Healthcare Transition for Our Patients

Heartland Genetics Services Collaborative
10th Annual Conference – Kansas City
April 24, 2014

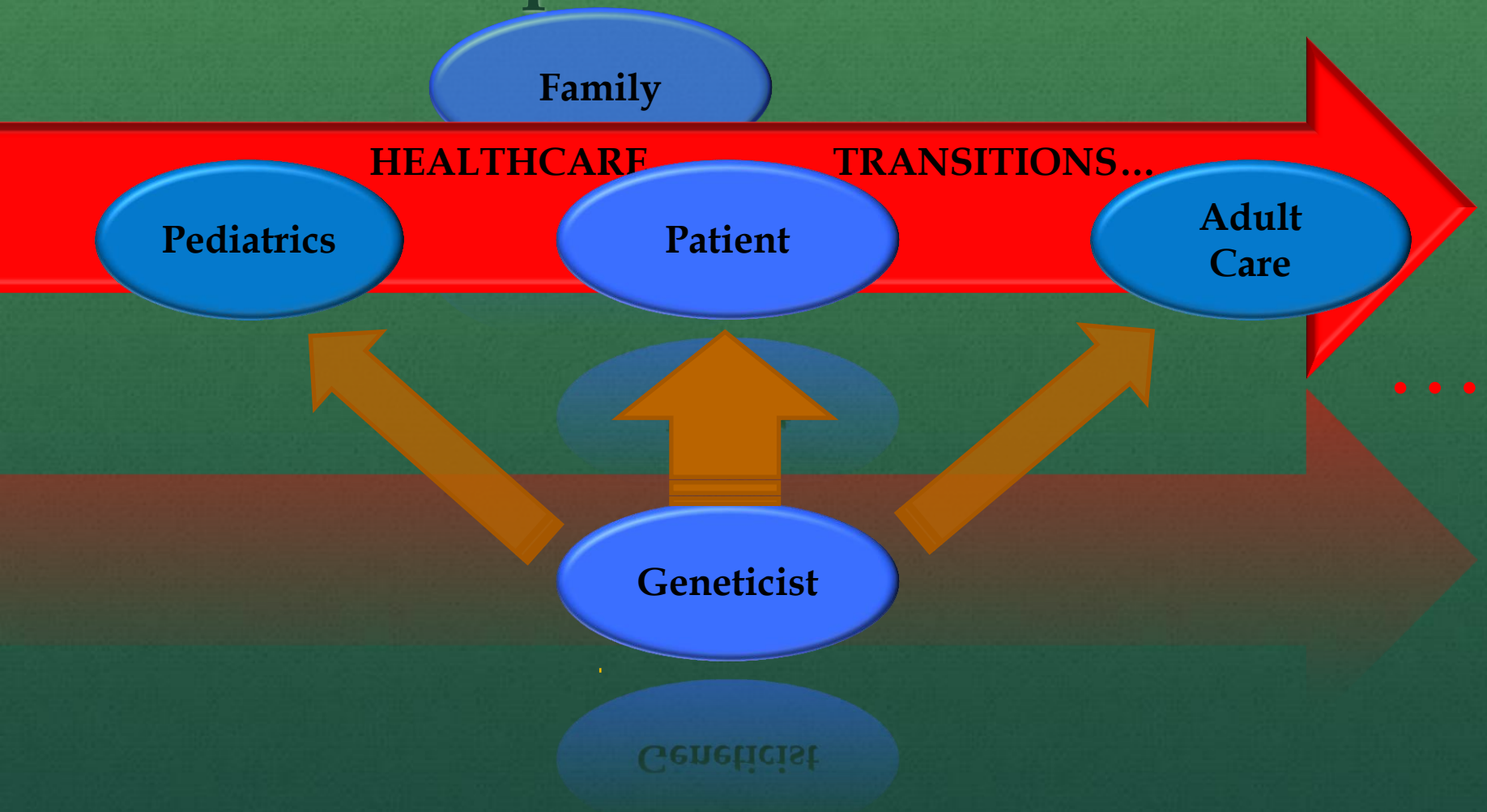
What Brought Us Here?

