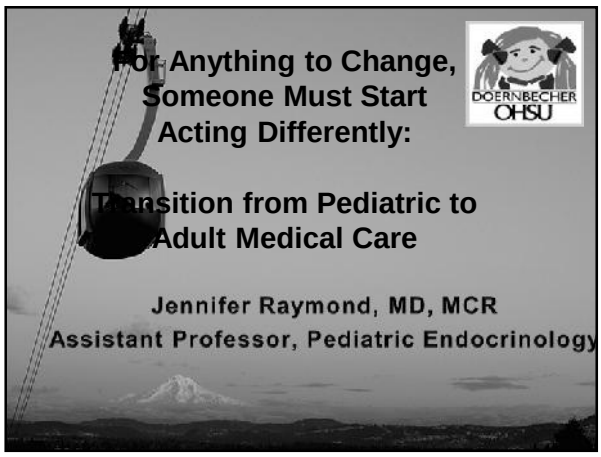



## Importance of Transition and Oregon Data

## Game Plan

- Importance of Transition and Oregon Data
- Pediatric and Adult Data
- Challenges for Young Adults
- Transition Approaches
- Resources and Recommendations

## Transition = Major Medical Issue

>500,000 youth turn 18 years of age each year

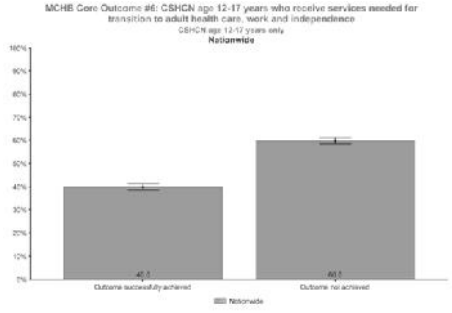
– Eventually transition to adult care

Transition away from home difficult for all

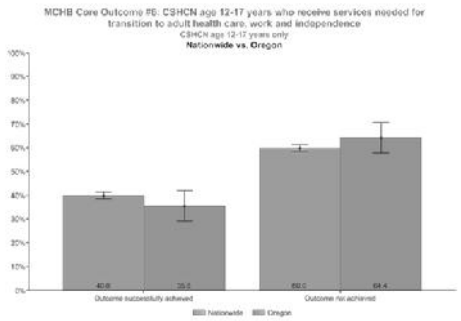
– Especially those with special health care needs


## Not Prepared for Transition

- National Survey of Children with Special Health Care Needs (CSHCN) 2009-2010



## Not Prepared for Transition




## Our Patient Baseline Data

Table 2

| STATES | Meeting National Transition Outcome | Pediatrician as Team Primary Care Provider | Discussion About Transition to Adult HCP Needed But Not Happened | Discussion about Changing Health Needs Needed but Not Happened | HCPs "sometimes" or "never" encourage YSHCN to take increased Responsibility for Care | Discussion About Insurance Needed But Not Happened |
|---|---|---|---|---|---|---|
| NATIONAL | 41% | 87% | 27% | 38% | 23% | 66% |
| Missouri | 34 | 90 | 21 | 29 | 24 | 58 |
| Nebraska | 34 | 84 | 39 | 39 | 15 | 68 |
| Minnesota | 33 | 92 | 23 | 23 | 16 | 61 |
| Vermont | 32 | 68 | 19 | 26 | 17 | 61 |
| New Hampshire | 32 | 82 | 20 | 27 | 19 | 62 |
| North Dakota | 31 | 85 | 26 | 29 | 21 | 56 |
| South Dakota | 31 | 82 | 18 | 32 | 13 | 58 |
| Kansas | 30 | 82 | 23 | 28 | 16 | 56 |
| Maine | 30 | 91 | 32 | 26 | 17 | 61 |
| Ohio | 30 | 91 | 30 | 33 | 18 | 66 |
| Utah | 30 | 88 | 26 | 26 | 18 | 59 |
| Washington | 30 | 90 | 24 | 30 | 16 | 66 |
| Colorado | 30 | 87 | 17 | 46 | 17 | 54 |
| Wyoming | 30 | 90 | 24 | 33 | 17 | 61 |
| Massachusetts | 30 | 80 | 20 | 30 | 20 | 62 |
| Montana | 30 | 84 | 26 | 27 | 17 | 54 |
| Pennsylvania | 30 | 83 | 20 | 24 | 24 | 64 |
| Idaho | 30 | 87 | 21 | 24 | 22 | 65 |
| Wisconsin | 30 | 90 | 20 | 26 | 18 | 66 |
| Illinois | 30 | 90 | 30 | 27 | 21 | 61 |
| Oklahoma | 30 | 88 | 26 | 40 | 21 | 64 |
| Oregon | 30 | 90 | 21 | 32 | 20 | 64 |
| Connecticut | 30 | 79 | 21 | 40 | 20 | 60 |
| Kentucky | 29 | 90 | 30 | 34 | 24 | 61 |
| Utah | 29 | 87 | 22 | 38 | 23 | 66 |
| Delaware | 29 | 90 | 23 | 42 | 20 | 61 |
| Alaska | 29 | 88 | 28 | 33 | 25 | 61 |
| Nevada | 29 | 90 | 28 | 34 | 24 | 66 |
| West Virginia | 29 | 88 | 30 | 29 | 19 | 61 |
| Indiana | 29 | 84 | 27 | 35 | 21 | 66 |

