

ental Health Massachusetts Department of Mental Health Task Force on Behavioral Health Services and Supports for People with Autism Spectrum Disorder and Mental Health Issues

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Introduction

Task Force Formation and Goals

In January 2014, the Department of Mental Health (DMH) established the Massachusetts Department of Mental Health Task Force on Behavioral Health Services and Supports for People with Autism Spectrum Disorder and Mental Health Issues (Task Force) to study best practices related to understanding Autism Spectrum Disorders (ASD) and co-occurring severe mental illness and their treatment. Chaired by DMH Deputy Commissioner of Clinical and Professional Services Kathy Sanders, MD, the Task Force included clinical experts and representatives from the Department of Disability Services (DDS) and DMH. To prepare for the work ahead, DMH conducted a survey of its employees about the training and clinical needs they experience in the course of their work with individuals and their families with both an ASD and severe and persistent mental illness (SPMI) or serious emotional disturbance (SED). The expectation for this task force was twofold: to achieve a better understanding of the needs of individuals and families living with SPMI/SED and ASD in order to provide appropriate and effective treatment and supports within DMH; and to align DMH's role as the State Mental Health Authority in establishing standards for the care and support of those living with ASD and co-occurring SPMI/SED throughout the Commonwealth. This report reflects an inclusive process of meetings and interactions among stakeholders including legislators, agency directors, managed care companies and families.

In August 2014, the Massachusetts House and Senate passed and the Governor signed into law Chapter 226 of the Acts of 2014. This landmark legislation, known as the Omnibus Autism Bill, established a legislative commission for ASD chaired by an Executive Director with a membership of 35 appointees. This Commission's task is to oversee the implementation of the ASD Commission Recommendations (July 2013). Additionally, the bill expands the mission of DDS to include serving those with intellectual disabilities and developmental disabilities. The bill specifically acknowledges that a person with a developmental disability may have mental illness but provides that no person with a developmental disability can be considered mentally ill solely by reason of having a developmental disability diagnosis. It further authorizes DDS to license residential and day programs offering services for those with developmental disabilities and for DDS to provide an annual report on its activities and programs. This Omnibus Bill directs the Board of Education to create an endorsement of expertise in ASD for special education teachers. There are provisions for creating Achieving a Better Life Experience Accounts for individuals and families to assist in procuring services. The Omnibus Bill also requires DMH and DDS to develop a plan to provide services to individuals with both severe mental illness and a developmental disability and who are eligible for services from both agencies, due to the Legislature by December 31, 2015. The goal of this collaboration is to facilitate communication between DMH and DDS; to create protocols to determine which services will be provided by each agency; and to ensure that an individual who is eligible for services from both agencies receives all services for which an individual is eligible. Accordingly, much of the work started by this Task Force will be taken up by the collaborative effort by DDS and DMH. In that context, this report provides an overview of the issues surrounding ASD and SPMI and suggests a direction in the <u>training</u>, <u>services</u> and <u>interagency activities</u> needed to serve this population.

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National Perspective

"The assumption of most people is that all behaviors are related to an ASD diagnosis. The assumption will leave mental health issues that exist untreated and may, in fact, exacerbate symptoms."

- Center for ASD and Related Disabilities, the University of South Florida

Over the past 50 years, ASD rates have exploded. While the prevalence of ASD was estimated at 5 per 10,000 in the 1960s and 1970s, the Centers for Disease Control and Prevention's (CDC) ASD and Developmental Disabilities Monitoring Network estimates that today, about 1 in 68 children has been identified with ASD (ASD)(CDC, 2014). These new findings demonstrate that ASD is "one of most frequent of all childhood neurodevelopmental disorders" (Dvir, Madaan, Yakutis, Frazier & Wilson, 2011).