- Activities Completed:
  - Facilitated a focus group
  - Conducted 5 clinic site visits
  - Surveyed Genetics providers using the Knowledge Attitudes & Practices Survey(Jeanine Schulze, MS, LCGC)
  - Participated in the Got Transition Learning Collaborative (Jae Lindsay Chaloner, MS, LCGC & Ashley Davis, MS, LCGC)

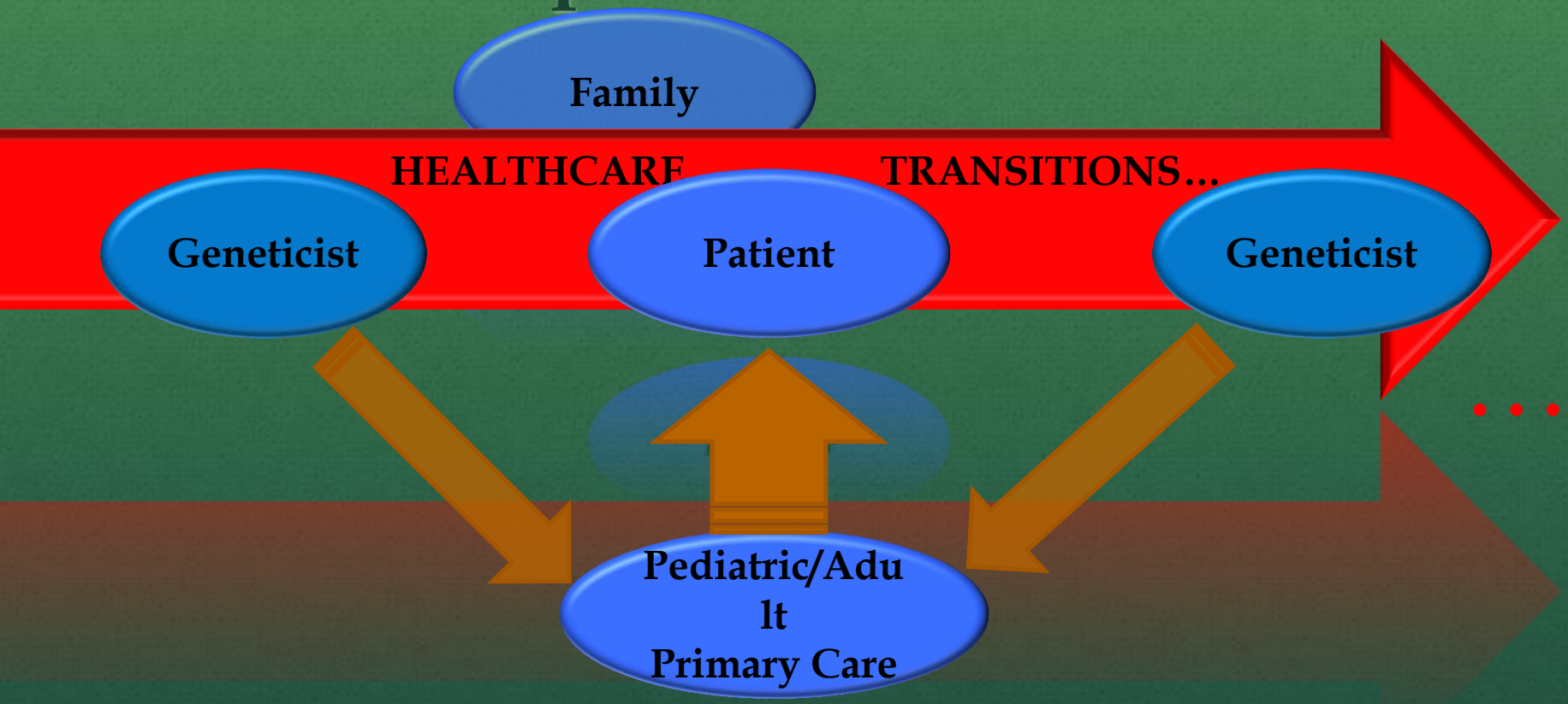
What Were the Common Themes?