Source: Analysis of the 2005 - 2006 National Survey of Children with Special Health Care Needs, prepared by The National Alliance to Advance Adolescent Health for the National Health Care Transition Center.

## Our Pediatric Patient Population

**Transitioning Diabetes Care - Youth**

Age: _____ (yrs.) Duration of Diabetes? _____ (yrs.)

Circle One: Private Insurance CHP or WA Medicaid No Insurance Not Sure?

| | Yes | No |
|---|---|---|
| 1. *My family has talked about the eventual need to transition* my diabetes care from a pediatric to adult doctor. | [ ] | [ ] |
| 2. I have *brought up the issue of transition of care with our diabetes doctors*/nurses. | [ ] | [ ] |
| 3. *I am anxious and worried about transitioning care* from my pediatric diabetes doctors/nurses to adult diabetes doctors/nurses. | [ ] | [ ] |
| 4. *I have received or been presented with information* regarding transition to adult diabetes care services from the clinic. | [ ] | [ ] |
| 5. *I have obtained information regarding transition* to adult diabetes care services either from websites or other sources outside of the clinic. | [ ] | [ ] |
| 6. *The doctors/nurses have brought up the issue of transition* from pediatrics to adult care with me. | [ ] | [ ] |
| 7. It is *my family's responsibility to transition care* to adult diabetes doctors. | [ ] | [ ] |
| 8. It is *the adult and pediatric diabetes doctors who are responsible for transitioning care*. | [ ] | [ ] |
| 9. It is my understanding that *adult diabetes care will involve a diabetes doctor, diabetes educator,* | [ ] | [ ] |

**Transitioning Diabetes Care - Parent**

Age of Child w Diabetes: _____ (yrs.) Duration of Child's Diabetes? _____ (yrs.)

Circle One: Private Insurance CHP or WA Medicaid No Insurance

| | Yes | No |
|---|---|---|
| 1. *We have talked as a family about the eventual need to transition* diabetes care from a pediatric to adult doctor. | [ ] | [ ] |
| 2. We have *brought up the issue of transition of care with our diabetes doctors*/nurses. | [ ] | [ ] |
| 3. *We are anxious and worried about transitioning care* our child's pediatric diabetes doctors/nurses to adult diabetes doctors/nurses. | [ ] | [ ] |
| 4. *We have received or been presented with information* regarding transition to adult diabetes care services from the clinic. | [ ] | [ ] |
| 5. *We have obtained information regarding transition* to adult diabetes care services either from websites or other sources outside of the clinic. | [ ] | [ ] |
| 6. *The doctors/nurses have brought up the issue of transition* from pediatrics to adult care with us. | [ ] | [ ] |
| 7. It is *our personal responsibility to transition care* to adult diabetes doctors. | [ ] | [ ] |
| 8. It is *the adult and pediatric diabetes doctors who are responsible for transitioning care*. | [ ] | [ ] |
| 9. It is our understanding that *adult diabetes care will involve a diabetes doctor, diabetes educator,* | [ ] | [ ] |

