

Transition of Medically Complex Adolescents to Adult Care

Alice P. Alexander, MD

Associate Professor of Internal Medicine and Pediatrics, University of Arkansas for
Medical Sciences

Program Director, Internal Medicine/Pediatrics Residency

Objectives

- Recognize the potentially vulnerable young adult patients that are being treated within our healthcare system.
- Describe some differences between pediatric and adult healthcare that impact youth.
- Understand the national initiative to improve transitions and the components of this initiative.
- Recognize that patients with intellectual and/or developmental disabilities represent a unique population of transitioning youth and know where to find resources for caring for these patients.

Failed transition - Jayden

- 23 yo pt with CP, dysphagia, seizure disorder – wheelchair-bound, nonverbal, works in a sheltered workshop. Weighs 60 lbs and is 4 feet tall.
- Had multiple hospitalizations at a children's hospital through his teen years – he was told at the end of last hospitalization at age 21 that he could not return there.
- Next fall, pt collapsed at home and began moaning with severe pain – taken by ambulance to the adult academic medical center.

Jayden's Family's Experience

- No needles small enough for patient; no pediatric blood pressure cuffs; no diapers
- Radiology didn't have the appropriate feeding tube
- "The staff acted like they had never been around anyone like Jayden."
- Parents aggressively campaigned to return to the children's hospital

Why talk about this now?

- More children are surviving chronic disease
 - Approximately 80-90% of children with CP survive to age 30
 - Predicted survival for CF was 25 in 1985 and 37 in 2007
 - Cancer survivors comprise about 1 in 600 adults between 18 and 34

Who has 'special health care needs'?

- Every year 500,000 children with special health care needs become adults
- “...those who have or are at increased risk for a chronic physical, developmental, behavioral, or emotional condition and who also require health and related services of a type or amount beyond that required by children generally.”

Models of transition care

- Disease-specific – patient moves from pediatric specialist to adult specialist
- Adolescent – patient moves from pediatric provider to adolescent provider to adult provider
- Primary care – FP or M/P provider serves to coordinate care and to consult specialists
- Single site – adult and pediatric providers in the same place

• Adapted from <http://www.hivcareforyouth.com/adol?page=md-module&mod=03-02-05>

Six Core Elements of Healthcare Transition

- www.gottransition.org
- Originally published as “Supporting the Healthcare Transition from Adolescence to Young Adulthood in the Medical Home”
- Joint effort between the AAP, AAFP, and ACP
- These are goals
- Geared towards primary care providers
- It takes a village

The Ideal State

- Transition policy – implemented by age 14
- Create a registry of young adult patients
- Assess and track readiness for adult health care for all youth/families
- Use transition action plan to address gaps and set goals
 - Name and notify adult physician of pending transfer and arrange for individualized introduction
- Assure direct communication with adult provider and team, send ‘transition package’ to adult practice
- Pediatric team makes contact with adult team after transfer to ensure success

Who is at high risk of failed transition?

- Survey of children's hospitals regarding adult inpatients
 - Diagnoses included CP, cancer, sickle cell, CF, CHD
 - Adult CP patients tended to stay in the pediatric system the longest
 - Congenital heart disease has had the greatest growth in transition-aged patients

Pediatrics. 2011 Jul;128(1):5-13. Epub 2011 Jun 27. **Adults with chronic health conditions originating in childhood: inpatient experience in children's hospitals.**
Goodman DM, Hall M, Levin A, Watson RS, Williams RG, Shah SS, Slonim AD.

But aren't most adolescents pretty healthy – even those with chronic conditions?

- Study of rheumatology patients aged 18 to 21 at one academic center
- Mean age at last peds visit was 19.5
- 30% were hospitalized in year prior to transfer
- 30% had increase in disease activity in year following transfer
- Nine of 31 subjects missed their first adult rheumatology appointment

