MaineHealth

Operation Access Navigating The Current System

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Interventions

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- Interventions may:
  - Increase functional communication
  - Maximize the ability of the child to function and participate in the community – have to remember our own bias in this
  - Reduce core symptoms/behaviors that are truly interfering
- Treatment plans are usually multidisciplinary, may involve parent-mediated interventions, and target the child's individual needs
- Ideally Applied Behavioral Analysis based – should recognize that this is controversial for some but comes in many forms
- In Maine this is often a patchwork of services prior to school age

Interventions

Speech-Language Therapy

- Given current EI model will have to access medical model- at less than 36 months
- Increase functional and social communication (Glickman COE webinar in this!)
- Gestures & signs
- Augmentative & Alternative Communication (AAC)
  - Picture exchange communication system (PECS)
  - AAC device

Occupational Therapy (OT)

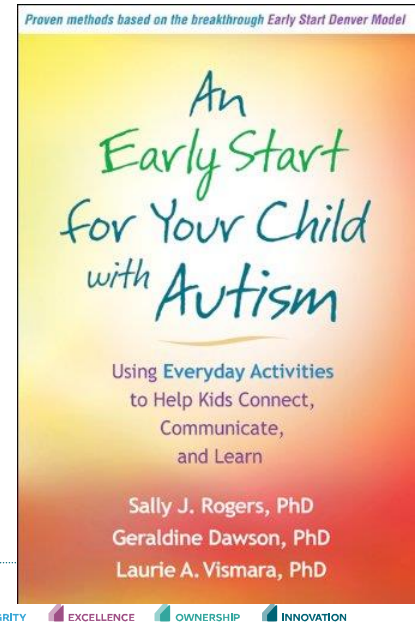
- Given current EI model have to access medical model- in home or clinic based at less than 36 months
- Encourage independence
- Self help / adaptive skills
- Sensory differences
- Emotional regulation
- Flexibility
- Play skills
- Attention

Child Development Services Part C Early Intervention for ME

- Part C (think C for crib) covers children birth to 36 months
- Autism counts as an established condition that qualifies for EI
- If qualifies for CDS services then Individual Family Service Plan (IFSP) written, reviewed q 6 mos
- Uses primary service provider model- so services tend to be limited- focus on training the parent to assist the child's development ESDM-P – "can be individualized if not making progress"
- Of note P-ESDM can be started prior to diagnosis- and I have seen this happen
- If receiving services in part C, then should be starting transition process at around 33 months to Part B of CDS at 36 months
- Make sure you have CDS releases in office to have families sign to be able to get records- still working on more consistent communication from CDS

Early Start Denver Model (ESDM)

- Parent coaching used in ME is based on ESDM
- A naturalistic developmental behavioral intervention (NDBI) based on ABA using play and daily routines -empathizes natural environments and positive relationships
- 18-48 months manualized curriculum
- Relationship-based intervention
- Provided in the child's natural environment
- Considered by most to be neuroaffirming
- Book written for parents: *An Early Start for your Child with Autism* as well as videos Helpisinyourhands.org
- Meta-analysis 2020, 12 studies, 640 children- improvements in cognition and language overall (but no significant effects ASD symptoms, adaptive, social communication, repetitive and restrictive behaviors)



Evidence P-ESDM

A Randomized, Community-Based Feasibility Trial of Modified ESDM for Toddlers with Suspected Autism
J Autsim Dev Disord 2022

- Have not found study directly comparing the more intensive ESDM model to P-ESDM
- Many early studies university based, highly trained coaches, study exclusions likely greatly limited who participated
- More recent study comparing P-ESDM (PC) to Enhanced Community Treatment Group (ECT)
  - Based in Canada, study period was prior to diagnosis of autism, RCT, 49 children
  - Both groups could receive other services with exception *PC group could not receive speech*
  - PC group 1 60 minute coaching session per week for 24 weeks
  - PC group had higher mean hours per month total 7.35 hrs vs 6.47 hrs but one to one less 1.43 hrs vs 2.46 hrs
  - No difference in expression language gain, PC group did gain more receptive language
  - Parents in PC group had higher quality of life, satisfaction and self efficacy scores
- It should be noted that could not do study if already had diagnosis and were unable to speak, read and write English (unless there was a family member that could) "criterion never applied"
- In addition this study was for services prior to diagnosis – in Canada services increased when services in place