- Information & Education
- Tools & Resources
- Protocols

Emerging Question: What is the Role of the Geneticist & Other Specialists?



Emerging Question: What is the Role of the Geneticist & Other Specialists?



How Did We Respond?

- Bring people together
  - Heartland & New York Mid-Atlantic Collaboratives
    - Share ideas & experiences
      - Learn from each other

What Have We Done?

- Engaged a Healthcare Transition Learning Collaborative to include:
  - 3 topical webinars
  - 2 face-to-face meetings
  - 2 conference calls
- Gathered Information through:
  - Guest speakers & panel presentations
  - Worksheets
  - Large & small group discussions

Pursuing Recommendations

- Design strategies that put youth and families in the “driver’s seat”
- Develop a “universal model” for healthcare transition
- Develop a transition flow chart and protocols

What is TRANSITION?

TRANSITION is the purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centered to adult oriented health care system.

It is frequently characterized as:

- a dynamic, lifelong process that seeks to meet individual needs"
- a "patient-centered process"
- flexible, responsive, continuous, comprehensive and coordinated

Challenges to Smooth Transitions

- From the Pediatrics side of the continuum
  - Families and youth established history and trust
  - No reimbursement for transition activities
  - Limited number of known adult providers for referrals
- From the Adult providers side of the continuum
  - Lack knowledge of pediatric and congenital conditions
  - Lack of good medical summaries and communication with previous providers
  - Youth not “mature” and lack self-care skills
  - No reimbursement for care for “complex patients”

Two Medical Worlds

VARIABLE	PEDIATRIC World	ADULT CARE World
Personal Medical History	Well known	Unfamiliar
Pediatric Disease Knowledge	Common	Unfamiliar
Co-morbidities	Primarily Viral Infections	Cancer, diabetes, Atherosclerosis
Location of Providers	Centralized	Diffused
Support for patient	Interdisciplinary Team-based Care	Fewer resources available
Focus	Family, whole child	Individual, disease-specific
Need for Primary Care	Important	Critical

Increasing Numbers

- 4.5 million youth [ages 12-17] in the U.S. have a special health care needs
- 65% of whom are moderately to severely affected
- About 33% have a behavioral, emotional and/or developmental condition
- 750,000 of these youth turn 18 every year
- Most live well into adulthood. For example,
  - Cystic Fibrosis: median survival age is mid 30s
  - Sickle cell disease: Mid 40s

D. Lotstein, MD - 2013

Introducing Social Capital

A Strategy for Making Transitions More Possible

Building Social Capital: Strategies for Making Transition More Possible

- SOCIAL CAPITAL can be understood as bridge-building!
- SOCIAL CAPITAL is the sum of the resources accumulated by an individual by virtue of building a durable social network of relationships of mutual acquaintance and recognition.
- Significant KEYS are:
  - Focus on the individual
  - Resource building
  - Network of relationships
  - Of mutual acquaintance and recognition

Relevance of Social Capital

- Social capital[izing] helps bridge the gap[s] faced by patients, families AND medical practitioners between the disparate worlds of PEDIATRIC care and ADULT care - as patients move along [transition] the course of their life.

How Can We Establish Social Capital?

- First, help individuals build ASSETS [e.g., self-determination skills] that are genuinely valued by others in the network.
- Second, develop OPPORTUNITIES in the adult provider community and identify the skills required.
- Third, make CONNECTIONS between the individual and the provider where they can interact concretely with one another.
- The key is building assets that are recognized and valued by both parties.

