The Current State of Health Care Transition From Pediatric to Adult-based Care

Riley Hospital for Children Indiana University Health

INDIANA UNIVERSITY SCHOOL OF MEDICINE

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October 5, 2017

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Objectives

Participants will understand:

1. The current epidemiology of CYSHCN in the US
2. The morbidity & mortality associated with poor health care transitions
3. The current status & models of transition clinical programs

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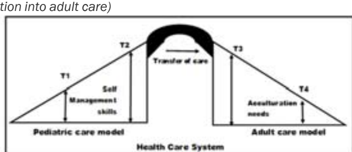
Health Care **Transition**

Deliberate process of moving safely and seamlessly from child to adult oriented health care.

- Up the on-ramp
  - *(preparation to leave pediatric care)*
- Across the bridge
  - *(safe transfer of care)*
- Down the off-ramp
  - *(integration into adult care)*



Preparation for transition

- Medicaid youth 1,355 ages 16-17
- Adolescent Assessment of Preparation for Transition 26-item survey
- Quality of health care transition preparation scored 0-100, counseling on medication, transition self-management and planning
  - prescription medication (57-58%),
  - transition self-management (36-30%)
  - transfer planning (5%-4%)
  - no sig difference by health plan, sex, dx

– Sawicki, Pediatrics Jul 2017

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Youth to Young Adults Perspectives

Tuchman LK. Child: Care, Health, & Dev, 2008

Teen self management concerns

- Teens w/ T1DM (n=15), Parents (n=25)
- Teens' concerns - taking over responsibility for T1DM management
- Parents' concerns - immediate and long-term negative outcomes of teen self-management, financial resources, health insurance
- Teens / parents concerns - nocturnal hypoglycemia and uncertainties of teen no longer living in parent's home

• Ersig AL. J Peds Nurs 2016

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Transition of youth at 12 HIV clinics

- Challenges of substance use, mental health issues, assoc stigma
- Perceived adult HIV clinics less supportive and require increased patient responsibility
- Data sharing and communication between clinics low, explained by insufficient resources and time to make contacts
- Insurance coverage - ability to stay on parent's insurance until 26 vs. teens' disclosure and risk of info learned from insurance bills

  - Tanner AE. J Peds Nurs 2016

Health care provider attitudes

- Swedish health providers, n =201
- Youth age, maturity, family situations - important initiators for transfer
- Joint meeting with the patient (82%)
- Presence of a transition coordinator (76%)
  - more important to peds than adult provider
- Individualized transfer plan (55%)
- Barriers - lack of funding (45%), limited clinical space (19%)

  - Sparud Lundin C. BMC Health Serv Res, 2017

Center for Health Care Transition

got transition

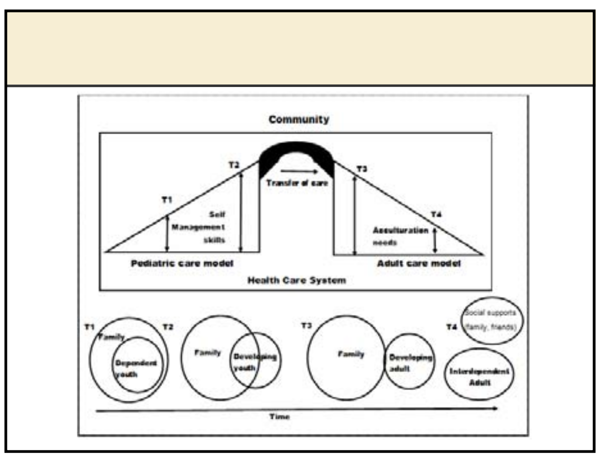
Recommended Health Care Transition Timeline

AGE: 12	14	16	18	18-22	23-26
Make youth and family aware of transition policy	Initiate health care transition planning	Prepare youth and parents for adult model of care and discuss transfer	Transition to adult model of care	Transfer care to adult medical home and/or specialists with transfer package	Integrate young adults into adult care

Prefrontal cortex governs judgment and decision-making, fully develops by age 25.

Adleman NE. Neuroimage, 2002.
Picture - Gogtay, Giedd, 2004.

www.gottransition.org



6 CORE ELEMENTS of HEALTH CARE TRANSITION

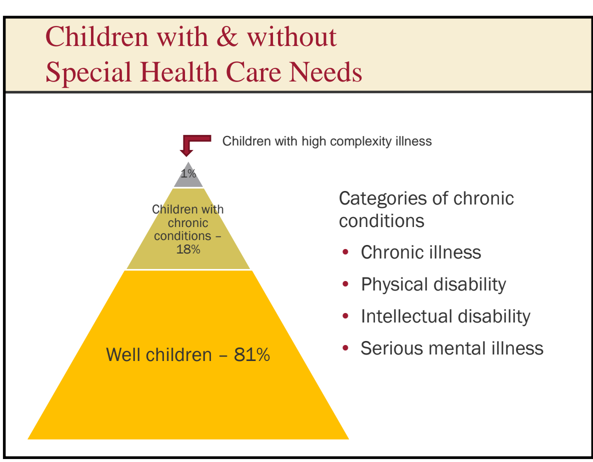
An Implementation Companion to the Algorithm

