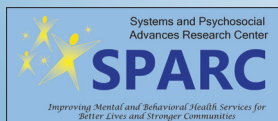




Current Issues in Serving Adults with Non-ID Autism Spectrum Disorder and Significant Mental Health Disorders

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Report from the Systems and Psychosocial Advances Research Center (SPARC)

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INTRODUCTION

Following is a review of documents and information gathered and summarized to assist the Massachusetts Department of Mental Health (DMH) to begin the process of developing a more responsive system of care for adults with Autism Spectrum Disorder (ASD) who have serious mental illness, but who do not have an Intellectual Disability (ID) (who are not served by the Department of Developmental Services or DDS). These adults have in the past been identified as having “High Functioning Autism” or HFA or as having Asperger’s Syndrome or AS. These distinctions and sub-groupings have been dropped from DSM-5. However, many people with Asperger’s syndrome retain the term and prefer it. Of note, there may be some adults with HFA or AS who are served in their state’s Developmental Disabilities programs along with adults who have co-occurring Intellectual Disabilities (ID) and ASD. Stakeholders also commented that they suspect many adults with unspecified disabilities and even with severe and persistent mental illness have undiagnosed ASD.

Outline

First, ASD will be defined and a brief overview provided. Secondly, mental health challenges of people with ASD are reviewed. Research reviewed here was prepared for the next Diagnostic Manual – Intellectual Disabilities 2 (DM-ID 2) by Dr. Jean Frazier and myself. The review reveals very limited systematic study of the specific needs of adults with an ASD who have co-occurring mental illness, and even less addressing means to promote improved service outcomes. A summary of information obtained via several interviews conducted with stakeholders is also provided. A few of the isolated specialized programs serving adults with significant mental health service needs are described in connection with these interviews. There are actually numerous programs identified as offering something to help adults with ASD. However, on deeper review, many of these provide limited information about how routine community based mental health services are modified or expanded to accommodate any special needs of the target population.

Next, examples of web documents describing needs and services for adults with an ASD as assessed by state government entities attempting to implement policy changes for this target population, is presented. In some states, there is no separation of discussions addressing needs and services for adults with ASD who do or do not have a co-occurring ID (though this division exists in many places). More commonly, policy papers and systems analyses do not address the needs and services available for adults with ASD based on whether or not they do or do not have co-occurring mental health disorders. Availability and access to services known to help promote health and wellness for the population are often addressed, such as access to transition planning and to appropriate educational and vocational opportunities. A significant emphasis appears to be placed on the need for adults with ASD to have help in seeking and sustaining employment and meeting housing needs. Despite widespread agreement that things such as access to vocational supports training, placement and life coaching are needed and helpful services, there appears to be limited resources allocated to achieve the stated goals. Where mental and physical wellness promoting services are available, access is often limited and the programs are unavailable to many adults with “high functioning” or normal IQ ASD. Very little seemed to be described in the way of gaps or suggested solutions to a lack of specific ASD-informed community based mental health services and supports.

Following the above, some of the national initiatives and laws with impact on adults with ASD are also cited.

A brief summary is provided with some initial suggestions for consideration for next steps, and what the stakeholders reported were current needs to better serve this population.

AUTISM SPECTRUM DISORDER, HIGH FUNCTIONING AUTISM AND ASPERGER'S SYNDROME

Autism Spectrum Disorders (ASD) is the newer term applied in the literature and in DSM-5, for what was formerly labeled Pervasive Developmental Disorders in DSM-IV-TR.

Autism spectrum disorder (ASD) is the name for a group of developmental disorders. ASD includes a wide range, “a spectrum,” of symptoms, skills, and levels of disability.*

People with ASD often have these characteristics:

- Ongoing social problems that include difficulty communicating and interacting with others
- Repetitive behaviors as well as limited interests or activities
- Symptoms that typically are recognized in the first two years of life
- Symptoms that hurt the individual's ability to function socially, at school or work, or other areas of life
- Some people are mildly impaired by their symptoms, while others are severely disabled.

Treatments and services can improve a person's symptoms and ability to function. Families with concerns should talk to their pediatrician about what they've observed and the possibility of ASD screening. According to the Centers for Disease Control and Prevention (CDC) around 1 in 68 children has been identified with some form of ASD.

***<http://www.nimh.nih.gov/health/topics/autism-spectrum-disorders-asd/index.shtml>**

Asperger's syndrome features: AS affects each person differently, although there is a core set of features that most people with AS have, to different extents:

- People with AS have normal to very high intelligence and have good verbal skills.
- Challenges with the use and understanding of language in a social context.
- Trouble understanding what someone else is thinking and feeling (called theory of mind or perspective taking).
- Needing to be taught social behavior that is “picked up on” intuitively by others.
- Difficulty understanding non-verbal cues such as hand movements, facial expressions, and tone of voice.
- Challenges with organization, initiation, prioritizing, all called executive functioning tasks.
- Focusing on small details rather than the bigger picture
- Most people with AS have intense interest areas such as movies, geography, history, math, physics, cars, horses, dogs or reptiles. These interest areas change every 3 months to several years
- Friendships are usually formed through mutual interest areas or activities.
- Most people with AS view the world in black and white with difficulty compromising or seeing the gray areas.
- Most individuals with AS describe themselves as feeling different, like aliens in our world.
- Anxiety and/or depression are major components for many people with AS and may affect their ability to function.
- Some individuals with AS have extreme and debilitating hyper- or hypo-sensitivity to light, noise, touch, taste, or smell. The environment can have a profound impact on their ability to function.

The current review is primarily aimed at addressing needs of adults with ASD who do not have a co-occurring Intellectual Disability or ID. These individuals are often referred to as having “High Functioning Autism” or HFA or as having Asperger’s syndrome.

Services and supports when provided to youth with ASD can be critical in preventing later emotional and behavioral struggles. Like most people, young adults with ASDs who have the support of family and friends, personal and social relationships, employment and housing are less likely to develop severe mental illness or when affected, have less severe or chronic forms. However, unlike typically developing peers, people with HFA or AS are more likely to:

- Receive their ASD diagnosis later in life (often missing out on receiving early intervention services)
- Be lonely, isolated
- Be unmarried
- Be unemployed
- Be unable to achieve independence
- Be socially motivated but socially awkward (wanting relationships but struggling to form and maintain them)
- Be psychiatrically misdiagnosed when having an emotional or behavioral challenge, especially with confusion regarding what symptoms derive from mental illness and what challenges are the result of having an ASD
- Express emotional and physical distress via externalizing behaviors
- Have severe anxiety (often manifested behaviorally) that is missed, while Bipolar Disorder and Psychosis may be over diagnosed
- Have extreme “melt downs” and severe symptoms that are driven by contextual influences, with a return to baseline when influencing conditions resolve
- Have emotional and behavioral challenges that require help and treatment but may not always be secondary to an Axis I psychiatric syndrome or responsive to usual medication interventions
- Be overmedicated, related to co-occurring aggression and to misdiagnosis and “treatment resistance”
- Have atypical neurological substrates with different risks for adverse drug events than people with typical developmental histories
- Have unmet health needs - including medical problems and medication side effects that provoke distress induced emotional and behavioral challenges that will “mimic” or significantly worsen an existing mental health disorder
- Be less responsive to unmodified, usual outpatient mental health treatments, even when diagnosis is accurate (sometimes once per week or twice per month “talk” therapies are ineffective)
- Need specialized help that is designed with an understanding of core features of ASD
- Have large discrepancies between areas of functioning such as having intact verbal fluency with major challenges to social cognition and/or visuospatial abilities
- Have major sensory sensitivities and atypical sensory profiles
- Have executive functioning challenges even with a “normal” Full Scale IQ
- Be exposed to bullying and other traumatic events with long term effects on mood and behavior for many and with atypical clinical presentations

MENTAL HEALTH CHALLENGES – FROM THE DM-ID 2

(Manuscript in preparation)

Laurie Charlot, PhD & Jean Frazier, MD

<http://www.dmid.org>

Individuals (across the lifespan) who have an ASD are at elevated risk for experiencing both physical and mental health problems. More research has been presented with regards to youth but the research addressing older teens and young adults is important to systems and policy change needed to prevent and better serve adults who have a serious mental illness. Stakeholder all feel that more can be done to reduce risk for mental illness and for poor life outcomes (see below).

