

Transitions of Care Best Practices

Stephen Meister, MD, MHSA, FAAP
Nancy Cronin MA
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National Demographics




Outline:

- Transition Data
- Where Are We
- Where Do We Need To Go




Prevalence Data

- ❖ 1:6 Developmental Disability (<https://www.cdc.gov/ncbddd/developmentaldisabilities/about.html>)
- ❖ 1:68 Autism Spectrum Disorders (<https://www.cdc.gov/ncbddd/autism/data.html>)
- ❖ 1:150 Chromosomal Condition (1:691 Down Syndrome) (<http://www.marchofdimes.org/baby/chromosomal-conditions.aspx>)
- ❖ 1:323 Cerebral Palsy (<https://www.cdc.gov/ncbddd/cp/data.html>)




Review of Newest Data Available

- ❖ U.S. Centers for Disease Control updated its findings :
 - An average of 1:68 children are diagnosed with a ASD. (ADDM Project)
 - National Health Interview Survey – parent report phone survey reported that 1:45 children were diagnosed with ASD.
 - The growing epidemic is worldwide. (*Studies in Asia, Europe and North America have identified individuals with an ASD with an approximate prevalence of 0.6% to over 1%.*)
- Studies in Asia, Europe, and North America have identified individuals with ASD with an average prevalence of about 1%. A study in South Korea reported a prevalence of 2.6%. [[Data table \(http://www.cdc.gov/ncbddd/autism/documents/asd_prevalence_table_2013.pdf\)](http://www.cdc.gov/ncbddd/autism/documents/asd_prevalence_table_2013.pdf)]
- Some studies indicate that the increase in ASD prevalence is leveling off in the United Kingdom (<https://www.autismspeaks.org/science/science-news/study-finds-autism-prevalence-has-leveled-united-kingdom>)

 <http://www.cdc.gov/ncbddd/autism/data.html>


Current Data Provides Incomplete Picture of ASD Prevalence

- DOE data only documents students who receive services under the Autism category; it does not include students served under other categories such as *Other Health Impaired* and *Multiple Disabilities*
- MaineCare data reflects only those individuals who:
 - Were eligible for MaineCare services during the given time period
 - Have a primary diagnosis of ASD
- DOE data and MaineCare data cannot be linked at this time to allow broader analysis of service characteristics