Pediatric Care Setting	Adult Care Setting
1. Transition policy	1. Young adult privacy & consent policy
2. Registry – tracking & monitoring	2. Registry – tracking & monitoring
3. Transition preparation – readiness assessments, education	3. Transition preparation – re-assessment, ongoing education
4. Transition planning – written plan	4. Transition planning – verify implementation
5. Transition and transfer of care – medical summary, plan of care	5. Transition and transfer of care
6. Transition completion	6. Transition completion

got transition? www.gottransition.org

Cooley WC. AAP-ACP-AAFP. Pediatrics, July 2011.

Children with & without Special Health Care Needs



Categories of chronic conditions

- Chronic illness
- Physical disability
- Intellectual disability
- Serious mental illness

- Sam Pacer is a 17 year old male with history of mild intermittent asthma and seasonal allergic rhinitis. Sam has had infrequent and mild exacerbations of asthma over the last 7 years. He has Medicaid SCHIP insurance. His prescribed medications are prn albuterol and loratidine.
- Sam is a junior in Hoosier High School, generally a B student. He lives with his parents and younger sister. Sam plays basketball on the high school team. He reports that his home life is pretty good. He has a well established circle of friends. He has tried cigarettes on a few occasions. He reports that his girlfriend is his first intimate partner and she gets depo shots. His violence and depression screening is negative.
- Sam can't remember the names of his medicines. He doesn't know what insurance he has. He doesn't typically keep track of his doctor appointments.

81% of youth without chronic conditions

Transition needs

- Routine, regular adolescent care
  - Health education
  - Screening
  - Risk avoidance counseling
  - Reproductive health
- Sustain health insurance
- Adult primary care provider
- Assume role as decision maker
- Navigate the health system

Patients' View of Pediatric vs. Adult Medicine

Pediatric Medicine

- Family-centered
- Developmentally oriented
- Focus on wellness
- Prescriptive
- Nurturing
- Interdisciplinary

Adult Medicine

- Autonomy
- Disease oriented
- Expect disease progress
- Collaborative
- Self-responsibility
- Multidisciplinary

Eiser C. Diabet Med, 1993.

Scope of Practice

Pediatric Medicine

9% visits for routine chronic care

- Asthma 9% ages 0-18
- ADHD 5.4%

Rezaee ME. Prev Chron Dis, 2015

- Obesity
- Allergies
- Development behavior issues

Adult Medicine

33% visits for routine chronic care

- Hypertension 32.5% ages 45-64
- Hyperlipidemia 21.5%
- Arthritis 17.3%
- Diabetes 13.9%
- Depression 12.2%
- Asthma 5.7%

NAMCS, 2012

Age Limit of Pediatrics

- AAP September 2017
- Pediatric care may begin periconceptionally and continues through gestation, infancy, childhood, adolescence, and young adulthood.
- Establishment of arbitrary age limits on pediatric care should be discouraged.
- Payers should not place limits that affect a patient's choice of provider based on age.
- Pediatric medical and surgical subspecialists could consider their scope to be specific conditions, rather than specific age range, and provide care into adulthood in conjunction with adult primary care and surgical colleagues.

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Timing of Transition

- Developmental readiness – provide scaffold
- Stable health problems
- Characteristics of the adolescent and family
- Availability of skilled pediatric and adult health providers – promote trust and responsibility

Health Insurance for Young Adults in Indiana

- Medicaid Disability
  - qualify through Social Security
- Healthy Indiana Plan – Medicaid expansion
  - income based
- Parent Employer Plan
  - average policy $3,380/person
- Student Health Plan
  - average policy $850
- Own Employer Plan
  - full-time and part-time options
- Federal exchange
  - platinum covers 90% costs, gold 80%, silver 70% + subsidy, bronze 60%
- COBRA
  - expensive, up to 18 months
- 2016 penalty for no insurance
  - 2.5% household income or $695/adult, whichever higher

– Healthcare.gov , USNWR, 1/11.

