Written Public Comments

IACC Full Committee Meeting

March 19, 2013

List of Written Public Comments

Note: Personally Identifiable Information (PII) has been redacted in this document

Laura Ericson

January 25, 2013

Subject: Public Comment

My name is Laura Ericson. I am the mother of a 21 year old autistic son with serious mental health issues. I am also a special needs advocate and I work with families of special needs children and adults. I commend the commitment of the IACCP to support and expand federal funds for autism spectrum disorder research and treatment. I would urge you to target more funding for the support of young ASD adults transitioning from school to independence, employment and post-secondary programs. They are a particularly vulnerable group with great potential if provided access to treatment and support.

There is a huge bubble of young autistic adults who have grown up without the services and support available to younger children on the spectrum. Many of these young adults have struggled in school and in their community to understand how to function in their world. Too many have failed, leaving them discouraged, undereducated, isolated and simply unprepared to create productive, meaningful lives. There is still a stigma and misunderstanding of developmentally disabled people and an assumption by both the autistic person and society that they are different and somehow not entitled to the same goals and success as “regular” people. Yet, with greater understanding through research and funding into the types of supports and practices that help autistic adults achieve measurable success in all facets of their lives and interactions with others, we can help them become productive, contributing members of society. Shorter-term, targeted investments in young adults on the spectrum can lead to long-term positive outcomes, often with a net savings to both the government and the families.

Our son, [PII redacted], is an example of what is wrong and also hopeful in our current network of support and research into autism. [PII redacted] had various diagnoses growing up, ranging from learning disabled to attention deficit disorder (ADD) and nonverbal learning differences to pervasive developmental delayed. We were advised by the school district that an autism diagnosis would be stigmatizing. Actually, I suspect now that their advice might have been rooted in the district’s desire to avoid the higher level of support mandated for autistic children. He struggled in school and worked twice as hard as his peers to even score in the bottom quarter of his classmates. He didn’t understand conversations and nuances and struggled to communicate with his peers. Although he desperately wanted friends, social interaction was a puzzle with too many pieces missing. He was teased and bullied throughout his childhood with increasing cruelty. We didn’t understand how isolated and bullied [PII redacted] was and he couldn’t explain or admit how miserable his life was. When he was 15, he was brutally attacked at school by two “friends” who punched and kicked him repeatedly over 45 minutes. Later evidence and testimony noted that over 40 kids were present during the assault but no one came to his aid. The school never contacted the police who were called by the hospital due to the severity of the attack.

Our son tried to make sense of what had happened to him, but for people on the spectrum, the world is mystifying and he couldn’t process the shock, pain and shame. He received virtually no support from the school district and we were given no advice or guidance on public or private support services to help him. He developed severe PTSD and his ability to function plummeted. Eventually he had several psychotic episodes and over time has been hospitalized four times. He is currently on 5 strong psychotropic medications and is barely able to think or function. Given his autism, he lacks self-awareness and the ability to express how he feels, so treatment is difficult. Also, so little research has been done on dual diagnosis autism and serious mental illness, including PTSD and schizophrenia, that psychiatrists and psychologists can only guess at what medications may be effective or at least, less toxic, particularly to the autistic brain which has a different structure and processing than neurotypical brains.[PII redacted]'s schizophrenia was triggered by environmental influences and trauma. We didn't understand how vulnerable he was and neither did the medical professionals who lacked training and understanding of autism and the terrible consequences of stress and trauma on bewildered, developmentally disabled children and adults.

Like most families of autistic children, we have spent tens of thousands of dollars on his care and treatment and my life has been consumed with finding help and services for him. If public and private officials in the schools and community agencies had understood autism and the special vulnerability of the disabled to abuse and mental illness, I think our path might have been very different. Our son is extremely gentle, and he is much more likely to be victimized than to react with violence. We know there are other young people who chose a more destructive path. With greater resources and treatment, our country can reduce the stigma, ignorance and tragic consequences to the individual and society of autistic young people who are unable to cope with a world they don't understand or fit into.

[PII redacted]'s story is a tragedy of what might have been and what went wrong, but there is hope. [PII redacted] was finally diagnosed as autistic and became a client of the California regional centers through the Lanterman Act. He is in supported living and has 24/7 staff support. He has the same social and independent living challenges, but his staff (whose wages average $9/hr) are helping him create a structured and stable life. It's not the life he dreamed of, but it now has possibilities and the regional center can address both his developmental and mental health challenges. He is extremely fortunate to have these services. They are the exception, both in California and in the United States. Due to severe state budget cuts, regional center services have been decimated and thousands of autistic or otherwise developmental disabled children and adults are no longer able to qualify for these and other urgent services that make the difference between at least a functional life and one that ends up on the streets, in jail or worse.