## Oregon Data

Table 2. Trends in State Performance on National Transition Outcome and Related Components, 2005/2006 and 2009/2010

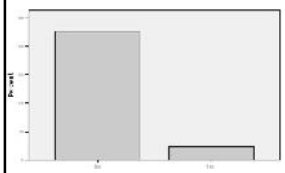
| States | Meeting National Transition Outcome | Discussion with HCP About Transition to Adult HCP Needed But Not Happened | Discussion with HCP About Changing Health Needs Needed But Not Happened | Encouragement by HCP to Take Increased Responsibility for Care "Sometimes" or "Never" Occurs | Discussion About Insurance Needed But Not Happened |
|---|---|---|---|---|---|
| Oregon | 44**38** | 12**18** | 23**30** | 20**29** | 41**49** |

**Significant at the 1% level

Source: Information for this table was obtained from the 2005/2006 and 2009/2010 NS-CSHCN available for analysis from the Data Resource Center for Child and Adolescent Health. Prepared by The National Alliance to Advance Adolescent Health for the National Health Care Transition Center, January 2012.

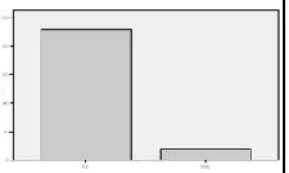
## Have a transition plan?

Youth




No – 90.7% Yes – 8.3%

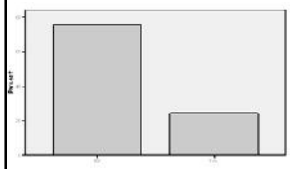
Parent



No – 91.8% Yes – 8.2%

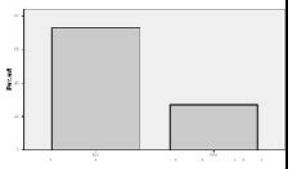
## Talked about transition?

Youth



No - 75.5% Yes - 24.5%

Parent



No - 73% Yes - 27%

## Our Adult Patient Population

*We are trying to discover the best way to transition our child patients with Type 1 diabetes to adult diabetes providers. We would like to learn more about your experience in that process. Thank you for taking the time to answer these questions.*

1. At what age were you diagnosed with Diabetes? Age _____

2. At what age did you switch from your childhood diabetes doctor? Select one answer from below:

a. Age 14-16 b. Age 17-19 c. Age 20-22 d. Older than age 22 e. Always had the same MD, never switched

3. What was your reason for changing to a new doctor?
_____

4. How did you feel about changing doctors at this time?_____

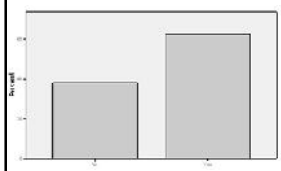
5. How much time went by between your last pediatric diabetes visit and your first adult diabetes visit? Select one:

a. 3-4 months b. 4-8 months c. 8-12 months d. 1-2 years e. Greater than 2 years

6. How did you find an adult diabetes doctor? Check one please:
___Always seen by an adult MD
___Went to a transition clinic with both a pediatric and adult MD
___Pediatric MD recommended an adult MD
___Recommendation from a patient, friend, family member
___Other_____

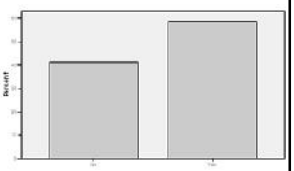
## Adult clinic same as pediatric?