Finding a primary care doctor

1. Geography
2. Family medicine, Internal Medicine, Medicine–Pediatrics
3. “In-Network” with your insurance
4. Personal referral, current physician recommendation
5. Open panel slot, taking new patients
6. Logistics – transportation, hours of operation, hospital privileges
   “Find a Doctor” on hospital website
7. Personality - Give it a try!
   www.bcbs.com/blog/five-tips-for-choosing-a-PCP.html

Promoting self-management

- Starting early in including youth in discussions of their health and related issues.
- Encourage children to report their concerns and accomplishments.
- Begin some private discussions with the child, increasing with time.
- Discuss transition-related issues
  - Skills at health system navigation
  - Health literacy

Primary care implementation

- D.C. Medicaid MCE
  - 66% SSI-eligible age 18-25 have pediatric PCP
  - Proprietary complexity measure – biopsychosocial
  - 61% of ID - no annual PCP visit
- Intervention
  - 3 pediatric practices train in 6 core elements
    - McManus M. J Peds Nurs 2015.

Sample policy *"What is health care transition?*

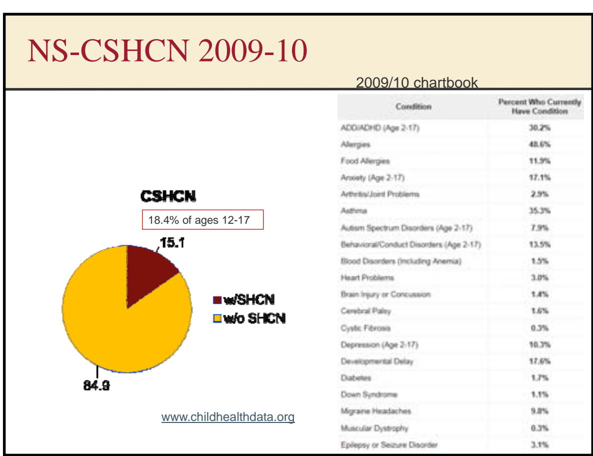
- *Health care transition means changing from pediatric (child) health care to adult health care.*
- *A good transition takes planning.*
- *HSCSN, your doctors, and others can help you and your family, starting at or before age 18, to:*
  - *Learn about your health needs and skills in order to set your health goals.*
  - *Take charge of your health with your doctor.*
  - *Learn about legal changes when you become an adult at 18.*
  - *Plan for help, if needed, to make your own health care decisions.*
  - *Find a new adult doctor before age 22.*
  - *Find DC programs for adults with disabilities."*

Health and health care knowledge and skills	Proportion needing to learn n (%)*
I call for my own doctor visits. (n = 28)	22 (79%)
I have a file at home for my medical information. (n = 28)	21 (78%)
I know or I can find my doctor's phone number. (n = 28)	18 (64%)
I know how to get referrals to other providers. (n = 28)	18 (64%)
Before a visit, I think about questions to ask. (n = 29)	18 (62%)
I carry important health information with me every day (e.g., insurance card, allergies, medicines, emergency contacts, medical summary). (n = 29)	17 (58%)

Results n=35

- Policy shared 30 (86%)
- Readiness assessment 29 (83%)
- Transition plan 29 (83%)
- Medical summary 29 (83%)
- Transfer package sent 16 (46%)
- Adult pcp scheduled 16 (46%)
- Adult pcp visited 9 (26%)
- Feedback collected 10(100%)

NS-CSHCN 2009-10



www.childhealthdata.org

2009/10 chartbook

Condition	Percent Who Currently Have Condition
ADD/ADHD (Age 2-17)	30.2%
Allergies	48.6%
Food Allergies	11.9%
Anxiety (Age 2-17)	17.1%
Arthritis/Joint Problems	2.9%
Asthma	35.3%
Autism Spectrum Disorders (Age 2-17)	7.9%
Behavioral/Conduct Disorders (Age 2-17)	13.5%
Blood Disorders (Including Anemia)	1.5%
Heart Problems	3.0%
Brain Injury or Concussion	1.4%
Cerebral Palsy	1.6%
Cystic Fibrosis	0.3%
Depression (Age 2-17)	10.3%
Developmental Delay	17.6%
Diabetes	1.7%
Down Syndrome	1.1%
Migraine Headaches	9.8%
Muscular Dystrophy	0.3%
Epilepsy or Seizure Disorder	3.1%

18% US children w/ special health care needs

- Primary care – ADHD, intermittent asthma
- Cardiology – cyanotic heart disease, arrhythmias
- Dev Peds – spina bifida, cerebral palsy
- Dental
- Endocrine – diabetes, thyroid disease
- ENT – hearing loss
- Genetics – Marfan syndrome, PKU
- GI – inflammatory bowel disease, cirrhosis
- Hematology – sickle cell anemia, hemophilia
- Inf Dis – HIV/AIDS, immunodeficiencies
- Nephrology – renal failure, polycystic kidney
- Neurology – muscular dystrophy, epilepsy
- Neurosurgery – baclofen pumps, CNS shunts
- Oncology – stem cell transplant, cancer survivors
- Ophthalmology – vision loss
- Orthopedics – limb amputee
- Pulmonary – cystic fibrosis, chronic lung disease
- Psychiatry – autism, bipolar disease
- Rehab Med – traumatic brain injury
- Surgery – enteral stomas
- Rheum – systemic lupus, juvenile arthritis
- Urology – bladder exstrophy, cloacal anomaly