Sample IFSP

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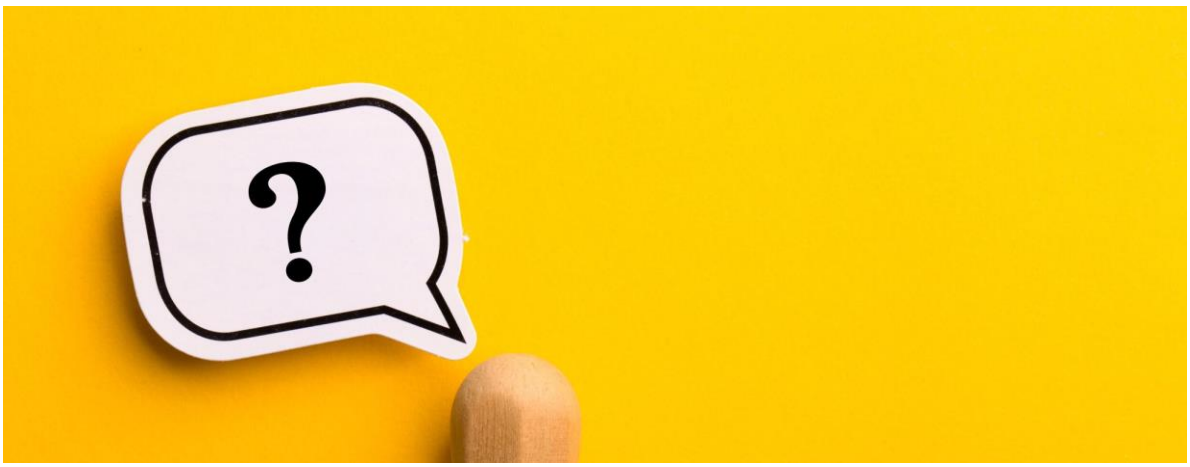
How can we advocate for more across the state? What is the right number of hours?



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A Multisite Randomized Controlled Trial Comparing the Effects of Intervention Intensity and Intervention Style on Outcomes for Young Children With Autism
Rogers et al J Am Acad Child Adolesc Psychiatry 2021

- 87 children with ASD, mean age 23.4 mo assigned to either ESDM or discrete trial training for either 15 or 25 hours per week 1:1 for 12 months, 3 sites total
- All parents also received coaching
- Neither treatment style nor intensity had overall effect on child outcomes of autism symptom severity, expressive communication, receptive language, and nonverbal ability
- Initial severity did not predict one intervention style to another in terms of progress
- 1 of the 3 sites showed that more intensive therapy was better for children with higher autism severity – so cannot say that 15 hrs is always as good as 25 hrs

Determining Associations Between Intervention Amount and Outcomes for Young Autistic Children: A Meta-Analysis

JAMA Pediatrics 2024

- Eligible studies studies quasi-experimental or randomized clinical trial testing
- At least 50% children with ASD 8 yrs or younger,
- 144 studies, 9038 children, ave age 49.3 months, 82.6% male
- Did not find that increased intensity of intervention led to increased gains (even though some individual studies do show that), no minimum hours reported making challenging to interpret
- Could not take into account any parent mediated intervention (in other words time caregivers putting in)
- Bottom line- there is no set perfect number, 1 hour too little, 40 hours likely too much for toddlers and early preschoolers– current system does not leave us a lot of opportunity to individualize easily