The Gap between Pediatric and Adult Care

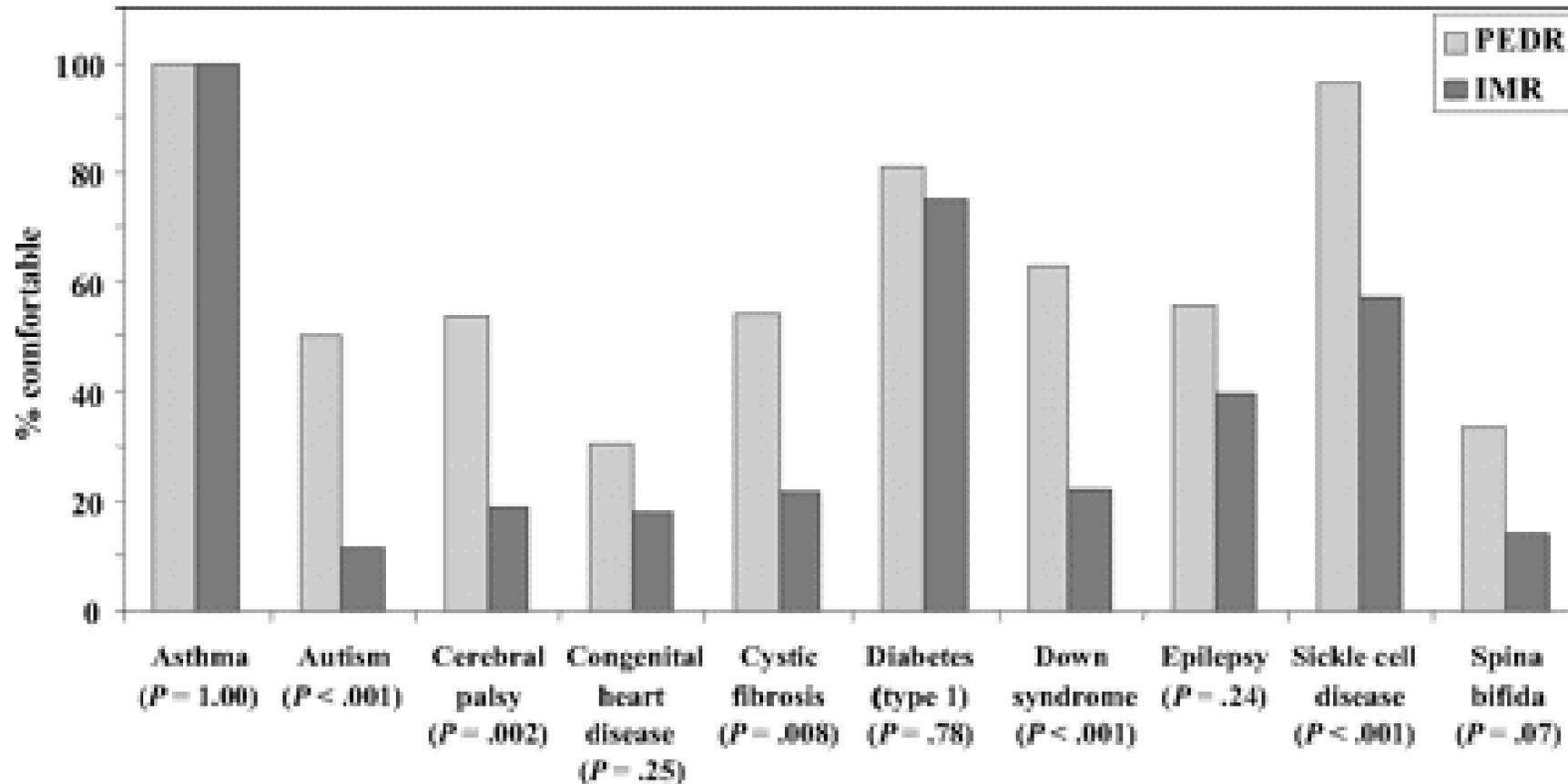
- Peds: Family-centered, prescriptive, nurturing, inexperienced in adult prevention services and with patient autonomy
- Internists: Collaborative, cognitive, unfamiliar with resources for disabled people, less experienced with incapacitated patients

Adapted from Ciccarelli, M., "Clinical Orientation to Center for Youth and Adults with Conditions of Childhood." Originally from Eiser et al., "Coming of age with diabetes: patients' views of a clinic for under-25 year olds." *Diabetes Med* 1993; 10:285-259.

