

Oral Public Comments

**IACC Full Committee
Meeting**

January 17, 2018

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Hello, my name is Lee Wachtel, and I am a child psychiatrist working at the Kennedy Krieger Institute in Baltimore, where I run an inpatient unit for children, adolescents and young adults with autism who require hospitalization for severe, often life-threatening, and certainly life-limiting, challenging behaviors. I have been in this position for nearly 15 years, and would like to speak today on behalf of my patients, and their families, many of whom have remained under our care at KKI for years, right into adulthood.

The vast majority of our patients are significantly afflicted, and would be characterized in the DSM5 as having autism requiring extensive supports and with intellectual disability. They don't come to KKI for their autism or ID, however, but rather for the severe self-injurious, aggressive and disruptive behaviors that they display, often within the context of further severe psychopathology that can run the gamut from anxiety, mood and psychotic disorders, and more. These kids are really suffering, and so are their families. These parents will move heaven and earth for their children – one of the hardest parts of the job is telling moms and dads on our waitlist that we don't have a bed for their bloody and battered child TODAY – but none of our parents are glad that their child has autism, or see their son or daughter's autism and associated suffering as part of neurodiversity. In fact, most of the parents would sell their soul for their child to not have autism. As one parent who spent 30 years campaigning for the best services for his son recently told me, "I would walk through perdition's flames for my son, but I don't buy into the autism fairytale."

Not my words, but those of a parent who has walked the autism walk for 30 years. And I hear many such comments. I know very well that this type of response, and the mere existence of the types of severely afflicted autistic kids in our care, flies in the face of the overriding 2018 agenda for autism, where everything is rosy and diverse, and some even suggest the removal of the autism as a psychiatric illness. I would suggest that the DSM5 characterization of autism does not accurately describe the condition, and that there are likely many conditions currently all thrown together into the autism rubric, which only hinders science and our ability to make important advances to help everyone along this range of diagnoses. But I'm less for splitting hairs over diagnosis, and more for making sure that those who don't currently fall into the happy and hopeful side of the diagnosis – at least not happy and hopeful today, but with the potential for so much improvement – still have a voice, and do not become the black sheep of the autism community just because they aren't blogging or reciting soliloquies at Lincoln Center. Because these autistic kids with severe behavioral, psychiatric and medical concerns, as well as significant cognitive disability, really do exist, and so do their families, who are less than enamored with autism, and are frankly heartbroken and exhausted. These kids need our understanding and help just as much as the autistic child contemplating best strategies to succeed at college. And these kids will continue to need the support of the autism community as they become adults, as they will not be able to live independently, will require extensive supports and substituted decision-making, and can't be pushed into models that just don't meet their unique needs.

I encourage the IACC, and autism community in general to consider several things. First, the IACC needs to prioritize research on the treatment of self-injurious and aggressive behavior. These behaviors are highly prevalent — studies show about 1/3 of autistic kids engage in SIB and over half in aggressive behaviors, yet very little attention is paid to this devastating problem. The IACC should host a panel focused on these dangerous behaviors. Not only are these behaviors dangerous to the children and families involved, but they often preclude participation in inclusive, community-based educational and vocational programs. These behaviors are often physiological in etiology — typically from a co-morbid

psychiatric disorder, and do not represent “communication” from non-verbal individuals. It is a medical problem that requires medical solutions.

Second, the IACC must promote a choice-based approach to service provision that ensures adults with aggressive and self-injurious behaviors have a place to go when their families can no longer safely care for them. Some autistic adults have severe behaviors that cannot be managed in community settings. They may not exhibit them all the time, but they need to be somewhere with experienced caregivers who can manage dangerous behaviors when they do occur, with access to professionals who can treat them, as well as structured programs to maximize community access as well as providing satisfying site-based programming. This population needs to be surrounded with well-trained, well-paid aides, because the health and happiness of these adults depends almost exclusively on that one variable. The IACC should write a white paper focused specifically on the service needs of this population.

Finally, we need to invite more parents of severely affected autistic children to have seats on the IACC. These parents represent children who can't represent themselves, and they require a voice.

Thank you.

The Mission of My Time Inc is to support, educate, empower, enlighten and uplift parents of a child diagnosed with autism and developmental disabilities to live a life they deserve in their community.

Suggested presentation title:

“Me Time” and Advocacy

Short description of presentation:

A recreational and social activities program for parents of a child with a disability. Parents will learn how to form a support and social system that actually works.

Advocacy

As a parent of a child with autism, you are your child’s best advocate. It is ultimately your responsibility to assure your child is receiving the appropriate services.

First, it is important to educate yourself on ASD and in particular your child’s disability.

Second, collaborate with your child’s teacher, programs and school while forming a good relationship.

Third, understand your rights under the law, which will be the key to your success.

Parents while advocating are getting the appropriate resources as well as respite care for oneself

Main topics covered:

Sometimes the everyday demands of life seem too great to overcome and families will experience stress and/or crisis as they try to survive raising a child with Autism. Parents of a child with Autism rarely thinks of respite for themselves.

When parents understand they are not alone and they can actually enjoy their life even though they have a child with a disability, they eventually see themselves as a better caregiver.

