

Presidential Address, 2013 A Charge for the Future

Marc J. Tassé, President, 2012–2013

On behalf of the Conference Planning Committee, it is my sincere pleasure to welcome you to the “Queen City,” Charlotte, North Carolina, and the American Association on Intellectual and Developmental Disabilities (AAIDD) 136th Annual Meeting. The theme of this year’s conference is research, practice, policy—and there’s no better setting for such a conference than the Carolinas! This year’s AAIDD annual conference promises to be a forum where researchers, clinicians, practitioners, educators, policymakers, and advocates will be able to share cutting-edge research, effective practices, and valuable information on important policy initiatives.

I want to start my presidential address by thanking all the attendees for joining us for the AAIDD 136th Annual Meeting. This conference could not be the success it is without your presence and participation. I also want to thank all our colleagues from across the United States and the world who traveled to Charlotte to present their work and share their ideas and findings with us. I’ll come back to this point in a minute. I would be remiss if I did not acknowledge the important contribution to the success of this meeting of all those who provided their time and wisdom on the Conference Planning Committee and the Local Arrangements Committee as well as the large group of volunteers, and of course none of this could happen without the diligent work of the AAIDD staff and Dr. Maggie Nygren, AAIDD executive director and CEO. Please join me in thanking all these individuals in making this annual meeting the success that it is.

This year’s annual meeting was preceded by a series of exciting and stimulating preconference workshops on topics ranging from findings from the AAIDD Cuba Delegation, the National Task Group on Dementia, DirectCourse’s Comprehensive Competency-Based Training Approach, Supports Intensity Scale and Individual Support Planning, and Ethical Issues for Psychologists.

We opened our conference with a blue-ribbon plenary panel on research, practice, and policy in

the area of autism spectrum disorders. We heard three fantastic presentations from Drs. Joe Piven (University of North Carolina), Connie Kasari (University of California–Los Angeles), and Susan L. Parish (Brandeis University). The opening plenary was an excellent example of the richness and importance of research, intervention, and policy issues and their interplay in the area of autism spectrum disorders. Our other panel presentation had a distinguished group of federal partners, including Drs. Melissa Parisi (Eunice Kennedy Shriver National Institute of Child Health and Human Development; NICHD), Gloria Krahn (National Center on Birth Defects and Developmental Disabilities at the Centers for Disease Control and Prevention; NCBDD CDC), and George Jesien (Association of University Centers on Disabilities). This illustrious federal panel discussed the importance and role played by these agencies in supporting research and practice as well as the importance of policy matters in continued funding of these programs in the area of intellectual and developmental disabilities.

Our biggest challenge this year in organizing the conference was reviewing and evaluating the great number of high-quality proposals submitted. We received almost 300 proposal submissions from across the United States and more than a dozen countries around the world. The conference was rich with 24 break-out panel presentations on topics including aging, health, employment, quality of life, transition, cross-cultural issues, end-of-life, forensic, supports, direct support workforce, inclusion, systems change, self-advocacy, spirituality, parenting, funding issues, and postsecondary education. In addition to these rich break-out sessions, we had more than 150 stimulating poster presentations from students, recent graduates, early careers professionals, established professionals, and researchers from around the world.

Today and tomorrow, our conference wraps with a series of postconference workshops that will offer continuing education units on a variety of

topics, including writing for publication, lessons learned from states using the Supports Intensity Scale, assessment of intellectual disability in capital cases, religion and spirituality, positive behavior supports, trauma-informed care, and dysphagia. These workshops offer some very practical hands-on training from highly respected and skills practitioners. I trust many of you will be taking advantage of these workshops before heading home.

Our Conference Theme: Research, Practice, Policy

This year's conference theme was selected to highlight and remind us of the importance of interdisciplinary and interprofessional collaboration for the field of intellectual and developmental disabilities. Our field has had many accomplishments in research, intervention, and policy that have had significant impacts on improving the lives and outcome for persons with intellectual and developmental disabilities (IDD) and their families.

Many years ago, a Norwegian physician by the name of Dr. Asbjorn Folling discovered that a group of individuals with intellectual disability had particular characteristics, and this led to his discovery that these individuals all had inherited a recessive gene that resulted in their bodies' inability to break down an amino acid called phenylalanine. The condition, called phenylketonuria (PKU), if undetected, would result in a build-up of phenylalanine to toxic levels in the individual's central nervous system, resulting in severe cognitive impairments. A relatively simple treatment consisting of a strict diet that eliminates all foods high in protein, which are rich in phenylalanine, eliminated the devastating effects of PKU on infant brain development. Infant screening for PKU commenced as early as the 1960s, resulting in the identification and treatment of PKU and thus preventing thousands of children from developing intellectual disability.