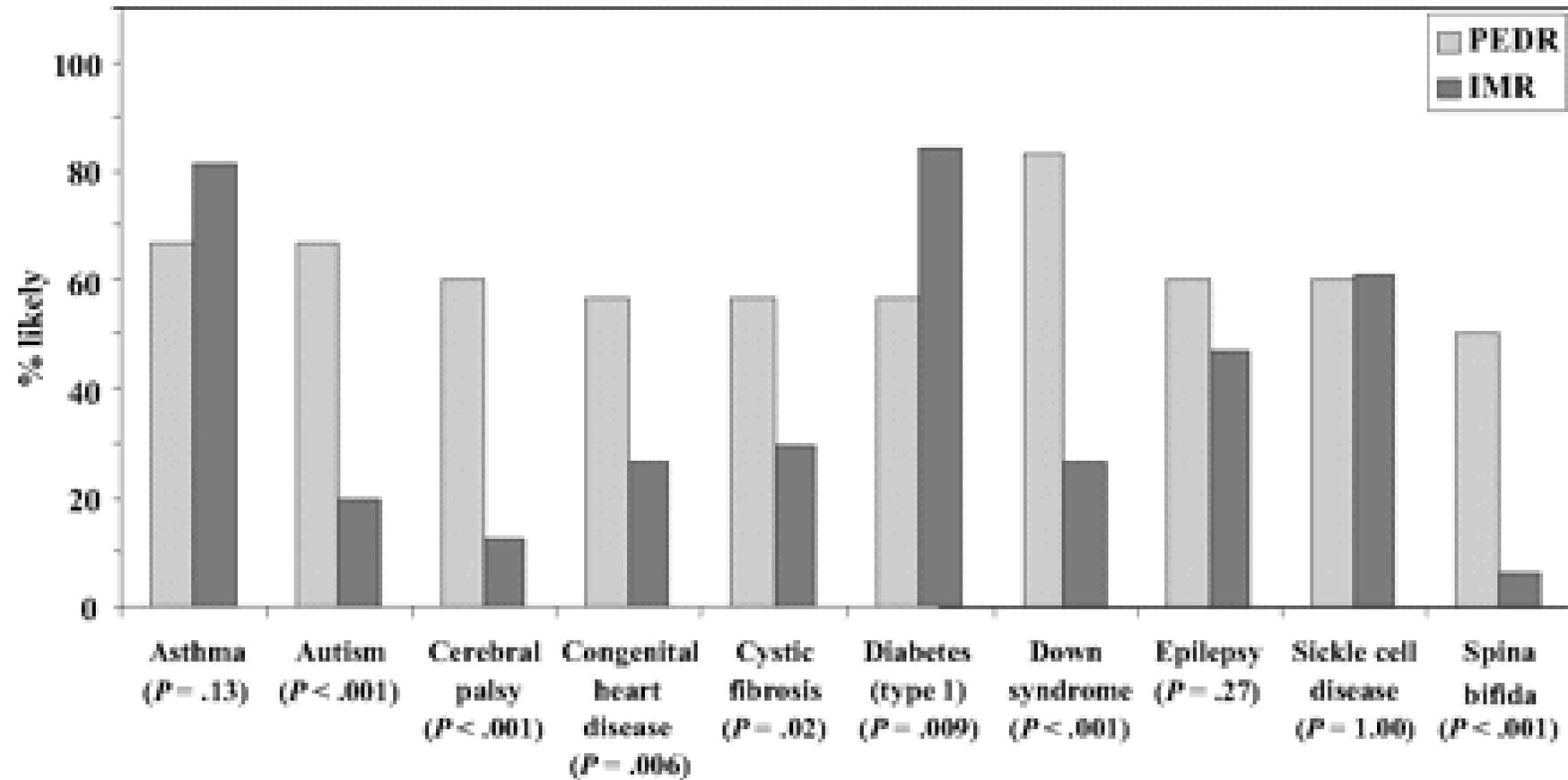
What's so hard about taking care of these kids?

- Internists have a low level of comfort with childhood onset diseases.
- Internists lack training in adolescent development and behavior.
- Transitioning a patient takes a lot of time, and families have high expectations.
- Young adults may have a lot of psychosocial needs that an internist's office isn't prepared to meet.
- Some of these patients are disabled and will face end-of-life issues at an early age and early in the doctor-patient relationship.

How comfortable are trainees with management of childhood-onset disease?



Do residents expect to take care of adults with childhood-onset disease?



How can we as internists improve care for young adults?

- Improved knowledge re: childhood-onset conditions – know your resources
- Communication with pediatric providers
- Population-based management strategies – this is a vulnerable population
- Use assessment tools in practice to help improve care

Transition tools for young adults

- Medical summary form
- Self-care assessment
 - Caregiver and pt versions – at 4th grade reading level
 - Recognizes that transition is a process – individuals do not leave pediatric care as fully formed adults

<https://www.acponline.org/clinical-information/high-value-care/resources-for-clinicians/pediatric-to-adult-care-transitions-initiative/condition-specific-tools>

