number of remission vs. partial responders or treatment nonresponders?)

2. How do we deal with the considerable heterogeneity of most psychiatric disorders in terms of variation in clinical presentation (semiology), age of onset, gender, severity, comorbidities, and secondary forms that occur in the context of other genetic/metabolic, medical, neurological, and neurodevelopmental disorders?

3. Can we improve our efficacy rates with better pharmacogenomic and molecular pharmacologic data; subtyping syndromes based on shared temperamental traits; intermediate end phenotypes based on comparative studies of neuroimaging, neurophysiological and other symptom and genetic/metabolic markers? This process is closer to the research domain criteria approach outlined by the NIMH.

4. How do we integrate dueling heterogeneities: heterogeneity associated with varying levels of ID, and co-occurring medical, neurological, behavioral, and psychiatric disorders?

5. How do we integrate psychosocial variables in an era of gene-environmental interaction and epigenetic effects on development, variations in psychopathology, and medication sensitivity and responsiveness? Do we need to fine-tune the biopsychosocial model to capture the new approaches emerging from the neurosciences?

6. How do we disseminate these new ideas to patients and families, clinical service providers, and other members of the treatment teams; the taxpaying public; policy makers, and politicians who control the purse strings?

These are topics for exploration over the next year. Be patient as we try to unravel some very complex but intriguing aspects of the neurosciences revolution as it applies to individuals with ID.

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**US Public Policy Update**

Eliminate Discriminative Practices against Persons with Mental Illness and Co-Occurring Intellectual Disability: Let Their Voices Be Heard

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The following article is provided through the NADD US Health Policy Committee. It addresses the impact of stigma on individuals with mental illness and co-occurring intellectual disabilities. Throughout history the United States has faced many challenges in efforts to eliminate discrimination. Women were once considered of less importance and/or of less value in society than men. There were expectations of servitude and few educational opportunities. Women did not have a voice when it came to democracy for change as they were not allowed to vote. Women stood up in protest to demand their rights. Today women, although they continue to face discrimination in the workplace, for the most part are recognized for their important contributions and in most cultures face injustices that pale in comparison to the injustices faced in the past.

For centuries, the African American people faced cruel and inhuman injustices. There were extreme abuses of power against them. They had no voice when it came to democracy for change as they were not allowed to vote. They often lived in deplorable conditions and had few opportunities for improvement to their lives. They were not allowed equal access to public places. They were not allowed to eat in public restaurants or use public transportation. They had separate entrances to medical facilities. They went to segregated schools where they were issued used and outdated books. They used the back door of public theaters where they sat in an upper chamber separate from other theater patrons. It was not until the equal rights movement in the 1960s that this population of people achieved equal rights, and, while we continue to face some injustice, again it pales in comparison to the injustice faced by this population in the past.
We overcame inequality in public education. Persons with intellectual development disabilities (IDD) including those with co-occurring mental illnesses (MI) were at one time often declared uneducable and sent home to live their lives in virtual seclusion from society. Now, persons with IDD have rights to public education.

In our modern world, most feel that discrimination has for all intents and purposes made great strides towards equality for all. Granted we have made tremendous advances. However, discrimination still exists and is often overlooked. Recently, in 2015, I attended a theatre performance in a local theatre. It was an Elvis impersonator, and the group I was with was very excited to be in attendance. What I experienced when I got there was humbling to say the least. You see, I was with a group of persons with IDD. I had accompanied my daughter and my grandson, who is a member of this population. It saddened my heart to see and hear how this group of people was treated in public. As we entered the building I heard whispered comments “what are those people doing here? Oh lord this is going to be a mess.” Others whispered under their breath “they won’t be sitting near us.” Sure enough, we didn’t sit among those without disabilities. We climbed two flights of stairs and sat in the upper chamber away from others. I was appalled. Those without disabilities who could have easily taken the two flights of stairs sat on the first floor. Those with disabilities, most of which required significant assistance getting up the stairs, put their safety at risk to be able to experience what most of us take for granted. At the start of the performance the audience was encouraged to enjoy themselves, to not hold back from “making some noise.” But in the upper chamber those with disabilities were encouraged to remain quiet, and not express their excitement, so as not to disturb others. At intermission, those with disabilities waited in their places while those without disabilities were served refreshments. When this was completed, those with disabilities were helped down the two flights of stairs and given one cookie and a small glass of soda and then helped back up the two flights of stairs to see the final part of the performance. Unlike how most people would have reacted to such treatment, they were, for the most part, happy and continued to be excited. They did not know they were being discriminated against. And like other groups in the past who had no voice, this population of people while they are given the opportunity to vote, do not understand the process, therefore they have no voice in the democratic process and rely upon those who do understand to advocate for their rights.