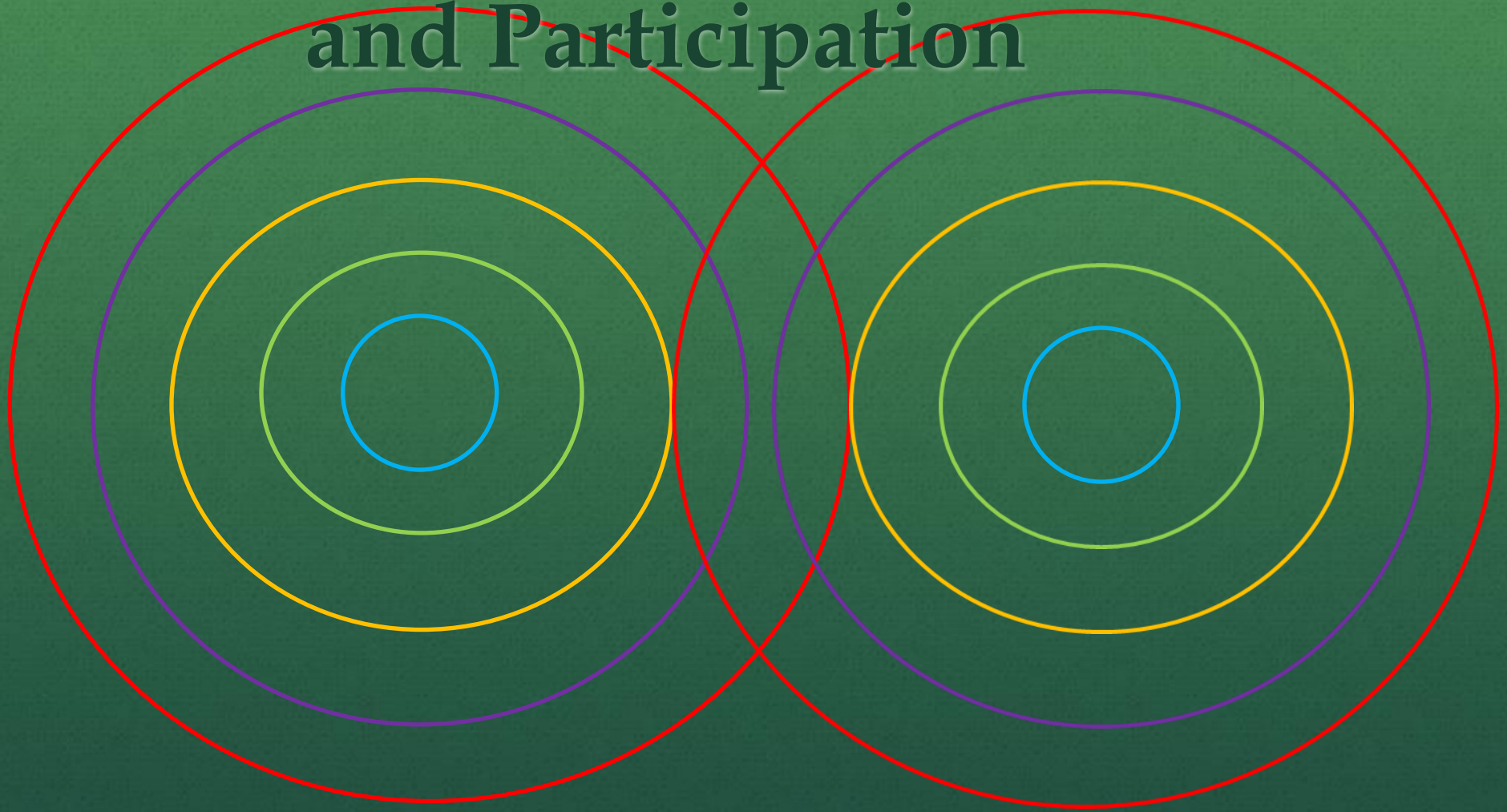
Social Networks

- Developing social capital allows an individual to actively (proactively) participate in their networks
- It legitimizes their access to those networks and
- Building social capital accrues benefits to all participants in the network!