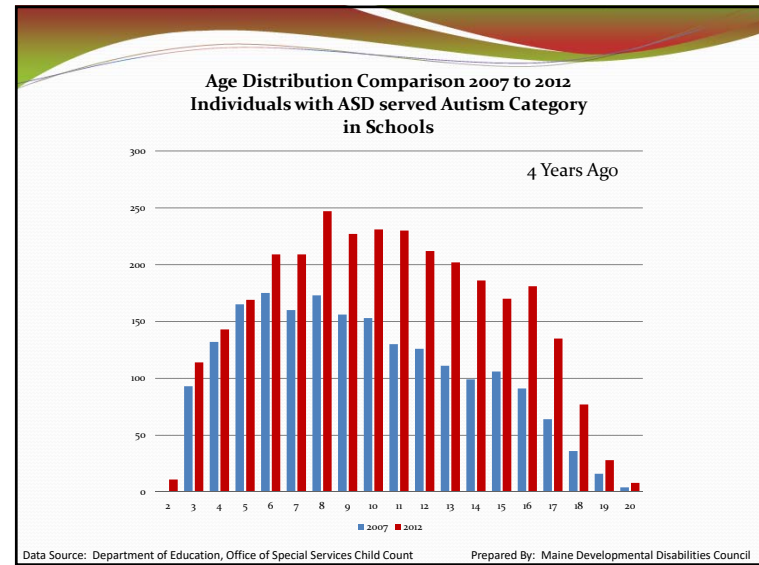
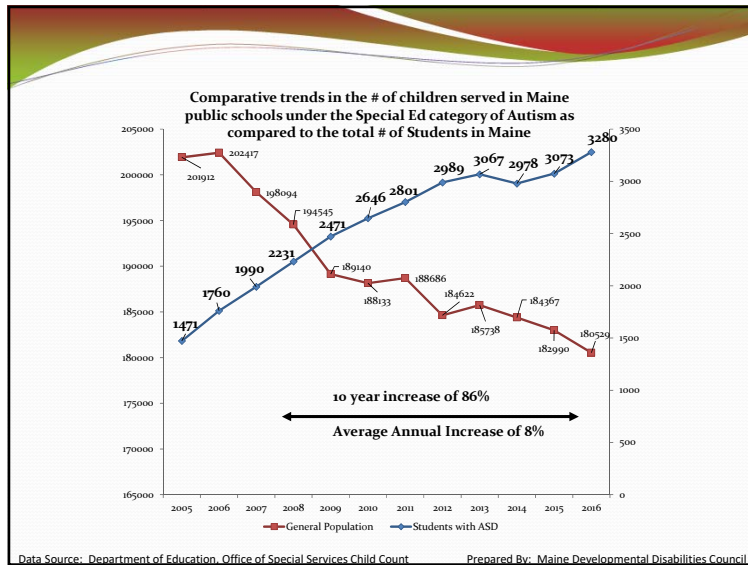
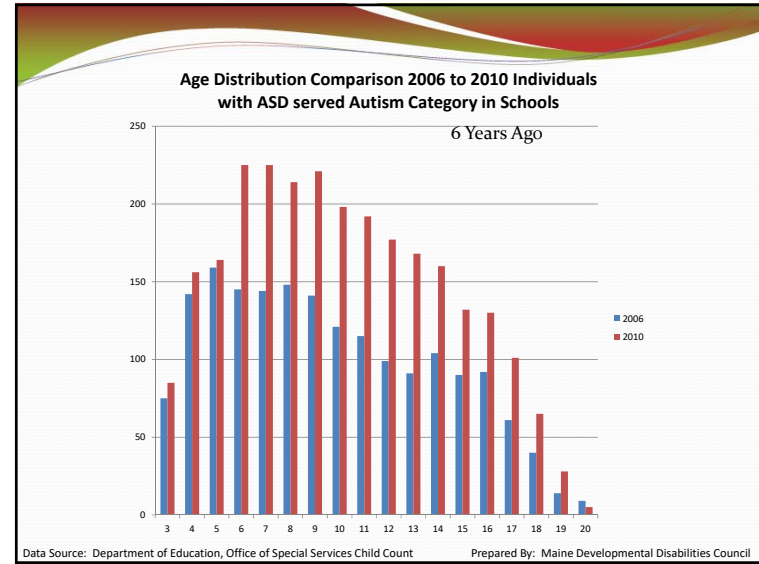
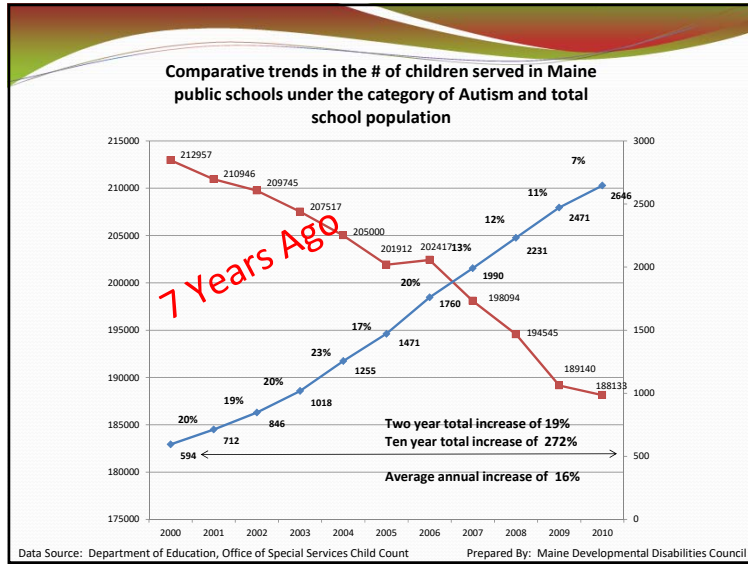
Maine Demographics