Recent studies show that children with ASD receive psychiatric hospitalization services more than children in the general population. In addition to behavioral disturbances and challenges in regulating emotions common to children with ASD, these children had co-morbid psychiatric conditions (Siegel & Gabriels, 2014). Studies by the Human Services Research Institute have identified that upwards of 30% of individuals with ASD and an intellectual disability have a co-occurring psychiatric disorder. Of that number, "49% are taking medications for behavioral disorders, including for mood disorder, anxiety, behavior problems, and for psychotic disorders." (National Core Indicators Brief, April 2011). In its summer 2014 publication, the ASD Spectrum News identifies that as many as 27% of those with ASD have symptoms of bi-polar disorder and those symptoms are likely to look different than they do in people who do not have ASD.

While individuals with ASD may respond to pharmacological treatment, it is often challenging to help them manage their medication and side effects. This is partly due to the difficulty many people with ASD have in communicating what side effects they are feeling. (ASD Spectrum News, Summer 2014).

The University of South Florida's Center for ASD & Related Disabilities noted in its report <u>ASD & Mental Health Issues: A guidebook on Mental Health Issues Affecting Individuals with</u> <u>Autism Spectrum Disorder</u> that while the core deficits of ASD have been well-studied, a less investigated cause of impairment in individuals with ASD is the occurrence of co-morbid psychiatric disorders. According to recent epidemiological studies, nearly three out of every four individuals with ASD meet criteria for a (co-morbid) mental health disorder.

Unfortunately, co-morbidities are often overlooked in the ASD population, with serious negative consequences on quality of life, school and family functioning, and access to appropriate treatment. Whatever research and data is being examined, the conclusion is

inescapable: The challenges of supporting people with ASD (including those with or without an intellectual disability) and with co-occurring mental health needs are a significant public policy issue that needs to be addressed. In particular, the lack of comprehensive and coordinated services — a problem which the above-referenced legislation is designed to address — is having a significant impact on people with ASD as well as their families who provide most of their care.

A 2014 position statement from NADD, an association for persons with developmental disabilities and mental health needs, stated: "In view of the high prevalence of psychiatric disorders among people with IDD, this group should not be considered as a special population, but as a core constituency in both health and human services settings." More than 30 national, state and local organizations, including the American Association on Intellectual and Developmental Disabilities, the ARC of the US, Easter Seals, National Association of State Directors of Developmental Disability Services, and the National Association of State Mental Health Program Directors sponsored and support this stance.

The position statement drew upon a number of findings and makes 11 recommendations. A key conclusion was: "In terms of service provision, these program elements are put into operation through supports and interventions that address a person's needs for appropriate assessment, diagnosis, and treatment; flexible funding that is individualized to support meaningful outcomes; family supports; unified coordination of services and supports across service providers and state agencies; ongoing technical assistance to build provider expertise; targeted cross-disciplinary training for clinicians, administrators, and direct support professionals; family-based education; effective interagency collaboration and coordination among state DD, MH/behavioral health (including mental health and substance abuse), child welfare, and corrections (including juvenile justice) agencies; responsive crisis intervention services; and ongoing data collection, performance measurement, and outcome assessment."

The challenge in designing, implementing and sustaining a comprehensive network of supports to individuals with ASD with co-occurring mental health needs and very diverse needs is enormous. However, we believe the challenge can be met by taking a comprehensive, multi-strategy approach.

DMH is committed to working with DDS, the Commonwealth's lead agency in the implementation of supports to people with ASD and their families. While DMH has a role in directly providing or ensuring the provision of quality mental health services to this population, it is critical to develop effective partnerships and collaborations with DDS as the primary service provider, MassHealth, community provider agencies, managed care organizations (who have an increasing role in funding many of the key services), and most importantly, persons with ASD and their families. Since families are providing much of the

support to their loved one with ASD, it is critical to actively engage and support families in ways that are important to them. While some of the recommendations outlined below can be implemented within existing resources, some will need an infusion of new funds.