Realization of the need for respite for parents/caregivers nonclusive of the child

- Parents realizing their friendship circle decreasing when they tell their friends they have a child with a disability
- Unable to socialize
- Finding the appropriate respite for their child so they are able to get respite themselves
- Not having a support circle with other caregivers or parents going through the same issue

To create a social and recreational program for parents to learn that taking time to rejuvenate, revitalize themselves, develop and build new positive relationships with other caregivers they too can be happier, healthier and less stressed.

For parents of a child with a disability, time is a rare gift. Making time for each other, as man, wife and child not just mom and dad, should be a priority in parenting a child with a disability and key for keeping the marriage intact and healthy. It does not have to be anything fancy, but always make time for each other. We provide the activities that stimulates and encourage each parent to be positive and healthy while participating in the recreational and social program. Parents are given the opportunity to develop the required skills needed to improve their social and recreational life. During this time, parents will share experiences, discuss common joys and concerns, and encourage public awareness and acceptance of families of children with a disability. Our goal for these parents is to be of good mind, body and soul. If parents don’t take care of themselves, who is going to take care of their child?

Recreational and Social Activities: The best reason to take part in these recreational and social activities is help lessen or eliminate stress. Happiness, contentment, fulfillment comes from the feeling that your life is in balance, and when we work too hard with not enough down time, our minds and bodies suffer.

Results of program:

Changes in parents attitude and how they view themselves is a great accomplishment
Parents are learning to better utilize their time in which they make time for themselves

- Opportunity to meet and learn from other parents in a relaxed and supportive environment
- Networking developing positive and supportive relationships with each other
- Discuss common joys and concerns
- Encourage public awareness, embracing and the acceptance of families of children with Autism

Main conclusions, recommendations and ‘take-away’:

Creating a positive recreational and social environment
Understanding the importance of self-care vs taking time for yourself
Developing positive and supportive relationships that will give you the motivation to be a part of a group in which you really belong and you are not alone
Parents understand that advocating for their child is critical however, let’s look at the question who is advocating for them, the parent in self-care and respite? At My Time Inc , we do.

A short bio or CV of the speaker:

Lucina Clarke, Executive Director My Time Inc MS. Sped, 10 years ago saw the need for parent support and education in her community. Hence created My Time Inc with her husband and implementing a Me Time program with advocacy. Lucina saw the frustration of non-acceptance of parents even among their peers thereby losing friendships of others due to the fact they were raising a child with a disability. Most parents are faced with the challenges of navigating the social services and educational systems. Therefore being an informed parent, they are able to advocate in receiving the appropriate resources for their child with Autism and other disabilities.

A short description of the organization:

Founded in 2007 by Lucina and her husband who saw the need in the community to educate and empower parents in finding the appropriate resources for their child with Autism and other Developmental Disabilities.

Contact details and website of the speaker and/or organization:

Lucina Clarke
www.mytimeinc.org
917 933 9875
646 789 3144

Shari Chase

January 17, 2018

There are 3 points I would like to make

First of all we have a wealth of knowledge and resources in our youth today., especially in our masters degree students. They are trying to find their purpose and make in impact on the world.

These students are motivated in several ways. These students show the desire to continue to learn and make an impact. They are not funded and hence they would be apt to respond well to grant offerings' to dedicate their time to find interventions and devices to help with anxiety, self -regulation and advancements that can be individualized for those on the spectrum.

This is a very competitive environment and often recognition is what is desired. Let us make national awards for the advancement of Autism devices and interventions to inspire the students and other academia to concentrate their efforts on improving the life of those with autism.

Second our retired work force needs to make more money to thrive in their communities. Lets encourage through tax credits and grants those same people who have perfected their skills and encourage them to start mentor programs for those on the spectrum.

Third we need vocational programs that teach people on the spectrum in the method they need to excel. Let us offer alternatives to the verbal response and offer alternative ways to deliver messages and knowledge.

Let us start incentive programs for businesses to start apprentice programs to allow those on the spectrum the chance to learn and practice their new skills in a real time environment. And finally lets lobby to ask fro those who do employee those with special needs the ability to keep the tax credits as long as they maintain a high standard of work environment and continuing employment. With this we will have a work force that will continue to excel and then can eventually pay back as future mentors.

With this said this is the way to help all become contributory citizens.

Thnk you
Shari Chase

Dear ICCAC,

My name is Shari Chase I am the Maryland State health Leader, a surgical consultant and TV host. My education was as a Pharmacologist and educator and most of all I am a parent to a young 21 year old with Autism.

This is the most challenging and heart breaking job. It is a one where hopes and dreams have been robbed of my child and myself. The cliff that we fell down, is a bottomless pit with tangles and twists and no map to follow. Yes there are days we walk in the roses but more that are struggles.

The agencies are unequipped to guide and educate those with autism and the post high school education is surely not customizable for those with Autism and this is a shame. DDA has no watchdogs so people simply fester.

These intelligent sensory burdened individuals are pushed to the side, under estimated and left to sweep, bag and fester when they have the drive to excel and become contributory citizens. We must partner with agencies and retirees as guides.

There must be vocational programs, interventions that can be taught and then done at home. Colleges need to create visual programs so our citizens with autism can flourish.

Please stop spending so much time finding a way to stop Autism. It will not happen. Instead immediately demand that vocational, educational interventional programs are required to be customized to those of us who think in pictures, People with Autism are unique and they have so much to offer, so please, open the door for them to be their best .

Shari Chase