A large portion of the extant research in autism addresses possible causes and pathways to the disorder or interventions aimed at core features and skill building (i.e. intensive early intervention). Many fewer investigations address the specific area of psychiatric comorbidity. A number of articles provide a good overview of intervention models for the treatment of youth with ASD who have challenging behaviors. ABA has the greatest published evidence base (for detailed reviews of autism interventions and ABA - see Bishop & Lord, 2010; Virues-Ortega, 2010; Vismara & Rogers, 2010).

Youth with ASDs have been found to experience ADHD and mood and anxiety disorders at high rates (and as the most common of their psychiatric disorders). First-degree relatives show a pattern of elevated risk for mood syndromes (Lainhart & Folstein, 1994; Leyfer et al., 2006; Sasson et al., 2013). Leyfer and colleagues (2006) performed in-depth individual assessments on 109 youth with ASD (ages 5–17) and found phobias to be the most common comorbidity. Levy, Giarelli, Nicholas, Reaven, and Rice (2010) studied a large cohort of 8-year-old children with ASD in a multisite investigation of psychiatric and medical comorbidity. Psychiatric disorders were documented in 10% of the sample and 16% had a neurological disorder. They noted that comorbid psychiatric, neurologic, and medical diagnoses may delay identification of ASD.

Only a few investigations have examined rates of psychiatric disorders in individuals with ASD in larger population-based studies, and the majority of these focused on children. Often, with population based studies, recorded diagnoses are used and the youth were not directly assessed. Rosenberg, Kaufmann, Law, and Law (2011) used a national registry to review the community diagnosis of psychiatric comorbidity in 4,343 children with ASD. Lifetime prevalence of psychiatric disorder by age 16 in youth with ASD was determined to be 49% in contrast to reported rates for the general population of 37%. Having a diagnosis of Asperger's syndrome or pervasive developmental disorder not otherwise specified (PDD NOS) conferred greater risk of receiving a psychiatric disorder diagnosis relative to autistic disorder.

Even fewer studies address rates of disorder in adults with ASD. Joshi and colleagues (2013) studied a population of clinically referred adults, and also reported high rates of depression and anxiety. The most comprehensive population based study that included some direct examination of adults with ID and ASD was conducted by Melville et al. (2008). Individuals in this study included over 1000 adults with ID, 77 of whom were then diagnosed with an ASD. Individuals with ASDs had a higher rate of problem behaviors than the population of people without ID, but similar rates to a matched control group with ID without ASD. Similar rates of “mental ill health” were found. Anxiety and affective disorders were the most frequently reported disorders. Adults with ASD were less likely to have recovered from mental ill health at 2-year follow-up.

A number of studies have noted higher rates of internalizing disorders among subjects with ASD who have either less ID or no ID when compared with individuals who have more significant cognitive challenges. Diagnoses that involve descriptions of internalizing symptoms may simply be easier to identify or may have developmentally driven variability in terms of observable or “surface features.” Specifically, youth and adults with more significant developmental challenges may present more like younger children, and display non-specific signs of irritability and aggression when distressed from problems such as anxiety or depression. Associated agitation and challenges to affect regulation may be viewed as evidence of bipolar disorder. Of note, studies using direct patient assessment with semi-structured interview tools reveal lower rates of psychosis and bipolar disorder, and higher rates of anxiety and depression. LoVullo and Matson (2009) for example, assessed psychiatric disorders using an informant-based psychopathology tool in institutionalized adults diagnosed with ASD, most of whom had severe or profound ID. They reported high rates of bipolar disorder and very low rates of anxiety disorders and ADHD in contrast to most other investigations reporting rates of specific psychiatric comorbidity.

Charlot and colleagues from the UMass EK Shriver Center examined psychiatric inpatients with ID with and without ASD who were diagnosed with depression. There were few differences between the inpatients with the exception that individuals with ASD had overall more symptoms of anxiety and depression (Charlot et al., 2008). Ghaziuddin and Zafar (2008) found depression and anxiety to be the most common psychiatric disorders in a clinical sample of adult outpatients with ASD and less ADHD than generally found in studies of youth. These authors and others suggested clinicians should be cautioned that phenomenology may be affected by developmental considerations, especially expressive communication. In very young children, anxiety may be manifested by tantrums, freezing, rapid speech, and other atypical features. Individuals with ASD and ID may engage in anxiety-based aggression (“fight or flight”), which may be missed because of a lack of self-report of internalizing symptoms. White and colleagues (2009) emphasized that “assessment of anxiety disorders in ASD should be conducted using multiple informants and modalities, as children with ASD often do not display age typical symptoms of anxiety.” Also, when agitated behavior is accompanied by poor sleep, psychomotor agitation, and aggression, there may be an overdiagnosis of conditions such as bipolar disorder (Charlot et al., 2008). In general, individuals with less cognitive impairment may receive certain diagnoses more because of the classification systems we employ, which rely heavily on self-report of internal states, to make a diagnosis. Use of behavioral descriptions of the possible manifestations of mood symptoms when interviewing informants, and use of multiple sources for informant-based reports as well as direct observations, may increase information regarding “internalizing” symptoms.

Psychosis has been studied less frequently in people with ID, but has been addressed in limited numbers of investigations with participants with ASD. Starling and Dossetor (2009) reviewed literature and described the difficulties inherent in differential diagnosis of psychotic disorders in individuals with ASD. They noted that the two disorders share many similar characteristics including perceptual abnormalities, thought disorder, catatonia, and deficiencies in reality testing. In an international investigation, van der Gaag, Caplan, van Engeland, Loman, and Buitelaar (2005) examined multiple clinical groups and found that developmental effects and verbal abilities had a significant effect on the detection and differentiation of psychotic symptoms. In these investigations, the effects of cognitive impairment and communication challenges were discussed as critical factors that may create significant diagnostic challenges when clinicians must try to differentiate developmentally driven errors in thought processes from true psychotic ideations.

As noted by Mazefsky et al. (2012), yet another lingering question for future research is whether or not individuals with ASD experience separate and distinct comorbid psychiatric “syndromes” in most cases,

or rather, if the clinical presentations in question are the result of shared neurological pathways and other causal mechanisms. Accurate diagnostic classification is challenging when evaluating people with cognitive challenges, and is further complicated when assessing children or adults with ASD (with and without ID). There may be a disconnect between research regarding psychiatric comorbidities and what occurs in practice. Data from numerous surveys suggest that both people with ID and people with ID and ASD are increasingly treated with antipsychotic medications, whatever the diagnosis. “Mislabeling” and confusion about the complex roots of aggressive and disruptive behaviors and affect dysregulation in patients (young and old) with ASD may be the most significant cause of the over-use of antipsychotic medications, and the high rate of multi-drug regimens in general. Mazefsky et al. (2012) found a high rate of discordance between carefully and comprehensively assessed diagnoses of ASD and psychiatric comorbidity, and the diagnoses that the youth studied had been given. In general, these authors found evidence of teens having been labeled with what appeared to be inaccurate diagnoses, numerous different diagnoses; and probably, not the most effective treatments based on these. The “disconnect” was most pronounced unsurprisingly for youth who had some of the most negative outcomes, those with multiple inpatient psychiatric hospitalizations. Among this subset of the sample, for example, most had not been diagnosed with ASD (with clear evidence of the syndrome) and carried diagnoses of ODD for which the evidence was not present.

