDD) and speak to you on this year's theme, "Addressing Workforce Challenges: Promising Trends in Policy, Practice, and Research." When I first chose this topic, I could not have predicted the workforce challenges that would be presented to each of us over this past year due to the impact of Covid 19. I chose this year's theme for a much more personal reason. I was experiencing the medical, clinical, administrative, and direct support workforce through a new lens. A lens that would further shape my appreciation and offer me insight into some possibilities for the future.

I recall the day vividly. In May 2017, my dad was diagnosed with dementia. We went to his favorite restaurant for lunch to celebrate his 87th birthday with his siblings, and then onto the VA hospital for a medical appointment. He had been spending more and more time at my house and I was getting concerned about him being alone. He had recently had his driver's license revoked and was focused on getting it back. He needed a letter from his physician. I knew that he would not be getting his license back.

Dr. Lawrence knew us well. She had been his primary care physician at the VA for many years. She knew how he prided himself on being in excellent health. She worked to adjust his metformin as his diabetes improved as he aged. Without a word spoken between us, I knew that she could sense my concern. She listened to my dad and suggested we meet with the social worker who could assess his ability to drive. Though I knew that he was forgetting things, it was not until I witnessed him take the cognitive assessment test that I realized the extent of his impairment. He could not tell the time on the clock, he could not recall the current president, and he certainly could not remember 5 words "Person, woman, man, camera, TV." However, he was charming and flirtatious,

and I realized he was very proficient at deflecting the questions and pretending to understand.

At that time, I had been providing services and supports to people with intellectual and developmental disabilities (IDD) for 31 years. I had been a direct support professional in large institutional settings and in individualized community-based settings. I had coordinated in-home and out-of-home respite for families. I had been in leadership roles ranging from Program Director to Executive Director. I had studied public policy at the Heller School at Brandeis University and earned a Master's in Management of Human Services with a focus on Intellectual and Developmental Disabilities. But in that moment, my roles reversed from professional to family member, from service provider to service recipient. In the following three years, I would assist my dad to utilize in-home supports, respite, adult day habilitation, occupational therapy, physical therapy, speech therapy, self-directed supports, environmental adaptations, transportation services, assistive technology, psychiatry, social work, inpatient rehabilitation, and finally long-term care.

Why Workforce? Why Now?

You may be wondering how that story relates to the topic of this year's conference. On April 26, 2021, the US Census Bureau released results from the 2020 Census, showing the slowest population growth (7.4%) since the 1930's (7.3%) and the second slowest rate of expansion since the government began taking a census in 1790. While this trend was not unexpected, it does verify what has been known for quite some time, the birthrate in the US has dropped, and the population in the US is aging.

Well, what about this last year, 2020? Certainly, as the busyness of life slowed down in the throes of a global pandemic and people had to remain home in quarantine, we might expect to see an upward trend in the birth rates. According to a report published in May 2021 by the National

Center for Health Statistics, the U.S. birth rate fell 4% in 2020, the largest single-year decrease in nearly 50 years. The rate dropped for mothers of every major race and ethnicity, and in nearly every age group, falling to the lowest point since federal health officials started tracking it more than a century ago. Projected demographic changes over the next decade will require radical shifts in our recruitment, retention, and support strategies to assure ongoing quality supports for people with IDD. As baby boomers age and retire, not only will the US labor force diminish in size, but we will see increased competition for healthcare, leadership, direct support, and in-home support professionals.

The AAIDD Membership Experience

In preparation for this year's conference, I facilitated a series of three virtual focus groups on the topic of workforce issues, fears, and opportunities. Each focus group was one hour in length, and identical questions were posed to each group. These focus groups sought to draw upon the experiences, insights, and beliefs of AAIDD members across sectors on workforce challenges. We discussed current challenges and trends, promising innovations, and future directions. Most of the participants were from the east coast of the United States. Eighteen members took part and represented all sectors of the Association in a variety of roles. Some participants identified as holding multiple roles. We even had two former AAIDD presidents participate. I deeply appreciate the participants for sharing their time and their wisdom. While I have identified discussion themes, they inevitably interrelate, and some concepts carry through several themes. I have noted the themes not necessarily in order of importance but based upon the frequency with which they were mentioned and the number of participants that contributed to the topic. As each theme is highlighted, the input from focus group participants has been supplemented by additional resources.

