MN Autism Early Intensive Intervention Benefit
Notes from the clinical/professional retreat
Sept. 24-25, 2013

Benefit Mission: To ensure timely access to culturally meaningful, individualized, child and family-centered interventions founded in science-based practices, that promote best possible long-term outcomes for individuals with Autism Spectrum Disorder (ASD) and their families at home, school and in the community.

Retreat Purpose: Bring together clinical and professional experts in the field of ASD from diverse disciplines and perspectives. Share ideas and integrate information to advise the Department of Human Services (DHS) in minimum standards for best practices in diagnostics, treatment, progress monitoring, parent engagement and care coordination based on current science, for the new ASD Early Intensive Intervention benefit for children with autism spectrum disorder from birth to 18 years of age and their families.

Day 1: Topics and Ideas Generated

1. Diagnostic Requirements: How does a child get in the door?

Dimensions to Consider:

- Distinguish between content and process: Content : Tools, Process : Wisdom, how to get there
- Differentiate between what is Excellent (best practice) vs. Practical (Good enough)

Capacity Dimension:

- How do we balance reaching the largest number of children without being insufficient in Dx process but also not restricting access
- Backlog considerations, time from referral to diagnosis and diagnosis to treatment
- Could diagnostic process begin with an educational assessment that adds a medical component?
- Consider a continuum of services : a child with Red Flags but no diagnosis may begin to receive early intervention through the schools, then may be referred for a "good enough" diagnostic assessment to get in the medical service door
- Checks and balances, need a "firewall" between evaluation and treatment to prevent conflict of interest. This presents a capacity issue. MN has a deficit of professionals who can diagnose. Many providers in MN provide diagnostics and treatment out of necessity and not by design.
- Expand role of the primary physician in diagnosis beyond screening and surveillance
- Medical Home, pediatricians are part of the team
- Expand who can assess, i.e. OT's see lots of kids early. How can they be a part of diagnosis and referral?
- Each discipline has their own standards for diagnosis and treatment. What needs to be included so that the evaluator has something common to look at?
- Down side of early identification or "flagging" for possible ASD is impact on parent's mental health and availability to child, stress on family.

Role of early intervention (education) in diagnostics:

- MN has a strong EI program historically, in-depth training in ASD and diagnostic tools such as the ADOS.

- Must meet evaluation within 45-day time-line from referral for birth-3 year olds. Only looks at one aspect of child and not holistic i.e. Medical, Mental Health, etc. concern with early intervention as main vehicle

Interagency Dimension:

- Collaboration and interface with other agencies and services, prevent duplication, reduce waiting lists, prevent families from having to re-tell their story
- Streamline process with physician referring to mental health professional and collaboration begins
- Define minimal criteria to get in the door, an entry evaluation vs. best practice/ "Gold Standard"
    - Propose two phases of diagnostic process
        - Core diagnosis process to qualify for medically necessary entry criteria with a focus on ASD criteria. Starting point for services.
        - Over-time incorporate a comprehensive, multidisciplinary diagnostic process
        - Need a level of care coordination at this initial stage and throughout. Need for continuity between diagnosis and treatment.
- Define when to refer for more extensive, differential diagnosis. Need an algorithm for this. What triggers a more comprehensive evaluation?
- How can we have "both/and" and not one model for ASD but create a system with multiple models.

Cultural and language access dimension:

- Competing cultural issues around disability, role of parent in treatment, response to diagnosis and response to resources offered. Parents can be good reporters for Dx if we keep it culturally relevant. Which instruments is less important here. Cultural piece more important in treatment than diagnosis. Interpreters need training in ASD, assessment tools, and terminology. Need to see these children in broader context of their community, family and culture.

Age Dimension:

- path is different depending on age and the definition of the population the benefit is intended for
- Who has the capacity and is best set up organizationally to implement diagnostics or be the lead in a collaborative process? Education/early intervention/Part C? Community Mental Health? Medicine?

Family Risk Dimension:

- How families receive news must be part of Dx, identify a social worker or case manager up front.

Severity Dimension:

- What is required to get at this measure?

Funding Source Dimension:

- Payer policies are not aligning with diagnosis and treatment.
- Separate diagnosis meaning from billing

Essential Components of ASD Diagnostic Assessment

- Distinguish between diagnosis for services vs. comprehensive evaluation of needs of family and child
- DSM-5: more complicated to meet criteria, more focus on history now and more focus on functional skills vs. IQ
- Care coordinator/guide to get through the right door, do all families need this?
- Involvement of Medical and Mental Health Professionals

"Good Enough" ASD diagnostic Assessment: entry-level diagnosis for initial access to service

- Requires a culturally and linguistically competent perspective to Dx process

- Performed by an experienced clinician

Parent Interview/Developmental and Medical history:

- Parents are good reporters and often see concerns before any other professional. Need to view through a culturally relevant context. Cultural sensitivity. (ADIR, Autism Diagnostic Interview Revised)