While this is certainly a challenging population with a high rate of aggressive and disruptive behaviors, it’s possible that outpatient interventions could have been more successful if their concerns had been conceptualized within the framework of their ASD. P. 7

Efforts to distinguish between clinical features that are representative of core aspects of ASD versus those suggestive of a comorbid psychiatric syndrome have been systematically attempted, using the ACI. At the University of Utah, Leyfer and colleagues modified the Kiddie- Schedule for Affective Disorders and Schizophrenia (K-SADS) to study rates of psychiatric disorders in samples of youth with ASD (Kaufman et al., 1997; Leyfer et al., 2006). Mazefsky et al. 2012 more recently reported on use of the modified K-SADs, that they have called the Autism Comorbidity Interview (ACI; Leyfer et al., 2006). The tool was developed to address concerns related to misidentifying exaggerated core features of ASD as symptomatic of psychiatric illness or the reverse error (labeling psychiatric symptoms as features of ASD).

In a similar effort (to improve the accuracy of symptom identification as it contributes to a diagnosis), Charlot and colleagues from the University of Massachusetts Medical School and the EK Shriver Center published one study introducing the Mood and Anxiety Symptom Survey (MASS), presenting an initial validation study (Charlot, Fox, et al., 2007). The MASS is a semi structured interview tool in which informants report on symptoms of mood and anxiety disorders covering DSM-TR-IV and DM-ID symptom criteria. For each symptom criteria, multiple behavioral anchors are provided, including a variety of descriptions of what a person with ID might do or say if experiencing the symptom. The anchors were drawn from prior research and clinical experience of the authors. However, follow-up work or further validation of the tool has yet to be published. The methodology of providing multiple behavioral descriptions for each symptom criteria was intended to decrease problems with interpretations of terms such as “anxiety” or “depressed mood” that are rated by untrained informants in many screening tools. Unpublished data have demonstrated a moderate to high degree of convergence between diagnoses suggested by the MASS interview and those based on administration of a modified K-SADS in a sample of adolescents with ID (restricted to anxiety and mood disorder categories).

In some investigations, it has been noted that people with ID (with and without ASD) may be more likely to be diagnosed with psychotic disorders when assessed by clinicians with limited training in the field. Lunsky and Bradley (2007) discussed the problem of using data from non specialists in IDD when describing psychiatric disorders. Specifically, they found significantly lower rates of psychotic disorders based on more rigorous evaluations done by specialists, and higher rates of mood and anxiety disorders when compared with diagnoses that were from non-specialists. For example, 62% of patients were given a diagnosis of a psychotic disorder by non-specialist in comparison with 26% of patients seen by clinicians with a specialization in assessment of people with IDD.

The role of contextual and psychosocial factors on the occurrence and persistence of psychopathology in youth and adults with ASD and ID has received little attention. Longitudinal designs may be the most critical to reveal the power of such influences, and add understanding to the complexities of the developmental trajectories for comorbid emotional and behavioral challenges. Simonoff and colleagues (2013) examined psychiatric symptoms using the SDQ (Strengths and Difficulties Questionnaire) and examined the stability of child, family and other risk factors for psychopathology in a sample of 81 youth diagnosed with an ASD, at ages 12 and 16. Lower IQ and adaptive functioning predicted higher hyperactivity and total difficulties scores. "Greater emotional problems at 16 were predicted by poorer maternal mental health, family-based deprivation and lower social class."

Nylander and colleagues (2013) examined ADHD and ASD in a sample of adults and contrasted rates and nature of psychiatric comorbidity and psychosocial functioning for the two groups. Lifetime rates for psychiatric disorders were greater for adults with ASD as compared with patients without ASD, with major depression and "multiple anxiety disorders" being the most frequent diagnoses identified. They also noted that adults with ASD overall, "functionally more impaired." (p.344)

Some controversy has surrounded the question of Bipolar Disorder diagnoses in youth with and without ASD, with reports suggesting that the syndrome is diagnosed much more in the US and that rate of diagnosis has increased markedly over the last decade. The development of the new diagnostic category of Disruptive Mood Dysregulation Disorder in DSM-5 was aimed at addressing some of these issues, after longitudinal findings that only a small number of youth with highly complex presentations, irritability and aggression developed Bipolar Disorder as adults (Leibenluft, 2011). Other studies describe overlap between core symptoms of ASD, challenges to affect regulation, stress or anxiety responses and symptoms of mania (Mazefsky et al., 2013). However, when the syndrome does occur in people with an ASD, it is associated with extremely severe clinical challenges.

Other Comorbidities

Individuals with ID and ASD have high rates of comorbid medical problems. Gaier, Kern and Geier (2012) conducted a prospective, cross-sectional review of the health and challenging behaviors of individuals with ASD and found high rates of a number of health problems. Among the most common were gastrointestinal problems found in 48% of the sample, incontinence - 57%, sleep problems-57%, lethargy - 26%, anxiety - 74%, eating disorders - 94%, and behavioral challenges - 89%. Parents reported significantly more GI problems in children with ASD (42%) when compared with siblings who did not have an ASD (12%).

Medical problems have also been implicated in the development of and exacerbation of challenging behaviors in people with an ASD (Buie et al., 2010). Mazurek and colleagues (2013) for example, found

a relationship between anxiety, GI problems and sensory challenges in youth with ASDs. Chaidez and associates (2014) noted higher rates of GI problems in children with ASD and ID compared to peers with typical developmental histories and described a relationship between these medical concerns and challenging behaviors. Youth with GI problems in the RUPP studies had more severe challenging behaviors and responded less well to psychoactive medications.

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INTERVIEWS WITH STAKEHOLDERS

Interview with AANE

Dania Jekel, MSW - Executive Director

This organization is a major source of education, training and supports for individuals with Asperger's syndrome and they were able to provide a very comprehensive, informed and sensitive overview of the needs of this population related to promoting positive mental health and responding to needs when there are serious mental health needs.

Asperger/Autism Network - AANE
The Asperger/Autism Network (AANE) works with individuals, families, and professionals to help people with Asperger Syndrome and similar autism spectrum profiles build meaningful, connected lives. We do this by providing information, education, community, support, and advocacy, all in an atmosphere of validation and respect. AANE provides support and community to:
<ul style="list-style-type: none">• Adults with Asperger Syndrome (AS) and their parents, partners, siblings, grandparents, friends, employers, & relatives,• Families of Children and Teens with AS, and• Educators and other Professionals who work with people with AS.• They may have received a diagnosis of Asperger Syndrome, Autism Spectrum Disorder, Social Communication Disorder, PDD-NOS, or Non-verbal Learning Disorder. AANE does not require that a child, teen, or adult have a formal diagnosis in order to attend our educational events or explore our services.
These individuals may struggle to varying degrees with social communication, organization, and perspective-taking. They may also have sensory sensitivities and anxiety. In general they have average to superior range I.Q. and they are verbal but find it difficult to use their language skills to develop relationships and navigate their environment.