| My Health | <i>Please check the box that applies to you right now.</i> | <i>Yes, I know this.</i> | <i>I need to learn.</i> | <i>Someone needs to do this... Who?</i> |
|---|--|--------------------------|--------------------------|---|
| I know my medical needs. | | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| I can tell other people what my medical needs are. | | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| I know what to do if I have a medical emergency. | | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| I know the medicines I take and what they are for, and when I need to take them without someone reminding me. | | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| I know what medicines I should not take. | | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| I know what I am allergic to, including medicines. | | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| I can name 2-3 people who can help with my health goals. | | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| I can explain to people how my beliefs affect my care choices. | | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Using Health Care | <i>Please check the box that applies to you right now.</i> | <i>Yes, I know this.</i> | <i>I need to learn.</i> | <i>Someone needs to do this... Who?</i> |
| I know or I can find my doctor's phone number. | | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| I make my own doctor appointments. | | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| Before a visit, I think about questions to ask. | | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| I have a way to get to my doctor's office. | | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| I know I should show up 15 minutes before the visit to check in. | | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| I know where to get care when my doctor's office is closed. | | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| I have a folder at home with my medical information, including medical summary and emergency care plan. | | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| I have a copy of my plan of care. | | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| I know how to fill out medical forms. | | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| I know how to ask for a form to be seen by other another doctor/therapist. | | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| I know where my pharmacy is and what to do when I run out of my medicines. | | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| I know where to get a blood test or x-rays if the doctor orders them. | | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| I carry my health information with me every day (e.g. insurance card, allergies, medications, and emergency phone numbers). | | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |
| I have a plan so I can keep my health insurance after 18 or older. | | <input type="checkbox"/> | <input type="checkbox"/> | <input type="checkbox"/> |

Other disease-specific toolkits currently available

- Congenital heart disease
- Type I Diabetes
- Turner syndrome
- Growth hormone deficiency
- Sickle cell disease
- Hemophilia
- End-stage renal disease
- Juvenile idiopathic arthritis
- Systemic lupus erythematosus

A Case: Mr. Jones

- 40 yo with undetermined cause of intellectual disability. Has a history of seizures that have been well controlled for many years on phenytoin.
- Was cared for by his mother until her death last year. Now primary caregiver is pt's sister.
- He is able to communicate with some grunts and single words. He is independent with personal hygiene and feeding, but he lacks complex planning abilities: he cannot pick out a weather-appropriate outfit and cannot prepare a meal. He is very neat and likes to keep his belongings organized. He enjoys playing with lighters (that have the cartridges removed) and has a large collection of these.

Today's visit

- His sister's chief concern about him today is ongoing issues with "stomach pain" – he points to his stomach and makes a noise like he's uncomfortable.
- He has undergone an EGD and colonoscopy which were reportedly normal. He has been started on Prilosec but she's not sure this has made much of a difference for him.
- His sister reports that he's been very "cranky" – she can usually take him to public places like fast food restaurants but recently he's been acting out and yelling loudly. You make a move to help Mr. Jones up onto the exam table and he swats at you with his other hand.

Some questions

- Are you as an internist likely to see patients like Mr. Jones?
- How would you classify Mr. Jones's intellectual disability?
- How do you communicate with and examine Mr. Jones?
- How can you help with his behavioral issues?

Some definitions

- ID = neurodevelopmental disorder; deficits in cognitive and adaptive function; begins in childhood
- DD = severe chronic disability manifested before age 22, substantial limitation on at least three major life activities, is likely to continue indefinitely, due to a mental or physical impairment (ADA definition)
- Individuals with DD do not always have ID
- Today's discussion focuses more on ID

Intellectual disability

- Prevalence – estimates anywhere from 0.5 to 2% of the US population
 - One recent study in Ontario – 0.78%
- This population is much sicker than the general population
 - Up to 5 times more likely to have a preventable hospitalization
 - High rates of ED utilization
 - Highest health care utilizers are “dual diagnosis” individuals

See <https://www.porticonetwork.ca/web/hcardd> for references

| Intellectual Functioning ^{a, b} | Adaptive Functioning ^{a, c} (McCreary 2005) | Communication (Anderson 2002) |
|---|---|---|
| <p>MILD</p> <ul style="list-style-type: none"> ◦ IQ: 55-70 (± 5) ◦ Percentile scores: First to third ◦ Age equivalence (AE): 9-12 years ◦ Grade: up to Grade 6 | <ul style="list-style-type: none"> ◦ Unskilled job capability ◦ May need income support if jobs are scarce ◦ Often develops stable relationships but parenting skills are poor ◦ Decision making: likely capable of making familiar medical decisions | <ul style="list-style-type: none"> ◦ Uses a variety of sentence types (simple to complex) to communicate opinions, ideas, news, events, aspirations ◦ Vocabulary is extensive compared to adults with IDD in the moderate to profound range ◦ Uses language to initiate and interact ◦ Conversational difficulties may exist ◦ Uses the phone and communicates in writing ◦ Able to understand and use abstract language but may have difficulty expressing ideas in sequence ◦ Can usually follow meaningful, simple, 3-step commands |

| Intellectual Functioning ^{a, b} | Adaptive Functioning ^{a, c} (McCreary 2005) | Communication (Anderson 2002) |
|--|---|----------------------------------|
|--|---|----------------------------------|