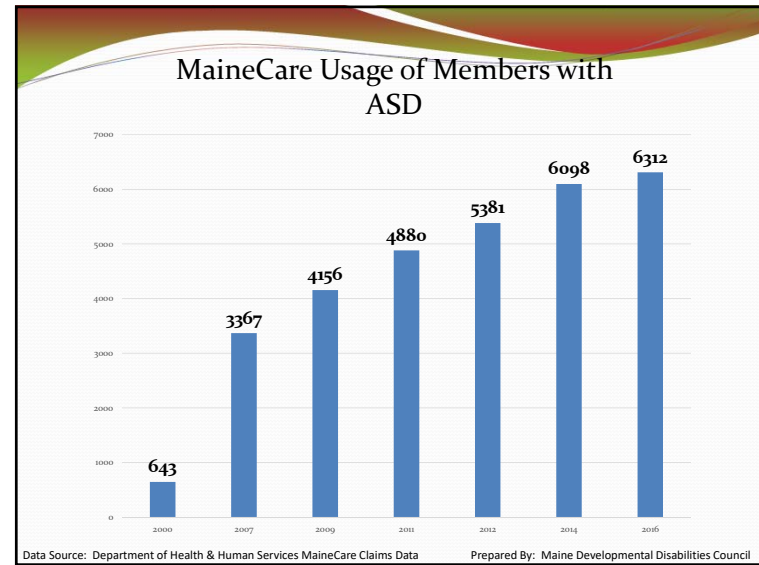
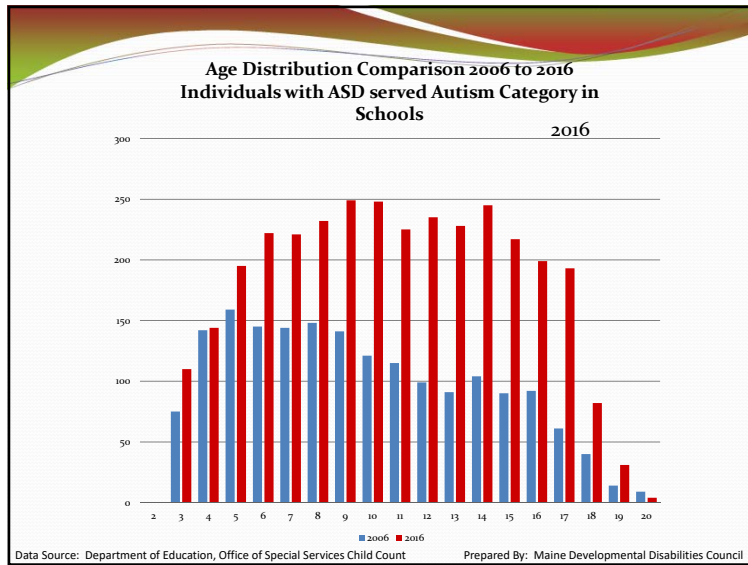
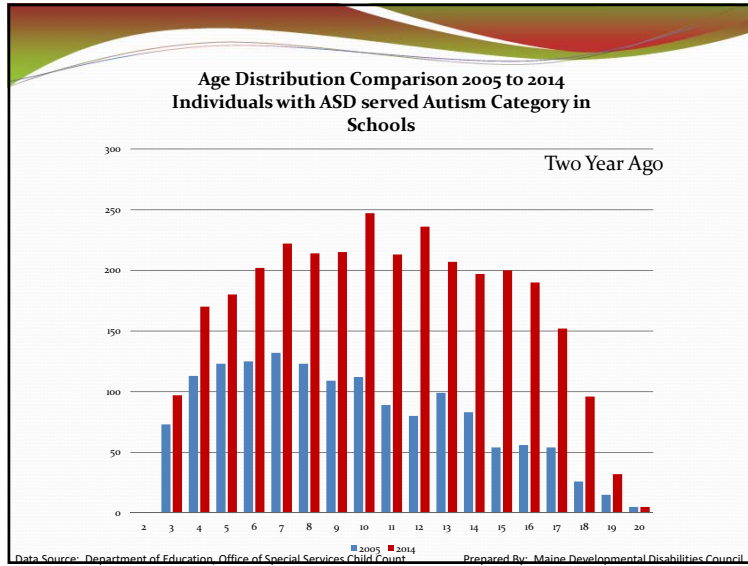
Most of these slides focus on Autism Spectrum Disorder due to that is the data available