We should also not forget that the benefits yielded from the work done in our field reach beyond persons with IDD.

Another important area of work stimulated by a practitioner in the field of intellectual disability is early childhood education. This was Dr. Maria Montessori, an Italian physician who worked with young children with intellectual disability. Maria Montessori had been influenced by the work of a couple of giants in the field of intellectual

disability, including Jean Itard and Edouard Séguin. The Montessori Method stresses the development of initiative and self-reliance by permitting children to do by themselves the things that interest them—self-paced learning under the guidance of a teacher. Montessori's work led to significant gains in learning in children previously thought to have little potential because of their intellectual disability. The Montessori Method demonstrated that this structured learning method and environment can have important beneficial results in children with cognitive delays but also in typically developing children. Today, Maria Montessori's educational approach is used around the world and has become a highly coveted educational strategy used with children of all intellectual abilities.

A final example of the richness of the work done in our field is in the area of applied behavior analysis and positive behavior supports. The science of using principles of behavior analysis to understand the function of behavior to promote learning and behavior change has been a critical part of intervention strategies in the field of intellectual and developmental disabilities for decades. We have used the science of applied behavior analysis and, more recently, positive behavior supports to teach new skills, promote pro-social behavior, and understand and reduce problem behavior. These approaches have been instrumental in our field of early intervention to promote inclusion, supported employment, and supported living, to name a few examples. These techniques are being used in all realms of daily life, including and increasingly with people without special needs. More and more preschool programs and school districts have adopted positive behavior support strategies to promote pro-social behaviors and the prevention of all forms of less desirable behaviors such as bullying, disrespectful behavior, aggression, and so forth.

So we can see how research and practitioners play key interactive roles in promoting improved research and intervention for persons with IDD. And, at times, these methods also have applications for everyone. Public policy and legislation also play a key role in research and intervention for people with IDD. We, at times, did not appreciate the important role research and intervention findings play in crafting and influencing policies. Their interrelatedness cannot and should not be understated. I want to name but a few important policies that have played a key role in promoting services,

programs, and research for persons with IDD. Early in the 1960s the Kennedy administration created important legislation now called the Developmental Disabilities and Bill of Rights Act (DD Act). The DD Act led to the creation of the University Centers for Excellence in Developmental Disabilities, DD planning Councils, and Protection and Advocacy Agencies in every state. During this same period we saw policy work that led to the creation of the National Institute on Child and Human Development (NICHD), which has been an important source of research funding for the field of intellectual and developmental disabilities, including the IDD research centers. Other important legislation for our field has included the Individual with Disabilities Education Act (IDEA), Combating Autism Act, and also Rose's Law. Rose's Law is an interesting piece of legislation but important because it resulted in the removal of stigmatizing language such as "mental retardation" from federal laws, replacing it with "intellectual disability." This aforementioned list is far from comprehensive. We have had a century of groundbreaking policy changes that have illustrated the work between policymakers, stakeholders, practitioners, and researchers. I selected these to make a point—not to identify them as more important than others not mentioned. Suffice it to say, policy, practice, and research are intertwined and interdependent, perhaps more than many really appreciate or admit.

Presidential Priorities for 2012–2013

Founded in 1876, the American Association on Intellectual and Developmental Disabilities is the oldest professional association concerned with intellectual and developmental disabilities. I am truly honored to have the privilege to serve as president for 2012–2013. We have a great group of board members, a dedicated staff, and a very dynamic executive director/CEO. Despite these difficult economic times, our association is in good financial health. An exciting characteristic of our association that strikes me as indicative of the strength of our membership and leadership is the products that we continue to develop and deliver to the field. The credit for all this is a shared one. It is shared among our board members, our executive director/CEO, the staff in the national office, and especially you! All of our key products (e.g., the terminology and classification manual and user's

guide, Positive Behavior Supports Training Curriculum, Supports Intensity Scale, annual meeting—yes, I include this as one of our key products—*Good Blood, Bad Blood*, online courses, and webinars) are largely the result of the hard work and brain power of our members.

I have three basic priorities that I have set for my presidency. Following are my priorities—not necessarily in order of importance.

1. Build on our strength as an interdisciplinary professional association and our research strengths in developing tools for the field.

The major functions of AAIDD are to:

- support its members leadership in activities that affect people with IDD;
- publish and promote cutting-edge research, tools, and materials that inform policy and practice;
- develop and implement educational opportunities for professionals, policy makers, and others;
- engage in activities that promote progressive public policy.