Glickman Lauder Center Of Excellence STEPP program

- Accessed through specialized section 28 rehabilitative community services funding (as opposed to school based), limited spots in Portland area, 13 slots with current staffing
- 3 hours per day/5 days per week total (3 days in home, 2 days toddler center, 1 hour speech there typically with some home carryover) = 15 hours per week
- Uses RUBI program which aligns with ABA for caregiver education to build skills and reduce challenging behavior
- Direct Instruction for child in communication, play, socialization, self-care, cognition and motor skills using ABA within functional activities and routines that are meaningful to the child and family
- Peer/Group- participation in weekly toddler social groups to provide opportunities to develop social skills as well as develop the skills needed for group learning
- Attempted to do trainings elsewhere in state utilizing section 28 providers- limited interest (Counseling and Trauma Therapy Associates, Portland Area completed training), grant from DHHS not renewed- Are there still options to consider variations?

Case management services

- EI and CDS case management- only for services directly related to EI, CDS, and school
  - may help to access Katie Beckett if no Mainecare but will not refer to outside services (or even discuss them necessarily)
- Targeted Case management (TCM) services (Mainecare/Katie Beckett waiver needed)
  - Time limited based on need – but can keep justifying the need
- Behavioral Health Home Case management services (Mainecare/Katie Beckett waiver needed)
  - Case manager, RN (not providing medical care), peer support and supervision
  - Tends to be longer term
  - Need to meet monthly at least
  - Likely better for children with significant needs
- Case managers are the pathway to in-home support!
- Invite case managers to your visits! Much easier than tracking them down later and can hand off appropriate follow up tasks for them
- https://www.maine.gov/dhhs/sites/maine.gov.dhhs/files/inline-files/State%20of%20Maine%20Service%20Guide9.15.21.pdf

In home supports- are we fully utilizing a potential way to deliver more services to younger children?

- Section 65 HCT
  - Uses mental health diagnosis (ASD or other)
  - Typically clinician and BHP combination
  - Do not necessarily have specific ASD training but can be helpful, especially with more verbal children
  - 3-6 months typically with occasional extension to 9 mos
- Section 28
  - BHP working with child on skills of daily living, variable training
  - Need to have documented delays in adaptive functioning
  - Some schools actually using for direct support in classroom
- Specialized Section 28
  - Must have ASD diagnosis
  - Has support of BCBA along with BHPs

Child Development Services Part B

- Age 36 months to starting kindergarten
- If received part C then should have been transitioned to Part B- parents need to understand that
- Often have updated evaluations as part of that transition
- If referred after age 36 months then will often need more extensive evaluation, again if autism suspected they should be referring for that evaluation– evaluation should include at least psychological/educational, speech and language testing and occupational therapy evaluation
- If qualify for services the Individual Education Plan written –ideally receive specially designed instruction (could be in special purpose preschool or mainstream setting with supports), speech and OT if needed
- Discussed that being transitioned to School Administrative Units by 2028 with CDS still assisting

Individualized Educational Plan

- Description of the student including strengths and concerns
- Disability category
- Often summarizes most recent testing (viewing original reports best)
- Goals and Objectives
- Special Education Placement
- Related services (psychological services, parent counseling and training, speech therapy, physical therapy, occupational therapy)
- Time and duration of services
- Evaluation mechanisms

Communication with schools

- Health Insurance Portability and Accountability act of 1996 (HIPPA) vs Family educational Rights and Privacy Act (FERPA) consideration
- Child Development Services falls under Department of Education and so requires that their specific release is signed in order release their documents
- CDS does typically get release signed for PCP, trying to be more consistent in sending at least written notice but encourage families to keep and bring copies of all testing, IFSP, IEPs and scan
- Review testing briefly to assure that family understands conclusions/diagnoses
- Consider narrative based teacher questionnaires periodically to assess progress and determine if any concerning behaviors
- If have telehealth capability can always include school on visit if relevant
- If concerns/recommendations to school be sure to put as suggestion for team to consider- IEP team has final say on IEP but carefully worded suggestions still may be considered