I have become much more aware of the discrimination against persons with IDD over the past 2 years. After 20 years of working with people with IDD and/or MI, I recently began a position that involves crisis intervention to those with IDD/MI. What an eye-opener. While I was aware of the negative social impact and stigmatization of having IDD, until this point I was not aware that discrimination of persons with IDD existed at such magnitude. It didn’t take long for me to realize that access to mental health care for those with IDD is hardly equal to access to mental health care for those without IDD. I was so naive. I thought that access to health care was available to all and that physical access for those with handicaps had for the most part ended discrimination. I have come to realize that equal access means more than wheelchair ramps at public facilities and designated parking. It must also include access to inpatient psychiatric care, therapeutic interventions, and counseling.

In our modern world one would think that this problem would have already been resolved. So I can only conclude that most people, like my former self, are unaware of the problem. Therefore, there has to be a voice for those with IDD/MI and it must be strong and relentless, as it has been in the past for those that have been faced with discrimination.

Persons with IDD/MI, currently do not have equal access to psychiatric inpatient treatment nor do they have equal access to therapeutic interventions and counseling services. While I am not aware of any studies or surveys that have been conducted, I can attest to the fact that in the past two years, I have come to realize that in the State of Texas many, if not most, psychiatric inpatient facilities (with the exclusion of the state hospitals) have criteria for admission that excludes those with IDD who have an Intelligence Quotient of less than 70. As a person who has many years of experience working for the local authorities for intellectual disability, let it be known that this excludes all of the persons being served through the local IDD authorities, all of whom have an IQ of 69 or below. As the movement toward deinstitutionalization moves forward, this problem cannot be ignored. Not only is it wrong to discriminate based on disability, communities need to be equipped to provide for the service needs of this population of citizens.

I believe that part of the problem exists due to ignorance regarding the need for mental health
services for this population, the misguided belief that persons with IDD do not benefit from therapeutic interventions, and the lack of therapeutic programming that is currently in place within the psychiatric inpatient and outpatient facilities.

There is a great need for equal access to mental health treatment for persons with dual diagnoses of IDD and MI. There has to be a solution. Therapeutic intervention can be adapted for persons with IDD. Admission criteria to psychiatric inpatient treatment can be revised to eliminate exclusionary criteria of those with MI and co-occurring IDD. Treatment programs and Discharge criteria from psychiatric treatment facilities can be adapted using a person-centered approach to treatment.

At the annual Texas Counsel which will be held in June 2017, the challenges of providing mental health services to persons with co-occurring IDD and avenues toward change will be addressed. It is but a first step toward the journey of eliminating yet again discrimination toward some of our valued citizens.

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**DSP Interests and Concerns**

**Building Competence: Health and Wellness**

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Direct Support Professionals are often the first people to notice changes in the individuals in our care. They often know the individual best and are able to identify small changes that could be signs of illness. Many individuals in our care are unable to tell us with words how they feel, but they can and do frequently tell us by a change in the way they act or the sounds they make. When changes occur, DSPs often describe the person as being “not right” or “not themselves.” How the change is described to a primary care doctor or clinician will make a difference in the health care provider’s ability to understand the value of the observation, figure out what the problem is, and treat it.

The qualified DSP recognizes that for people with IDD/MI behavioral symptoms are often a key component to the diagnosis and treatment of health disorders. The DSP takes time to maintain accurate and complete documentation in accordance with agency/organizational guidelines. He/she organizes and communicates this information in useful ways. The DSP teaches skills to assist individuals in monitoring their symptoms and maintaining personal records.

When you notice that something is not right, it may be helpful to think about describing your observations by comparing them to how the individual usually behaves or appears. When you look at the person or think about what you are seeing, ask what is different from what you usually see. Be sure that you document — clearly, concisely and completely. Subtle changes are often missed. Failing to document what you do observe can lead to delays in care that have adverse outcomes for the person.

Communication with the healthcare professional on behalf of an individual with a dual diagnosis is important in assisting the physician to make the correct diagnosis and order the proper medications/treatments. Caregivers are often aware of valuable information about the individual’s health, likes/dislikes, wants/needs, and behaviors and are usually the first to be aware of any changes in the individual, whether physical or behavioral. Information and concerns regarding the individual are communicated verbally or through documentation in their notes to other caregivers and healthcare providers. Effective communication between caregivers, supervisors, and healthcare providers is vital. Providing a general picture of the individual and reporting any changes observed can mean the difference between life and death in some instances. When an individual has an appointment to see a physician, it is important that caregivers not only effectively report the necessary information to the physician, but also document the outcome of the appointment to ensure that all of the doctor’s orders are followed.