It is fine and worthy to try to identify the causes of autism and to provide young children with intensive interventions that have proven to be very effective. But – what about all the teenagers and adults who have grown up without interventions and are thrust into a world they don't cope with very well. We know that the human brain is plastic and capable of change and adaption throughout the life span. Young, disabled adults take even longer for their brains to mature. Wouldn't it make economic and scientific sense to provide intensive research and intervention to this large population of autistic young adults to provide them and society with better outcomes?

Thank you for your time and consideration of my comments.

Sincerely,

Laura Ericson
Monte Sereno, CA. 95030
[PII redacted]

Lauren Agoratus

January 29, 2013

Subject: Request for Public Comment

Regarding today's discussion of insurance coverage of autism: Medicaid covers due to EPSDT (Early Periodic Screening, Diagnostic, and Treatment) mandate for children. And yes autism coverage should be included in EHB (Essential Health Benefits) in exchanges. Even in states like ours where there is an autism mandate, 75% are exempt due to ERISA (Employee Retirement Income Security Act for self-funded/self-insured plans exempt from state regulation). The BEST argument is to use federal mental health parity law for both private and public plans.

Lauren Agoratus
Family Voices NJ

Gayle N. Mandell

February 1, 2013

Subject: Older adults with Autism

I recently typed a transcript of one of your meetings (1/29/13) during which there was a call for additional advocacy, service delivery, etc. for older adults with autism. Although I don't know anyone with autism, I saw the movie about Temple Grandin and was very moved by it. As an American who is over 65, I'm wondering if it would be advantageous for IACC to partner with American Association of Retired Persons (AARP) in its endeavors to improve the lives of older Americans with autism.

Thank you for your work.

Gayle N. Mandell
Norfolk, VA

Veronica

February 1, 2013

Subject: federal autism insurance coverage mandate

Is the U.S. government going to mandate federal insurance coverage for autism in the Affordable Care Act? What happens when some jobs opt out by paying the penalties? Where does that leave the patient? Thank you.

M. L. Ferreira

February 4, 2013

Subject: Release of the IACC Strategic Plan for Autism Spectrum Disorder Research - 2012 Update

Simply, I can´t understand this.

With the level of published information and controlled anecdotic evidence about the gastrointestinal, metabolic, biochemical, mitochondrial as dysfunction. toxicological, immune, autoimmune conditions, viral-fungal-parasitic- bacterial infections (and conditions as PANDAS-PITAND-PANS), oxidative stress, inflammation, microglial activation and more that is available- and almost daily updated and with more books of mainstreamed doctors on these issues- this update only shows an update without the needed urgency to consider properly all these conditions, many times present together in one individual and conditioning all the others approaches success.

As a mom of a child diagnosed with autism with many of these conditions together, the failure to address the importance to the individuals and the groups for life´s quality- beyond the focus on genomics or brain imaging or prenatal risk is beyond my understanding. They should and they can be tested, diagnosed and treated today with many resources available, not in 10 years. With the proper testing at the adequate number of children/teens and adults, the detection of the vulnerable individuals to the use of combined pediatric tools and exposures as a whole (food, infections, xenobiotics) could be possible.

Please, consider this with the needed sense of urgency.

M.L. Ferreira
Argentina

Scott Badesh

February 18, 2013

Subject: Public Comment

On behalf of the Autism Society, I want to thank the members of IACC and particularly Chairman Insel for the leadership in identifying service needs as a high priority of the work of IACC this year. The Autism Society is the nation's largest grassroots autism organization helping people who today live with autism. The need for services today is extensive and growing. As our nation works on addressing its fiscal issues, we must also examine how best to use limited federal funds to achieve effective and measurable outcomes in helping each person living with autism maximize his/her self sufficiency and independence. The need for a delicate, but required balance of the use of funds for research and services is very important if we are going to meet our social commitment of helping those in need today. While we applaud the wish of IAAC to pursue autism being included in health care insurance, we also need to make sure that the most vulnerable of our society are provided services each day to advance their quality of life. And, we encourage the members of IAAC to look at the need to advocate for increased involvement of the US Justice Department, Department of Education, Department of Labor and Department of Housing in coordination discussions, particularly since so many living with autism face discrimination and violation of their basic civil rights regularly.

The Autism Society welcomes the opportunity to be an active participant in the important national discussions on how best to help those who seek the caring and compassionate response of the federal government.