There are several factors that establish AAIDD as the best place for cutting-edge research, tools, and materials that inform IDD policy and practice. AAIDD has a long history in publishing some of the field's best journals, including *Intellectual and Developmental Disabilities* as one of the field's leading practice journals and the *American Journal on Intellectual and Developmental Disabilities* as the oldest and more respected research journal. This is the professional home for thousands of interdisciplinary practitioners, researchers, and leaders within the field of intellectual and developmental disabilities. Whether mentioned in legislation, the U.S. Supreme Court, or among stakeholders, families, or colleagues, AAIDD is seen as the authoritative organization on matters related to IDD. We must keep our focus on evidence-based and data-driven product development and ensure that we, as an organization, continue to deliver high-quality tools and materials that are needed to advance the quality of supports, services, and knowledge.

2. Support and promote students and early career professionals.

Our association can only sustain its leadership through succession planning and grooming the next

generation of educators, researchers, leaders, policy-makers, practitioners, and so forth. We must make every effort to include students and early career professionals on our association task forces, committees, and work groups. The vitality of our association can only be ensured by the inclusion of senior leaders and more junior rising stars among our membership. This is a win–win proposal that will benefit all and promote high-quality work and outcome.

I am committed to continuing the great work of the last several AAIDD presidents in supporting the students and early career professionals who have recently formed their own special interest group. Below are some suggestions of ways you and I can support AAIDD students or 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.

Please e-mail me any suggestions or ideas you have to increase the participation and meaningful involvement of students and early career professionals in our association life and annual meetings.

3. Influence the American Psychiatric Association as it redefines “mental retardation” in the DSM-5.

This priority is to make certain that we educate and guide the American Psychiatric Association (APA) as it continues its work in crafting the fifth edition of its *Diagnostic and Statistical Manual of Mental Disorders* (DSM-5). Of particular concern is that the DSM-5 revisions of the condition formerly called “mental retardation” currently include APA's proposal to rename the condition “intellectual developmental disorder.” As you know, there is a national consensus in the United States, including federal legislation, to replace “mental retardation” with “intellectual disability.”

In addition to proposing a radically different terminology that lacks all support from the field of intellectual disability, the current version of the DSM-5 diagnostic criteria are the following: (a)

significant deficits in intellectual functioning—profile of cognitive abilities; (b) significant deficits in adaptive behavior including daily life, communication, social participation, functioning at school and work, personal independence at home and in community where these limitations result in a need for ongoing support at school, work, or independent life; and (c) that these significant deficits originate during the developmental period.

The adoption of a different terminology and the proposed DSM-5 diagnostic criteria are fraught with the potential to harm people with intellectual disability and their families. In a June 14 letter to the APA and the DSM-5 Neurodevelopmental Disorders work group coauthors, AAIDD wrote a detailed letter expressing our concerns and making clear suggested changes. AAIDD's concern regarding the DSM-5 proposal to adopt “intellectual developmental disorder” is that it is regressive and divergent with the currently accepted terminology of “intellectual disability.” We have in the United States legislation called Rose's Law that was signed by President Obama that has replaced “mental retardation” with “intellectual disability” in federal law. All professional and disability organizations have adopted “intellectual disability.” The DSM-5 adopting a different terminology will lead to confusion, inconsistency, and will hurt people with intellectual disability and their families. Adopting a different terminology, accepted by no one else, could affect federal and state determination of eligibility for benefits and services in schools, social security insurance, Home and Community Based Services (HCBS) waivers, as well as research communication and evaluations in the forensic arena, including capital cases.

Other concerns include that the lack of an operational definition of the age of onset could potentially lead to different determinations of the age cutoff across states or even between state agencies. We also suggested the APA make more systematic their definition of adaptive behavior as being represented by conceptual, practical, and social skills. Finally, we cautioned the DSM-5 against deemphasizing individualized standardized testing in favor of clinical assessment and recommended APA strengthen the language regarding measurement error.

I want to draw your attention to this important matter and encourage you to familiarize yourself with the AAIDD concerns with the DSM-5 proposal. We also applaud our colleagues in other

national and international organizations who have endorsed the AAIDD position, including The Arc [of the United States], Special Olympics International, Inclusion International, American Psychological Association–Division 33, and American Academy of Developmental Medicine and Dentistry. We expect other groups to continue adopting our letter as a model in communicating their concerns to the DSM-5 work group. We should all be extremely concerned about the current direction being taken by the DSM-5.

In closing my presidential address, I want to thank you again for joining us in Charlotte for the 136th AAIDD Annual Meeting and for choosing to be a member of AAIDD. I hope to see many of you next year in Pittsburgh, Pennsylvania. Do not hesitate to contact me should you have any questions, concerns, suggestions, and ideas how we can further advance the mission of our association, and let me know how you can become involved in strengthening AAIDD! Thank you.

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