DMH ASD Survey

To better gauge the baseline understanding of ASD among staff, we completed the ASD Survey in January 2014 with a total of 142 responses from a variety of DMH employees including clinicians, case managers, and administrators. We estimate that out of the nearly 21,000 individuals with severe and persistent mental illness or serious emotional disturbance who are approved for DMH services, between 500 and 1,000 individuals have co-occurring ASD, nearly 40% of whom are 18 years old or younger. The respondents actively work with DDS, the Department of Children and Families (DCF), Department of Youth Services (DYS), local school systems, & community agencies on behalf of those with co-occurring SPMI/SED and ASD. The needs identified in this survey center around training, services and state agency resources.

I. TRAINING

The need for training emerged as a major theme among the responses. In particular, we identified four major areas of training needs:

- 1. Training for practitioners and management staff to understand the diagnosis and treatment of ASD
- 2. Training to provide ongoing support for optimal community integration of the person with ASD and SPMI/SED
- 3. Training on the Role of each Agency involved with ASD
- 4. Specialized training on differentiating SPMI/SED from ASD symptoms

The mission of DMH is to provide services to individuals with SPMI and children and adolescents with SED. DMH service authorization requirements are based on the diagnosis of SPMI that is not otherwise attributable to a developmental disability. It is critically important we make available specialized training in differentiating symptoms of SPMI from those of ASD in order to understand the clinical presentation of co-occurring SPMI and ASD.

II. SERVICES

Survey respondents highlighted the need for comprehensive services for people with ASD and their families to better integrate within the community:

- 1. Services that provide social skills training for the individual with ASD. DMH staff recognize that many adults with ASD with or without SPMI require social skills and integration training to allow them to be more independent and fully integrated within their community, thereby decreasing their isolation. Responses recommended that habilitative skills training be developed to include effective written and oral communication, life skills including independent living skills, vocational/career training, along with social/recreational activities.
- 2. *Family Services.* The family is often the primary support and caregiver available to an individual with ASD. This is true long after the individual has matured into adulthood. Fully understanding the needs and preferences of families will better help us identify services and supports that will be meaningful, effective, and useful. Services like family and individual respite, support and psychoeducational groups, and specialized parenting services and sibling and non-traditional family support groups are examples of family centered interventions that would be valuable.
- 3. *Community Services*. In order for individuals with ASD to be integrated in community life, it is crucial that appropriate community centers and social opportunities designed for the specific needs of individuals with ASD are available. Job coaching and placement services should also be available within the community. Specific clinicians and community resources that already serve people with ASD are a critical component. Developing these specialized resources will be necessary in communities where individuals with ASD are served. School systems should incorporate these kinds of supports so they can improve their ability to provide the specialized services necessary for the full integration of children with ASD into school life.

III. AGENCY RESPONSE

Most of those who responded to the DMH ASD Survey recognized the meaningful and important role that state agencies do and should provide those with ASD.

1. Better interagency collaboration around the service needs of individuals and their families as well as in identifying resources to provide these services is needed.

- 2. There is a role for DMH as the State Mental Health Authority in establishing best practices for effective treatment and skill development for both practitioners and individuals served.
- 3. The agencies need to know about and be able to access the current resources on behalf of those whom they serve in the spirit of "no wrong door."
- 4. More programming specific to those with ASD and ASD/SPMI is needed across agencies.
- 5. Multi-funded specialized placements for individuals with co-occurring ASD and mental illness must be considered

Task Force Recommendations

The Task Force focused on the major areas outlined by DMH staff in the survey. Task Force members identified the gap between the service array available and accessible to those with ASD and ASD/SPMI and the services needed to best serve this population as a major consideration. It should be assumed that the term SPMI includes both SPMI and SED when both adults and children are included in the following recommendations.

Populations

To effectively address the needs of children and adults with ASD and co-occurring mental health needs, it is important to understand the spectrum of need on which they fall and to recognize that individuals along the spectrum have both similar and very different needs. This understanding is critical to developing and implementing strategies to address them. This diverse need requires a comprehensive collaboration across responsible state agencies, the multiple funding agencies (state, managed care organizations, health plans, school systems), families, consumers, and community-based organizations that provide a range of services and supports to individuals and their families. By advancing this collaboration, the roles of the various stakeholders will become clearer as will the responsibilities of the respective state agencies as providers or funders of services, and of DDS and DMH as the state authorities to insure that appropriate developmental and mental health services are available to citizens of the Commonwealth.

The spectrum of individuals' needs is:

1. People with ASD with mental health needs eligible for DDS

2. People with SPMI/SED, who also have autism, who are eligible for DMH

3. People with ASD and SPMI eligible for both DDS and DMH

4. People with ASD not eligible for either DDS or DMH

5. People with ASD eligible for MassHealth or private insurance payers with or without eligibility for DDS or DMH

Recommendation 1: DMH will work with DDS in establishing a process for joint reviews of individuals in critical need who are eligible for DDS and who have a serious mental health need and are authorized for DMH services. This will allow both agencies to partner in developing the appropriate services for people who present with unique and serious challenges.

The Omnibus Autism Bill clearly expects close collaboration between DMH and DDS in providing services to individuals with ASD who have a co-occurring mental illness.

It is therefore critical for DMH, DDS and the Center for Health Information and Analysis (CHIA) to implement a memorandum of understanding (MOU) for interagency data sharing. This MOU will enable joint client record reviews and data linking projects. The latter will (1) assess prevalence in MA relative to national estimates; (2) inform service need for the 5 spectrum categories relative to available resources; and (3) track care quality as well as service utilization and outcomes.

We will establish a collaborative statewide process to identify and review all people with ASD with co-occurring mental health needs within our respective systems. This process will include youths and young adults who are "aging out" of special education programs and are transitioning to adult-serving agencies (the so-called "Chapter 688" population). The goal of this process is a coordinated approach to working with the individuals and their families to ensure appropriate services are available.

We will design training to include DDS and DMH leadership, practitioners, and case management staff to be beneficial when serving individuals with ASD and SPMI. Five areas for training are identified:

- 1. *The distinction between ASD and SPMI.* For instance, gaining an understanding between the interaction/intersection about ASD and mental illness would benefit many practitioners and staff in developing treatment plans and supports once the person is authorized for DMH services.
- 2. *Diagnostic skills, assessment practices, treatment planning and pharmacotherapy* of individuals with co-morbid ASD and SPMI.
- 3. *Education on providing ongoing support to ASD/SPMI consumers and families.* Supportive activities beneficial to this population include providing social skills training, effective communication skills, behavioral planning and monitoring, as well as increasing knowledge about community resources and supports available. It is important to note that these supportive activities are more habilitative as opposed to the rehabilitative services that are central to the recovery-focused model of care within DMH for individuals with SPMI.
- 4. *Greater understanding of the current behavioral health system*, namely of the various state agencies including MassHealth, DMH, DDS, Massachusetts Rehabiltation Commission (MRC), and Bureau of Substance Abuse Services (BSAS). Knowledge about the current programs and services available in these agencies, as well as where agencies interact with one another would allow staff to be more helpful to individuals with ASD/SPMI and their families.
- 5. *Better understanding of the family role and dynamics around an individual with ASD.* Practitioners and staff want to better comprehend how to provide the necessary family support required by ASD family/caregiver households. Training individuals with ASD and co-occurring severe mental illness and their families about their conditions and how they can be best served is critical. It is imperative to recognize the important role that families play in the ongoing support, care, treatment and integration of their child or adult child with ASD and co-occurring SPMI.

<u>Recommendation 2</u>: Given the importance of training, DDS and DMH will establish a joint training committee to develop and oversee all ASD related trainings in both agencies. This committee will review trainings for DDS and DMH staff and will work together on joint trainings for staff from provider agencies, particularly those who contract with both agencies.

<u>Recommendation 3</u>: DMH will work with DDS and other key stakeholders to assess the feasibility of organizing a day-long conference around people with ASD and co-occurring mental health needs.