Youth

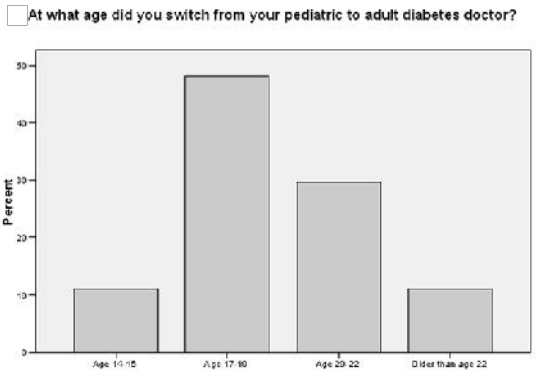


No – 37.9 Yes – 62.1%

Parent

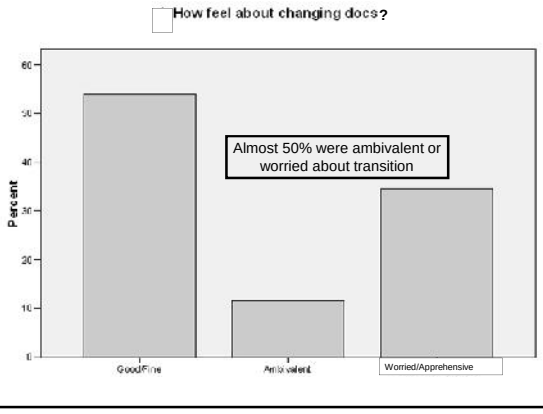


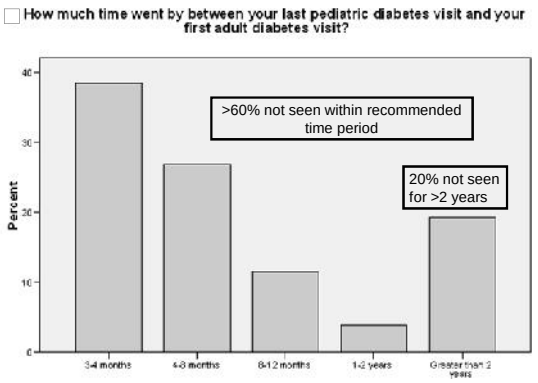
No – 41.2% Yes – 58.8%




## Timing of Transition?

| Timing of Transition | Youth Responses (in years) | Parent Responses (in years) |
|---|---|---|
| "At what age do you feel the diabetes clinic should begin talking about transition with patients?" | 17.0 (SD = 1.67) | 16.6 (SD = 1.75) |
| "At what age do you feel pediatric patients should start seeing the doctor/nurse alone?" | 17.5 (SD = 1.68) | 17.7 (SD = 1.66) |
| "At what age do you feel young people should be transitioned from pediatric to adult care?" | 18.2 (SD = 1.64) | 18.3 (SD = 1.60) |






## Challenges of Transition

## Interruption of Care

- Worst metabolic control
  - ↓ follow up
  - ↑ hospitalizations
- More complications

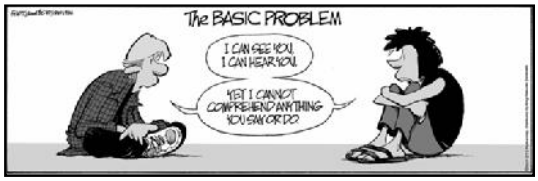
**Table 2: Problems in transition of diabetes care: comparison between Calgary and Montreal***

| Problems | Calgary (n=79) | Montreal (n=135) |
|---|---|---|
| Problems during transition reported by patients (%) | 46 | 33 |
| Interruption of care** (%) | 11 | 10 |
| Currently without regular follow-up (%) | 14 | 13 |
| Either expressed having a problem or had a loss of follow-up (%) | 32 | 30 |

*No statistical difference was found between the 2 cities
Results expressed as a percentage of respondents
**Defined as a delay of >12 months between 2 medical visits

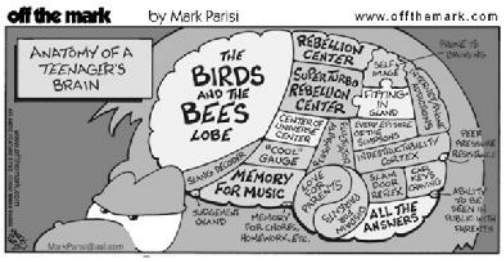
Wysocki et al. J Dev Behav Pediatr 1992; 13(3), 194-201.
Pacaud et al. Can J Diabetes 2005; 29:13-18.