Apples are NOT Oranges!

It is important to "grow" the kind of social capital that you can spend later!

Building Layers of Recognition and Participation



Applying Social Capital to the Realities of Healthcare Transition

Learning Collaborative I

- *Learning Collaborative One* engaged small and large group work addressing the elements of:
  - Patient ASSETS
  - Developing OPPORTUNITIES, and
  - Making CONNECTIONS to the Adult Providers.
- Introduced perspectives from Med-Peds and Youth Panel

Questions Addressed Were:

- What does it mean to say someone is “transition ready? Or, NOT transition ready?
- What would you do to build the ASSETS of these adolescents? What activities facilitate asset building?
- Describe engaged and willing adult providers AND what would you do to develop OPPORTUNITIES to access adult providers?
- What activities facilitate strong CONNECTIONS to adult providers?

Products and Outcomes

Social Capital Activity Menus

Action Steps

Learning Collaborative II

- Perspectives from Adult Providers and Transition Coordinators
- Challenges to Implementation of Transition Activities
- Evaluating the Social Capital Activities Menus

Social Capital: Youth Assets Menu

Social Capital for Transitions: Activities Menu #1

Building Young Adult Assets

		✓ your interests
1.	Include patients as genuine participants in decision-making activities	
2.	Provide Tools to Aid Patient in Self-Care, Self-Determination	
3.	ENGAGE youth by asking THEM questions	
4.	ENGAGE parents in the process of "letting go"	
5.	Promote Pediatric-side facilitation of Patient Independence	
6.	Promote a "strengths based" perspective focusing on what the patient CAN do	
7.	Pair patient with an older patient (mentor) who has already accomplished some of these transitions	
8.	Promote integration of patients into broader social groups (clubs, sports, church groups, Scouting, support groups, etc.)	
9.	Develop a "How To" Guide for parents	
10.	Develop a "Celebrity" presence for young patients to respond to	
11.	Create monthly FUN EVENTS: Rodeo, Food fights, Christmas night, Camp-out, etc.	
12.	Provide for Behavioral Health/Stress Management needs	
13.	Start Transition planning at Birth/Early Infancy	