It will not come as a surprise that the workforce topic of greatest concern is recruitment and workforce shortages. This was particularly a concern of the provider community. Across all sectors, participants agreed that the primary reason that applicants are attracted to jobs in our field is the people. Our field offers an opportunity to connect with others in a way that is very compelling. Many of us here today can probably

think back to the impetus to volunteering or applying for that first job in the field. When asked in interviews “what brings you here today?” many a candidate has responded with the heartfelt answer “the desire to make a difference.”

Focus group participants shared concerns that the candidate pool is limited at all levels. They emphasized the importance of attracting quality candidates and indicated that the reputation of the hiring organization does play a factor in attracting candidates of quality. Existing employees are a key potential recruitment tool. When employees feel good about where they work and what they are doing and are invested in the services, they tend to draw others. Moreover, talented staff tend to refer those that they believe will offer value. Therefore, organizations that invest in and value their employees, will reap the benefit of attracting new candidates via employee referrals. Referral incentives for employees who refer candidates who are hired and successfully employed is a potential strategy to consider.

Interviewing also plays an important role in being able to hire the best possible people. When the interview is a thoughtful process that connects people with what they are good at, the result may be increased productivity and satisfaction. Candidates must understand the position they are interviewing for and the expectations of the role. In offering a realistic job preview, employers and candidates are likely to make a more informed choice.

Several participants spoke about the importance of an efficient onboarding process. Bureaucratic bottlenecks that result in time delays, such as delays in scheduling, background checks, references, etc., often result in loss of candidates. As one Executive Director stated, “good candidates get hired quickly. At times I have heard that a candidate accepted another position and I lost them by a day or two.” As Taryn Williams discussed in her plenary session earlier today, an accessible application and interviewing process is also critical to recruiting candidates with disabilities. The onboarding process must be designed to maximize the pool of qualified candidates, not wean them out.

As demographic trends contribute to workforce shortages, we will see increased competition for scarce human resources with industries and individuals of means who may be able to pay a premium. It is important to identify and maximize

opportunities to become the employer of choice despite competing markets. We will talk more about the theme of competition a little later.

The next theme that emerged quite often was that of training and professional development. Participants felt strongly that professional development had to occur at all levels of the organization – not just for frontline staff. A concern was that organizations invest in mandatory training to meet compliance requirements, but not as much in competency based professional development. Quite often when funding is cut, professional development opportunities are adversely impacted.

Each of the focus groups spoke to the importance of curricula that is competency-based and standardized. The importance of Dr. Amy Hewitt's work in this area was referenced often. While this type of evidence-based curricula is widely available and a valuable tool in promoting professional development, all too often organizations are providing training that was developed without any of these core competencies in mind. This type of curricula is seen as fundamental to tying competencies into compensation and the ability to earn a living wage. Participants indicated that credentials would ideally be portable and tie into higher education credits. Micro-credentialing, mini-qualifications that demonstrate skills, knowledge, and/or experience in a given subject, was offered as an option to explore.

While training is traditionally skill-based, this must include humanistic, mindful skills such as the ability to keep one's composure, navigate stressful events, and the importance of self-care for the care provider. Organizations who invest in equipping their supervisors with support and development to be effective in their roles experience the benefit in retaining staff. This focus on continuing education for all, including people with IDD, reflects the value of each employee as an important contributor to the workforce. Professional development must provide pathways to thrive in current roles and attain skills for future roles.

No workforce discussion is complete without addressing the issue of staff retention and career progression. Turnover is costly, both financially and in terms of relationships and quality. The National Core Indicator collaborative started the annual Staff Stability Survey in 2013 and we currently have data through 2019. In 2019, over 3,600 providers in 26 states reported an average turnover rate of 42.8%. We know that 2020

presented unprecedented challenges that impacted Staff Stability, and so we will be watching closely for the next report.

