

# GOT TRANSITION, A HEARTLAND EXPERIENCE

Ashley Davis

## Past Transition at OU Children's Physicians Genetics Clinic

- Joining the project
  - Heartland Regional Genetics and Newborn Screening Collaborative
  - HRSAGrant:U22MC03962
  - Dr. Klaas Wierenga and genetic counselors
  - Health Care Transition Index – Level 1 (Basic)
  - A transition policy was not in place in the Genetics clinic

## Transition at OU Children's Physicians Genetics Clinic

- Parent advocate
  - Provided the view from the parent's perspective
  - Helped us think outside of the medical realm
  - Observed in the clinic to understand how our Genetics clinic operates
  - Helped us understand that a Genetics clinic functions much differently than a pediatrician's, primary care physician's, or internists' office
  - Available to meet with families and answer questions

## Transition at OU Children's Physicians Genetics Clinic

- Genetics clinic
  - 4 geneticist, 1 physician assistant
  - 5 genetic counselors
  - 1 genetic resident
  - All NEW patients must be seen by a geneticist and/or genetic counselor
  - New and return patients are booked during the same time slot
  - Patients are split among the genetic counselors
  - New appointment on average takes 2+ hours
    - Review records, pedigree, pregnancy, medical and developmental histories, physical exam, discussion of testing, diagnosis
  - Return appointment on average takes 30-60 minutes
    - A genetic counselor is not always assigned to a return patient

## Transition of Care Policy

### OU Children's Physicians Pediatrics Genetics Clinic Transition of Care Policy for Youth and Young Adults

- OU Pediatric Genetics models its transition policy upon the guidelines provided by the National Health Care Transition Center. We believe that a smooth transition from adolescence to young adulthood includes the clear shift from a pediatric to an adult health care model. This transition process requires joint planning from the provider, patient, and family for the preparation and implementation of transition beginning at age 14. At age 18, most youth in our practice will transition to an adult model of care with modifications as needed for those with intellectual disabilities. Incorporation of transition services within the genetics specialty aims to ensure continuation of medical care into adulthood, an especially vulnerable period for chronically ill or medically complex patients. We honor the preferences of the youth and family regarding the eventual transfer of care to an adult primary medical home, but we generally expect this to occur at sometime between 18 and 21 years of age.
- Our approach to the care of young adults age 18 and older meets HIPPA and state policy and consent requirements making the young adult the sole decision-maker about care and about the sharing of personal health information. Exceptions to this approach require legal authority through the signed consent of the young adult, legally valid custodial care or power of attorney documentation, or an adjudicated guardianship arrangement.

## Transition Registry

- To identify transition age youth and enroll in a registry
- Spreadsheet format, searchable
- Ages 14-22 identified by patient schedule the week prior
- Mostly return visit patients
- Tracking and monitoring progress toward transition goals
- Also kept a side registry of patients *NOT* seen, but that fit the age range (to catalog reasons why we were missing certain groups, or why certain referrals were not indicated for enrollment in transition)

## Transition Registry

OU GENETICS TRANSITION REGISTRY											
DOB	Calc Age	NAME	Diagnosis #1	Diagnosis #2	ICD9 Codes	Physician / Genetic counselor	Met with	INSUR status. Y/N	Insur Secure Until (yr)	Date Last Seen	Next Contact/A ppt
1/23/1234	18	Name X	47, XX, +dic(15)(q13)	Intellectual Disability	758.9, 783.40	Name X	GC	Y		1/1/12	10/1/2012

DATE	DATE	DATE	DATE	DATE	DATE	DATE	DATE	DATE
Transition Policy & Visit Discussed	Readiness Checklist In Use	ACTION Plan Developed/In Use	Adult PCP Named/ chosen	Adult PCP/ Communi cation with	Transfer of Care - Achieved	Package of Care information Sent?	Transition Closure / Finish	Other
Yes	Yes	Yes	No	No				

## Transition Readiness Assessment

- Restructured to address the areas in which genetics/specialty could be most helpful
- Given at first transition visit
- One for youth and one for parents
- Measure of where they are in terms of independence and desire to acquire skills needed to manage their own health care
- Stepping stone to help guide ACTION PLAN

OU GENETICS TRANSITION READINESS ASSESSMENT {parents}	Yes my child does this	I want my child to do this	No my child is not able to do his, why?	My child needs to learn this	Someone else will have to do this – Who and Why?
I know my diagnosis					
I can explain my diagnosis and health care needs to others					
I carry information about my diagnosis to share with other doctors					
I know when I need to seek urgent medical attention related to my diagnosis					
I know what to do if I have a medical emergency related to my diagnosis					
I carry important health care information with me daily (such as your insurance card, emergency, doctor, and pharmacy phone numbers, medications, allergies, diagnosis, and medical summary)					
I know what medications I take					
I know when my prescriptions need refilled and how to refill them					
I call to make my own appointments and cancel appointments					
Before my appointments, I prepare a list of questions or concerns that I want to ask the doctor					
I know I have the option to see the doctor by myself					
I collect and organize medical records from my doctors visits					
I pay the co-payments for my medical visit					
I co-sign the privacy and consent forms					
My family and I have a plan so I can keep my healthcare insurance after I turn 18					
I know the doctor (PCP) I plan to visit when I turn 18 for adult care					
I know the doctors I plan to use for specialty care (cardiologist, neurologists, ENT, etc.) as an adult					