Scott Badesch
President/COO
Autism Society of America

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Dena Gassner

February 22, 2013

Subject: Testimony

[PII redacted]
To Whom It May Concern:

My name is Dena Gassner and I am a licensed social worker who provides direct hand-over-hand systems navigation support services to transition aged teens and adults diagnosed with PDD-NOS through Asperger Syndrome. I am also the parent of a college student with PDD-NOS who benefits from the College Asperger Support Program at Marshall University. Although the opinions expressed here today are my own, I am also an advisory board member to the Autism Society of America and Global and Regional Asperger Syndrome Partnership (GRASP).

I am writing to express my gratitude for the IACC hearing my testimony provided in writing and in person at the January 2013 Meeting.

That being said, I wanted to take this opportunity to expand on my prior testimony to discuss a significant gap in support for students engaged in transition to post-secondary programming as well as those obtaining a "late diagnosis."

Upon receiving a diagnosis for a child, in order to maintain family system equilibrium the family has to experience the grieving process. In my private practice, the longer the space between the first sometime confusing manifestations and obtaining the diagnosis, the greater the likelihood of unsettling misunderstandings, trauma and even outright abuse. Further, it's been my personal experience that unlike my peers who obtain a proper diagnosis at a more conducive time and received services early on, those obtaining later diagnosis are groomed to repress their needs.

As such, much like early intervention for young children, it's equally important that those obtaining a late diagnosis received intensive intervention to reconnect with their unique needs, to develop individual scripts to disclose their condition to friends, family and employers and lastly, to help them as individuals understand their identity.

It's my strong opinion that the burden for this falls first, upon the public school system for students who are not discovered via Child Find. If the individual is not still in school, this process falls on the shoulders of Vocational Rehabilitation.

It's been my experience that the clients I have that require the most intensive mental health services in collaboration with their autism condition are those clients that have not had the opportunity learn about their own unique manifestation of autism and develop scripts and strategies for coping. Further, they may have been denied supports to grieve what they didn't get that they so desperately needed and the loss of opportunity that ensued.

Without this integral work, progress is limited.

Please discuss this void in supports and consider action to request these key elements are provided via the Core Curriculum as guaranteed under IDEA and under Rehabilitation Regulations.

Thank you,

Dena L. Gassner, LMSW

Dawn Loughborough

February 22, 2013

Subject: IACC Public Comment

Autism is Medical

This written comment is for the Interagency Autism Coordinating Council meeting scheduled for February 26, 2013 to discuss oral and written comment from January 29, 2013.

The current care paradigm for Autism Care is missing physiological care pathways. Currently the pathway for Autism diagnoses channels children into behavioral therapies, speech and occupational therapy, and psychiatric models. Autism parents want to have a special patient population defined for the medical needs of our children. At the January 29, 2013 IACC meeting, I described Autism is Medical in my oral comment and in more detail via written public comment.

I write to the IACC members to request that you follow up on the physiological needs of our children with Autism:

1. Include physiology as a strategic objective for the IACC 2013 Strategy focused on immune, neurological and digestive clinical concerns with autism. Create a special patient population for Autism.
2. Enable our existing health care delivery system to regard Autism as physiological. Currently, our children are identified by behaviors, but underlying those behaviors are medical concerns that need to be assessed and treated appropriately. Parents want the same medical investigation, lab tests, and referrals that any other special patient population is afforded.
3. Reduce overall long term costs of autism care by treating the underlying causes of Autism. Many of our medically treated children improve and/or recover.
4. IACC should form focus groups with physicians and parents to create this new medical pathway.
5. Interview families. Create new science models that think outside the box that enable research to get our children well again. Use a patient centered model. The clinical trial approach is too slow and laborious. Track clinical data and analyze trends to inform and perfect treatments over time.
6. Families and their practitioners have discovered many resolutions to autism’s medical challenges. Society needs treatment protocols for hospitalization, pediatrician’s offices, and clinics. Parents want health record (perhaps EHR) tracking for clinical care to inform best practices, standards of care, patient centered care, and continuous improvement for our children’s clinical care.

Take action for our children. Make 2013 the year to address the medical needs of our autism population.

Thank you.

Dawn Loughborough

M. L. Ferreira

March 5, 2013

Subject: Comment

With the lack of consideration of medical issues in ASD and PDD and their importance in life´s quality, the lack of interest in the proper study of vulnerable population to xenobiotics, vaccines and antibiotics in combination first 3 years of life (combined with environmental pollution and introduction of food) of the majority of this committee (except Lyn Redwood, Jan Crandy and Geri Dawson) unfortunately there is no sense to try to warn about the importance of all these issues because they are dismissed at face value. Even more, some years ago USA could be a hope in terms of true innovative science through the NIMH and the IACC; today, these are part of the problem and bring no solution or answer or practical approach- not even one- to the myriad of struggles that families like mine around the world must face every day: the consequences of undetected, un tested, undiagnosed and untreated medical problems : gastrointestinal, metabolic, biochemical, nutritional, endocrinological, toxicological, immune and autoimmune conditions, viral-fungal-.bacterial- parasitic infections, mitochondrial dysfunction (not disorder), oxidative stress, inflammation and microglial activation.

