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)
- 1:150 Chromosomal Condition (https://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]
- Some studies indicate that the increase in ASD prevalence is leveling off in the United Kingdom. [Data]

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
Comparative trends in the # of children served in Maine public schools under the category of Autism and total school population

Two year total increase of 13%
Ten year total increase of 272%
Average annual increase of 18%

Data Source: Department of Education, Office of Special Services Child Count
Prepared By: Maine Developmental Disabilities Council

Age Distribution Comparison 2006 to 2010 Individuals with ASD served Autism Category in Schools

6 Years Ago

Data Source: Department of Education, Office of Special Services Child Count
Prepared By: Maine Developmental Disabilities Council

Comparative trends in the # of children served in Maine public schools under the Special Ed category of Autism as compared to the total # of Students in Maine

10 year increase of 86%
Average Annual Increase of 8%

Data Source: Department of Education, Office of Special Services Child Count
Prepared By: Maine Developmental Disabilities Council

Age Distribution Comparison 2007 to 2012 Individuals with ASD served Autism Category in Schools

4 Years Ago

Data Source: Department of Education, Office of Special Services Child Count
Prepared By: Maine Developmental Disabilities Council
Age Distribution Comparison 2005 to 2014
Individuals with ASD served Autism Category in Schools

Two Year Ago

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Data Source: Department of Education, Office of Special Services Child Count
Prepared By: Maine Developmental Disabilities Council

Age Distribution Comparison 2006 to 2016
Individuals with ASD served Autism Category in Schools

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Data Source: Department of Education, Office of Special Services Child Count
Prepared By: Maine Developmental Disabilities Council

MaineCare Data

MaineCare Usage of Members with ASD

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Data Source: Department of Health & Human Services MaineCare Claims Data
Prepared By: Maine Developmental Disabilities Council
Growth in Number of Children and Youth (0-20) identified with an ASD in receiving MaineCare services

Average 10% Bi-Annual Increase

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% 36%
6-12 1,304 1,653 1,914 2,083 2,084 0% 8% 26% 60%
13-17 774 933 1,193 1,389 1,349 -3% 13% 45% 74%
18-20 239 327 412 569 960 -2% 21% 71% 134%
21-26 184 240 429 576 644 12% 90% 168% 290%
27-64 296 324 620 732 790 8% 27% 144% 167%
65+ 9 12 26 36 35 -3% 35% 192% 289%
Total 3,367 4,464 5,381 6,098 6,312 4% 27% 52% 87%

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. 35% response rate - 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

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

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
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

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

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

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?
- An informed consumer
- Understanding their healthcare needs
- Knowing how to work the system
- Understanding what benefits are available to them
- How to select a provider that meets their needs
- Opportunity for choice

Parent/Guardian
- Understanding your rights and what you no longer have access to as you transition to your adult medical record
- Knowing what your insurance covers for your adult child
- Teach children how to be an informed consumer
- Contact local medical providers
- Support plans with medical provider "presumptive guidelines"
- How to select a good fit

Child/Doctor
- Know where to transition to adult specialty care
- List of places to refer for adult care
- Ensure continuity of care with medical providers
- Warm handshake to adult care
- Understand the transitioning of medical providers (adult vs pediatric)
- Medicaid provider relationship

Adult Medical Provider
- Need additional medical training to understand the complex needs of patients with complex medical issues
- Comprehensive history taking with the patient
- Accessible caregivers and staff
- What do they need?
Transitioning Youth to Adult Health Care

Transition Readiness

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

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

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

- Living arrangements
- Employment or post secondary education
- Recreational/leisure activities
- Behavioral health/health care
- Transportation
- Social skill activities
- Sexual expression
- Personal Hygiene and grooming
- Nutritional requirements
- Physical/cardiovascular expectations
- Spiritual life
- Guardianship
- Financial planning
- Health and Life Benefits
- Types of services needed

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

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

Thank you!!!

Questions?

College Support Program for Students with ASD (2011) Autism Training Center at Marshall University web source: