Appendix C: Constraints to achieving successful ASD services

I. Family/Professional Partnerships

1. Lack of physician and family time, knowledge, support, and training

- Professionals lack training in ASD, as well as in family dynamics, and as providers are not prepared to address the intense demands of ASD screening, diagnosis, and management of treatment. This creates frustration and conflicts with families as opposed to partnerships.
- The intensity and complexity of ASD service needs can be a disincentive for some professionals to fully engage in ASD service delivery and support of families, especially when they are faced with limited time, reimbursement, and inadequate resources.
- ASD is a relentless, labor-intensive and often harrowing chronic condition that can overwhelm individuals and families and drain energy, leaving little time to devote to becoming skilled family advocates and to building collaborative professional partnerships.
- Families become frustrated with a provider system that is not well prepared to deal with ASD and lose respect for providers who lack ASD knowledge and often look to families for guidance, as the families are forced to become the most informed members of their children's care needs.
- Families do not feel supported by providers in discussion alternative care options and often must proceed on their own with strategies involving detoxification, diet, nutritional supplements, etc.

2. Lack of understanding and communication regarding ASD-related issues

- Inadequate public education about ASD, leaving families and professionals with inadequate knowledge and support to form a common knowledge base and foster strong, trusting relationships.
- There is often poor sharing of information and best practices, so that the successes and failures of different strategies are rarely disseminated.
- Individuals and families with ASD become isolated and are not linked with other families or supported by professionals.

3. Failure to establish integrated systems of care and the medical home

- Many families of children with ASD do not consider their doctor to be an integral member of their child's life, nor do they believe they have a medical home.
- Negative interactions between families and professionals are the result of systems inadequacies including: lack of coordination among various health, early

intervention, special education, and social service providers; ambiguous and delayed diagnoses; long waits for services; and unplanned transitions

- Lack of understanding and full acceptance of the Medical Home approach to care, including a lack of understanding the importance of a full partnership with families, leads to ineffective family/professional partnerships.

II. Early and Continuous Developmental and Medical Screening for Autism Responses

1. Lack of adequate provider time, training, information and reimbursement

    - Providers need the proper training to recognize ASD-typical signs, and direct families to information on a local developmental specialist. Currently, most primary care physicians are only allotted 15-20 minutes for a well-baby check-up. With time constraints such as these, pediatricians do not routinely screen general development; if they do, they typically do not follow standards as described in the tool's instructions.
    - The economics of medical practice also militate against the use of screening tools; the time spent on screening a child for a developmental disability is money out of a physician's pocket.
    - Although newer residents now participate in a mandatory behavioral-developmental rotation, and learn at least one form of developmental screening and surveillance, the more experienced physicians who were trained prior to the late 1980's did not; only very recently have residents been exposed to ASD screening tools.

2. Lack of an effective screening referral network

    - Screening is hampered by the inadequacy in many communities of an appropriate referral network; physicians have little incentive to screen if diagnostic and other services are not readily known or available.
    - Pediatricians lack enough information about the critical importance of early intervention for children with ASD. Doctors hold a great deal of power, and their referral to an appropriate specialist for intervention is important.

3. Inadequate screening methodologies

    - A proper diagnosis takes hours, and must be conducted by trained professionals.
    - Tools that are effective across a broad age range must be adapted to the process flow of a primary care clinic to be of practical use.
    - The false positive rates of existing instruments are too high, creating unnecessary alarms and work for parents and care providers, who do not have access to experts for the proper interpretation of the screening results.

4. Lack of the ability to deliver a comprehensive diagnosis

    - Access to an experienced individual to interpret developmental screenings is crucial to providing the proper early intervention. In some states, families must travel great distances for diagnosis, then must try to have the diagnosis interpreted and services delivered in their own community. Children need to have local available testing and treatment that is tailored to their needs.

5. Lack of effective practice

    - Waiting times for expert diagnostic evaluations are far too long, and negatively impact the screening practices of primary care providers.

III. Access to all needed autism health, mental, education and social services

(A) Access to health/mental services

1. Ineffective integrated service systems and medical home

    - There is a significant lack of case coordination resources and advocacy, sub-specialty involvement, and resource sharing.
    - There is a high rate of staff turnover, especially in the roles of key supporters of medical home concept. The current systems (physical, behavioral, developmental health, and education) play against each other in this arena to the detriment of the child and family.
    - Knowledge, resources, and unwillingness by some organizations to work together.

2. Lack of availability of comprehensive services and coordinated, multi-disciplinary providers

    - Developmental and behavioral services for ASD are often not considered medically necessary.
    - There is no coordinated service system.
    - Lack of mental health providers to whom the PCP can refer.
    - Overall lack of mental health services and lack of insurance or public funding for the services that are available.

3. Lack of Interagency Coordination

    - Confidentiality rules and regulations can be real or perceived barriers.

4. Inadequate time, resources, and reimbursement

- Lack of time to screen.
- Services not covered in insurance packages.
- Lack of time and reimbursement for appropriate Medical Home services, especially care coordination or for interdisciplinary groups to meet and discuss patients.

5. Lack of education, training, and support for families, professionals, and the community

   - Training programs and higher education have not stressed integrated care; disciplines are distinct and separate; there is little in the way of cross-training.
   - Lack of enough trained professionals.
   - Lack of training in screening and identification of mental health issues.
   - Lack of understanding and training in ASD and mental health issues by primary care providers.

(B) Early intervention services

1. Lack of integrated service systems in the community

   - There is no bridge from research and university clinical program high-quality models to practical issues of provision in Birth to Three Early Intervention Systems in a community setting.
   - Lack of collaboration between medical waiver providers, private providers, and IFSP or special education teams.

2. Inadequate time, resources, and reimbursement

   - There is a lack of appropriate staff needed to implement the intensity and duration of early intervention services.
   - A good deal of time is needed to train the multiple methods of early intervention.
   - There is a lack of access to experienced program managers in rural settings.
   - There is a lack of focus on resources (financial, etc.) into early intervention for all developmentally-delayed young people who benefit from a high intensity of services.
   - There are not enough special education teachers with expertise in autism, and therapists of varying disciplines skilled in working with the ASD population.
   - There is not enough use of up-to-date technology.
   - Early intervention programs do not receive the necessary funding, or even funding comparable to current preschool programs.
   - There are funding constrains to replicating good programs; working with autistic children is expensive.

3. Lack of Education, training, and support of families, professionals, and communities

    - Administrators and teachers lack enough ASD-related training.
    - School systems are not educated to assume competence in ASD children.
    - Many early intervention providers do not receive training on how to implement effective, data-based instruction.

(C) Education services under Section 504 and IDEA

1. Lack of integrated service systems

    - There is a disincentive to direct educational resources to other than strictly academic areas.

2. Lack of services and effective Section 504 and IDEA programs

    - In many states, the Individual Education Plan is not effectively implemented. It carries no legal clout, and although accommodations are written down, there is no mechanism to insure that these are implemented.
    - Schools are often responding to students and families reactively, so they never take the time to develop high quality programs. Rather, they do what parents ask, but then end up with a mish-mash of services that are not effective.
    - A side effect of No Child Left Behind is that schools are so focused on preparing for and taking high stakes tests, they have become unfriendly environments for any diverse learners. Children with autism are a particular challenge because they need focus to be put on social skills sometimes more than academics. Although all of the data on inclusion suggests that there are no negative side effects on typically developing children, including performance on standardized testing, there seems to be a myth that including children with autism in a classroom with interfere with a school's ability to make adequate yearly progress as defined by NCLB.
    - Some children with autism, when they are doing very well, are told that they do not qualify for special education support. A diagnosis of autism should insure children with special education support AND extended school year services from diagnosis to 21.
    - Lack of standardized definition. A good working definition could be "an educational situation where both the person with autism and the regular education students benefit in a meaningful way.
    - Lack of support often results in "inclusion by proximity" and nothing else where the regular education students do their work and the special education student does something totally different.
    - There are disagreements between proponents of the different models– sometimes evidenced by unwillingness to combine the techniques in situations where a collaborative approach might be beneficial.
    - Promotion of non-evidence based therapies.

- Resistance to utilizing ABA principles and strategies in the educational setting.
- Lack of awareness and recognition of pragmatic language impairment in individuals with adequate vocabulary, syntax, grammar.
- Lack of recognition of the importance of social skills development as an educational issue.

3. Lack of appropriate testing, outcomes measurement, time, resources, and reimbursement

   - There is a lack of individualized approaches due to the heavy reliance on standardized testing.
   - There are limited resources that go towards education.
   - There is a lack of funding for parents to enroll their children in special schools. These schools are primarily funded by public school systems unable to provide for these children.
   - There is a lack of availability of sophisticated assistive technology (e.g., augmentative communication) evaluations.

4. Education, training, and support for families, professionals, and the community

   - There is a lack of time to train on the job considering priorities of the NCLB focus.
   - There is a lack of pre-service training at Institutes of Higher Education for general education teachers, especially across the spectrum.
   - There is a lack of qualified instructors trained in the use of these techniques.
   - There is a lack of ongoing training for instructors working in the field.
   - Teachers and others that come into contact with those having special needs need sufficient support.
   - Proper preparation for the ASD child, the regular education students, the special education teacher and aides, as well as the regular education teacher, are all needed.

(D) Access to Social Services

1. Integrated service systems/medical home

   - There is inadequate organization at state and local level, training, and resources.
   - There are insufficient social service agencies that provide services that work as part of the team—there are no wrap-around services that build onto school program.

2. Comprehensive services provided by coordinated multi-specialty providers

   - There is a lack of availability of respite services for families.
   - Behavior support for families as necessary.

- There is little eligibility for adult services for ASD adults with IQs over 70.
- The perceived stigma with receiving "social programs"—even Medicaid.
- Lack of social programs' familiarity with ASD.

IV. Adequate Public/Private Insurance for Children, Youth, and Adults with Autism

1. Benefits and coverage

- The most pressing issues regarding the development of appropriate insurance benefits is the lack of agreement regarding what constitutes an appropriate service and treatment package for individuals with autism, and the lack of qualified treatment providers.
- Benefits are often limited to traditional medical services. Applied behavioral analysis (ABA) and other services shown to be successful for children with autism are often not covered services. Even with covered services, no coverage is available for habilitative care.

2. Medicaid and private insurance terms of coverage—diagnoses, medical necessity, and waivers

- There is not enough availability of coverage by the Medicare systems or private insurance plans.
- In private insurance, the behavioral and physical health components of the company insist that payment responsibility does not belong to them, effectively denying prior authorizations and payments for necessary services.
- Medicaid services are not consistent. Families who can navigate the system well may receive adequate services; other families in the same community may get no services.
- Autism is still considered by many as a behavioral or emotional disorder instead of a neurodevelopmental disorder with anatomical correlates in the CNS.
- Few insurance programs cover the actual diagnosis of autism.
- Many companies will not cover ASD based on "pre-existing condition" clauses.
- There has been no establishment of appropriate, reimbursable CPT codes for autism and its treatment.
- There is no reimbursement at a meaningful level for in-home support for behavioral and other challenges related to being on the autism spectrum.

V. Community-based, Coordinated Service Systems Organized for Easy Use

1. Integration of autism services into broader system of care

- There is a lack of family organizations, parents, youth, and schools collaborating to take a role in drawing attention to the need for an integrated service system.

2. Interagency coordination

    - Agencies are not set up for the sort of collaboration necessary to deliver adequate autism services.
    - Entrenched bureaucracies have a number of territorial issues, difficulty making change, a low comfort level, and competing interests, all of which inhibit the successful implementation of needed service mandates.

3. Access to information

    - Confidentiality rules and regulations impede the appropriate sharing of information.

4. Time, resources, and reimbursement

    - There is a significant lack of funding and trained providers to integrate and coordinate service systems, which results in families with ASD members constantly waiting for the services necessary to their needs.

VI. Constraints to Successful Youth Transition to Adult Services, Work, and Independence

1. Transition planning and programs taught at transition

    - There is not enough time, money, training, and resolve to form the types of relationships with young people needed in order to ease their transition.
    - School districts do not always understand the regulations associated with transition planning, and thus do not have a mechanism in place to ensure a smooth transition.
    - There is no paradigm for people with autism at this stage for scaleable services. The cost to society for providing these scaleable services will usually be more than repaid by the taxes remitted by a person earning a salary.
    - There is a lack of professionals with the knowledge to point the families and youth in the right direction to make the transition to work, or find the financing for education.

~~1.~~2. Services tailored to youth and adults

    - There is a lack of ongoing treatment services, and service facilities, for adults once they turn 21.

3. Education and training of families, professionals, and the community

    - Lack of trained professionals who work with adults with disabilities.

- ASD individuals are not effectively coached on how to enter the work force, or how to transition from one job to the next.