Where things are at presently per this interview:

- Individuals with High Functioning Autism or Asperger's syndrome (HFA or AS) who have emotional or behavioral challenges (the "dual population") is a large under served population.
- AANE receives frequent calls for help and advice regarding where to access help.
- Based on their extensive experience with the population and in their collaborations with other stakeholders, they suspect there are:
 - Numbers of people undiagnosed who have an ASD, served primarily in psychiatric settings.
 - Many individuals "newly eligible" for DDS services who have a mental health comorbidity.
 - Access to appropriate, effective services is lacking for many people in need.
- There are two major Autism Centers in Massachusetts, but individuals and their families cannot always access them. The access barriers include:
 - Systemic barriers:
 - Inadequate funding for enough expert services
 - Insurance based
 - Geographical/Transportation related barriers:
- Lack of transportation or distances too far to reach the specialized Centers
- UMass CANDO (Child and Adult Neuro-Developmental and TAY (Transition Age Youth initiative), led by Dr. Jean Frazier, were described as having the very best of services and have served more children

than adults but are expanding their adult and transition age service components.

- The Luria Center (formerly Ladders) affiliated with Mass General Hospital and run by Dr. Christopher McDougal also has excellent services for people who can access them, in the Boston area. They have a specific sub-program ASPIRE for adults with ASD. The impression was that there were more “developmental” services at the Luria Center and more mental health services available at CANDO. (See descriptions of these Centers below).
- People in other areas, especially western Massachusetts have much less access to needed care.
- Care in the generic service system is often inadequate or inappropriate when unadjusted for the specific needs of people with an ASD. People with AS or HFA do very poorly in EDs and usual mental hospitals or psychiatric units.
- Training for people who provide services to adults with HFA or AS is a major need across the spectrum of professions and locations in the Mental Health (MH) system.
- There is need for special attention to the fact that individuals with HFA or AS may have severe “melt downs” in reaction to contextual influences (daily life stress) and then be at baseline and functioning well soon after (not always signifying i.e. psychosis). Awareness of the unique challenges people with an AS or HFA face is critical and understanding that...”their neurology is different” - such that over reliance on psychoactive medications, inappropriate diagnoses (over diagnosing psychosis, bipolar disorder and missing anxiety issues) are all significant concerns that contribute to morbid outcomes and over use of expensive and restrictive care options.

AANE has provided a lot of help but is under funded and cannot meet the needs of all who would benefit from some of the specialized help they offer.

As noted by the AANE organization, the Luria Center program and its Aspire group offers specialized services and care to adults with “high cognitive” ASD. Below is a brief description of Aspire. Mental Health assessments and care are available through the Luria programs and service system. However, like CANDO, many parents and individuals have difficulty accessing these services related primarily to geography but also to availability of openings at times.

See *Summary Suggestions* below which includes a number of needs suggested by the AANE.

Interview with Dr. Jean Frazier

Director of the Eunice Kennedy Shriver Center at UMMS (Includes: Child and Adolescent Neurodevelopmental Initiative (CANDI), the Center for Autism and Neurodevelopmental Disorders (CANDO) and the former Eunice Kennedy Shriver Center for Developmental Disabilities.)

Dr. Frazier described the CANDO (Center for Autism and Neurodevelopmental Disorders) and TAY (Transition Age Youth) initiatives and discussed their efforts to expand services to include more access for adults with AS and HFA. Dr. Frazier noted that they are serving a large number of adults with HFA or AS who have mental health needs. They have a specialized multidisciplinary team approach when conducting evaluations of individuals with ASD who have mental health challenges and have worked on cases with forensic involvement. The CANDO program is eager to collaborate with stakeholders and continue discussions with DDS and DMH about meeting the unique needs of the target population.

Two areas of special focus have included work to reduce ED visits for psychiatric challenges for youth and adults with ASD and discussions about expanding specialized Medical Home services along the lines of the system that has been quite effective in use presently in Utah (see attached paper addressing the Utah model). I visited the program some years ago, and this Medical Home provides multidisciplinary and holistic care to children and adults with developmental disabilities (including people with an ASD) using Medicaid dollars, they were able to demonstrate savings over care as usual.

Below is an outline of currently available services at UMass CANDO and they are developing a more detailed description of adult ASD services presently - <http://shriver.umassmed.edu/programs/cando>

CANDO - Center for Autism and Neurodevelopmental Disorders

Autism Spectrum Disorder (ASD) and Neurodevelopmental Disorders Prescriptive Practice - (4-25 years)

Dr. David Cochran & Mary Jeffers-Terry, ANP

Youth with ASD requesting psychopharmacological evaluation and treatment

Youth with ASD with question of psychiatric diagnostic clarification

Developmental Behavioral Pediatrician (DBP) - (5-16 years)

Dr. Roula Choueiri

Youth with ASD who have a complex profile and who need re-evaluation for diagnostic clarification

Interdisciplinary Team Evaluation and Short-term Treatment for Youth with ASD and Complex Profiles (3-22 years)

Psychiatry, Occupational Therapy (OT), Speech and Language Pathology (SLP), Family/Autism Resource Specialist, Care Coordination

Dr. David Cochran, Dr. Mary Beth Kadlec, ScD, OTR/L Pamela Billings, MEd, OTR/L, Susan Swanson, MA, CCC-SLP, Sandra Osborne, Autism/Family Resource Specialist

Youth with ASD or other neurodevelopmental profile requiring psychiatry evaluation along with OT, ST, and community resources

DBP will be involved in assessments of youth between 3-5 years and involved in assessments of older youth as needed

Child Neurology will be consulted as needed

After the assessment typically short term intervention for up to 16 weeks will occur with transition to community based services; In these cases, youth may return as needed

We work closely with the school systems and with Case managers of DDS, DCF, DYS, and DMH

For highly challenging cases care may be more ongoing in nature.

Child Neurology – (all ages)

Dr. Andrew Zimmerman

Individuals with ASD and comorbid neurological complications, including epilepsy, medical (metabolic), and/or psychiatric conditions

Providers from Benedict will refer all patients with ASD to see Dr. Zimmerman in CANDO

Neuropsychological Testing – (6 years to adult)

Dr. Brian Dessureau

Dr. Dessureau provides 8 hours/week to CANDO for testing.

Referrals are only “in-house”, i.e., made by CANDO providers for this service.

Fragile X Behavioral Health Clinic – (all ages – children and adults)

Dr. Frazier, Dr. Cochran, Dr. Van Silka and other members of the CANDO team as needed, including OT, Speech and Language, Resource Specialist, and BCBA

Persons with a diagnosis of Fragile X Syndrome and behavioral challenges

Provide Diagnostic and Psychopharmacologic consultations

Provide ongoing follow up and prescriptive practice as indicated

Services for Transition Age Youth and Adults with Autism and Developmental Disorders – (18-upwards years)

Dr. Van Silka

Psychiatric evaluation and treatment

Additional Services in CANDO

Anxiety and OCD Clinic – (5- 16 years)

Dr. Phoebe Moore and Dr. Ashley Hart, Clinical Psychologists, Dr. James Yon, Psychiatrist

Diagnostic evaluation and, if indicated, short-term (8-16 weeks) Cognitive Behavioral Therapy (CBT)

Psychopharmacologic evaluation and short-term intervention

Attention Deficit / Hyperactivity Disorders (ADHD) Clinic – (5- 16 years)

Dr. Yael Dvir

2-3 week psychiatric evaluation and short-term psychopharmacologic treatment for the majority of patients with ADHD needing a second opinion and who have therapies in place.

In extremely complex cases care may be ongoing.

Child Behavior Clinic – (birth – 5 years) – Training Clinic

Dr. Peter Metz, Psychiatrist & Dr. Wynne Morgan, Psychiatrist

Diagnostic assessment and short-term treatment

Mood Disorders Clinic - (6-22 years) & Psychosis Clinic – (6-22 years)

Dr. Yael Dvir, Psychiatrist

4 week psychiatric evaluation and short-term psychopharmacologic treatment for patients needing a second opinion and who have therapies in place.