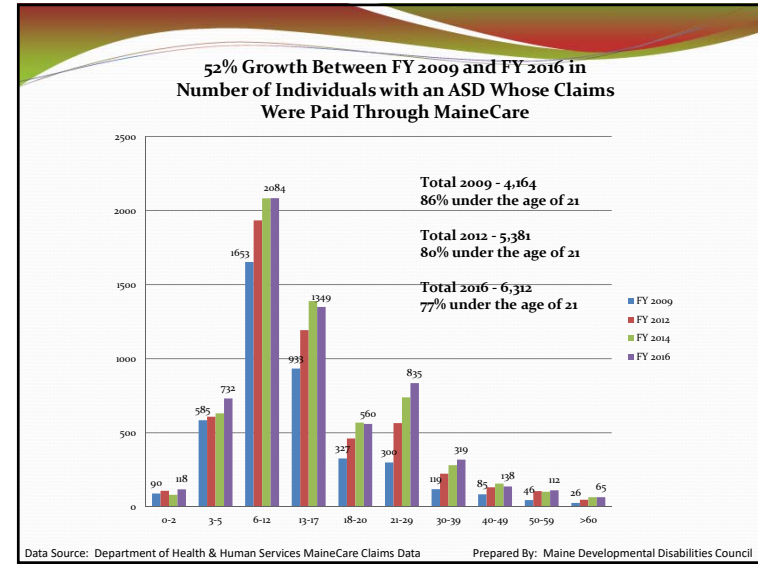
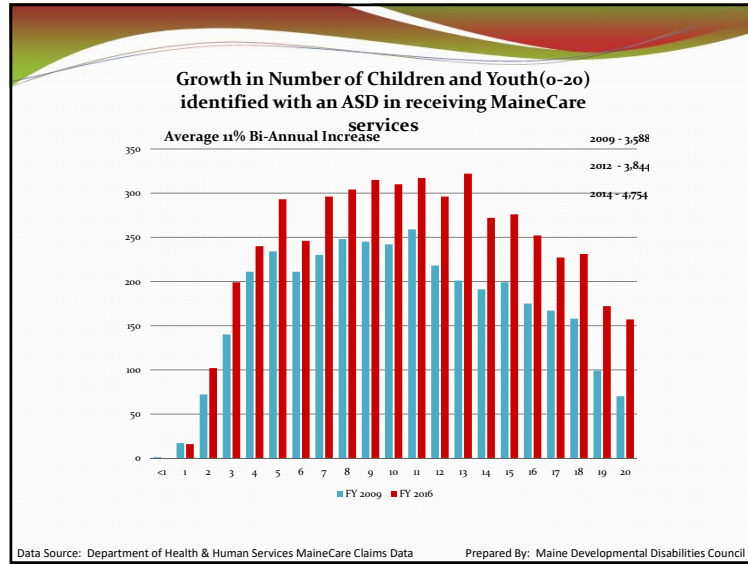


School Data









Age	2007	2009	2012	2014	2016	2 yr % Increase	4 yr % Increase	7 yr % Increase	9 yr % Increase
0-2	91	90	108	82	118	44%	9%	31%	30%
3-5	470	585	609	631	732	16%	20%	25%	56%
6-12	1,304	1,653	1,934	2,083	2,084	0%	8%	26%	60%
13-17	774	933	1,193	1,389	1,349	-3%	13%	45%	74%
18-20	239	327	462	569	560	-2%	21%	71%	134%
21-26	184	240	429	576	644	12%	50%	168%	250%
27-64	296	324	620	732	790	8%	27%	144%	167%
65+	9	12	26	36	35	-3%	35%	192%	289%
Total	3,367	4,164	5,381	6,098	6,312	4%	17%	52%	87%

Data Source: Department of Health & Human Services MaineCare Claims Data Prepared By: Maine Developmental Disabilities Council

10 Years Ago What Pediatricians Say...

- 2/3 Reported transition planning begins between 18-20 years for **all** patients
- 4/5 Perceived there was a lack of available adult primary care providers for CYSHCNs
- 4/5 Perceived there was a lack of available specialists