| | | |
|--|--|--|
| <p>MODERATE</p> <ul style="list-style-type: none"> ◦ IQ: 40-50 (± 5) ◦ Percentile scores: Below the first ◦ AE: 6-9 years ◦ Grade: up to Grade 2 | <ul style="list-style-type: none"> ◦ Supported employment ◦ Income support ◦ Regular residential supervision ◦ Help with banking and shopping ◦ Childrearing is beyond level of understanding and capacity ◦ Decision making: support with medical decisions is required | <ul style="list-style-type: none"> ◦ Uses phrases and simple sentences to communicate for various purposes, including expression of preference, emotion, interests and experiences ◦ Vocabulary adequate for daily functioning ◦ Asks and responds to questions about concrete information ◦ Some abstract language use in talking about past events ◦ Follows meaningful 2-step commands without support |
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| Intellectual Functioning ^{a, b} | Adaptive Functioning ^{a, c} (McCreary 2005) | Communication (Anderson 2002) |
|--|---|----------------------------------|
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| | | |
|---|--|--|
| <p>SEVERE</p> <ul style="list-style-type: none"> ◦ IQ: 25-35 (± 5) ◦ Percentile scores: Below the first ◦ AE: 3-6 years ◦ Grade: up to Grade 1 | <ul style="list-style-type: none"> ◦ Continuing support and supervision in residential and day programs needed ◦ Unable to manage family responsibilities ◦ Decision making: not capable of making most medical decisions except if familiar with the issue and provided sufficient support | <ul style="list-style-type: none"> ◦ Uses single- and two-word combinations, gestures and/or signs to indicate basic needs and to comment about his/her environment ◦ Vocabulary limited ◦ Gives and shows objects, points ◦ Comprehension still limited to the immediate environment but able to understand some action words ◦ Can follow meaningful 1-step commands with or without support (e.g., repetition, gestures) |
|---|--|--|

| Intellectual Functioning ^{a, b} | Adaptive Functioning ^{a, c} (McCreary 2005) | Communication (Anderson 2002) |
|--|---|----------------------------------|
|--|---|----------------------------------|

| | | |
|--|---|--|
| <p>PROFOUND</p> <ul style="list-style-type: none"> ◦ IQ: < 20-25 ◦ Percentile scores: Below the first ◦ AE: 0-3 years | <ul style="list-style-type: none"> ◦ Continuing 24-hour support and supervision needed ◦ Unable to manage family responsibilities ◦ Decision making: can be presumed to be not capable of making medical decisions | <ul style="list-style-type: none"> ◦ Nonverbal or uses single words, gestures and/or signs to indicate basic needs ◦ A few words possible ◦ May appear non-interactive ◦ Comprehension limited to people, objects, and events in the immediate environment ◦ May follow some routine commands due to understanding the situation rather than the actual words |
|--|---|--|

What causes ID?

- Environmental factors
 - Fetal alcohol exposure
 - Trauma
 - Infections
- Genetic factors
 - Major causes: Down syndrome, fragile X
 - Most cases of severe ID in developed countries are thought to be due to genetic causes

Is knowing the cause of ID helpful?

- Specific syndromes are associated with certain health conditions
 - Genetic testing may be helpful for families
 - Current standard of care in pediatrics: chromosomal microarray and fragile X testing in all children with global developmental delay or intellectual disability
 - Whole exome sequencing may identify a cause in some individuals with severe ID
-
- deLigt et al. “Diagnostic exome sequencing in persons with severe intellectual disability.” N Engl J Med 2012; 367:1921-1929

Back to Mr. Jones

- Severe intellectual disability – in this case, his receptive language capabilities exceed his expressive capabilities
- How do you help Mr. Jones and his family with his behavioral issues?

Behavior change may be due to physical discomfort

- Dental problems – single biggest unmet health need in individuals with ID
- High prevalence of GERD, particularly in people with profound ID
- High prevalence of constipation – sedentary lifestyle, restricted diet
- Pain is probably undertreated
- Behavior = communication
- From IDD toolkit video 3 - <https://vimeo.com/user43458700> and iddtoolkit.org

If sources of physical discomfort are ruled out

- Environmental changes can trigger problem behaviors
- Grief or loss can affect behavior
- Changes in sleep can affect behavior
- Primary psych disorders causing behavior changes are a possibility – but rule out the simple stuff first

How are you supposed to examine this patient?

- Show-tell-do approach – try to be at the patient's level
- Distraction – for Mr. Jones, a lighter
- Be flexible
- Enlist support from family/caregiver

• Adapted from https://www.porticonetwork.ca/documents/38160/99698/Primary+Care+Toolkit_FINAL_ym2.pdf

More from Mr. Jones

- Mr. Jones's sister tells you that he recently had all his teeth pulled. Since then, he has been on a diet of mostly liquids and smoothies.
- He has not been having regular bowel movements.
- Behavior symptoms improved with treating constipation.