Investing in employees, and this is across sectors, pays big dividends. As one participant stated, we can look to Southwest Airlines, ranked #1 in the Workforce 100 of companies that excel in people management by Workforce.com. They have the highest customer satisfaction rating in the industry, and they have gotten there by focusing on a fun, engaging work environment for their staff. When we think of our employees as customers, we find that customer satisfaction correlates with quality services. Organizations must care for their front-line workers, thus enabling them to deliver quality supports.

The flip side is also true. When staff do not feel supported, they lose their sense of compassion. They burn out. Interestingly, the strategies shared transcended work settings. As simple as it sounds, focus group participants emphasized the importance of checking in and letting employees and co-workers know you care. This feedback came from providers as well as those who work in university and public policy settings. Without this, people start to feel disenfranchised.

While the personal outreach is important across settings, there are variations across settings. Providers reported that the secret to retaining front line employees is the quality of their direct supervisor. Invest in frontline managers and committed staff will stay. A Gallup poll of more than 1 million employed U.S. workers concluded that the No. 1 reason people quit their jobs is a bad boss or immediate supervisor. Seventy-five percent of workers who voluntarily left their jobs did so because of their bosses and not the position itself. People join organizations, they leave managers.

Some worried that as support settings are more individualized and less congregate, there may be a risk of isolation. Without co-workers, it can feel lonely. When there is no sense of belonging and limited oversight, bad things can happen. It is critical to build connection, not only with co-workers and supervisors, and with individuals and their families, but with those in the community as well. Believing in the capacity and potential of people with IDD is key to staying engaged. That core belief in people and passion for supporting that potential, attracts and retains good people and fosters that expanded support system.

Finally, another reason that people leave their jobs, and at times, leave the field completely is the sheer volume of expectations and requirements, at times competing with one another, as well as the messages that certain expectations may send. For example, consider supporting a transition-age youth. While the goal may be to support them to make choices that will get them to where they want to be as an adult, one must also be mindful as to what the Individuals with Disabilities Education Act (IDEA) requires, and what the Workforce Innovation and Opportunity Act (WIOA) requires, and what the Americans with Disabilities Act (ADA) requires regarding services in the community. It can become overwhelming to integrate all the various expectations, and each state's system is slightly different. Another example of an expectation that many are grappling with right now is Electronic Visit Verification (EVV). EVV is an electronic system providers use to record information when delivering in-home or community-based services. The Department for Medicaid Services is transitioning to EVV for its 1915(c) Home and Community Based Services (HCBS) waivers. While many argue that EVV will streamline paper documentation and reduce administrative burdens over time, an unintended consequence may be losing some members of the direct support workforce who either are unable to technologically meet the requirements, or who feel that the trust in them is being questioned. Some people may even choose not to self-direct any longer due to the expectations of EVV. It is imperative that policies are implemented into practice in a way that makes sense and does not feel so overwhelming.

The focus groups also discussed the importance of career progression. In many provider organizations, the career ladder is limited. The most common option for talented direct support professionals (DSPs) is to become a manager or assistant manager. Most providers who participated in the focus groups indicated they predominantly hire from within. They indicated that internal candidates were already familiar with the organizational culture as well as policies and procedures. They also noted that hiring from within is simply necessary due to the limited pool of external candidates.

Several participants noted that not all good DSPs are good managers. Each position requires a unique set of skills. It is imperative to identify those who aspire to be managers in the future and provide them with training in supervisory skills as

well as on the job exposure to the responsibilities that a manager has. What about those who do not aspire to become managers? In some settings there may be a clinical track. Again, early identification, training, and exposure are the best way to foster this progression.