Neuropsychological testing is available

We involve school personnel and case managers of child and adult agencies

For extremely complex cases care may be ongoing

Pediatric Psychiatry Consult Liaison Clinic

Dr. Negar Beheshti, Psychiatrist

Short-term psychopharmacological treatment post-hospitalization

Occupational Therapy – (infants – 25 years)

Dr. Mary Beth Kadlec, Pamela Billing

Occupational therapy evaluation and short-term treatment

We offer care coordination and work closely with families and community based providers to transition to community based care

Speech and Language Therapy - (infants –25 years)

Susan Swanson, Speech/Language Pathologist

Speech and language evaluation and short-term treatment

We offer care coordination and work closely with families and community providers to transition to community based care.

Autism/Fragile X Family Resource Specialist - (infants – adult)

Sandra Osborne

Consultation to families and providers re: community resources

Note: We collaborate as indicated with UMass Audiological, Genetics, Gastrointestinal, and Sleep Clinics.

Adult Services that are available within our broader system of care:

UMMHC

- Patient centered consultation and treatments. (Psychiatry, care management and applied behavioral analysis) provided based on contract with state and provider agencies (Dr. Robert Baldor, Dr. Van Silka, Dr. Paula Ravin).
- Medical Home for high risk patients with significant behavioral, medical and psychiatric acuity (Dr. Baldor, Dr. Silka, Dr. Ravin)
- Outpatient Access to patients from Family Medicine and UMass Memorial Medical Group (Dr. Silka)

Community Health Link

- Worcester: 12 Queen Street- outpatient evaluation, counseling, groups and psychiatric treatment for adults 18 and over with Developmental Disabilities, supported by the Department of Developmental Services (DDS) and insurance payments. Most are DDS clients.
- Fitchburg: 275 Nichols Road- outpatient evaluation, counseling, behavioral consultation to staff and families, day treatment program, competency evaluations, and psychiatric treatment for adults 18 and over with Developmental Disabilities supported by DDS and insurance payments. Most are DDS clients.

Other Massachusetts Resources:

Eunice Kennedy Shriver Center at UMass Medical School

shriver.umassmed.edu

Advocacy, education and training, research regarding ASD.

HMEA Autism Resource Center

www.autismresourcecentral.org

The Mission of HMEA's Autism Resource Central is to support families which include a family member with Autism Spectrum Disorder, to empower families to raise their children and support their adult children to be full members of their communities and become responsively independent and effectively interdependent, so that they are valued as gifted people and protected from harm.

Lurie Center for Autism

The **Lurie Center for Autism** is an integrated and multidisciplinary clinical, research, training and advocacy program dedicated to treating individuals with autism spectrum disorder and other developmental disorders. The Lurie Center is the primary clinical care and clinical research site implementing the broader goals of the Lurie Center for Autism.

The Lurie Center is born out of a philosophy that people with developmental disabilities deserve to be viewed as individuals, each with personal patterns of talents and challenges. We strongly believe each individual deserves the opportunity for access to the quantity and quality of services needed to reach his or her full potential, regardless of economic, social or ethnic background.

The Lurie Center is a multidisciplinary program designed to evaluate and treat children, adolescents and adults with a wide variety of neurodevelopmental conditions. Individuals seeking evaluation or services for the following conditions are frequently referred to the Lurie Center:

Autism spectrum disorder (ASD), including Asperger's disorder, pervasive developmental disorders-not otherwise specified (PDD-NOS), and autistic disorder

- Developmental delays
- Intellectual disabilities
- Angelman syndrome
- Fragile X syndrome
- Rett's disorder
- Tuberous sclerosis
- Tourette's disorder
- Williams syndrome
- Other neurological conditions.

We specialize in caring for individuals with neurodevelopmental disorders with complex profiles who may also have accompanying conditions such as Attention-Deficit Hyperactivity Disorder (ADHD), anxiety, depression, cerebral palsy, seizure disorders, sleep problems, gastrointestinal conditions, and many other physical or cognitive concerns.

Our physicians evaluate patients and develop a comprehensive plan for each patient, which can be shared with the caregiver, referring physician, school and/or community program. Care is taken to help the family locate appropriate resources. Long-term follow-up care is provided via periodic consultations.

<http://www.massgeneral.org/children/services/lurie-center/appointments.aspx>

“**MGH Aspire** helps children, teens, and adults with high cognitive autism spectrum disorder or a related social profile make social connections and develop independence. At MGH Aspire our participants learn age and developmentally appropriate skills needed to succeed at home, school, in their communities or in the work place.” <http://www.massgeneral.org/children/aspire/default.aspx>

Aspire is dedicated to providing children, teens, and adults with a high cognitive autism spectrum disorder or a related social profile with the knowledge and skills necessary to make social connections and develop independence leading to successful and fulfilling lives.

- Framework/philosophy All of Aspire’s programs and services help participants to increase their ability in 3 major areas:
 - Social competency, Self-awareness, Stress management.
- Programmatic categories Aspire’s programs and services are offered within one or more of the following categories:
 - Recreational, social, educational, community and employment.
 - Therapeutic perspectives Aspire uses a multi-disciplinary approach that is tailored to the needs of the individual.

Interview with Dr. Joan Beasley

Director of the Center for S.T.A.R.T. Services

Research Associate Professor, UNH, IOD

Dr. Beasley’s START model has been implemented in a number of states across the US. In many of these programs, adults with AS or HFA are served in these programs. In many instances the START programs are implemented by vendor agencies who bid and are then awarded a contract by the state, and are supported with state funding. In some states, individuals with ASD who do not have co-occurring ID are excluded from state funded services directed at people with developmental disabilities. In these states, the eligibility requirements for developmental disability services and waivers are dependent on having ID. Some states however do have Autism waivers, and even some have specific ones for adults (see example waiver in Addendum).

The Center for START Services at the Institute on Disability/UCED

The Center for START Services at the Institute on Disability/UCED at the University of New Hampshire is a national initiative that works to strengthen efficiencies and service outcomes for individuals with intellectual and developmental disabilities (IDD) and behavioral health needs in the community.

The START program model was implemented in 1988 by Dr. Joan Beasley and her team to provide community-based crisis intervention for individuals with IDD and mental health needs. It is a person-centered, solutions-focused approach that employs positive psychology and other evidence-based practices.

Cited as a model program in the 2002 U.S. Surgeon General’s Report on mental health disparities for persons with intellectual/developmental disabilities, START is a comprehensive model of service supports that optimizes independence, treatment, and community living for individuals with IDD and behavioral health needs.

START is an evidence-informed model that utilizes a national database. The Center for START Services was established in 2009 at the University of New Hampshire’s Institute on Disability/UCED.

The Center for START Services provides technical support, clinical expertise, and training and consultation services that support the development of:

- Comprehensive Evaluation of Services & Systems of Care (local and state)

- A systems linkage approach to service provision
- Expert Assessment & Clinical Support
- Outcomes-Based Research & Evaluation
- Short-Term Therapeutic Resources and Opportunities
- Cross Systems Crisis Prevention & Intervention Planning
- Family Support, Education & Outreach
- Interdisciplinary Collaboration
- By supporting the development of the cornerstones of the START model as outlined above, START programs and their participants experience an array of benefits including:
 - Reduced use of emergency services and state facility/hospital stays
 - High rates of satisfaction by families and care recipients
 - Cost-effective service delivery
 - Increased community involvement and crisis expertise in communities
 - Strengthened linkages that enrich systems, increase resources, and fill in service gap

Interview with Dr. Beasley (continued)

Dr. Beasley described a special project in which she was engaged by the Connecticut state DMHAS Medical Director. Dr. Beasley facilitated discharge and community re-integration of adults with developmental disabilities placed in state mental hospitals. Many of these individuals had AS or HFA. She provided intensive consultation and by training to the state hospital staff, engaged a community vendor agency and also worked to train the agency staff and consulted regarding the development of residential care options designed to meet the needs of these unique patients. The project was very successful and numbers of individuals who had been chronically institutionalized have remained successfully in community settings. Careful transition planning aided its success as did accessing the UMass Multidisciplinary Dual Diagnosis Evaluation Team (Now operating out of Becket Family Services and directed By Laurie Charlot).