Other health issues in adults with ID/DD

- Specific causes of ID/DD associated with specific health problems
- Health watch tables available at <http://vkc.mc.vanderbilt.edu/etoolkit/physical-health/health-watch-tables-2/>

Currently available “Health Watch Tables”

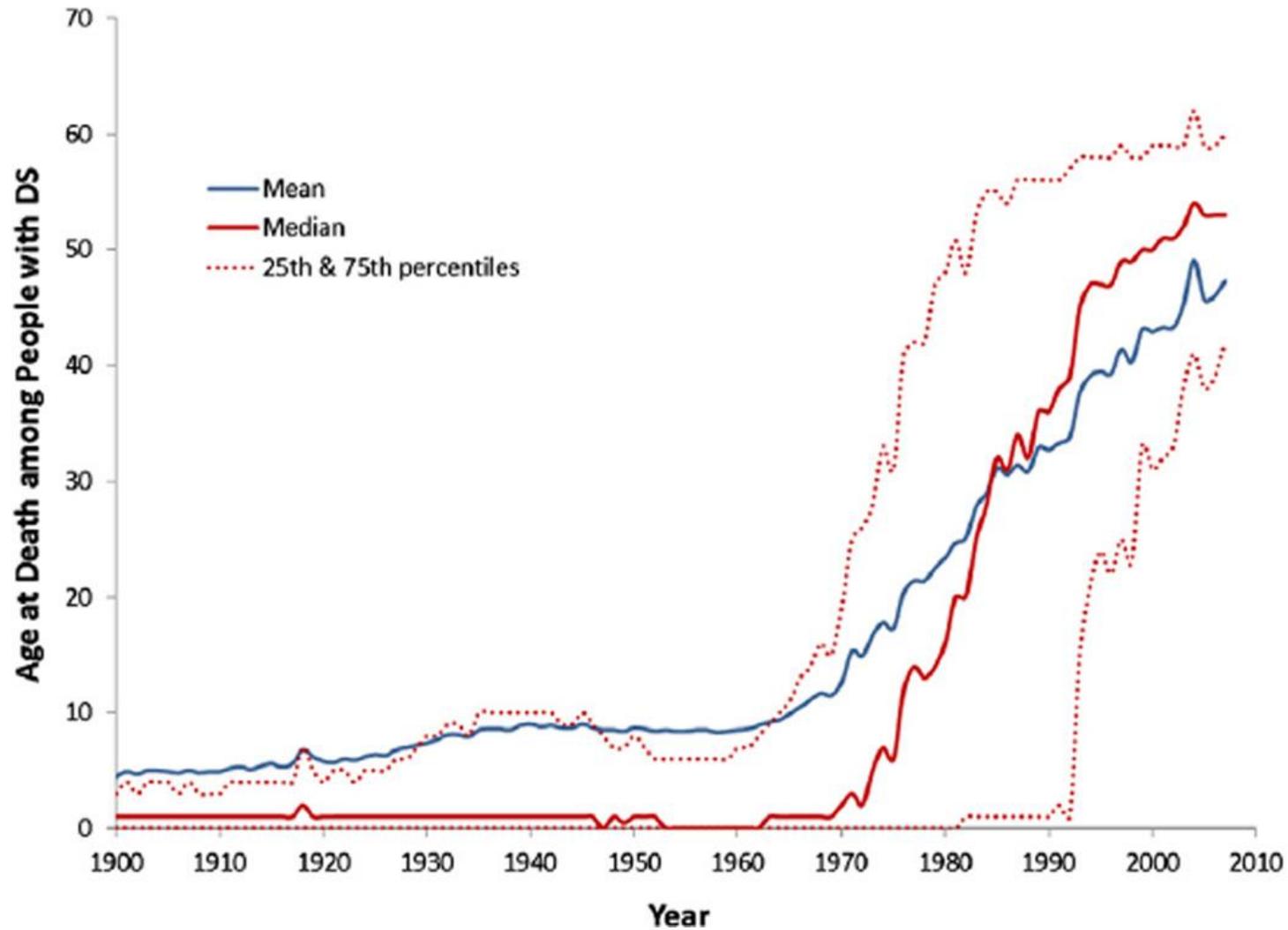
- Autism
- Down syndrome
- Fetal alcohol spectrum disorder
- Fragile X syndrome
- Prader-Willi syndrome
- Williams syndrome
- 22q11.2 deletion syndrome (DiGeorge/velocardiofacial)

Down syndrome

- Incidence at birth – about 1/700
- Prevalence in the US = 250,000 individuals living with DS
- Dramatic increases in life expectancy with modern healthcare
- About 40% of individuals with DS have CHD

- Presson A et al, **Current Estimate of Down Syndrome Population Prevalence in the United States**. J Pediatr. 2013 Oct; 163(4): 1163–1168.