It is also important to recognize that, while one might think of the DSP as an entry-level position, we all know it is a very skilled position. We must learn to create career progression for those who wish to grow in the DSP role. This must be a career path that associates competencies with pay - so that a DSP can be valued for the skills they bring, and as they develop additional skills over time. The more competencies you bring, the more you are paid.

To foster career progression and retention of talented employees within organizations and within the overall Service system, supervision must include development of a career development plan. Each employee should be asked where they want to be in 5 years or further. That allows for a discussion of what the path looks like to get there. This type of engagement from not only the direct supervisor but also embedded in the organizational culture fosters connection to the agency and an incentive to stay. It also is as employees move on. As Dr. Kepley shared in the opening plenary, by 2025, the Health Resources and Services Administration, (HRSA), forecasts a shortage of more than 10,000 Behavioral Health providers including psychiatrists, psychologist, social workers, and mental health counselors. Those career development plans may result in a plan that leads in some of those directions.

When asked about succession planning, most of the focus group participants were unaware of any formal strategy to prepare for the future through succession planning. Those in higher education noted the shift from tenured faculty to adjunct faculty and noted that when a faculty member retires, their knowledge is gone, along with their knowledge of the history in their area of expertise and how that history can guide thinking about future planning. Those in policy and research noted the risk that when people retire, their research ends as does the subject matter expertise.

As for providers, while there was some effort to cross train and encourage senior leadership to identify and mentor others, there were others who did not have the bandwidth to focus on this type of planning, while recognizing it is critical for the long term. Val Bradley's guidance in her 2006 AAIDD

presidential address was referred to by focus group participants. She spoke to the importance of succession planning “so that the “hand off” to the next generation is done in a thoughtful and strategic fashion. We owe it to those whom we support to nurture those who will come after us, regardless of what generation we are in. This is true whether you are a self-advocate, a case manager, a residential supervisor, a family member, a state commissioner, or an executive director. . .Sustainability requires an unbroken chain of concern and competence. That will mean identifying people in our own organizations, encouraging them, and giving them the opportunities to develop their own reputations.” Those words of wisdom are still true today, and there is still work to be done.

Having said this, we must look beyond individual agency strategies and solutions to address the need for career progression. We must have state and federal initiatives that are consistent with this goal. Again, the NCI Staff Stability survey and the resulting report is an excellent resource to help states examine workforce challenges including retention and progression, track their own performance over time, compare results across states, and to establish benchmarks. In the focus group discussions, examples were shared of initiatives that are taking place within states. For example, the state of Mississippi is working with the Department of Education on the Complete to Compete program designed to remove barriers to completing 2- and 4-year degrees. Others described innovative programs that worked well but ended with a change in leadership. When the champion leaves, it can be difficult to sustain programs without legislative or statutory support. One of the core principles of the American Jobs Plan proposed by the Biden Administrations is to connect workers with good jobs now and for the future. Specifically, the plan calls for Congress to invest in evidence-based approaches to supporting workers. This includes wraparound services to support workers paired with high-quality training and effective partnerships between educational institutions, unions and employers.

The next area that came up repeatedly was that of competition as it relates to compensation. Certainly, compensation and the ability to pay and earn a living wage were themes that were raised throughout each of the focus groups. As we look toward the future, compensation ties in with each of the factors we have already discussed, recruit-

ment, professional development, competencies, and retention. A statement that captured the sentiment is “We are asking people to do skilled work on unskilled wages.”

It was striking how often concerns about compensation were expressed as the inability to compete. While this has been a concern for some time, it has been magnified during Covid 19. Service providers often find themselves competing with hospitality and retail industries. Concerns were raised that while they could not pay more than Walmart or McDonalds, the expectations and necessary skills were much greater, and the work at times can be much more emotionally taxing. One provider noted that people made much more on unemployment during Covid than they could working full time, without the concerns for their health and safety.