Also, Dr. Beasley further discussed the START Professional Learning Communities (PLCs), and how these have assisted the START Teams in many states to provide education and training to many mental health providers and systems partners in the more unique aspects of providing mental health services (including crisis prevention and intervention services) to people with neurodevelopmental disorders including ASD. The START PLC is described below.

Dr. Beasley also acknowledged a lack of a national approach but mention too that every state and system of care has at least some unique characteristics so it makes sense to conduct a more systematic and comprehensive systems analysis locally.

From the Center for START Services Website: <http://www.centerforstartservices.org>

The START Professional Learning Community

The START Professional Learning Community (PLC, previously called the START Network) began in 2011 and has continued to develop an identity of commitment, collaboration and cultivation of learning. The START PLC is comprised of all START Programs across North America who share resources, information and expertise through structured learning environments facilitated by the Center for START Services. The PLC is a means to help unify and enhance the service systems providing supports to those

with IDD and behavioral health needs. It is an evidence-based, cost-effective solution for the need for more training across disciplines to share and develop knowledge while growing communities.

There are several shared attributes of all START PLC members:

- Commitment among members to be available to one another through support and knowledge sharing.
- Members have a desire and are dedicated to continuously learning and expanding knowledge to advance the field as a whole.
- Members quickly apply new knowledge to day to day practice. The sharing and application of new knowledge and skill creates greater confidence and enthusiasm and increasing satisfaction and morale amongst START team members.
- The PLCs themselves, regardless of their context or focus, also share several commonalities:
- A group of people who share and critically interrogate their practice in an ongoing, reflective, collaborative, inclusive, learning-oriented, growth-promoting way;
- A collective enterprise that seeks to share and act on learning to enhance effectiveness as professionals, advocates, and;
- A community of supportive, continuous inquiry and improvement that draws innovation from a diverse range of people. START Programs participate in PLC activities on many levels including internal peer review and learning opportunities, engagement with the local community through Clinical Education Teams and other learning opportunities and on a national level. The Center for START Services currently provides the following learning opportunities:

Conference Calls: Conference calls are held annually with teams across North America. The calls allow projects to share updates, news, and resources to increase awareness of the diversity of START projects and provide networking opportunities among participants.

Annual Luncheon. The Center for START Services typically hosts an annual national forum for networking among START programs in various locations.

Study Groups: The START Network provides opportunities for collaborative learning through a number of study groups. The Clinical Director's Study Group, Resource Center Director's Study Group, Clinical Team Leader Study Group meet on a monthly basis. The Children's Study Group, Medical Director's Group and Program Directors meet quarterly. The purpose of these study groups is to have a forum to discuss issues and topics directly related the relevant START job position. On occasion, other disciplines can be invited to certain study groups, especially when special guests and/or presentations are scheduled to occur.

Online START Information Center: The Center for START Services has developed a comprehensive online information center for all START teams. Links to past trainings, publications, and more provide vital value-added resources for all START Programs.

Quarterly National START Newsletter: The Center for START Services offers a quarterly newsletter that is sent to all network members which offers a letter from the Director of the Center for START services, highlights and news from the START Programs across the country along with important programmatic and quality updates.

Annual National START Training Institute: A two and a half day training institute designed to bring innovative and new evidence-based research and practice information to the START network along with other providers who support or are interested in supporting individuals with IDD and behavioral health needs.

Local Cross Discipline Learning Group Courses: In 2015, the professional learning community expanded to include the development of local, regional, and statewide groups representing a cross section of providers and disciplines as part of the National START training for trainers. The PLCs consist of up to 10-12 learners with an instructor. Each “course” takes 6-12 months to complete. Examples of courses currently under way across the US include: Mental Health Aspects of IDD (Intellectual/Developmental Disability), Crisis Prevention and Intervention, Child MH and IDD. Participants include mental health providers, residential providers, self-advocates, and case managers.

Interview with NADD CEO, with Parent Member, Sue Gamach

The National Association for the Dually Diagnosed:

NADD is a not-for-profit membership association established for professionals, care providers and families to promote understanding of and services for individuals who have developmental disabilities and mental health needs. The mission of NADD is to advance mental wellness for persons with developmental disabilities through the promotion of excellence in mental health care.

NADD is recognized as the world’s leading organization in providing educational services, training materials and conferences. NADD has been influential in the development of appropriate community based policies, programs and opportunities in addressing the mental health needs of persons with ID/D.

NADD’s Mission

“To advance mental wellness for persons with developmental disabilities through the promotion of excellence in mental health care.”

NADD is committed to a seven-fold strategy:

- We encourage the dissemination and exchange of pertinent information.
- We promote educational and training programs.
- We foster the development of appropriate resources and services.
- We advocate for appropriate governmental policies.
- We support research focused on identification, diagnosis and treatment.
- We seek to stimulate public and professional interest.
- We seek to establish a vision of mental wellness

Moreover, we urge a sustained effort by the professional community to meet the mental health needs of persons who have ID/D. There must be a new appreciation of the person’s ability to learn and develop, as well as a focus on his/her inner life, needs, strengths and motivation. These, we submit, are the cornerstones of the only equitable response to persons who have too long been underserved.

Interview: Dr. Fletcher and the NADD parent representative reinforced almost all of the same points raised by the AANE leadership, emphasizing the need for education and training of all levels of service provision. Dr. Fletcher described conversations he had with the National Directors of State Developmental

Disabilities services and with National State DMH Directors group and emphasized that policies and services for adults with ASD appear to be varied state by state. As others have noted, there is no cohesive or specific national policy regarding how to best serve this population. They noted that adults with ASD are sometimes refused services from mental health providers who may attribute co-occurring mental health concerns to the person's neurodevelopmental disability. However, also, people served in mental health settings may have issues related to their disability that are not taken into consideration when planning treatment for their psychiatric disorders. They saw education and training as the primary need to improve mental health care for adults with HFA and AS who have co-occurring mental health needs.

NADD <http://thenadd.org>

REVIEWS OF STATE SERVICE SYSTEMS AND POLICIES AFFECTING ADULTS WITH ASD: WEB-BASED REVIEW

Connecticut

“The importance of effective services cannot be overstated. . . . Without effective services, individuals with ASD are much less likely to live independently, become productively employed, or establish social relationships.” (p.1)

As noted by the stakeholders interviewed, the Connecticut survey found that services are available through individual school districts, small programs in state agencies and private practitioners, but these are “inconsistent in approach and quality and do not meet the level of need.”

Section 27 of Public Act 11-6 was described, which required a study of issues related to the needs of persons with ASD, including the feasibility of a Center for Autism and Developmental Disabilities. The *Autism Feasibility Study workgroup* was formed, including providers, academics, advocates, and consumer representatives.

Like almost all parties interviewed and summary surveys reviewed, it was concluded that there is “inadequate availability of effective services, including behavioral treatment, psychiatric care, primary medical care, social skills and communication training, individualized educational support within the public and private education system, transition services, vocational support, housing, social/ recreational opportunities and specialized residential/inpatient placement.”