Age at death in persons with Down syndrome



Mean, median, and 25th and 75th percentiles for age at death in persons with Down syndrome, 1900–2007. The mean and median age at death for persons with Down syndrome have increased significantly over the past 40 years. From Presson A et al, **Current Estimate of Down Syndrome Population Prevalence in the United States**. *J Pediatr*. 2013 Oct; 163(4): 1163–1168.

Down syndrome – ongoing health issues

- Increased risk for hypothyroidism
- Increased risk for development of celiac disease
- Ongoing risk for development of vision or hearing problems
- High risk of acquired valvular heart disease – MVP, AR, ?MVR
- Continued risk of spinal issues d/t atlantoaxial instability
- Early dementia – 77% of adults age 60-69 with DS will have dementia dx – more likely to have seizures

Down syndrome patients and the adult health care system

- Adults with DS are at high risk of incomplete transition
- 205 adults with DS aged 18-45 at one academic center (Michigan) – data from 2000-2008
 - 52% of adults still received components of their care from pediatric providers – total costs were higher in the mixed provider group even when CHD status was controlled for
- Primary care physicians for adults with DS had low rates of adherence to screening recs for psychiatric disorders, OSA, hearing/vision loss

- Jensen KM¹, Taylor LC, Davis MM. Primary care for adults with Down syndrome: adherence to preventive healthcare recommendations. *J Intellect Disabil Res.* 2013 May;57(5):409-21.
- Jensen KM, Davis MM. Health care in adults with Down syndrome: a longitudinal cohort study. *J Intell ect Disabli Res* Oct2013; 57(10): 947-958.

Prader-Willi syndrome

- Lack of expression of genes in the paternally inherited chromosome 15q11.2-q13 region
 - Manifests in childhood as poor tone, poor suck, short stature, small hands/feet
 - All have some degree of intellectual disability
 - Insatiable appetite, development of morbid obesity
 - Growth hormone treatment in childhood has beneficial effects on body composition
-
- Angulo MA, Butler MG, Cataletto ME. Prader-Willi syndrome: a review of clinical, genetic, and endocrine findings. *Journal of Endocrinological Investigation*. 2015;38:1249-1263.

Prader-Willi syndrome: health risks

- Consequences of extreme obesity: OSA, type II DM, HTN, obesity-hypoventilation
 - Calorie restriction necessary; bariatric surgery may not be helpful
- Vomiting is rare – if present, it is a sign of serious illness
- Individuals with PWS have a high tolerance for pain
- Severe skin picking is common
- High risk of central adrenal insufficiency
- Adapted from <http://vkc.mc.vanderbilt.edu/etoolkit/physical-health/health-watch-tables-2/prader-willi-syndrome/>



Case 2: Megan

- Megan is 21 years old and is transitioning care from Children's Hospital, where she has been followed for her entire life.
- Megan was diagnosed with PDD-NOS and anxiety disorder as a school-aged child. She successfully completed high school via a special education program. Her intellectual disability is classified as mild; her autism spectrum disorder makes expressive language more difficult for her. Megan's mother also has mild intellectual disability.

Megan's visit today

- Megan presents to the clinic for a checkup today with her mother and grandmother. Megan's grandmother reports that Megan doesn't like doctors and doesn't usually talk to any physician other than her psychiatrist. Megan is sitting on the exam table, repeatedly wringing her hands.

How can you help Megan?

- How can you best communicate with Megan?
- How can you help her successfully navigate the adult health care system?

Autism

- Definition: requires deficits in social communication/interaction and restricted, repetitive patterns of behavior, interests, and activities
 - Prevalence – who knows?
 - Associated ID in about 50%
-
- Prevalence of Autism in a United States Population: The Brick Township, New Jersey, Investigation.
Jacquelyn Bertrand, Audrey Mars, Coleen Boyle, Frank Bove, Marshalyn Yeargin-Allsopp, Pierre Decoufle. Pediatrics Nov 2001, 108 (5) 1155-1161

Communication tips for individuals with ID/DD and/or autism

- Address the patient first – assume that he/she understands
- Clarify caregiver role – “Who did you bring with you today?”
- Ask how the patient communicates

Communication tips, continued

- Recognize that individuals may have different receptive and expressive capabilities
- Use concrete language
- Avoid open-ended questions
- May want to ask the same question a different way to clarify the response

Resources for adults with autism spectrum disorders

- www.autismandhealth.org – template for healthcare accommodations report

Autism Healthcare Accommodations Report

Name: John Doe

Date of Birth: 1981-6-6

The purpose of this report is to help you, your staff, and John Doe have more successful visits. Due to the heterogeneous nature of autism spectrum disorders (ASD), the information and recommendations in this report have been **custom generated** to be specific to John Doe.