Interagency competition is also a concern when health and human service agencies are competing against each other for finite resources. It is not uncommon for an agency to invest in onboarding and training a new employee, and just as they become proficient in their role, they may move to another provider where they can do similar work for .25 or .50 cents more per hour. With the demographic shifts that are occurring, as Americans age, we can anticipate increased competition for self-hired direct support professionals to assist baby boomers who have increased support needs and ample resources. Finally, the connection between compensation and the increasing minimum wage was raised repeatedly. Some states reported that as the minimum wage has risen and staff salaries have not, they are hiring staff at the minimum wage for the first time. In my own state of Connecticut, in 2018, legislation was passed requiring agencies to pay entry level DSP’s \$14.75 per hour, and for those already at \$14.75 or above to receive a 5% pay increase. At the time it was passed, it was a cause for celebration. as it raised the average wage from \$11.20 per hour. Just 3 short years later, providers were reporting that the Burger King at the airport was starting employees at \$18/hour. Starbucks and Aldi were starting employees at \$17/hour, resulting in serious staffing shortages. In June 2021, the state of Connecticut reached a landmark agreement that invests \$184.1 million over two years in the direct support workforce. This will raise minimum rate to \$16.50/hour in 2021 and an additional \$17.25/hour the following year. Those already above the

minimum will receive a 3% increase and \$30 million is reserved for enhanced health care and retirement benefits. While this is a bold step in the right direction, providers in the focus groups from other states echoed the similar sentiments about staffing shortages that are at levels not seen in recent memory.

Participants were quick to note that while compensation is not the only thing impacting recruitment and retention, it is a significant barrier that will require leadership, funding, and systems change to address. In addition to the need for powerful advocacy, truly addressing the issue of compensation and paying employees a living wage will also require leaders in the public and private sectors who are willing and able to make changes to the current systems. We must acknowledge that the current polarization of our politics is influencing our policy, and there may be some opportunities to take advantage of that. It is challenging to make national, system wide improvements when every state does things differently. While HCBS services may be thought by some as a partisan issue, the need for a strong vibrant workforce is not. Several strategies were shared. One theme was the need to walk away from our old ways of doing things and partner with other entities that we have not partnered with before so that we can maximize existing resources in our communities to afford individuals with IDD access to all that their community offers. Our industry cannot afford to be insulated; we must partner with complementary community entities to truly offer a rich array of community resources.

In conjunction with this suggestion was a call to the public policy experts and state agencies to also be willing to rethink the way things have always been done. One lesson that Covid 19 has taught us is that when government is able to relax some of the policies and procedures that prescribe how services and supports must be offered, we can sometimes foster creativity that allows for people to thrive. We also learned that entrenched bureaucratic systems must move faster and be nimbler. We long have talked about the importance of having the opportunity to make choices and have dignity of living a life with risk, and yet of course no one wants to contribute to something adverse happening. Finding that balance will be critical as we move forward from both a quality and a workforce perspective. Other recommendations included the need to move away from bricks and mortar institutional thinking, whether that be

large site-based day services, or congregate residential settings, and provide support in the environment that a person chooses. Several participants spoke to the need to support people in their homes, wherever that home is, with whoever those care providers are, and with whatever type of support is needed. The concept of caregivers who are family members who are reimbursed or supported to provide that service was raised as an area for further exploration. At a minimum, we must coordinate care with family members, including siblings.

As we confront increased workforce shortages, one option might be to supplement the current workforce with flexible supports such as peers, retirees, and part time staff with varied backgrounds. This was described as a more casual workforce of core Direct Support Professionals augmented by those who could develop relationships and provide supplemental supports. In all sectors, there was consensus that we must offer flexibility in work arrangements to the greatest extent possible. We must incorporate what we have learned over the past 15 months with the continued use of virtual meetings, allowing people to meet without travel, and offer the technology to make that possible.

Another area where leadership is essential is in diversity, equity, and inclusion initiatives. Participants indicated that DEI initiatives focus solely around compliance tend to backfire. While organizations must have very strong policies and those policies must be communicated to all stakeholders; the conversation cannot stop with policy. Clear expectations need to be backed up with a willingness to have difficult conversations and deal with conflict. This requires another skill set of supervisors, as they deal with conflict in such a way as to bring people together and foster healthy dialogue.