## Why don't they get it?



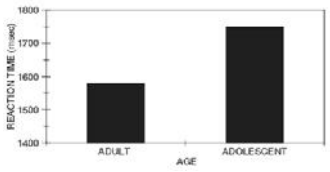

## Lessons Learned

- No transition plan
- ~17 years
  - Discuss transition
  - See doctor alone
  - Actually transition
- Worried/anxious
- Delay before first adult visit



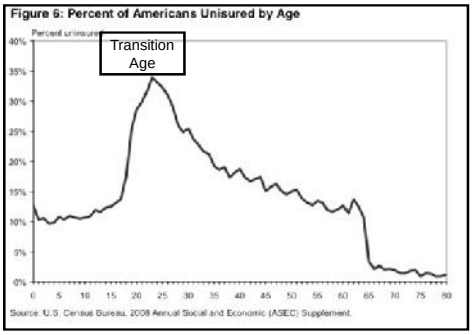
## Inability to Assess Risk

- Is it wise to…
  - Swim with sharks?
  - Drink Drano?
  - Set your hair on fire?
- Is anyone surprised?

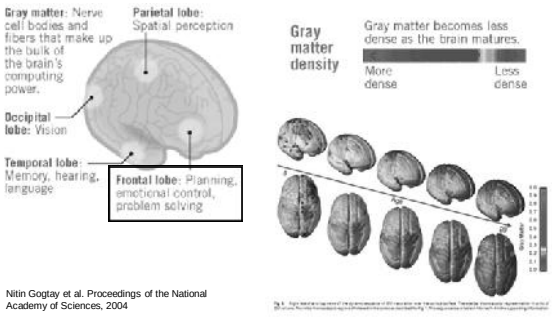



Baird & Fugelsang. Philosophical Transactions of the Royal Society of London, Series B: Biological Sciences, 2004, 359:1797–1804.

## Additional Challenges: Access to Health Care




## Frontal Lobe Development Incomplete




Nitin Gogtay et al. Proceedings of the National Academy of Sciences, 2004

## Differences Between Adult and Pediatric Clinics

## Multiple Transitions

- Graduation
  - College
  - Work
- Future career
- Leaving home
- Taking over diabetes care
- Loss of insurance


## Pediatric ➡ Adult Medical Care

- "Family focused" ➡ "Self-care focused"
- Development/Behavior ➡ Medical problem
- Support = parents ➡ Support = friends
- Physician with parents ➡ Physician alone
- Supportive ➡ Expectations
- Insured ➡ Uninsured

*** Not all providers fit into these categories. ***

Sawyer et al. J Paediatr Child Health 1997; 33:88–90
Visentin K et al. J Clin Nurs 2006; 15(6): 761-769.

## Successful Models Outside US

- Canada, UK, Australia
  - The Maestro Project
  - Drop out rate
    - 40% → 11%
- Components
  - Pediatric, adult clinic
  - Coordinator
  - Educational program

Van Walleghem et al. Chronic Dis Can 2006; 27(3):130-134.

## Control Matters

- Short term improvement beneficial DCCT
  - Intensive treatment = delayed complications
  - Poor control = earlier complications
- EDIC
  - Continued ↓ risk 4 years later
  - Even if diabetes control worsened

## Challenges with Outside Models

- Different healthcare systems
- Limited generalizability
- Insufficient resources/staff
- Inadequate funding
- Expensive

## Transition Models and Challenges

## What are clinics doing?

- Current Approaches
  - Patient and parent education
  - Transition coordinators
- Problems
  - Insufficient personal
  - Lack of funding
  - Not universally applicable
  - Not research based
  - Expensive

## Minimal Research in US…

- …but definite interest!
- Expert opinions available
- Clinical reports and guidelines
- No successful models
- Need more systematic, research-based approach

Bryden et al. Diabetes Care 2003; 26:1052-1057. Nakhla et al. JPEM 2008; 21:507-516.
Court et al. Diabetes in adolescence. Pediatr Diabetes 2009; 10(Suppl.12):185–194.
Weissberg-Benchell et al. Diabetes Care 2007; 30(10):2441-2446.