Fox et al. National Alliance to Advance Adolescent Health 2008 Fact Sheet n.6

10 Years Ago: What Adult Primary Care Providers Say They Need / Want....

- 95% Written transfer summary
- 95% “Support” from a specialist
- 84% Written information about condition impacting patient
- 91% Conversation with prior provider

N.H. survey run by the “special medical services” of Adult PCPs in fall 2007 to spring 2008. 33% response rate =180 – most were family physicians

What AAP in 2011 says we should do Implementing a Standard of Care

- Introduced Algorithm for PCPs
- Agreement on age to “officially” start (12 years)
- Creating a “time line”
- Transition Plans –(at age 14 years)
 - assessment measures for an accurate assessment of patient’s ability to transition
 - Updated regularly

AAP Clinical Report 2011: Supporting the Health Care Transition from Adolescence to Adulthood in the Medical Home

2009 Transitioning Youth to Adult Health Care

Adult Primary Care Providers Report


- Lack of training in childhood-onset and congenital disorders
- Fear that they are unable to meet patient’s psychosocial needs
- Lack of social work and care coordinators in practices
- Limited knowledge about social (?community) resources
- Time / financial concerns

Pediatrics, Peter et al. (2009) Transition From Pediatric to Adult Care: Internists’ Perspectives. Pediatrics;123:417

Maine Chapter AAP

Received grant from MDDC to conduct a series of focus groups to assess practices occurring in Maine that demonstrate current practices to transition youth from pediatric to adult medical care

Conducted a web-based survey and 5 in-person focus groups in different areas of the State and



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Maine AAP – Focus Groups

- Many medical providers are unaware that families and young adults struggle with transitioning successfully into adult providers for services such as
 - Routine healthcare
 - Specialty healthcare
 - Psychiatric Medication Management
 - Mental Health Services



Maine AAP Survey Highlights

- 66% (n=62) of practitioners said that families have approached them asking for help transition youth to an adult practice
- 81% (n=57) of practitioners have initiated transition from a pediatric practice to an adult practice



Maine AAP Focus Groups Highlights

- Mental Health programs transitioning within the internal program was easier if it is planned for and expected
- While some pediatric practices attempted to implement formal systems such as GotTransition the practices were not sustained due to lack of strong leadership and no financial incentives
- Adult service systems are varied and complex and there are very different supports and processes available for individuals with different disabilities, for example intellectual disabilities or cerebral palsy




Maine AAP Survey Highlights

- 62% (n=42) faced challenges when trying to transition a patient. Comments included
 - Difficulty finding an adult providers who understood disorders and/or able to care for kids with complicated needs
 - Challenged when adult provider provided inappropriate care such as removing all medications
 - Family or patient reluctance
 - Lack of system-wide standards for transition process
 - Limited providers accepting new patients



Maine AAP Survey Highlights


- 70% (n=50) either didn't know, or only somewhat knew, best practice methods of treatment and transition planning for youth with DD
- 82% (n=50) felt that transition is either very important or critically important
- When asked what their feelings/attitude around treating and preparing this population for a transition (n=50)
 - 14% responded that they are very comfortable with their knowledge and the process
 - 46% responded that they have a knowledge base but are not totally confident
 - 22% responded that they are fairly confident but want to learn more
 - 18% responded that they are not confident or comfortable at this time



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Maine AAP - Findings


- Need for reimbursement for transition planning
- Need a resource list of adult practitioners willing and able to serve young adults with complex patients
- Need for a warm handshake between youth and adult medical professionals
- Practitioners are receptive the idea of using a toolkit and other ancillary supports and acknowledge that this is necessary in a system of care to make transition planning efficient and effective



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Maine AAP - Findings

- Transition goes beyond the shift from a pediatric to an adult health provider. Successful transition must include the availability of social programs including employment, housing, and social activities to keep the young adults engaged and to promote their independence.
- Coordination between school transition and health transition is critical
- Providers need to better understand adult services and legal processes such as guardianship vs supportive decision making models




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MDDC Transitioning Youth to Adult Health Care

Leading the way in transitioning Youth with Special Health Care Needs (Ages 14-26) to adult Healthcare.