M. L. Ferreira
Argentina

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Eileen Nicole Simon

March 7, 2013

Subject: Response to the Conference Call on 6 Mar 2013
[PII redacted]

I listened to the conference call yesterday on Basic and Translational Research.

The IACC was established to explore reasons for the increase in prevalence of autism. Thus the focus must be on finding the neurologic impairments that underlie (a) the language disorder, (b) lack of environmental (and social) awareness, and (c) motor dysfunctions that underlie stereotyped mannerisms and poor fine-motor control.

The focus must be on factors that affect maturation of the brain.

Dr. Insel (I think) said we need to find autism biomarkers. Can I suggest possible biomarkers we already have, and that all represent brainstem impairments?

1 - The language disorder is distinctive:

Autistic children have difficulty rewording things they are told. Phrase fragments heard in one situation are used out of context in new situations, and include use of "you" rather than "I". They have missed the "baby talk" stage of development. Normal children extract words and syllables from what they hear, and very early learn to use these in new syntactic arrangements. The autistic child may not hear the boundaries between syllables and words. By adulthood most of us have the same difficulty trying to learn a foreign language.

2 - Aversion to particular sounds. Clapping the hands over the ears is distinctive.

3 - Stereotyped movements are what make autistic children stand out like a sore thumb.

4 - Poor manual dexterity, especially evident in handwriting.

5 - Poor eye-contact, or oculomotor dysfunction.

6 - Reports of autonomic system dysfunction, especially gastrointestinal problems.

The language disorder and aversion to noises suggests problems within the auditory system. Stereotyped movements may result from impairment within the basal ganglia. Poor manual dexterity suggests failure of fine motor maturation. Impairment of the oculomotor nuclei should be considered as possibly underlying poor eye-contact. Impairment of the autonomic centers in the brainstem may lead to GI problems.

These brainstem signs have long been known to result from abuse of alcohol, pain medications, and recreational drugs.

I agree that “metabolomic” biomarkers should be actively looked for. However, autism has many known genetic causes. Likewise many metabolomic markers should be looked for. Some may be toxic to the brain in varying degrees, especially in combination with environmental factors like oxygen insufficiency at birth.

Complications at birth might even be investigated as a biomarker for autism. Evidence of low Apgar scores is abundantly documented in cases of autism. Low Apgar scores should not be dismissed as non-specific. A low Apgar score is ominous for any child. Most do not develop autism. However, damage of the auditory pathway and basal ganglia resulting from asphyxia at birth has been amply documented both for monkeys and human infants.

Toward the end of the IACC meeting on January 29, treatments, therapies, and services were discussed as having more immediate priority than research on autism’s causes. Then Lyn Redwood spoke out that we need to stop this disability, and focus on prevention. I agree with Lyn. Promoting the search for biomarkers and impairments within the brain must be the greatest priority for the IACC.

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Karen Heffler

March 13, 2013

Subject: Autism Research

Dear Members of the Interagency Autism Coordinating Committee:

We wish to share our concerns about the potential role that tv/video/computer/phone screen time has on the developing infant mind.

We are asking that investigation be undertaken to answer these questions:

(1) What affect do these visual environmental factors have on the infant mind?

(2) What contributory role do these visual environmental factors have on the development of Autism?

Questions and observations detailing dose exposure including hours per day and types of exposure as well as size of screen, and degree of repetitive exposure could easily be incorporated into the National Children's Study and the Autism Baby Siblings Project. By currently not asking these questions, we believe a potential environmental contributing cause of autism has been overlooked.

Several of us, independently, have been concerned for many years about the possible contribution that tv/video (non-human visual input) may have on the developing mind and specifically the possible link to autism. Some of us have seen many children who were exposed to video/repetitive program viewing during their infancy who went on to develop autism. We are not aware of any research protocols in this area either funded by the NIH or any other organizations. Additionally, we could not find any research to refute this hypothesis. In essence, this environmental exposure is not being considered in any of our national studies on children, particularly looking at the earliest months of life.

In 1991, the risk of autism was 1 in 10,000, and now it is about 1 in 100. How has our world changed more in the time that autism rates have risen than the role that tv/video/computer plays in our lives and the lives of our children? Studies have shown that many infants watch 2 hours or more of tv/video in a day. This is a significant environmental dose related exposure. Do we know what impact this viewing and particularly repetitive video or program viewing can have on the infant brain that does not have the capacity to understand the lights and images and may be making neuronal connections to try to make sense out of the onslaught of images?

We know that the autistic brain becomes larger than the typical developing brain in infancy according to studies. A more recent study, Wolff et al., Differences in white matter fiber tract development present from 6 to 24 months in infants with autism. AmJ Psychiatry, 2012 Jun;169(6):589-600 suggests that aberrant development of white matter pathways may precede the manifestation of autistic symptoms in the first year of life. Higher fractional anisotropy values at 6 months was found in fiber tracts including Inferior longitudinal fasciculus (Distinguished Lecture Series, Center for Autism Research, S Paterson 3/7/13). The inferior longitudinal fasciculus is a band of fibers connecting the occipital (visual cortex) and temporal lobes. This research begs the question, what is/are the visual environmental factors that affect aberrant development of visual pathways detected as early as 6 months of age.

Well known to ophthalmologists, an infant who has a visual opacity at birth, such as a cataract, will have the capacity to develop vision in the eye if the cataract is removed in the first few weeks or months of life. However, if the opacity is not removed until later, vision does not develop in that eye despite the clear media. The human newborn brain is relatively underdeveloped and much of brain development takes place over the first few critical weeks, months and years. Do we know what effect the audiovisual input of tv/video/computer/smartphone viewing has on the infant mind?

Screen time is an environmental factor that is easily observable and quantifiable. If we are not clearly quantifying these factors on the National Children's Study, why not?? Without this information, we are not able to assess this as a factor in development. We have an opportunity and an obligation to find out if this is a causal/contributing factor.

There is an article out of Thailand which shows a connection. Chonchaiya, W. et al (2011) Comparison of television viewing between children with autism spectrum disorder and controls. Acta Paediatrica, 100:1033-1037. doi: 10.111/j.165`-2227. 2011.02166.

Michael Waldman from Cornell suggested the possibility and asked for additional research in 2006. We have not found any additional research.

Many potential causes of Autism have been studied: vaccinations, mercury, fungal overgrowth, immune deficiency, medications during pregnancy, food intolerance, and toxins. Hundreds of millions of dollars have been spent. None has been found to be a major causative factor such that changing that one exposure or event has reduced the number of new cases of autism. Genetic factors have also been implicated as playing a role and there have been some genes identified that may have a contributory effect. Genetic factors, however, do not seem to be the primary causative factor, but rather a predisposition in which additional factors play a role. It seems implausible that the genetic makeup of humans has actually changed over the last 25 years, but more likely that certain individuals are genetically more susceptible to a yet undiscovered toxin or exposure.

Additionally, videos with a pediatric audience such as Disney, We Sing and Sesame Street became mass produced and generally available in the late 1980's and early 1990's when the rise in autism rates began. In 2007 Journal of Pediatrics, Zimmerman, Christakis and Meltzoff, researchers at Univ of Washington found that among infants aged 8 to 16 months, exposure to baby DVDs/videos-such as Baby Einstein and Brainy Baby- was strongly associated with lower scores on a Communicative Development Inventory.

While the question of the role that tv/video/computer/phone screen time may play in the development of the infant brain is essential to study, it has now elevated to a critical level. As mentioned, the recent IBIS findings show higher white matter FA which seem to originate from the visual cortex. Now we must answer the question: What is the visual stimulation for this increased visual neural connectivity? A well designed study could answer this question in as small a time frame as two years.

Despite the fact that the American Academy of Pediatrics recommends no media before the age of 2, this recommendation is not commonly followed. Many pediatric offices and pediatric hospitals have tv's in their waiting rooms.

We respectfully submit our concerns and look forward to your thoughtful response. It is imperative that this be investigated in the National Children's Study and the Autism Sibling Studies. The financial impact of autism is billions of dollars, not to mention the devastating personal impact on these children and families. It is the responsibility of those who are entrusted by our society and our nation to study autism to investigate this environmental factor as a potential contributory factor in the neurodevelopment of autism.

Sincerely,

Karen F. Heffler, MD
Ophthalmologist and Parent of an Adult Son in the Autistic Spectrum
Advisory Board, Center for Special Needs, Philadelphia/SpecialNeedsPhilly.org
Advisory Board, Special Need Initiative of the Venture Philanthropy Partnership
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Stanton Peele, Ph.D, JD
Psychologist and Attorney

Rick Remington

March 15, 2013

Subject: Autism Speaks comments for March 19 teleconference

Autism Speaks wishes to submit the following written comments regarding services research and policy in preparation for the March 19, 2013 conference call of the Interagency Autism Coordinating Committee (IACC). These comments reflect and expand on the input we provided in the March 8 meeting of the Subcommittee for Services Research and Policy. Representatives from Autism Speaks will participate in the conference call and be available to discuss these points further.