It was noted that there is a “small group of providers and agencies. . . .diagnosing and delivering effective services and successfully helping individuals with autism and their families, but:

- There is inadequate provision of healthcare providers who have specialized training and experience in ASD, leading to misdiagnoses, ineffective treatment recommendations and reluctance by practitioners to work with individuals with ASD.
- There is inadequate access to effective services for individuals with ASD and their families utilizing evidence-based practices.
- Even in programs offering effective care, access to services is inconsistent

4 major goals were set:

- Improve and Expand Access to Qualified Professionals and Effective Services (Clinical Interventions and Community Support Services)
- Improve and Expand Access to Training, Consultation, and Learning Opportunities for Providers, Professionals, and Families
- Improve and Expand Access to a Comprehensive Service Resource Guide
- Implement Effective Services

The above included:

- An RFP for up to three (3) specialized inpatient hospital beds for individuals experiencing the most acute and complex ASD and co-occurring psychiatric disorders.

- Developing models for two pilot programs addressing areas of critical need:
 - In-home behavioral supports for adolescents
 - Social-recreational-respite capacity for individuals with ASD across the life span.

Pennsylvania

This state made some specific efforts around examining issues related to adults with ASD and has a major waiver. They were one of the first to establish an ASD specific waiver.

Again, as with other stakeholders and other state surveys, they reported the same kinds of system gaps, needs and problems:

- People with autism of all ages and their families are struggling to find the services they need and are often dissatisfied with the services that are provided.
- Adults - needs for supports and services often have increased while services become more difficult to access.
- The “shortage of providers is the most common barrier to accessing services.”
- The lack of effective interventions for challenging behaviors and mental health problems often lead to preventable crises.
- Unmet need for services for aggressive behaviors nearly doubles as individuals with autism age into adulthood (15%).
- Social skills training is among the most commonly reported unmet needs.
- Close to half of caregivers of students in middle and high school, and 1 in 3 adults, report an unmet need for transition services.
- A lack of or shortage of providers was the most common barrier for all services and was worse in rural areas, and in regard to adult services.
- Almost 1 in 5 report cost or lack of insurance as a barrier to receiving specialty health and education services.
- Caregivers face difficulty finding providers who understand autism and have the training required to address the needs of an individual with autism, particularly adults with autism.
- Twice as many caregivers of adults with autism, as compared to caregivers of younger children, report transportation as a barrier to accessing services.

California

Review examined housing, employment and social integration, and not mental health services though these services are key to preventing and reducing negative outcomes associated with emotional challenges.

Outcome studies of adults with ASD document that, independent of current ability levels, the vast majority of adults with ASD are either unemployed or underemployed.

- The majority of adults with autism continue to live with parents, siblings or older relatives.
- The current economic slowdown can be expected to have a direct, and negative, impact on the availability of adult services.
- For many individuals with ASD, the transition requirements of Individuals with Disabilities Education Act are poorly implemented with little attention to service coordination or direct family involvement.
- The Federal Department of Health and Human Services reports that the combined, annual average staffturnover rate for programs serving adults with developmental disabilities is 50% coupled with a staff vacancy rate of 10-12%.

- While appropriate and effective residential and employment models exist, access to these models is greatly restricted due, primarily, to a lack of adequate funding.
- The smaller the unit of service (e.g., individual supervised living or customized employment) the greater the likelihood for community integration.
- There is a great need for programs, services, and naturally occurring supports for such critical aspects of adult life as personal safety, transportation, leisure, health/wellness, and sexuality.
- The greatest impediments to the development of integrated lives of quality and dignity for adults with autism are system inadequacies coupled with a public perception of adults on the spectrum being unemployable.

*Source: State of California, Department of Developmental Services

Example State Based Adult ASD Waiver:

The **Pennsylvania Adult Autism Waiver** is designed to provide community-based services and supports to meet the specific needs of adults with Autism Spectrum Disorders (ASD). The intent of this waiver is to serve some of the many people with ASD that are not served by any waiver or who receive services through other HCBS waivers which do not meet their unique needs. The Department of Public Welfare (DPW) established the Office of Developmental Programs (ODP), Bureau of Autism Services (BAS) in February 2007 for the explicit purpose of assuring that people with ASD have supports and services to assist them in leading successful, happy, and safe lives in the community.

As the State Medicaid Agency, DPW retains ultimate authority over the administration and implementation of the Adult Autism Waiver. BAS is responsible for developing policies and procedures for waiver operations. Individuals request services through a toll free number at BAS. BAS regional staff and BAS contractors assess functional eligibility for the Adult Autism Waiver. The DPW Office of Income Maintenance (OIM) determines financial eligibility.

The Adult Autism Waiver offers Supports Coordination as a waiver service. The participant chooses his or her Supports Coordination Agency with assistance from BAS regional staff. The Supports Coordinator then conducts state-specified assessments and works with the participant and individuals he or she chooses to develop an Individual Support Plan (ISP). The waiver offers only agency-managed services. DPW will submit a waiver amendment to add participant-directed services upon selection of entities to furnish financial management services and information and assistance to support participant direction.

National Initiatives, Laws and Groups with Impact on Adults with ASD:

Despite a lack of any cohesive national Public Policy addressing the specific needs of individuals with HFA or AS, some national policies contain elements aimed at improving the lives of people with disabilities in general, for example, from 2015:

“White House Domestic Policy Council and the Curb Cuts to the Middle Class Initiative hosted the White House Summit on Disability and Employment. The Summit provided businesses, philanthropies, and disability advocates with information about new and existing Federal resources designed to help employers hire more individuals with disabilities, including the new Resource Guide for Employers. The Summit also offered opportunities for attendees to share their experiences in diversifying their workforce through effective strategies to successfully recruit, hire, promote, and retain employees with disabilities....”

In an increasingly global economy, we simply cannot afford to leave talent on the table. Individuals with disabilities possess the skills and talent to support themselves through meaningful employment...

Taken from: Advancing Employment Opportunities for People with Disabilities
 FEBRUARY 3, 2015 AT 4:11 PM ET BY CECILIA MUÑOZ

Autism Spectrum Disorders (ASD): State of the States of Services and Supports for People with ASD HHS-500-2006-000091/HHS-500-T0002 January 24, 2014

“In 2009, the Centers for Medicare & Medicaid Services (CMS) contracted with L&M Policy Research (L&M) and its partners, Truven Health Analytics (formerly the health care business of Thomson Reuters) and the National Association of State Directors of Developmental Disabilities Services, to address the growing need among federal and state policymakers and stakeholders for accurate and comprehensive information regarding available services and supports for people with ASD. The Autism Spectrum Disorders (ASD) State of the States of Services and Supports for People with ASD report stemmed from the Interagency Autism Coordinating Committee’s (IACC’s) 2010 and 2011 Strategic Plans.¹ The overall goal of this project was to capture information about services for people with ASD across all federal and state-level agencies and offices that could serve as a useful tool and be updated on an as-needed basis. In addition, the project aimed to identify gaps in data.”

Report includes a summary of **insurance mandates*** and ASD-specific waivers may be found in Appendixes and also notes states where MH Parity laws are in effect.

*Insurance mandates vary from state to state but can be critical as a first step in allowing access to evidence based ASD interventions that can help reduce poor outcomes related to emotional and behavioral health challenges.

Individuals with Disabilities Education Act and Americans with Disabilities Act* From Disability.Gov

Americans with Disabilities Act	Individuals with Disabilities Education Act
A civil rights law to prohibit discrimination solely on the basis of disability in employment, public services, and accommodations.	An education act to provide federal financial assistance to State and local education agencies to guarantee special education and related services to eligible children with disabilities.
DA	Individuals with Disabilities Education Act
Any individual with a disability who: (1) has a physical or mental impairment that substantially limits one or more life activities; or (2) has a record of such impairment; or (3) is regarded as having such an impairment. Further, the person must be qualified for the program, service, or job.	Children ages 3-21 who are determined by a multidisciplinary team to be eligible within one or more of 13 specific disability categories and who need special education and related services. Categories include autism, deafness, deaf-blindness, hearing impairments, mental retardation, multiple disabilities, orthopedic impairments, other health impairments, serious emotional disturbance, specific learning disabilities, speech or language impairments, traumatic brain injury, and visual impairments.