- Anna Speedway is an 18 year old with spina bifida. She comes to the children's hospital for specialty care from developmental pediatrics, urology, neurosurgery, orthopedics, dental, and ophthalmology. She has health insurance through her father's employer plan and supplemental coverage through Title V Children with Special Health Care Services program.
- She uses a motorized wheelchair, is a senior in high school and lives with her parents and siblings. She takes medication to treat her ADHD. With it, she is a B-C student, socializes with friends in school activities. Anna takes care of some of her own activities of daily living but still gets lots of assistance from her mother. She has not yet gotten her driver's permit.
- She is planning to go to college in the fall where she will live about 75 miles away from her family and the children's hospital.

Challenges in the transition of care for adolescents with AHDH

- ADHD treatment rates decline sharply from childhood into young adulthood
- Functional impairment often persists.
- Psychosocial therapy can play an important role in resolving functional difficulties
- Patient adherence to pharmacotherapy is a significant issue
- Careful, advanced planning to ensure continuity of medical and psychiatric care is essential
    - Robb A, Findling RL. Postgrad Med. 2013.

Youth & young adults with spina bifida

Utilization of hospital & physician services

- Annual rates of hospital admissions per 1,000 persons
  = 329 for youth & 285 for adults with SB
  19.4 & 12.4 X higher than for general population
- Annual rates of outpt physician visits per 1,000 persons = 8,031 for youth & 8,524 for adults with SB
  2.9 & 2.2 X higher than age-matched peers
- 12% youth & 24% adults with SB had a medical home
  - Young NL, et al. Arch Phys Med Rehab 2014.

Formal screening for psychological issues at transition

- 43 T1DM youth
- 16.3% w/depression, 20.9% w/diabetes distress
- 23.5% disordered eating (w/o assoc abn BMI)
- Depression (r = 0.31, P = .05), diabetes distress (r = 0.40, P = .009), disordered eating positively correlated w/ HbA1c (r = 0.63, P<.001)
- Disordered eating = majority of variance (df = 1; F = 18.6; P<.001).
  - Quinn SM. Endo Practice, 2016.

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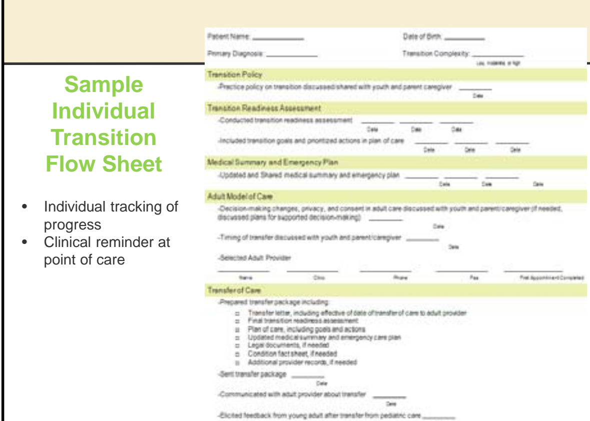


Sample Individual Transition Flow Sheet

- Individual tracking of progress
- Clinical reminder at point of care

Patient Name: ________ Date of Birth: ________
Primary Diagnosis: ________ Transition Complexity: ________

Transition Policy
-Practice policy on transition discussed/shared with youth and parent caregiver ________ Date

Transition Readiness Assessment
-Conducted transition readiness assessment ________ ________ ________ Date Date Date
-Included transition goals and prioritized actions in plan of care ________ ________ ________ Date Date Date

Medical Summary and Emergency Plan
-Updated and Shared medical summary and emergency plan ________ ________ ________ Date Date Date

Adult Model of Care
-Decision-making changes, privacy, and consent in adult care discussed with youth and parent/caregiver (if needed, discussed plans for supported decision-making) ________ Date
-Timing of transfer discussed with youth and parent/caregiver ________ Date
-Selected Adult Provider
________ Name ________ Clinic ________ Phone ________ Fax ________ First Appointment Completed

Transfer of Care
-Prepared transfer package including:
- Transfer letter, including effective of date of transfer of care to adult provider
- Final transition readiness assessment
- Plan of care, including goals and actions
- Updated medical summary and emergency care plan
- Legal documents, if needed
- Condition fact sheet, if needed
- Additional provider records, if needed

-Sent transfer package ________ Date
-Communicated with adult provider about transfer ________ Date
-Elicited feedback from young adult after transfer from pediatric care ________ Date

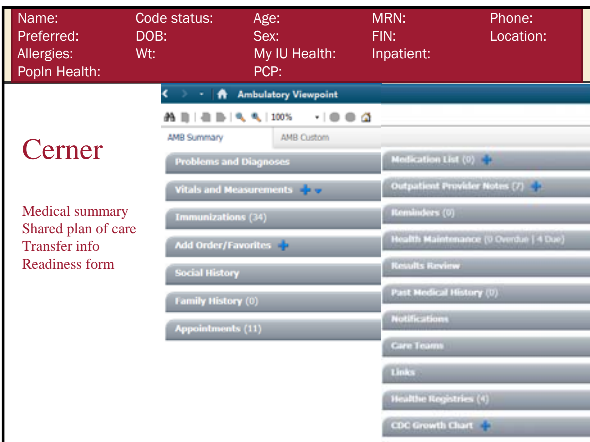
Medical Neighborhood

- Primary care education
  - Coordination
  - Co-manage chronic conditions, medical devices, unique co-morbidities
- Subspecialty providers
  - Co-manage with primary care
  - Contribute to shared plan
  - Develop working networks

Using EHR in transition

- Baylor EPIC-based transition planning tool
  - 4 subspecialty clinics – cardio, heme, neuro, ID
  - Patients ages 16–25 years, 303 visits
  - Nurses & case managers
- Sample of 13 questions – range 1-13 asked per visit
  - Can you tell me about your disease/disability?
  - What are the names of your medications?
  - What are they for? When do you take them? How much do you take?

• Wiemann CM. J Peds Nurs, 2015.



Plan of Care

Negotiated Actions:

- Goals
- Actions
- Who?
- By when?

Sample Plan of Care

Six Core Elements of Health Care Transition 2.0

- A plan of care is a common, shared document.
- It is used consistently by every provider within an organization.
- It provides a concise summary of health care events, current needed treatments, ongoing issues, and stated goals.
- It is a living, changing document owned and implemented by all involved in the daily life of the child.

Sample: Plan of care
Teen with Diabetes out of control

Patient, Family and Team Goals	Negotiated Actions	Process and Outcome Measures
Overall Aim: • Effective control and management of Type 1 Diabetes • Improved communication, collaboration coordination among teen, family, clinicians and school team.	• Support of teen and family to achieve goals • Enroll in a highly functioning medical home • Engage with the care coordinator • Hold/attend care conferences • Develop a Plan of Care; include endocrinologist input in the emergency plan (when and when not to admit teen to hospital according to need and/or blood glucose levels) • Align all coordinating partners with Plan of Care goals • Increase contact between medical home and school with frequent communications and collaboration • Overcome (persistent) communication and transportation barriers to establish regular counseling	• Access to medical home care • Actively engaged with a care-coordinator • Care conference regular attendance • Accessible shared Plan of Care with medical summary, goals with negotiated actions and emergency action plan attached • Increased contacts for regular communication • Teen receiving regular counseling • For 10 months following creation of the care plan and onset of care coordination, 2 ER visits and 0 diabetes related hospitalizations occurred.
Shared Goals • Transition to insulin pump (pending Diabetes control) • Obtain a driver's license • Improve school attendance/performance	• Work with diabetes educator every other week • Work with dietician every other week	• A1C and overall glucose "markedly improved" • Pump still pending • Decreased school absenteeism, school nurse office visits reduced, and classroom time increased.

* McAllister JW. Achieving a Shared Plan of Care with Children & Youth with Special Health Care Needs. An Implementation Guide. Lucille Packard Foundation, May 2014.

TRAQ

- Transition Readiness Assessment Questionnaire
  - Wood, Sawicki, Reiss, Livingood & Kraemer, 2014

http://hscj.ufl.edu/jaxhats/traq/

	No, I do not know how	No, but I want to learn	No, but I am learning to do this	Yes, I have started doing this	Yes, I always do this when I need to
Managing Medications					
1. Do you fill a prescription if you need to?					
2. Do you know what to do if you are having a bad reaction to your medications?					
3. Do you take medications correctly and on your own?					
4. Do you reorder medications before they run out?					
Appointment Keeping					
5. Do you call the doctor's office to make an appointment?					
6. Do you follow-up on any referral for tests, check-ups or labs?					
7. Do you arrange for your ride to medical appointments?					
8. Do you call the doctor about unusual changes in your health (For example: Allergic reactions)?					
9. Do you apply for health insurance if you lose your current coverage?					
10. Do you know what your health insurance covers?					
11. Do you manage your money & budget household expenses (For example: use checking/debit card)?					
Tracking Health Issues					
12. Do you fill out the medical history form, including a list of your allergies?					
13. Do you keep a calendar or list of medical and other appointments?					
14. Do you make a list of questions before the doctor's visit?					
15. Do you get financial help with school or work?					
Talking with Providers					
16. Do you tell the doctor or nurse what you are feeling?					
17. Do you answer questions that are asked by the doctor, nurse, or clinic staff?					
Managing Daily Activities					
18. Do you help plan or prepare meals/food?					
19. Do you keep home/room clean or clean-up after meals?					
20. Do you use neighborhood stores and services (For example: Grocery stores and pharmacy stores)?					

Self-Management - Promoting adherence in teens & young adults

- General factors associated with non-adherence
  - Health literacy, health beliefs, access barriers, mental health/substance use, quality of life, social supports, stressors, poor physician–patient relationship
- Specific factors associated with adolescent non-adherence
  - Disease acceptance, parent-youth conflict, peer normalization, loss of trust experienced with previous long-standing health team

– Pediatric transplant recipients - meta-analysis
– Fredericks EM. Curr Opin Organ Transplant, 2010

ACTION PLAN

Name: ______ Date: ______

GREEN LIGHT
Doing Well:
Here are the ways you can tell you are doing well:
- ______
- ______

These are things you need to do every day to stay well.
Follow this plan every day:

YELLOW LIGHT
Getting Worse:
These are signs of new problems:
- ______
- ______

You need to notice when your health is getting worse with the usual plan.
Add these to your daily routine:

RED LIGHT
Medical Alert!
These are urgent problems to solve right now:
- ______
- ______

If your attempts to help the problem don't work, you need to act now and get help.
Do this immediately:

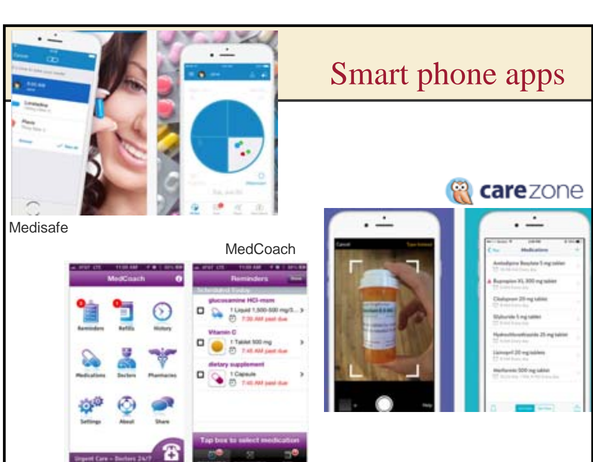
Call the Doctor's office NOW.
Tell them you have and urgent problem and you need help today!
Doctor: ______
Phone: ______

Reasons to get emergency medical help:
- ______
- ______
- ______

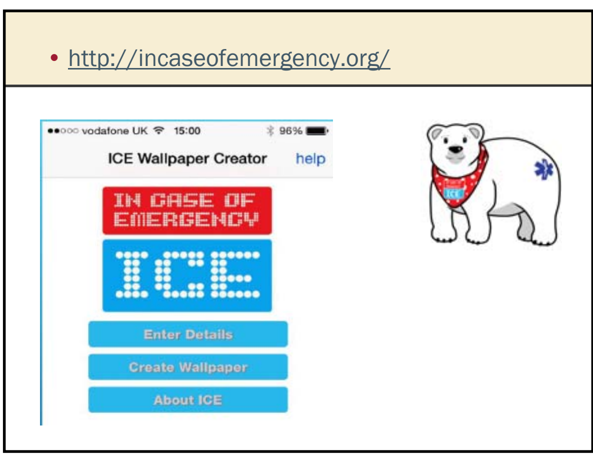
Go to the hospital or call an ambulance (Call 911):

Who else do you need to tell? ______

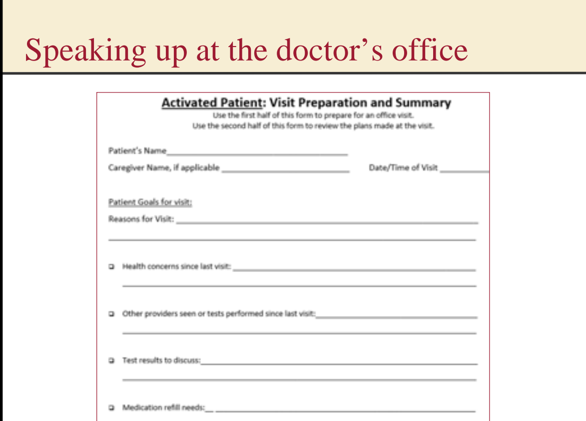
Smart phone apps



- http://incaseofemergency.org/



Speaking up at the doctor's office



Activated Patient: Visit Preparation and Summary

Use the first half of this form to prepare for an office visit.
Use the second half of this form to review the plans made at the visit.