One participant noted that the focus group participants did not represent the workforce that they supervise, and this is still true in many organizations. Leaders must be aware of what is happening on a global scale and the impact on members of their workforce. Leadership must be thoughtfully engaging in both organic and more formal ways. As one executive director stated, “I’m learning to shut up and listen.” It is also important to clearly message around what we do have in common. It is our shared commitment to the individuals who we support.

Implicit bias training was referenced as an effective tool to foster discussion and help people feel comfortable opening up. Implicit bias is focused on learning to identify and mitigate the involuntary and unconscious associations that produce bias. One participant shared that implicit bias training was so effective that the discussion transcended beyond individual insight to action around social justice issues and had a lasting impact. It allowed people to join together in a different way. Like any training, one workshop will not have a radical impact, but ongoing education can have a positive effect.

While there is no one right way, it is important to foster dialogue between staff on issues related to diversity and inclusion, so they feel comfortable talking about those things that are important to them. While some felt that the best strategy is to listen and respond as the conversations happen organically, others provided opportunities such as lunch and learns on a variety of topics relating to systemic racism, societal disparities, and pre-covid gatherings where people could get together and get to know each other a little bit better. These types of gatherings have been much harder to replicate virtually with people working remotely. Still others were working with organizations such as Workforce Now to assist in the shift in training, technical assistance, and the work itself to see some measurable improvement in those numbers.

This year's conference highlighted a number of excellent presentations on the power and potential of technology. In the preconference sessions, we heard presentations on current impact and future potential of technology in the areas of health equity, employment, communication, mental health, and, significantly, addressing the Direct Support Workforce crisis. I urge you to watch those sessions of interest, with an emphasis on the presentation by the team at the University of Minnesota entitled "Call to Action: Addressing the Direct Support Workforce Crisis Using Technology Based Solutions." As you can imagine, technology was one of the strategies that was raised in the focus groups to address some of the workforce crisis challenges. While technology will not replace the need for staffing supports, it can maximize the benefit of those supports, enhance access to supports, and be a delivery system for those supports. There is no question that technology will have a great deal to do with services and supports in the future. We will increasingly need technology and remote supports to supplement in-person supports to

maximize independence and full inclusion. As technology is more responsive and adept at aiding in routine tasks, DSPs will be able to focus on helping people to connect to their community in meaningful ways. Other aspects of technology that affect the workforce include the need to continue to shift from a paper-based system to an integrated online system. Over the past year and a half, out of pure necessity, we have made a huge leap forward in terms of our ability to shift from our traditional systems to more fully integrated electronic systems. We have learned how to keep electronic files and share information more efficiently. I know that the printer in my office that I used daily prior to Covid, is now rarely used. Procedures that used to require a wet signature are now working perfectly fine with electronic signatures. Quality assurance systems that traditionally relied upon on-site record review have been able to shift to remote record review. As face-to-face time becomes possible once again, it can be truly focused on quality measures. As the constraints caused by COVID-19 subside, it is critical that we do not move back to those old, comfortable ways of doing things.

As states continue to build assistive technology and remote supports into their waiver services, the applications of technology will expand. It is critical that we think of technology, not as a tool to reduce cost, but as an opportunity to enable independence and maximize the quality of supports available.

As I bring the 145th meeting of the American Association of Intellectual and Developmental Disabilities to a close, I have something to ask of each of you. To address the workforce challenges of today and prepare for those to come, we must join with one another, push one another, and learn from one another. The AAIDD community is as interconnected as the themes that I've outlined today. The provider community must rely heavily upon progressive policies and emerging research to guide the direction of our service system. The advocacy community must shine a light on what is important and what needs attention. Those with public policy expertise must continually assess promising research findings and evidence-based practices that can demonstrate positive outcomes. Students and early career professionals can learn from our history and chart the course for our future in policy, practice and research. Above all, as a professional association, we need to continually work with, listen to and learn from people with IDD and their families.

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