I Information to Assist with Patient Communication

Receptive speech: He can usually understand spoken language well.

Expressive speech: His ability to speak changes depending on the situation.

Alternatives to speech: He uses text-based alternatives to speech (text-based AAC, typing, written notes, iPhone app).

Reading: He can read at a college level.

Writing: He can write or type at a college level.

Telephone: He cannot use the telephone.

Other important information about John Doe's communication.

- He may have difficulty communicating, even if his speech sounds fluent.
- He often takes language too literally.
- He can write or type better than he can speak.

To help John Doe better understand what you are saying.

- Use very precise language, even if it means using longer sentences or advanced vocabulary.
- Write down important information or instructions.
- Try not to talk to him while there are other noises.

To help John Doe provide information more effectively.

- Read written notes that he brings to visits.
 - Give him examples of the types of things people may experience and ask him if he experiences them too.
 - Help him answer questions about time by linking to important events in his life.
-

II Other Recommendations to Help Visits Go Smoothly

Back to Megan

- Need to assess her level of understanding and her capabilities for self-care
- Promote independence when possible
- SW referral re: day programs, vocational training

Case 3: Madison

- You are seeing Madison today for a visit to “fill out paperwork.” She is 24 years old and has cerebral palsy, intellectual disability, and a seizure disorder.
- She is nonverbal, nonambulatory, and requires total assistance for all activities of daily living. She requires frequent suctioning and she is tube-fed. She smiles or laughs when she is happy and cries when she is uncomfortable. She is able to make eye contact with her family. She enjoys being out of her wheelchair and listening to music.
- Her primary caregiver is her brother. He has taken care of Madison since the death of their mother three months ago.

Madison's visit today

- Madison's brother is ready to go back to work. Madison has never been in any sort of school or day program because of an incident in Madison's early childhood when her mother felt that the school was neglecting her needs.
- Madison's brother has contacted United Cerebral Palsy about their day program. He has brought paperwork for you to sign regarding Madison's Medicaid waiver care plan.

How can you help Madison?

- What do you need to know about adults with cerebral palsy?
- What options are there to help families who care for individuals with severe developmental disability?

Cerebral palsy

- Definition: developmental disorder characterized by abnormal muscle tone, posture, and movement – most common childhood physical disability
- Spastic and dyskinetic subtypes
- Brain injury is nonprogressive by definition – however, the associated physical impairments are not necessarily static

Comorbidities associated with CP

- 50% with intellectual disability
 - 35% with seizures
 - 28% could not walk
 - 23% could not talk
-
- Novak I, Hines M, Goldsmith S, Barclay R. "Clinical Prognostic Messages From a Systematic Review on Cerebral Palsy." *Pediatrics* Nov 2012, 130 (5) e1285-e1312

Adults with CP

- Heterogenous population makes generalizations re: care of adults difficult
- Some musculoskeletal conditions worsen with age – hip osteoarthritis, spondylolysis, and cervical stenosis can cause functional decline in adulthood
- Bone mineral density tends to be low – poor nutritional status, poor functional status, and anticonvulsant use

- Murphy KP. Cerebral palsy lifetime care: four musculoskeletal conditions; *Developmental Medicine & Child Neurology* 2009, 51 (Suppl. 4): 30–37
- Trinh A et al. Musculoskeletal and Endocrine Health in Adults With Cerebral Palsy: New Opportunities for Intervention. *The Journal of Clinical Endocrinology & Metabolism* 2016 101:3, 1190-1197 ; Ozel, S., Switzer, L., Macintosh, A. and Fehlings, D. (2016), Informing evidence-based clinical practice guidelines for children with cerebral palsy at risk of osteoporosis: an update. *Dev Med Child Neurol*, 58: 918–923.

Care for the severely developmentally disabled

- 1500 Arkansans in human development centers (HDCs) – mostly adult population
- 4100 families getting services under the Medicaid waiver program
 - Designed to allow in-home care for patients who would otherwise be institutionalized
- About 3000 patients are on the waiver waiting list
- <http://www.arktimes.com/arkansas/family-vs-institutional-care-in-arkansas/Content?oid=3479388> – Family vs institutional care in Arkansas, by Benjamin Hardy, posted October 9, 2014, accessed December 7, 2016

Care priorities for Madison

- Continue waiver services that enable her to be cared for in her home
- Facilitate day program placement and therapies
- DME needs: suction machine, appropriate wheelchair

Resources

- Specific conditions – check health watch tables: <http://vkc.mc.vanderbilt.edu/etoolkit/>
- Condition-specific transition tools: <https://www.acponline.org/clinical-information/high-value-care/resources-for-clinicians/pediatric-to-adult-care-transitions-initiative/condition-specific-tools>
- Resources for adults with autism: www.autismandhealth.org



Questions?