Patient's Name____________________

Caregiver Name, if applicable ____________________ Date/Time of Visit __________

Patient Goals for visit:

Reasons for Visit: ____________________

- Health concerns since last visit: ____________________
- Other providers seen or tests performed since last visit:____________________
- Test results to discuss:____________________
- Medication refill needs:__ ____________________

Transition Service Models

- 17 intl models
  - DM, SCD, JIA, organ transplant, other
- 53% service coordinator
- 47% medical summaries
- 35% parental support
- 29% PCP transfer-of-care protocols

- Betz CL. Nurs Outlook 2016

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Models for Epilepsy Transition Clinics

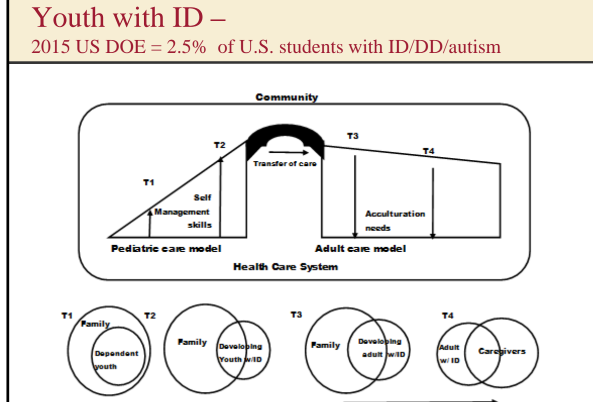
- Nova Scotia - Combined ped/adult specialists session
  - Transition clinic in adult hospital with child neurologist and adult epileptologist plus adult epilepsy nurse clinician.
  - Before first visit, pediatric neurologist prepared a detailed written summary and family prepared a written summary of psychosocial issues.
- Liverpool – Young adult clinic
  - Ages 16 to 22 attend transition service monthly in adult neurosciences center, supervised jointly by 1 of 2 adult neurologists and 1 pediatric neurologist.
- Edmonton – Nurse transition specialists
  - Pediatric epileptologist referral letter to adult epileptologist.
  - Family and patient meet with adult & pediatric epilepsy nurse clinicians, review key transition/transfer themes at >1 visits.
  - Patient (±parents) meets adult epileptologist.
- Paris – Dedicated adult receiver, detailed transfer info
  - Single, dedicated adult neurologist assigned to receive young adults.
  - Transfer included transfer summary from the pediatric epilepsy service plus complete access to all pediatric medical records.
  - Issues of note include psychogenic seizures and sexual maturation issues.

- Carrizosa J, et al. Epilepsia, 2014.

- T.J. is an 19 yo with autism who lives with his parents. He left school with a certificate of attendance this past spring. He has no verbal communication and never received augmentative communication services.
- He watches TV and plays videogames all day. Going to the doctor is difficult, he doesn't like to leave home. His parents provide for all of his needs. They haven't applied for special programs. They have not yet addressed his inability to speak as his own decision maker.
- It takes a team effort to help him adapt to the medical care setting. He has trouble waiting. He doesn't like getting a blood pressure check. He needs to pace when he is anxious. Procedures often require sedation.

Youth with ID –

2015 US DOE = 2.5% of U.S. students with ID/DD/autism



Youth and intellectual disability

- Tension points
  - before the transition
    - transition envisaged with fear and apprehension
  - during the transition
    - lack of cooperation/communication between pediatric and adult providers
  - after the transition
    - feelings of abandonment
      - Lariviere-Bastien D, et al. Semin Pediatr Neurol. 2013.
- Parents experience sense of abandonment, their own need to be resourceful
  - Davies H, et al. Can J Neurosci Nurs. 2011.

Health Care Delivery for Persons with ID

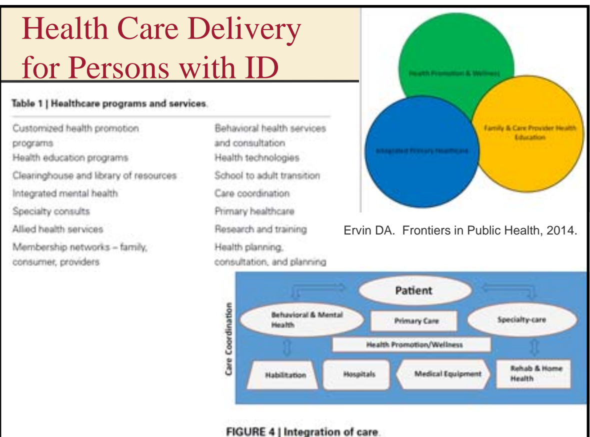


Table 1 | Healthcare programs and services.

Customized health promotion programs	Behavioral health services and consultation
Health education programs	Health technologies
Clearinghouse and library of resources	School to adult transition
Integrated mental health	Care coordination
Specialty consults	Primary healthcare
Allied health services	Research and training
Membership networks – family, consumer, providers	Health planning, consultation, and planning

Ervin DA. Frontiers in Public Health, 2014.

FIGURE 4 | Integration of care.