## Are we focusing on the wrong people?

Maybe providers are the critical first step?

Education about the transition process and challenges

Increased comfort with transition issues

## What can we do to help?

Consider patients, providers, and clinic

## What about adult providers?

Adult providers may be uncomfortable

Teens and young adults very different

- Used to more supportive environment
- Don't typically do what provider recs
- Don't really care

## Why do our patients struggle?

Not prepared

Not aware

Not planning

Providers aren't certain what they need

- Education? Resources? Discussions?

## Provider-Focused Intervention

- Passive, didactic education not successful
- Problem-based learning physician interventions
  - Successfully changed physician behaviors
  - Improved patient outcomes

Davis et al. *JAMA* 1999;282:867-836.
Davis et al. *Annals of Allergy, Asthma & Immunology* 2004;93(3):237-242.

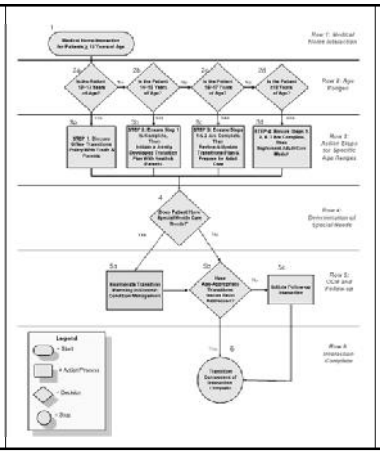
## Pediatric and Adult Providers Learning Together

- Cases presented
- Approaches discussed
- Potential barriers reviewed
- Potential solutions discussed
- Goals established
- Additional resources

## Health Care Transition Planning Algorithm

From AAP, AFP, ACP

Clinical Report – Supporting the Health Care Transition from Adolescence to Adulthood in the Medical Home. *Pediatrics*. 2011 Jul;128(1):182-200.



## What can we do now?

Begin transition process, plan at diagnosis
- The Society of Adolescent Medicine, 2003

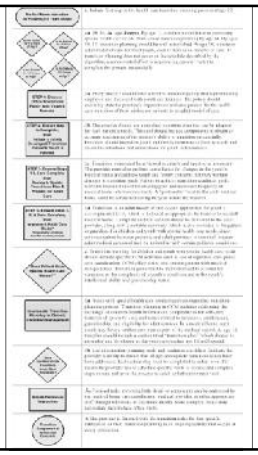
Visits alone
- Huang et al.
  - Wanted increased self-management
- Reid et al.
  - Seen alone earlier = More successful transition
  - OR = 6.59

Adults and peds work together

## Health Care Transition Planning Algorithm

From The American Academy of Pediatrics

Clinical Report – Supporting the Health Care Transition from Adolescence to Adulthood in the Medical Home. *Pediatrics*. 2011 Jul;128(1):182-200.