Transition to kindergarten- current process if preschool not within School Administrative District (SAU)

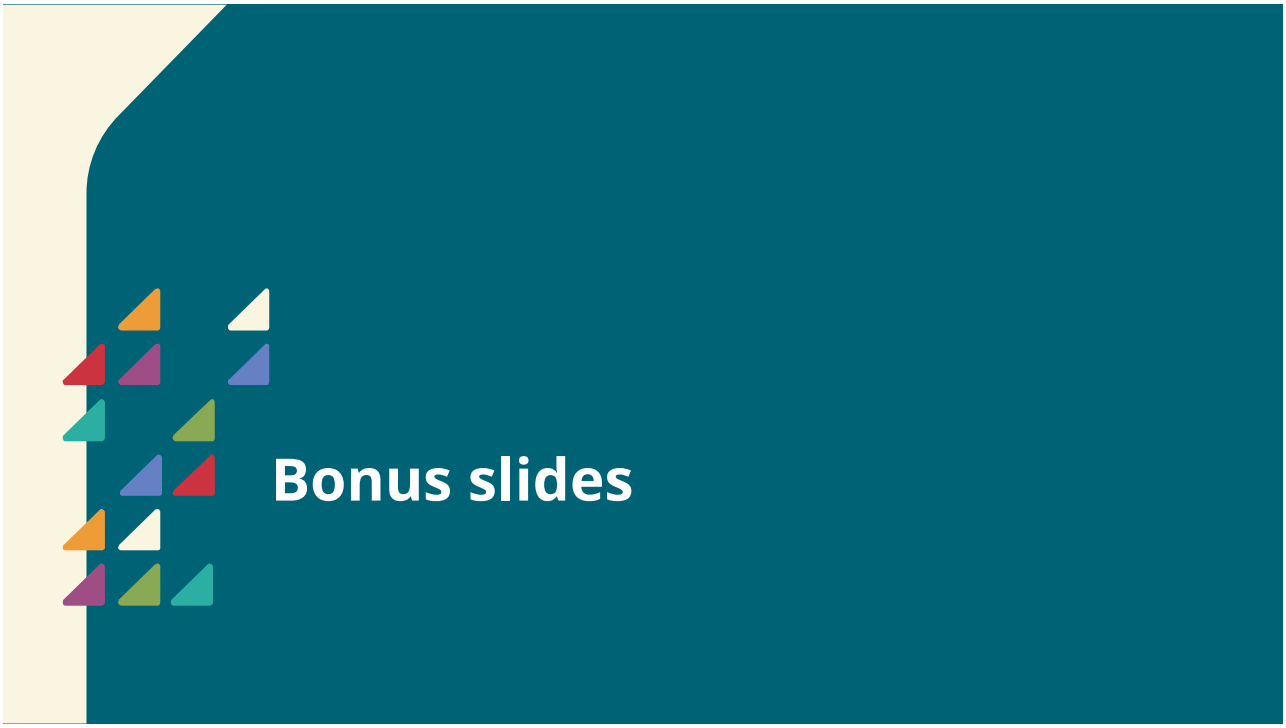
- Winter/spring CDS sends records to local SAU
- Local SAU reviews and may do observation at school or father more information
- Transition meeting then scheduled for spring including current team and SAU team to determine appropriate setting, supports and services for student
- Summer services (if qualifies) would still be responsibility of CDS
- Birthdate for kindergarten cutoff is October 15- if receiving services and has birthday between July 1 and October 14 can request to stay in preschool- I am less likely to recommend this now that preschool services limited, and kindergarten would be full day

What if older child in school who has not been diagnosed?