Decision-Making Capacity

- Assessment
- Opportunities to engage in choices and consequences
- Supported decision making
- Power of Attorney – springing and durable, person and estate
- Guardian –limited, full

Complexity Scale

- Low
- Moderate
- High

- *Level of transition support needs*

LEVEL OF SUPPORT

DIMENSION	1 (Minimal)	2 (Limited/Intermittent)	3 (Extensive)
1. Health	Health status stable, routine preventive care, may see specialist annually	Health status generally stable, regular office visits to review management, periodic consultation with 1 or more specialists	Health status unstable, frequent office visits, regular ER visits or hospitalization, frequent consultations with 1 or more specialists
2. Family	Family status stable, no major environmental stresses, traditional social supports present and utilized	One or more stresses may be present, family requires occasional support from office and other community resources	Multiple major stresses are present, family resources are overwhelmed, extensive community support needed or major concerns about care giving environment
3. Behavioral and Mental Health	Behavior health status is stable, routine anticipatory guidance	Regular office visits to review management or regular consultation/counseling with mental health providers	Behavioral health status is unstable, extensive supports from office and community professionals, may require day treatment program or in-patient treatment
4. Education	Routine monitoring of developmental/school progress, regular classroom with minimal support	Child has IFSP, IEP or 504 plan, most of child's needs are met in regular classroom, may require 1 special health procedure at school	Extensive support required, full time aide or special class for most of the day, or multiple special health procedures in educational setting
5. Special Issues	Child and family follow through with recommendations readily, limited need for decision supports, no or few cultural factors impact care, child/family proactively manage care	Child and family require extra time to understand healthcare rec's, regular need for decision supports, translator required for appts, occasional missed appts.	Extensive need for decision supports and care reminders, cultural issues are major barrier to care, limited capacity for self-management, or major disagreements with the care plan

Tickel, 2011 Total Score ________

Safe Transfers

- Handshake between two providers
  - Sender and Receiver

- Determine best way to pass information
  - linked EHRs, fax, phone, etc.
- Mark the occasion
  - "Graduation Visit" from the pediatric setting
  - "Introductory Visit" into the adult setting
- Clarify responsible medical team
  - During transition period between the last pediatric and first adult visit
    - Usually is the pediatric team

Transfer of care

- Method to maintain adult practice information
- Provide transfer of care information package
  - portable medical summary, transition plan, emergency care plan, chronic condition fact sheet.
- Pediatric provider remains available for consultation following transfer.
- Adult provider facilitates introduction of young adult to practice rules
  - Interest in learning about pediatric conditions

9/22/2017

Next Step Tips to Success

- Gain explicit support of key senior leaders
- Dedicated time
  - Administrative support & clinical transition improvement team
- Team
  - Pediatric and adult care champions, youth, care coordinators, clinical staff, EHR & data staff, payers, senior leaders
- Health Care Transition Charter
- Get to work!

• McManus, White, McAllister.

www.gottransition.org/resourceGet.cfm?id=331

Charter Content

- Aim
- Scope
- Population
- Rationale
- Strategies
- Key challenges
- Timeline
- Measures
- Evaluation plan

Idealized Pediatric System Health Care Transition Activities

1. Transition Policy

The practice has a written transition policy or approach, developed with input from youth and families that includes privacy and consent information, a description of the practice's approach to transition, and age of transfer. Clinicians discuss it with youth and families beginning at ages 12 to 14. The policy is publicly posted and familiar to all staff.

2. Tracking, Monitoring (registry)

The practice has an individual transition flow sheet or registry for identifying and tracking transitioning youth, ages 14 and older, or a subgroup of youth with chronic conditions as they progress through and complete all "Six Core Elements of Health Care Transition 2.0," using EHR if possible.

3. Readiness

The practice consistently offers clinician time alone with youth after age 14 during preventive visits. Clinicians use a standardized transition readiness assessment tool. Self-care needs and goals are incorporated into the youth's plan of care beginning at ages 14 to 16.

4. Planning

The practice has incorporated transition into its plan of care template for all patients. All clinicians are encouraged to partner with youth and families in developing transition goals and updating and sharing the plan of care. Clinicians address needs for decision-making supports prior to age 18. The practice has a vetted list of adult providers and assists youth in identifying adult providers.

5. Transfer of Care

The practice sends a complete transfer package (including the latest transition readiness assessment, transition goals/actions, medical summary and emergency care plan, and, if needed, legal documents, and a condition fact sheet), and pediatric clinicians communicate with adult clinicians, confirming pediatric provider's responsibility for care until young adult is seen in the adult practice

6. Completion (Graduation)

The practice confirms transfer completion, need for consultation assistance, and elicits feedback from patients regarding the transition experience.

got transition

Center for Health Care Transition Improvement
- cooperative agreement -
Maternal Child Health Bureau &
National Alliance to Advance Adolescent Health