Direct observation of the child:

- variety of perspectives i.e. caregiver, home, in comparison to sibs, peers, child care, school, waiting room
  - Structured observation: ADOS, CARS, STAT, cross walk with DSM-5 criteria

Developmental Assessment provides baseline for:

- Restricted repetitive behaviors including adaptive functioning and self-care
- Communication capacities
- Social Emotional capacities

Meets DSM Criteria:

- Focus on ASD criteria first for entry into services, then conduct comprehensive assessment
- Determine what trips a child into more comprehensive evaluation
- Is there a need for a medical diagnosis of ASD before services can occur?
- Add a medical component to educational evaluation so that a child can get diagnosed and service earlier
- Separate diagnosis meaning from billing. Payer policies are not aligning with these benefits
- Expand who can assess
- Distinguish evaluation of needs of family and child from evaluation to get into services

<u>Comprehensive Multidisciplinary Assessment</u>:

- rule out co-morbidity to allow access to an array of services
- Medical/differential diagnosis : genetic, neurological, Family Hx, OT, PT, Speech, hearing, vision, nutrition
- Sensory Processing/Regulatory capacities/Reflex Integration

<u>Common Assessment Tools Used:</u>

- **Functional/Adaptive**
  - Vineland
  - Sensory Profile
- **Developmental**
  - Bayley-R, Bayley- Social-Emotional Assessment Scale and Growth Chart
  - Mullen
  - Battelle
- **Diagnostic**
  - ADOS, child assessment
  - ADIR, Parent Interview
  - DSM V
  - SCQ
- **Outcomes**

- PEDI
- MCY
- ICFC

2. Parent Engagement

- Family assessment takes time and requires building trust and developing a relationship
- Credentials: quality of people doing the assessment
- Should be done in the home environment and include cultural and language interpreter
- Should receive meaningful information about the family system and dynamics
- Ask parents about their values, goals, and determine how to maximize the potential
- Need for care coordinator, navigator, guide to assist families through the right door
- Care coordinator assigned as soon as possible
- Determine what is critical for the family and then assist in determining what is critical to the family for the child
- Assessment of family and child routine
- Identify parent needs for support: grief, loss of hope, information about ASD, other mental health issues, stress
- Siblings need for support
- Families at risk for isolation (should be a key measure)
- Provide parent and culturally specific guidance with realistic hope, resources and disability specific information
- Foster early success: work one-to-one with family and child
- Range of treatment options available, multiple social needs of families
- Home-based (parents self-select intensity)
- State clear expectations of agency and parent
- Provide menu of options during diagnostic process and help parents determine best fit for child and family

Key Things to Consider

- Parent/caregiver partnership
- Parental supports and/or isolation
- Define family goals, resources, strengths, needs, readiness or ability to engage
- Eventually learn what approaches match better with which families
- Culturally meaningful
- Who performs parent interview and needs assessment?
- When and how to communicate about initial Dx; allow time to process after initial Dx.

Tools Used

- Parent Partnership Agreement (between provider and parent, revisit every 3-6 months)
- Determine quality of life indicators of improvement with parent
- Parent Stress Index
- Family risk assessment measure
- ECSII Early Childhood Service Intensity Instrument (Child/Caregiver Relationships and Environment)
- No one tool fits all, informal assessment with set of values, guidelines, range of approaches
- No one tool evaluates family “capacity”
- Parents self-evaluation on discrete trial training success (staff evaluate self as well)
- Routines-based Interviews; helps families think about their needs
- Measure quality of life improvements over time
- Parent satisfaction survey

Day 2: Topics and Ideas Generated

3. Individual Goals and Treatment Plan Development

- Goals need to be functional and generalizable to different environments and people
- Parents can evoke the same skills as providers
- Look at IEP process
- Measure achievement of goals identified, but not progress on DSM-5
- Differentiate individual goals and objectives vs. outcomes; outcome achievement leads to improvement
- Identify; What would it take to make life easier? For child; For family.
- Help parents understand what autism is; language improvements won't cure ASD
- Functional skills; demonstrate substantial change in functional skills in core ASD domains
- Individualized treatment plans; look at each child individually
- Target measureable/countable discrete behaviors (eye contact)
- Broad areas of focus; Cognitive flexibility, Language, Social Communication, Behavioral Regulation, Problem Solving
- Start with a range of skills to be building
- Identify domains for treatment targets
- DSM-5 is diagnostic and not a tool for treatment targets
- Focus on ASD features and other co-occurring developmental delays
- Look at levels of severity in comprehensive assessment