## Page 2 (parents)

**Feedback/Comments:**

**Questions:**

*If you answered, "No" or "Someone else will have to do this" – please explain why.*

**Current barriers to transitioning to adult care for you and your child, or in general?**

**Ways in which your child's specialist (specifically, Genetics) might help this process?**

OU GENETICS TRANSITION READINESS ASSESSMENT {youth}	Yes I do this	I want to do this / I would like support with this	No I'm not able to do this, Why?	I need to learn	Someone else will have to do this – Who and Why?	I don't know
1. I know my diagnosis						
2. I can explain my diagnosis and health care needs to others						
3. I carry information about my diagnosis to share with other doctors						
4. I know when I need to seek urgent medical attention related to my diagnosis						
5. I know what to do if I have a medical emergency related to my diagnosis						
6. I carry important health care information with me daily (such as your insurance card, emergency phone numbers, medications, allergies, diagnosis, and medical summary)						
7. I know what medications I take						
8. I know when my prescriptions need refilled and how to refill them						
9. I call to make my own appointments and cancel appointments						
10. Before my appointments, I prepare a list of questions/concerns I want to ask the doctor						
11. I know I have the option to see the doctor by myself						
12. I collect and organize medical records from my doctor's visits						
13. I pay co-payments for my medical visits						
15. I co-sign the privacy and consent forms						
16. My family and I have a plan so I can keep my healthcare insurance after I turn 18						
17. I know the doctor (PCP) I plan to visit when I turn 18 for adult care						
18. I know the doctors I plan to use for speciality care (cardiologist, neurologists, ENT, etc.) as an adult						

## Page 2 (youth)

### **Feedback/Comments:**


### **Additional Questions:**

- Of the questions on the front page, which one do you think you are doing BEST?*
- Of those questions, is there something you think you will never do?*
- Which of those questions would you like to do but just don't know how to do it?*
- Of those questions, is there something keeping you from being able to do them?*

### **How can we help out?**

## Transition Action Plan

- **Action plans** identify who is responsible for each action, when completion is expected, and who will track completion
- Mutual participation from provider, youth, and parent – guided by the transition readiness assessment and the needs of the youth/family
- Shared, clear responsibility
- Validates input from family/communication to others
- Updated at designated intervals throughout transition period



**Comprehensive Care Planning – Health Care Transition Action Plan**

NATIONAL HEALTH CARE TRANSITION CENTER

Youth's name: \_\_\_\_\_ DOB: \_\_\_\_\_ Parents/Guardians: \_\_\_\_\_  
 Primary diagnosis: \_\_\_\_\_ Secondary Diagnosis: \_\_\_\_\_ M#: \_\_\_\_\_  
 Original Date of plan: \_\_\_\_\_ Updated Last: / / / / /

Main Concerns/Goals	Current Plans/Actions	In Process	Date Complete
<i>Carry info about my diagnosis</i>	<i>Genetic counselor to develop a 1 pg "fact sheet"</i>	✓	<i>2/12</i>
<i>Collect &amp; organize my medical records</i>	<i>Back of fact sheet, the family will summarize 1 pg medical hx. to be carried together</i>	✓	<i>3/12</i>
<i>Find a PCP familiar with my diagnosis</i>	<i>GC to inquire with internal med., &amp; with other patients with shared dx</i>	✓	

Parent/Caregiver Signature: \_\_\_\_\_

Clinician Signature: \_\_\_\_\_

Got Transition? National Health Care Transition Center ©Center for Medical Home Improvement 1/17/2011 1

## Transition at OU Children's Physicians Genetics Clinic

	Jun-11	Jul-11	Aug-11	Sep-11	Oct-11	Nov-11	Dec-11	Jan-12	Feb-12	Mar-12	Apr-12	May-12	Total
New pt.	14	65	71	66	64	74	33	56	63	50	55	30	<b>641</b>
00-13 yrs	12	52	58	47	52	56	22	46	44	42	46	24	501
14-25 yrs	1	7	6	7	4	6	5	2	8	2	5	2	<b>55</b>
26+ yrs	1	6	7	12	8	12	6	8	11	6	4	4	85

## Transition at OU Children's Physicians Genetics Clinic

	Jun-11	Jul-11	Aug-11	Sep-11	Oct-11	Nov-11	Dec-11	Jan-12	Feb-12	Mar-12	Apr-12	May-12	Total
RTV	20	88	92	77	88	98	79	90	87	80	104	46	<b>949</b>
00-13 yrs	16	69	84	68	77	83	70	77	72	71	90	41	818
14-25 yrs	3	13	7	7	8	9	7	12	10	7	11	4	<b>98</b>
26+ yrs	1	6	1	2	3	6	2	1	5	2	3	1	33