- Get copy IEP and any school testing first if there is- sometimes parents don't know!
- Narrative teacher questionnaire, review of concerns with parents
- If concerns possible ASD and core symptoms are affecting academic progress then reasonable to specifically request in writing a meeting with the school to discuss evaluation
- If school does not will have to pursue privately, we see up to 6th Bday, hoping to expand- Operation Access 2 with psychiatry and others?
- If currently MaineHealth econsults, if not have been told they are working on that and we will take phonecalls!
- Possible free screens:
  - Childhood Autism Spectrum Test (CAST) https://psychology-tools.com/test/cast
  - Autism Spectrum Screening Questionnaire https://psychology-tools.com/test/autism-spectrum-screening-questionnaire
  - Autism Spectrum Quotient (AQ) (self administered, adolescents) https://psychology-tools.com/test/cast

Webinars and online resources – please "visit" them!

- Autism speaks does have information available in many different languages – some outdated in terms of diagnosis – opportunity?
- Maine Pediatric and Behavioral Health Partnership https://bhpartnersforme.org/
  - sponsored Echo Autism Burst April 2024 – recorded presentations will be online
  - Can also obtain psychiatric consultations – phone and video provider to provider
- Glickman Lauder Center of Excellence also had webinars available for viewing including one on medication https://www.mainehealth.org/maine-behavioral-healthcare/care-and-services/glickman-lauder-center-excellence-autism-and-developmental-disorders/webinars
- Of note, Glickman Lauder Center's waitlist for psychiatric services has shortened, must provide the original diagnostic evaluation with referral – yours will count!
- Autism Distance Education Parent Training (ADEPT) https://health.ucdavis.edu/mind-institute/centers/cedd/adept
- Free behavior modification app designed by Karen Bears PhD for parents of children with Autism: https://www.attendbehavior.com/maine
  - o For more info on the Attend Behavior App, contact Melinda Corey, Help Me Grow outreach specialist: Melinda.corey@maine.gov or https://www.attendbehavior.com/mainecare



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Things to keep in mind

- The school can bill Mainecare when available and appropriate- this does not preclude getting medical based clinic-based services
- Section 28 is one of the ways this is used in addition to therapies (speech, OT, PT, BCBA, transportation and nursing)- falls under “behavioral supports- rehab and community supports” (more often used in CDS but also sometimes in schools)
- IEPs are always based on educational needs and determined by the IEP team based on input from member of team and evaluations
- School day treatment programs use section 65 services under “behavior supports- day treatment” – social work reimbursable when it is a day treatment program only
- Ed techs do not meet CMS requirements so cannot be billed through Mainecare but school can use BHPs through section 65

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Local Family Resources- visit websites!

Help Me Grow ME

https://www.maine.gov/dhhs/ocfs/support-for-families/child-development

Maine Parent Federation

Family Support Navigator Program

http://mpf.org/

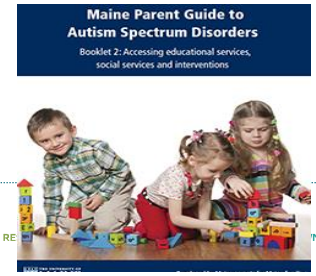
Autism Society of Maine
http://www.asmonline.org/

Autism Society's lending library
(https://www.asmonline.org/library/)

Maine Autism Institute for Education & Research

https://umaine.edu/autisminstitute/resources/

https://umaine.edu/autisminstitute/wp-content/uploads/sites/150/2018/11/Parent-guide-4-2nd-ed.pdf



Resources for providers

- Autism tookkit through AAP: Autism – Caring for Children With Autism Spectrum Disorder: A Practical Resource Toolkit for Clinicians (3rd Edition) member price $120 https://publications.aap.org/toolkits/pages/Autism-Toolkit#clinical
- Autism Identification and Collaborative Care through AAP free!
- Article From the American Academy of Pediatrics| Clinical Report| January 01 2020 Identification, Evaluation, and Management of Children With Autism Spectrum Disorder https://publications.aap.org/pediatrics/article/145/1/e20193447/36917/Identification-Evaluation-and-Management-of?autologincheck=redirected
- Vaccine Safety https://www.chop.edu/vaccine-education-center/vaccine-safety/vaccines-and-other-conditions/autism