What is successful transition to adult healthcare?	Parent/Guardian	Child/Doctor	Adult Medical Provider
<ul style="list-style-type: none"> ➢ An informed consumer ➢ Locating a provider ➢ Understanding their healthcare needs ➢ Knowing how to work the system ➢ Know what benefits are available to them ➢ How to select a provider that meets their needs ➢ Opportunity for choices. 	<ul style="list-style-type: none"> ➢ Understanding your rights and what you no longer have access to in regards to your child's medical record ➢ Knowing what your insurance covers for your adult child ➢ Teach child how to be an informed consumer ➢ Comfort level with medical provider ➢ Support plan with medical provider "anticipatory guidance" ➢ How to select a good fit 	<ul style="list-style-type: none"> ➢ Know where to transition to adult specialty care ➢ List of place to refer for adult care ➢ Provide anticipatory guidance list with tickler file ➢ Reimbursement for extra work ➢ Warm handshake to adult care ➢ Understanding of health presentation of individuals with C/SMN ➢ Medical provider relationship 	<ul style="list-style-type: none"> ➢ Need additional medical training to understand the complex needs of patients with complex medical issues ➢ Comprehensive history coming with the patient ➢ Accessible equipment and skills ➢ What do they need?



Maine Developmental Disabilities Council

Transitioning Youth to Adult Health Care

Transition Readiness

- Begins at age 14
- Conduct regular assessments
- Jointly develop goals
- Prioritize actions








Transitioning Youth to Adult Health Care

Skills They Need To Transition



- Calling in a prescription refill
- Scheduling appointments
- Speaking up at the Doctor's Office
- Managing medication
- Make and keep follow-up visits
- Determine methods to track health progress
- Work with your doctor to set health goals
 - Personal Hygiene
 - Self Care (i.e. taking medications on schedule)
 - Preventing secondary conditions
 - Managing medications
 - What to do when there is an "emergency"
 - Wellness
 - Sexuality

Transitioning Youth to Adult Health Care



Critical Questions For Families To Consider, When your child reach adulthood, what are your expectations for:

<ul style="list-style-type: none"> • Living arrangements • Employment or post secondary education • Recreational/leisure activities • Behavioral health/health care • Transportation • Social skill activities • Sexual expression • Personal Hygiene and grooming 	<ul style="list-style-type: none"> • Nutritional requirements • Physical/cardiovascular expectations • Spiritual life • Guardianship • Financial planning • Health and Life Benefits • Types of services needed
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Adult Service Application Timeline

- Age 16
 - Contact VR (Services will begin at age 18 but the transition plan and assessments should be done earlier)
- Age 17
 - Identify and meet with adult health practitioner
- Age 17.5
 - Apply for adult services through DHHS Office of Adults with Cognitive and Physical Disabilities (Even if the intent is to stay in children's services until the youth's 21 birthday.)
- Age 18
 - If appropriate, apply for SSI.
 - Apply for Mainecare
 - Note: Even if individual was eligible for SSI and/or Mainecare as a child they must re-apply as an adult.
 - Consider Support System For Success

Adult Services

- Adult Developmental Services through the Office of Cognitive and Physical Disabilities
 - Waiver Services – Non Entitlement Program
 - Must be >2 standard deviations on a adaptive scale such as the Vineland to be eligible
 - All Waiver services are closed to a waitlist
- Vocational Rehabilitation
 - Eligibility guidelines
 - For many to access must also have the waiver for long term support
- Mental Health System



Thank you!!!

Questions?



College bound? Some Tips to practice well before orientation

- Unstructured time
 - Unlike the typical college student's schedules many youth's schedules are highly structured so youth may struggle knowing how to fill the time up.
- Medications
 - Use only verbal/alarm prompts for medication
- Personal hygiene
- Know how to travel alone and use public transportation
- Appropriate coping strategies that can be utilized in most places
- Know how to do laundry
- Know how to manage money

College Support Program for Students with ASD (2011) Autism Training Center at Marshall University web source:
<http://mucollegesupport.blogspot.com/> accessed 9/15/2011