Mental Health Parity Law* from NAMI Website

Mental health parity describes the equal treatment of mental health conditions and substance use disorders in insurance plans. When a plan has parity, it means that if you are provided unlimited doctor visits for a chronic condition like diabetes then they must offer unlimited visits for a mental health condition such as depression or schizophrenia. However, parity doesn't mean that you will get good mental health coverage. Comprehensive parity requires equal coverage, not necessarily "good" coverage. If the health insurance plan is very limited, then mental health coverage will be similarly limited even in a state with a strong parity law or in a plan that is subject to federal parity. - See more at: <https://www.nami.org/Find-Support/Living-with-a-Mental-Health-Condition/Understanding-Health-Insurance/What-is-Mental-Health-Parity#sthash.zsbogymd.dpufs>

National Organizations Assisting Families and Individuals with ASDs

Autism Speaks <https://www.autismspeaks.org> is a large and influential organization that provides education, information and supports to individuals and families of individuals with ASD. Traditionally, Autism Speaks has mainly addressed the needs of children and adolescents with an ASD, but recently has been highlighting issues for adults as well.

Some other organizations that will assist families and individuals with ASD are listed on the Autism Speaks website: <https://www.autismspeaks.org/family-services/resource-library/other-autism-organizations>

The national organization, the **Autism Society** <http://www.autism-society.org/about-the-autism-society/affiliate-network/> is also an influential organization. Most states have an affiliate program, and these local entities are the main conduits for delivering information, education and supports. Its major works as described on their website include:

- Information and Referral services assisting individuals to find education assistance, recreational/social activities, support groups and other autism related programs and services.
- A supportive place where individuals on the spectrum, their families or others affected by autism can find help and guidance at any point in their lives.
- A sense of community, where you can find encouragement, comfort and companionship. Affiliates can assist with locating autism friendly and inclusive places and activities.
- Advocate at the local and/or state levels to implement changes in systems where improvement is needed so that all of those affected by autism may live a high quality of life.
- Awareness and education through newsletters, speaker series, conferences, trainings and much more.

SUMMARY SERVICE NEEDS AND SYSTEMIC GAPS

In general, all parties interviewed and the web review suggested that there really is no national policy directing the quality or quantity of services for adults with ASD. There are pockets of excellence in terms of general services and in terms of specialized and comprehensive mental health care, but these are locally developed generally and many individuals and families lack access. Many states have Autism Centers or Centers of Excellence in Autism that have lifespan services of some kind, but generally not enough services are available to meet the needs of all those who would benefit from access. A few states have looked at gaps in their own state and developed goals to improve care. However, usually, many small programs and grants exist with only a subset of people in need receiving specialized services from which they clearly would benefit. In addition to funding concerns, there are a lack of providers (agencies and individual professional providers) who have the training and requisite skills to serve the population.

Locally, parents and advocates noted that there are some excellent services available at the UMass Autism programs (CANDO, TAY), but that these cannot always be accessed by everyone in need. The Luria Center and ASPIRE programs in Boston also has excellent services, but not all individuals or families are able to access these services. Parents and advocates have suggested that there are problems with Mental Health (MH) clinicians attributing psychiatric symptoms and problems to the person's developmental disability (to the ASD), and then denying access to needed MH treatment. However, they also identified challenges with MH clinicians missing the presence and or impact of the ASD when treating a co-occurring mental illness. Inaccurate diagnoses and lack of access to assessment for adults were other problems noted.

“In general, there are not enough programs where clinicians with training or experience treating people with an ASD are providing care. A lack of education and training of the clinicians who provide most of the treatment (those not located within an ASD Center), was a major concern. The above was viewed then as leading to frustrating and suboptimal experiences for many adults with ASD who have behavioral health needs and are seen in an emergency situation at an ED, or who are treated on inpatient psychiatric units.”

Connecticut state review of services for people with ASD

Initial Suggestions/Needs:

- Systems analysis – stakeholder interviews and surveys and focus groups that include people with ASD and their family members, advocates; representatives from agencies providing vocational, residential and other services, and review of Medicaid Claims data
 - Consider engaging Dr. Beasley and the National Center for START Services since they have significant experience in conducting this kind of review and have significant experience in dual diagnosis services and systems for people with neurodevelopmental disorder and significant mental health needs
- Need a joint and collaborative effort to expand and improve services and insure access to services between the DMH and DDS agencies
 - Close collaboration across systems in process of planning (especially educational, mental health and developmental disabilities systems of care)
- Possibly develop a Massachusetts State Wide Adult ASD Advisory Council
 - Include people with HFA/AS
 - Planning for expansion and improvement of services and treatment options for the “dual population” needs to include individuals who have HFA or AS in the planning efforts

- Education and training for providers and agencies who may service or treat individuals with HFA who have emotional and behavioral challenges
 - Education and training across all aspects of the system of mental health care
 - Talk further with Dr. Beasley about START Professional Learning Communities
- Alternative ASD friendly emergency respite, to provide diversion from EDs
 - Engage agencies with existing expertise **Advocates Inc., HMEA**
- More access to multidisciplinary assessment for people with major mental health needs such as CANDO team and as employed in the Connecticut project described by Dr. Beasley
 - Invite Dr. Beasley to further describe the special Connecticut project noted above
 - Further discussions with Dr. Frazier
- Expanding specialized Medical Home services designed for adults with an ASD who have co-occurring Mental Health disorders
 - Discuss further with Dr. Frazier
- Commitment to adequately fund initiatives

Taking the “long view” as investment and recognize longer term major cost savings will result from investment in more appropriate and effective services to which people have reasonable access
- Pilot-outcomes to reduce ED use, psychiatric inpatient community hospital and state hospital bed days
 - Discuss further with Dr. Frazier
- Expand transition planning efforts Increased access to specialized Center based care and to multidisciplinary care
- Increased access to farm-community based programs and similar models to Gould’s Farm (<http://www.gouldfarm.org>)
- Increased availability for adults to receive assessment and obtain a diagnosis
 - More services such as those available but limited at UMass and Luria Center
- Need for special attention to teaching differential diagnosis of psychiatric disorders and other life challenges to improve accuracy of diagnosis and inform more appropriate and effective care
- “Autism friendly” or specialized respite care for people with HFA experiencing emotional or behavioral crisis
- Specialized, modified clubhouse style day services where individuals are helped to learn how to apply for work, other social and interpersonal skills needed for successful employment, other social and community issues and skills
- Family friendly mental health services that are inclusive of family as many adults with HFA or AS are still closely tied to family or reside with family
- Expand Life Management Assistance Program
 - Life Coaching program – providing help to individuals to apply to school for a job, grocery shop, arrange things in day to day life, often collaborating with therapist
- Expand availability of job coaching (need to alter the general approaches used in MRC where usually, after some coaching the coaching is discontinued, need more ongoing support or support fro longer periods of time)
- Expand access to social support groups, social skills building groups, address gender based issues
- Special teams/clinicians to provide informed and effective multidisciplinary assessment and care to dually diagnosed (AS and mental illness) who have forensic involvement
 - Dr. Frazier has a team
- Increased assistance in transition planning as a means to prevent serious mental health challenges developing

- Contact with Dept. of Education
- Recognition of the role of trauma in emotional and behavioral challenges of adults with HFA or AS
- Increased funding to allow access to specialized programs such as the Gould Farm program and similar programs