<u>Recommendation 4</u>: Make available educational opportunities for staff responsible for authorizing services and managing the appeals process. DMH recognizes the need for the respective agencies to increase clarity and consistency in applying the criteria for service authorization for people with ASD and serious mental illness. There is some confusion about the symptoms of ASD and SPMI and the role each plays in service authorization. In order to improve consistency in the application of its criteria, it is further recommended that DMH develop and implement the following:

a. DMH to work with the Area Medical Directors, Area Child & Adolescent Psychiatrists, service authorization staff and other key DMH staff to develop guidelines regarding service authorization of those with ASD and SPMI

b. Training for DMH Service Authorization staff so there is greater consistency across the state. One key component of the training will include family members (typically parents) of individuals with both ASD and SPMI to meet with DMH staff and discuss their children's needs and how DMH can better serve them.

c. Develop with DDS cross-trainings for both agencies' eligibility/service authorization staff on each agency's eligibility criteria, what is available from each agency, and how DDS and DMH can collaborate to make the system more responsive to families as they utilize the state human service system.

<u>Recommendation 5</u>: DDS and DMH will co-chair a working group charged with increasing the number of clinicians across the Commonwealth skilled in working with people with ASD. The members of this working group will include representatives from DDS, DMH, teaching hospitals, graduate schools, current practitioners, family members, consumers, community providers and managed care entities. The working group will consider ways to expand the pool of skilled clinicians, prioritize initiatives and provide the leadership on implementation. The working group will also be the coordinating point to explore foundation grants and other potential funding opportunities. The working group will:

a. Work with psychiatry residency training programs to develop a curriculum on the treatment of people with ASD and co-occurring mental illness

b. Explore the feasibility in developing a psychiatric fellowship program for at least one psychiatrist who is interested in a career working with people with ASD.

c. Sponsor Interagency Grand Rounds to provide a learning opportunity about best practices and share information and expertise.

<u>Recommendation 6</u>: The DMH Centers for Excellence in Research will contribute to the development of best practices for the training needs identified in this report.

Recommendation 7: Leveraging the care coordination, behavioral health services and best practices expertise of the Children's Behavioral Health Initiative (CBHI), the Department of Children and Families (DCF), and the Children's Behavioral Health Knowledge Center (CBHKC), DMH and DDS will collaborate to jointly develop and implement a special initiative to cultivate expertise in provider agencies, such as Community Support Agencies (CSAs) and the DDS funded ASD Support Centers to provide intensive case management and other CBHI services for children with ASD and their families.

Recommendation 8: DMH and DDS will explore with MassHealth the possibility of developing and certifying providers of evidence-based practices in the comprehensive range of behavioral health treatments for those with ASD and a mental illness diagnosis. These provider agencies could be identified as ASD Centers of Excellence (ACEs) or have a similar designation that is understood by consumers, families, advocates and others as provider agencies with a very specific skill set in serving people with ASD and a mental illness diagnosis. A steering committee will be created that includes representatives from interested managed care companies, MassHealth, DMH, DDS, providers, consumers and families and others. The steering committee will develop certification standards required of providers to be included in the ACE program. Once established, providers would be certified across the state so consumers will have greater access to quality and comprehensive services.

Recommendation 9: Comprehensive services that are habilitative and rehabilitative to meet the ongoing assessment, treatment, and support needs of those with ASD and SPMI require effective interagency collaboration in association with the insurance payors, community providers, and families. We are obliged within state government to establish a mechanism for numerous state agencies (including MassHealth) to work together to establish the needed services and supports. Our review begs the question: Should a Health Home for ASD be developed through the MassHealth Medicaid expansion associated with the Affordable Care Act? DMH and DDS will convene a workgroup of stakeholders, including MassHealth, to explore opportunities to include specialized ASD services in expansion initiatives under the ACA.