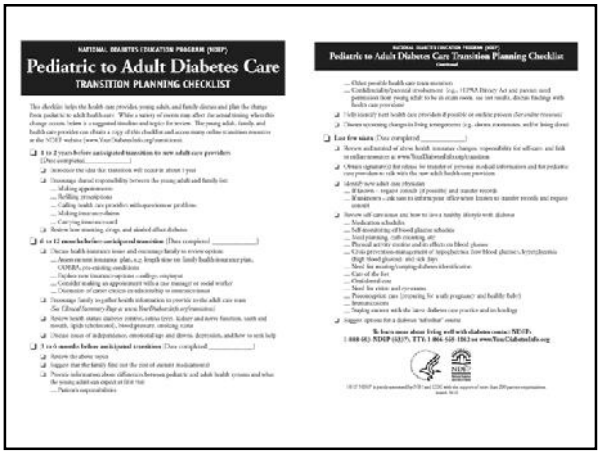


## Recommendations and Resources


http://www.gottransition.org/

Six Core Elements Health Care Transition

| Pediatric Health Care Setting | Adult Health Care Setting |
|---|---|
| **1. Transition Policy**<br>• Develop a practice health care transition policy and share with providers, staff, youth, and families<br>• Educate all staff about HCT best practices | **1. Young Adult Privacy and Consent Policy**<br>• Develop a practice young adult privacy and consent policy; share with providers, staff, patients, families<br>• Educate all staff about privacy and consent practices |
| **2. Transitioning Youth Registry**<br>• Identify transitioning youth (current/future) and enroll in a transition registry; monitor all preparation, planning and outcomes (e.g. coordination of care) | **2. Young Adult Patient Registry**<br>• Identify/enroll young adults in a practice registry; indicate levels of complexity; monitor admission to young adult model of care; note healthy/unhealthy status |
| **3. Transition Preparation**<br>• Assess and track all readiness for adult health care with youth and families<br>• Use the transition readiness assessment (youth, family) to address gaps in preparation, knowledge, and skills | **3. Transition Preparation**<br>• Discuss young adult model of health care (see definition) explain how to use the primary care practice including all access options<br>• Use/continue to use the transition readiness Assessment (youth, family) to address gaps in knowledge/skills |
| **4. Transition Planning**<br>• Address all health care transition needs/issues setting goals together with youth and family<br>• Use the:<br>-Health Care Transition (HCT) Action Plans:<br>Action Plan Example One<br>Action Plan Example Two<br>-Portable Medical Summary<br>-Emergency Care Plan (if needed)<br>• Name and notify adult primary care practice of youth's pending transfer of care date (one year out) and arrange for individualized introduction | **4. Transition Planning**<br>• Offer transitioning youth pre-transfer "get acquainted" materials and/or orientation(s) up to a year before transfer Prior to their first visit, request that:<br>Health Care Transition (HCT) Action Plans:<br>Action Plan Example One<br>Action Plan Example Two<br>Portable Medical Summary<br>-Emergency Care Plan (if needed)<br>• For all youth and young adult patients develop, use and update the HCT Action Plan, Portable Medical Summary, and Emergency Care Plan |



NATIONAL DIABETES EDUCATION PROGRAM (NDEP)

**Pediatric to Adult Diabetes Care**

**TRANSITION PLANNING CHECKLIST**

This checklist helps the health care provider, young adult, and family discuss and plan the changes from pediatric to adult health care. Within a variety of events that affect the actual timing, when this change occurs, below is a suggested timeline and topics for review. The young adult, family, and health care provider can obtain a copy of this checklist and access many online transition resources at the NDEP website (www.YourDiabetesInfo.org/transition).

☐ **1 to 2 years before anticipated transition to new adult care providers**

Pediatric to Adult Diabetes Care Transition Planning Checklist (continued)

☐ **Last few visits** (Date completed _____)