POLICY

IMPLEMENTATION OF THE AFFORDABLE CARE ACT (ACA)

Autism Speaks was heartened and fully endorses the decision made by the IACC at its January 29, 2013 meeting to more actively engage the Secretary of Health and Human Services on public policy matters affecting the autism community. An immediate policy issue concerns the coverage for behavioral health treatments as part of the ACA's Essential Health Benefits package.

The ACA directs the Secretary to define Essential Health Benefits (EHB) for certain individual and small group health plans. The EHB includes items and services within ten (10) benefit categories, including "mental health and substance use disorder services, *including behavioral health treatment*." The words "including behavioral health treatment" were added by amendment in both the House and the Senate specifically to ensure that the EHB covered behavioral interventions for individuals on the autism spectrum.

Under HHS regulations, each state is to select a single health plan as a benchmark, then supplement that plan to conform to the ACA's ten (10) benefit categories. Despite the clear language in the law, only about half of the states currently offer plans that provide autism-specific behavioral interventions. These states will specify interventions in the family of applied behavior analysis (ABA), the set of interventions with the most evidence to support them and the current standard of care for young children with autism.

Most marketplace insurance plans covering autism-specific behavioral interventions will do so because it is a state-required benefit under the benchmark plan. In a few states, it may be offered as a habilitative service under "rehabilitative and habilitative services and devices," a separate benefit category under the EHB. The Secretary has not required insurance plans to cover these autism-specific treatments as part of "behavioral health treatment;" thus, there is no consistent national standard for autism coverage.

The IACC believes all benchmark plans should provide robust and consistent coverage of autism-specific behavioral interventions. More than a decade of controlled clinical trials and more than three decades of single-subject studies have shown that these interventions significantly increase IQ, language abilities, and daily living skills, while reducing the debilitating symptoms of autism. As a result, the American Academy of Pediatrics (AAP) and the United States Surgeon General has endorsed these interventions. In addition, the ACA requires new health insurance plans to cover preventive services without cost-sharing, including autism screening for children at 18 and 24 months. But the potential gain from these screenings will be lost if families lack appropriate access to evidence-based treatments for their children. The creation of state health insurance marketplaces provides an important opportunity to address the health needs of a segment of the population that has long experienced critical coverage gaps. Thirty-two (32) states now have comprehensive autism insurance laws. Autism Speaks urges the IACC to advise the Secretary in writing to set a consistent and robust standard under the ACA for coverage of behavioral health treatment across all states.

SERVICES RESEARCH

TOOLS

Create a Comprehensive Functional and Community-based Assessment Tool

There is a need for a comprehensive, functional community-based assessment tool that will provide concrete information about the strengths and challenges for transition-age students with ASD. The assessment should be conducted through observation in natural environments such as the home, school, or local community of the individual. The results of the assessment will help identify the skills the individual needs to develop in order to live and work as independently as possible in adult life.

Eliminate IQ Requirements

The current Health and Community-Based Services (HCBS) waiver presents challenges for long-term services and supports for people with ASD. These systems were designed to meet the needs of people with intellectual disabilities, not specifically for people with ASD. In some states, people with ASD do not meet categorical eligibility criteria due solely to their cognitive abilities. When an autism or ASD diagnosis is not included in the eligibility definitions, an individual's qualification of an intellectual disability (i.e. an intelligence quotient below 70-75 and adaptive behavior limitations) is the defining factor. As a result, people with ASD who have borderline, average or above-average cognitive abilities are typically ineligible for services under HCBS waiver programs.[1]

Outcomes Orientation: Develop Tracking Measures for Students as They Leave School

Considerable resources and effort are involved in supporting a learner with autism while they are in the school system. As identified through IDEA, the transition process should be:[2]

- Outcome-oriented
- Based upon the student's strengths and areas of need
- Focused on instruction and services for education, employment and other living skills

Based upon the identified criteria, there should be data on how well the transition plan achieved the goals that were identified.

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[1] U.S. Government Accountability Office (2006): http://ici.umn.edu/products/prb/213/default.html

[2] See: http://idea.ed.gov/explore/view/p/%2Croot%2Cdynamic%2CTopicalBrief%2C17%2C

Define What Makes a Successful Outcome

A successful outcome includes employment, community integration and to live as independently as possible. An individual with autism should be able to become a productive member of society. From a federal perspective, the desired result can be found in the very first finding of Congress in IDEA[3], which refers to "our national policy of ensuring equality of opportunity, full participation, independent living, and economic self-sufficiency for individuals with disabilities."[4] Preparing children with disabilities to "lead productive and independent adult lives, to the maximum extent possible" is one of IDEA's stated objectives.[5]

- In the first two years after high school, over half of young adults with ASD had neither held paid employment nor enrolled in vocational training or college. This "no participation" rate was higher than that of any other disability group tracked in the study – including those with intellectual disability. Six years after high school, only a third of young adults with autism had attended college and barely half had ever held a paid job.