<u>Recommendation 10</u>: Develop a Community of Practice/Learning Collaborative to support families of individuals with intellectual and developmental disabilities with or without mental health needs. Providers of services to this population would also benefit by participation in a dynamic Learning Collaborative as well. We recommend that the DDS ASD Support Centers, Community Support Agencies as well as newly formed work groups developed through the initiatives and recommendations within this report work to establish this level of service for both providers and families.

Recommendation 11: DMH and DDS will work on strategies to implement respite services for family caregivers of persons with ASD and mental health needs. DMH will also work with DDS in exploring what is the best way to provide families with sons and daughters, with cooccurring mental health needs, with support in the necessary care coordination and care management.

Recommendation 12: The DMH Centers of Excellence in Research will work to identify evidence based and best practices for treatment and service needs for individuals with ASD and SPMI and their families.

Conclusion

The task of providing coordinated services to individuals with ASD who also have SPMI is enormous and far reaching in scope and expectation. DMH is committed to working closely and collaboratively with DDS and other state agencies to ensure that needed services for those with co-occurring ASD and SPMI are available. Much can be accomplished within existing resources and with stakeholder collaboration to better respond to the needs children and adults with ASD and co-occurring mental health needs and their families. Some of the recommendations and initiatives we present can begin quickly, while others will develop over time. Infusion of additional resources is needed to meet the ultimate goal of this work which is to establish a comprehensive specialized service array with expertise to assess and treat throughout the continuum of care for individuals with ASD and SPMI and their families.

There are several primary areas on which we must focus to succeed in achieving the best outcome for citizens living with ASD and SPMI.

Behavioral Health Services

Among the most significant issues facing children, young adults and adults with ASD and mental health needs and their families is the inadequacy of the mental health system to respond to their mental health needs. Some individuals will meet the definition of serious and persistent mental illness and be authorized for services from DMH; others will be eligible for services from DDS, but require skilled behavioral health services to address their mental health needs; and yet others will not be eligible for services from either DMH or DDS but need services to address their mental health condition. Addressing the comprehensive need for behavioral health services within this population requires attention to the following areas:

1. Emergency services, including mobile crisis intervention

2. Outpatient services including home and community based, with clinicians skilled in working with individuals with ASD

- 3. Psychiatric services, with psychiatrists skilled in working with individuals with ASD
- 4. Community support programs
- 5. Substance Use Disorders treatment
- 6. Inpatient Services

The key to quality, comprehensive and accessible services is to work with managed care companies that have capacity for networks of qualified providers and that fund a range of behavioral health services both for the MassHealth and the commercially insured population. It is critical that individuals and families know which provider agencies have the commitment and expertise to respond to their needs. One initiative to consider is working with managed care companies (discussions have already occurred with Beacon Health Strategies and Massachusetts Behavioral Health Partnership) to develop a model for ASD Centers of Excellence (ACE) focused on members with co-occurring ASD and a mental health diagnosis. By certifying providers (service agencies and practitioners) into an ACE, insured members will be afforded comfort and confidence that the providers they or their family members are seeing are able to manage the specialized mental health needs of individuals with co-occurring ASD and behavioral health conditions.

Long term Services and Supports

In this report we identified the need for training and education for the families and caregivers of individuals with ASD who have a mental health need so that these family members may better understand the prognosis and how best to help their family member. We also identified the need to educate families about how to teach their children better communication skills. While acknowledging that often the experts in supporting people with ASD with co-occurring mental health needs are their families, it is important to recognize that there are many families for whom training and support is very much needed. Collaboration between DMH and DDS is necessary to develop family training that addresses both the ASD and mental health needs of individuals with co-morbid ASD and MH conditions.

Effective communication skills are fundamental for any individual with ASD with or without a mental health need. Basic improvements in verbal and nonverbal skills are essential for quality of life and independent living for those with ASD. Additionally, independent living skills are necessary for living apart from family members as well as career placement and development. Social/recreational activities promote social skills, friendships and networking opportunities. This needs to be taken into account when there are needs for structured day programming, vocational and job training and supports, and for some, residential or assisted living as part of an overarching care delivery system supporting those with ASD and SPMI.