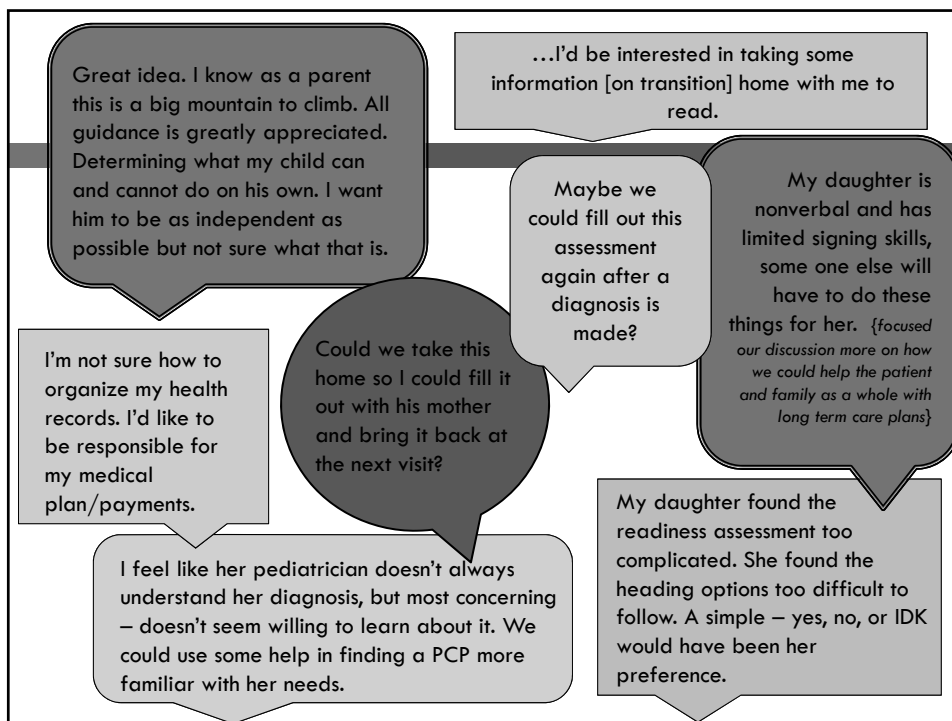
## Transition at OU Children's Physicians Genetics Clinic

	Jun-11	Jul-11	Aug-11	Sep-11	Oct-11	Nov-11	Dec-11	Jan-12	Feb-12	Mar-12	Apr-12	May-12	Total
Transition patients	1	0	2	2	1	3	1	4	1	1	2	0	18

Patients entered into the Transition  
Registry not yet began the process  
= 57

## Lessons Learned + Successes + Challenges

- “determine what is most important to you and your practice”
  - Readiness checklist tailored to Genetics practice (v. primary care)
- Common themes:**
  - Helping patients connect with a (new) PCP that is familiar with their diagnosis or willing to learn
  - Genetic counseling for the youth themselves about their diagnosis, talking about their diagnosis with others, inheritance pattern, and recurrence risk
- New patients v. return patients**
- Pilot project v. policy change**
  - Shared goal of other providers in our clinic / support staff
  - Long term?



## Current Transition at OU Children's Physicians Genetics Clinic

- Proposed to all genetic providers that if a patient fits the “transition” age range briefly introduce the topic
- Arrange a genetic counseling only visit to meet one-on-one to discuss transitioning from a pediatric to adult model of care

## Future Transition at OU Children's Physicians Genetics Clinic

- Continue the "pilot" project
- Desire to move beyond pilot project in the OU Genetics Clinic
  - Buy in from all practitioners in the clinic
  - Continue to "discover" how Genetics can help facilitate transition in primary care
- Combine lesson's learned from all Heartland Genetics projects
  - Qualitative Project Accessing Transition Practices in Genetics Clinics in the Heartland Region
  - KAP Survey
  - Got Transition Collaborative
- Support other Genetic Clinics affiliated with Heartland Genetics to incorporate the transition process to meet their patient's needs
- Dream – Other specialty clinics use OU Genetics transition process in their clinic to assure a healthy and smooth transition for all specialized pediatric care

## Future Transition at OU Children's Physicians Genetics Clinic

- Final thoughts
- Challenges
  - Three to four months to "find our place"
  - Mental and Emotional barriers
    - Conference calls heard other clinics "discover" from each other
    - No documented successes like the other clinics
    - Continued trying to "look like" the other clinics
- Reassessed
  - Exceptional differences
  - Unique transition process
  - Dr. Pickler's understanding of Specialty Clinics differences
  - Team with the family/patient and not necessarily with the primary care physician