Identify new adult care physician

Arrange with care team and new to have a healthy lifestyle with diabetes

Support options for a diabetes "refresher" course

To learn more about living well with diabetes contact: NDEP-

1-888-693-NDEP (6337), TTY 1-866-569-1162 or www.YourDiabetesInfo.org

Six Core Elements Health Care Transition

| 5. Transition and Transfer of Care<br>Transfer from pediatric to new adult care location: | 5. Transition and Transfer of Care<br>Transfer from pediatric to new adult care location: |
|---|---|
| • Assure direct communication with adult PCP and team (email, phone, in person "handshake")<br>• Use the tool - Transfer of Care Checklist (pediatric, young adult)<br>• Send a "Transition Package" containing a transfer letter and items named above and in the Transfer of Care Checklist<br>• Initiate or coordinate specialty transitions as appropriate<br>• Transition to young adults model of care in same location: See Core Elements 3, 4, and 5 in the right-hand column | • Review Transfer of Care Checklist (pediatric, young adult) sent in the "Transition Package" to prepare for initial visits<br>• Talk with and receive communications from pediatric PCP/team (email, phone, in person "handshake")<br>• Provide office visit/encounters for transitioning young adults and continue with transition preparation and planning as needed<br>• Transition to young adult model of care in same location)<br>• Clarify PCP and coordinator of care contacts for young adult patients; implement Core Elements 3 and 4 as indicated; assist on-going specialty care transfers |
| **6. Transition Completion**<br>• Pediatric PCP/team are a resource for each transferred patient and their adult PCP/team following care transfer.Pediatric PCP/team receives contact with adult PCP/team ~3 months post transfer to ensure success and continuity of care<br>• Transition/transfer is declared complete | **6. Transition Completion**<br>• Consult with pediatric PCP/team as needed; each young adult is integrated using a young adult model of care; the adult practice declares successful and complete HCT<br>• Continue forward with a young adult model of care and appropriate care planning for all patients |

## Summary

- Transition of medical care is important and challenging
- Current transition approaches are non-existent or not working
- Resources and recommendations available
- Evidence-based research is needed
- Focus on providers critical first step?

NATIONAL HEALTH CARE TRANSITION CENTER

got transition?

STATES + State Innovations

Transition Websites

Maine

ChecklistATX

Maryland

Maryland Transitioning Youth

Minnesota

MYTransitions

New York

Healthy Transitions

North Carolina

NMSSE Draft Project

Washington

Adolescent Health Transition Project

## Questions

## Thank You

- HSDHC Transitions Committee
- Michael Harris, PhD
- Danny Duke, PhD
- Cheryl Hanna, MD
- Bruce Boston, MD

## Not Prepared for Transition

- National Survey of Children with Special Health Care Needs (CSHCN) 2005-2006
  - >161,000 with diabetes

MCHB Core Outcomes & Performance Measures

| Note: Shaded estimates do not meet the National Center for Health Statistics standard for reliability or precision (RSE greater than 30%). | | Among CSHCN WITH condition | Among CSHCN WITHOUT condition |
|---|---|---|---|
| **MCHB Core Outcome Measures** | | | |
| Youth with special health care needs who receive the services necessary to make appropriate transitions to adult health care, work, and independence (ages 12-17 only) | | | |
| Nationwide | % | 45.7 | 41.2 |
| | Est. # CSHCN | 41,532 | 1,588,500 |

Child and Adolescent Health Measurement Initiative. *2005/2006 National Survey of Children with Special Health Care Needs*, Data Resource Center for Child and Adolescent Health website. Retrieved 10/28/2010 from www.cshcndata.org

## Our Goal: Research Driven Practice

- Transitions committee
  - Research before development
- ID population
- Needs assessment
  - Tailor education and program

## Not Prepared for Transition

Outcome #6: Youth with special health care needs who receive the services necessary to make appropriate transitions to adult health care, work and independence -- CSHCN age 12-17 years only (details)

| | Outcome successfully achieved | Outcome not achieved | Total % |
|---|---|---|---|
| % | 40.0 | 60.0 | 100.0 |
| C.I. | (38.7 - 41.4) | (58.6 - 61.3) | |
| n | 7,195 | 9,027 | |
| Pop. Est. | 1,708,799 | 2,562,129 | |

C.I. = 95% Confidence Interval. Percentages are weighted to population characteristics. n = Cell size. Use caution in interpreting Cell sizes less than 50.

## Assessment of Intervention

- Metabolic control patients
- Self-management
- Follow up
- Patient and parent opinions
- Provider opinions

## Our Population

- N = 123 (Parent/Youth Pairs)
- Age 15.46 yrs
- Duration 6.05 yrs
- Type 1 DM 93.8%
- Insurance
  - Private 75%
  - Medicaid 19.8%
  - None 3.1%
  - Unsure 2.1%

## Adult Questionnaire

- < 28 years of age
- Previously transitioned
- Information on experience
- N = 40