ASD and SPMI are life-long conditions. People with ASD and serious and persistent mental illness who meet both DDS and DMH eligibility criteria are by definition, those with the greatest level of functional impairment. They will need appropriate long term services in the community. Some individuals may require residential supports either in their own home or in a group home. In order to provide a range of supports that will meet people's needs, DMH must in conjunction with DDS have a broad range of flexible, community based services to meet the changing needs of these individuals as they age.

While clearly DMH will need additional resources to provide quality long term services and supports to people with ASD eligible for DMH services, there may be potential opportunities to maximize services available through MassHealth. DMH will explore more thoroughly the potential of building on MassHealth's Adult Family Care (AFC) program. The AFC program offers the opportunity to provide a stipend to non-guardian family members as well as social work and nursing support that can meet the needs of families who are interested in providing supports in their home. The AFC program also offers the opportunity for AFC approved agencies to work with DMH and families to identify non-family caregivers to provide supervision and support to individuals with ASD who they would live with. Providing person-centered and family-centered supports in conjunction with DMH supports will offer families and individuals with ASD creative residential options. In addition, initiatives under development in association with the Affordable Care Act, such as Health Homes, offer opportunities to expand the pool of specialized resources available to individuals with ASD and their families.

Family and Caregiver Supports

The overall goal of supporting families with all their complexity and diversity is to maximize their capacity, strengths, and unique abilities so they can best support, nurture, love and facilitate opportunities for the achievement of self-determination, interdependence, productivity, integration, and inclusion in all facets of community life for their family members. Families should not have the sole responsibility or burden of the ongoing care, care coordination, and care management of their children with ASD and SPMI. It is important that our recommendations support a larger care delivery system that provides these necessary services for individuals with ASD and SPMI.

While many people with ASD live in their own home and some are supported in residential services in the specialized education or the adult human service system, family members remain the largest pool of caregivers for people with ASD. However, this intensive caregiver role exacts a heavy toll. In fact, the more supports families receive the less likely they will be looking for more costly residential services. In one study, more than 50% of family caregivers reported that they needed to reduce or stop working entirely while more than 25% reported spending at least 10 hours per week providing or coordinating care for their child (ASD Spectrum News, Summer 2014). Families seeking services for their children with ASD and co-occurring mental illness report being shuttled back and forth between agencies, many times not receiving any of the services they need. Families have been caught in a quagmire trying to determine which agency is responsible for their child's care.

These families need a streamlined system, where there is "no wrong door" for them to enter. One option that will be explored is building on the DDS-funded ASD Support Centers to provide the "no wrong door" to families with sons and daughters with ASD who are eligible for DMH or DDS services (or both). Another option we will explore is building on the Community Service Agencies. For example, families should be able to contact their local ASD Support Centers, which with the support of DMH and DDS, would be able to provide service navigation, training for families, social and recreational opportunities for people with ASD, assistance in understanding and accessing benefits through MassHealth services, and referrals to various community-based organizations that are available to provide services. With the agencies working together, individuals could receive services in a timely and efficient manner, enabling their families as caregivers to work with their loved ones, rather than spending their time navigating a disjointed system. In addition, the need for respite for the family caregiver is critical.

In conclusion, by structuring a cohesive system, stakeholders will be able to clearly understand what supports are available and who is eligible for what services. The stress on individuals and families will be decreased by providing a roadmap of consistent, quality programming where families feel their loved one's needs are being addressed. This in turn will ensure that quality supports are available for smooth transitions and consistency across the lifespan; an essential element to providing support to individuals with ASD diagnoses. To accomplish the recommendations and tasks in this report, convening one or more interagency committees is the starting point. These groups will develop requirements for services as well as outcome measures to monitor the progressive service system development. We expect and commit to forward evidence-based practices in a comprehensive and integrated network of services to best meet the service needs of those with ASD and SPMI.

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