- "The years immediately after high school are when people create an important foundation for the rest of their lives," said lead investigator Paul Shattuck, Ph.D., of Washington University's Brown School of Social Work, in St. Louis. "Yet many families with children with autism describe leaving high school as falling off a cliff because of the lack of services for adults with ASDs."

Communication of Entitlement and Eligibility of Services

During the transition years, families need to be educated on the eligibility requirements for entitlement services and alternative options when subsidies are not available.

Opportunity to Live Out of Poverty by Saving

An explanation of Social Security work incentives should be mandatory during transition. In addition, Autism Speaks is part of a broad coalition of disabilities organizations supporting legislation before Congress that would create tax-advantaged Section 529 savings accounts for Americans with Disabilities. The accounts would allow savings for an individual's adult needs, such as housing and transportation without jeopardizing their eligibility for Social Security, Medicaid and other benefits.

MEDICAID

Medicaid is a critical healthcare and funding component for adults with ASDs as well as other disabilities. One of its most critical support elements is the Home and Community-based Services Waiver. Although CMS provides guidance and oversight on Medicaid waivers, states have great flexibility on how they award waivers. Becoming educated about eligibility and waiting list rules can be very complicated, causing further delay in treatment for eligible adults. Because waiting lists are so long (over 20,000 in some states), adults with autism are suffering skill regression and, in some cases, behavioral challenges. Families are constrained from moving out of state to avoid starting at the back of the waiting list, even when there is financial or other hardships. We must improve access to Medicaid Home and Community-based Waiver Services to meet the growing demand and allow portability of Medicaid waiver services from state to state.

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[3] See: http://nichcy.org/schoolage/transitionadult#definition

[4] Individuals with Disabilities Education Act (IDEA): 20 U.S.C. 1400(c)(1)

[5] IDEA; 20 U.S.C. 1400(c)(5)(A)(ii)

EDUCATION (IDEA)

Teacher Training for Autism

As part of teacher certification, there should be a consistent module on autism and effective practices for including students with autism. Given the significant rise in autism prevalence during the past two decades, all teachers should have training. This is especially important for general education teachers, so that students with autism can be in the least restrictive environment with the proper supports and services.

Transition Services

Transition services need to begin at the age of 14 (which is now the case in some states) and the transition process should be coordinated over the domains of adult and independent living -- the community, employment, adult services, daily living skills, vocational and post-secondary education. Families have disclosed that a lack of planning for transition to adult services interrupts their children's access to care; students graduate and services dramatically decrease. More parent education is needed about how to navigate the adult system so that they do not end up settling for less than satisfactory options and a lesser quality of life for their children.
A number of important concepts pertain to transition services:

- Activities must be *coordinated* with each other
- Process must focus on results
- Activities must address the child's academic and functional achievement
- Activities should smooth a young person's movement into the post-school world

Adulthood involves a wide range of skills areas and activities. Preparing a child with a disability to perform functionally across this spectrum of areas and activities may well involve considerable planning, attention, and focused, coordinated services. We emphasize "coordinated" as transition activities should not be haphazard or scattershot. Services should be planned in synchronization with one another in order to drive toward a result.[6]

HOUSING

Choice and Options

The desire to live in one's own home and community is deeply rooted in the American spirit and tradition. Independence and self-determination are fundamental American values that unite us all as citizens. We share a civic duty to ensure that none of our fellow citizens are denied the right to choose where they live, with whom they live, and how they live. Adults living with autism, like all members of our society, deserve that opportunity to make these same choices. However, due to the overwhelming demand for housing among all people with developmental disabilities and the lack of appropriate support services, individuals and families are often faced with a decision to develop their own housing or wait an indefinite number of years before their adult child can move out of the family home.
Many individuals with autism face significant obstacles as they strive to gain this vital independence, and these challenges can serve to restrict their options from the start. For instance, some adults with autism have additional safety concerns, support needs, or other health issues that may narrow their

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[6] See: http://nichcy.org/schoolage/transitionadult#definition

possibilities of where they can live. Housing provides the primary framework for the support services that enable adults with autism to become independent members of their communities. A diverse range of housing and support options must be available in order to accommodate the broad autism spectrum. Autism Speaks believes that these options must not be further limited by government-imposed restrictions. Choice includes the type of housing or community setting in which an adult with autism will live. Limited government funding should not dictate where our fellow citizens live; rather, where people choose to live should drive where the government directs public resources.