4. Individual Progress Monitoring

- Determine what constitutes progress
- Each objective should be able to be graphed for progress
- Social interaction and skill building is more difficult and nebulous to measure
- Enable providers to use their own paradigm for measuring progress
- Need accountability measure of providers for a child to master an identified goal
- Video tape the child as a means of measuring and demonstrating progress
- Show progress in countable form; increase positive behavior, decrease negative behavior
- When building a mind it is not black and white and there is no one way to document progress
- There needs to be a combination of measures and certain standards that are required across treatment modalities
- Look at broad domains and population outcomes but don't lose the individual care and outcomes for families and kids
- Evaluate major benchmarks every 6 months
- ADOS is not a good outcome measure, most assessment instruments are not designed to measure progress
- Review case clinically, personal observations of child across environments
- Identify transitional tiers for services
- Many challenges since there are no comparison "averages" for individuals with ASD, only mild or severe
- No agreement on what constitutes social reciprocity
- Tracking of progress must be data driven
- Language domain; measure number of modalities the child can use across environments, good research on "functions" of language
- Define process for termination of a child from a treatment program; tiered process, bring in an outside consultant
- Need for providers to collaborate when child has been terminated or not succeeded in one program and moves on to another

- Neutral party provide evaluation for progress monitoring and need for termination of services or referral to other services
- Provide skill maintenance with highly trained PCA
- Two groups of kids- fast trajectory of growth and slower and more limited or plateaued; how to determine when to continue treatment and when to refer elsewhere or where treatment is maintenance of skills
- When to pursue change in methodology
- When to pursue medical/medication avenue to address behaviors (ADHD/Anxiety/Depression)
- Challenging behavior – rating of severity and progress, behavior changes as development changes.

5. Coordination of Care – Theme throughout the retreat

- Provide continuity across providers; home, school, medical, therapeutic treatment, social services and other agencies
- Cultural liaison
- Know what is offered by other providers; directory of resources across the state
- Medical home concept
- Behavioral Health Home
- Based on patient complexity
- Empower parents and teach how to become their own advocates/care coordinators (greater MN with fewer resources)
- Facilitate transitions to other programs and services
- Develop family peer specialist (parent to parent care coordination)
- Provide a common communication system where all providers can see each other's notes and provide consistency
- Determine best means of communication and access to services based on specific cultural needs and perspective

MN Autism Early Intensive Intervention Benefit
Clinical and Professional Retreat Solicitation

DHS solicited retreat participants through the state registry process. DHS worked to recruit a diverse and balanced distribution of disciplines and perspectives among the team of consultants. The ideal team included a mix of national and Minnesota-based experts with significant experience in serving culturally diverse communities in urban, suburban and rural populations with ASD. Professionals were sought with expertise in ASD who could objectively represent the following:

- Behavioral interventions
- Developmental interventions
- Medicine
- Occupational therapy
- Psychology
- Research methodology
- Social work
- Special education
- Speech therapy

External Clinical and Professional Retreat Participants

1. Suma Jacob- Associate Professor Adult and Child Psychiatry
2. Andy Paulson – Ph.D. Licensed Clinical Psychologist, Founder of Integrated Development Services in WI
3. Phil Sievers – MDE Autism Planning Director, Special Education
4. Michael Reiff – M.D. Developmental/Behavioral Pediatrician, U of M Autism Clinic
5. Judith Miller – MA, MBA, Licensed Speech Pathologist, Manager Rehab Therapies, Gillette Children's Hospital
6. Kathleen Muffly – MD, General Pediatrics, Park Nicollet
7. Amy Esler – Ph.D., LP Psychologist, U of M Autism Clinic, ADOS Trainer
8. Eric Larsson – Ph.D., LP, B.C.B.A.-D. Executive Director of Clinical Services, Lovaas Institute for Early Intervention
9. Carol Follingstad – PhD., Licensed Psychologist, Clinical Consultant, HealthStar, Integrated Counseling Services (Greater MN)
10. Cheryl Shachaf – Pediatric OTR, Certified Relationship Development Interventionist (RDI)
11. Donna Miller – B.S. Communication Disorders, M.Ed. Early Childhood Special Education, Autism Specialist, Wayzata Schools
12. Mariam Egal – Community Liaison, DHS Hennepin County Somali Pilot Project
13. Pat Pulice – MA, LP, Autism Services Director, Fraser Child and Family Center
14. Beth Fagin – LCSW/LMFT, Director of Pediatric Therapy, St. David's Center
15. Nancy Schussler – PhD, Licensed Psychologist, B.C.B.A.-D, Behavioral Dimensions
16. Richard Solomon – MD, Developmental Pediatrician, Medical Director, Center for Developmental and Behavioral Pediatrics, Ann Arbor MI, Founder of the P.L.A.Y. Project

DHS Retreat Participants

1. Anne Harrington –Planner Director Autism Services
2. Kim Anderson – Autism Project Manager, Continuing Care Administration
3. Jeff Schiff – Medical Director, Health Care Administration
4. Ellie Garrett – Health Services Policy Analyst, Health Care Administration
5. Julie Marquardt – Acting Director, Purchasing and Service Delivery
6. Pat Nygaard – MN Evidence-Based Practice, Children's Mental Health