Residential Supports

Working with individuals with autism requires an understanding of their learning styles, strengths and support needs. This is particularly important in a residential setting where the staff is responsible for vulnerable adults, yet there is currently no required training and/or certification for staff supporting individuals with autism in a residential setting. Standardized training should be implemented across the country with allowances for state variables.

EMPLOYMENT

Job Coach Training

Autism awareness training for job coaches is critical to provide the support and enable individuals with autism to keep their jobs. Employers support the need for well-trained job coaches.

Skills Assessment

In addition to a well-trained job coach, a key to successful job placement is determining the work strengths and support needs of adults with autism. The use of appropriate assessment tools such as job sampling and internships should be required and funded.

Long-term “Follow Along” Services

Funding for long-term “follow along” services for adults with autism is limited at best and often non-existent. A reliable funding source should be established through state vocational rehabilitation and/or developmental disability systems for adequate support.

Small Business Supports and Training

Small business initiatives present a promising avenue that adults with autism and/or their families have been starting to create a revenue stream for independence. There needs to be more consistent, increased funding with easier access to secure the funding. Technical assistance is the optimal way for these business ventures to succeed.

HEALTH CARE

Early Diagnosis

During 2012, the Autism Speaks Autism Response Team (ART) responded to over 21,000 emails and phone calls -- over 6 percent of these contacts concerned possible signs of autism. Increasing the availability of pathways to diagnosis and, ultimately, intervention is necessary to ensure better quality of life. Our ART team similarly field many calls citing waitlists of three-to-six months for entry into early intervention programs. It is critical to reduce these waitlists to avoid wasting valuable time before a child enters intervention. We also are aware of pediatricians who advise a passive approach, recommending that parents wait rather than refer them to a developmental specialist. Screenings and referrals need to be increased to prevent needless and potentially harmful delays.

Medical Care Throughout the Lifespan

When a teenager with special medical needs is ready to move from pediatric to adult care, healthcare transition services can help them make the switch. These programs are designed to prevent gaps in both care and insurance coverage. But according to a new study reported in *Pediatrics*, teens with autism receive transition services only half as often as those with other special healthcare needs. More worrisome, young people with autism coupled with associated medical problems are even less likely to receive transition support. For the study, researchers from the University of Missouri examined information about 806 adolescents with autism between the ages of 12 and 17. They compared the teens' access to healthcare transition services to that of age-matched young people with other lifelong conditions such as asthma or diabetes. Around half of teens with medical issues other than autism received healthcare transition support; less than a quarter of those with autism received such support. The researchers found that many young adults with autism lacked any access to healthcare for several years after they stopped seeing a pediatrician. This is especially worrisome because autism is associated with a range of medical conditions including epilepsy, gastrointestinal problems and sleep disturbances. Having multiple medical conditions further decreased the rate of using transition services, to under 15 percent, among the teens with autism.

Medical and Mental Health Co-morbidities

Several medical conditions are associated with autism, such as epilepsy (as high as 39% of individuals with ASD), gastrointestinal issues (up to 85%) sleep disorders, sensory processing disorder, and pica. Often it is difficult for physicians to diagnosis these co-morbid conditions. Mental health issues can also develop, especially in late adolescence and early adulthood. The most common are anxiety, depression and obsessive-compulsive disorder. For many, the symptoms of these illnesses are initially attributed to autism; it is important for health care providers to provide the same level of care and to treat some of the associated medical and mental health conditions regardless of the autism.

OTHER ISSUES

Autism-specific Training for Staff Supports

The United States has no standard training protocol for working with individuals with autism. Some provider agencies train staff, but employees can work at a day program or in a group home and receive no autism-specific training. Autism Speaks recommends standardized training for any individuals who work with individuals with autism.

Respite for Families

Families caring for a loved one with autism can experience a higher degree of stress than parents of typical children. Stress relief for the caregiver can be provided in the form of respite services. The Lifespan Respite Care Act has the potential infrastructure for this type of funding and support to be disseminated to the states.

Educating Families on the Costs of Services

The majority of families are ill-prepared to manage the cost of adult services. They have emerged from an educational entitlement system in which cost did not need to be factored into their son or daughter's needs. It is becoming more common for states to provide families with a budget to support their loved one through employment, respite, residential and day support services. These budgets can range from a low of $3,000 to as high as $175,000 for someone requiring significant one-on-one supports. Families need to be prepared for the actual cost of services, what they can or cannot expect from public funding, and how long they may have to wait.