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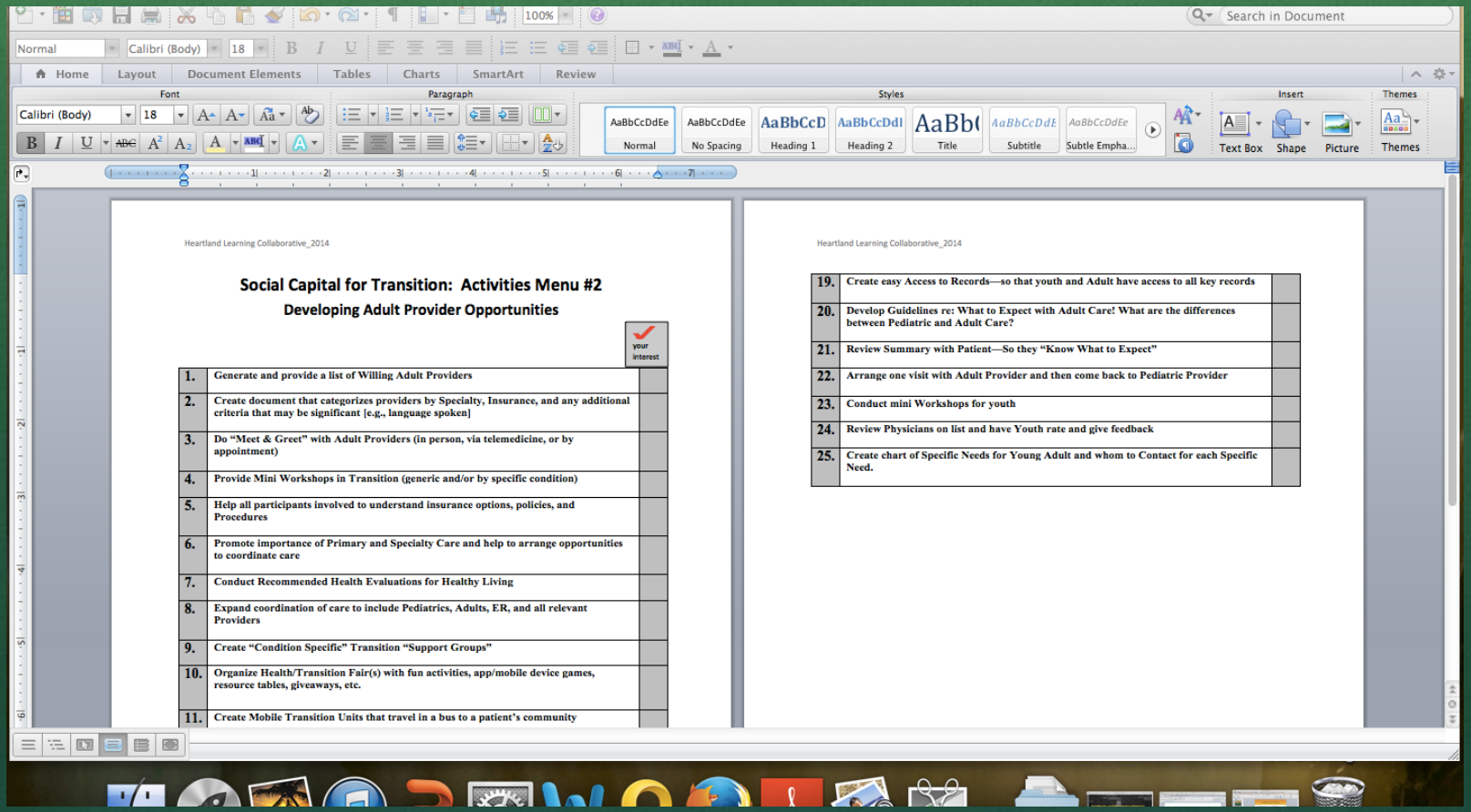
20.	Create "Dedicated" Transition Clinics	
21.	Develop "Best Practices" Transition Guidelines	
22.	Include "Healthcare Transitions" in education programs and trainings (e.g., Grand Rounds)	
23.	Make "Disease" Guidelines readily accessible to all	
24.	Explore and address "Financial" and "Guardianship" issues	
25.	During regular appointments - Develop "practical" opportunities for Patient/Family Education re: Transition and How to Access Relevant Knowledge	
26.	Create a universal Patient Portal for easy access to medical records	
27.	Facilitate communication between Pediatric and Adult Physician	
28.	Develop individual talents—what they're good at	

Social Capital: Opportunities Activities Menu



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Social Capital for Transition: Activities Menu #2

Developing Adult Provider Opportunities

		your interest
1.	Generate and provide a list of Willing Adult Providers	
2.	Create document that categorizes providers by Specialty, Insurance, and any additional criteria that may be significant [e.g., language spoken]	
3.	Do "Meet & Greet" with Adult Providers (in person, via telemedicine, or by appointment)	
4.	Provide Mini Workshops in Transition (generic and/or by specific condition)	
5.	Help all participants involved to understand insurance options, policies, and Procedures	
6.	Promote importance of Primary and Specialty Care and help to arrange opportunities to coordinate care	
7.	Conduct Recommended Health Evaluations for Healthy Living	
8.	Expand coordination of care to include Pediatrics, Adults, ER, and all relevant Providers	
9.	Create "Condition Specific" Transition "Support Groups"	
10.	Organize Health/Transition Fair(s) with fun activities, app/mobile device games, resource tables, giveaways, etc.	
11.	Create Mobile Transition Units that travel in a bus to a patient's community	

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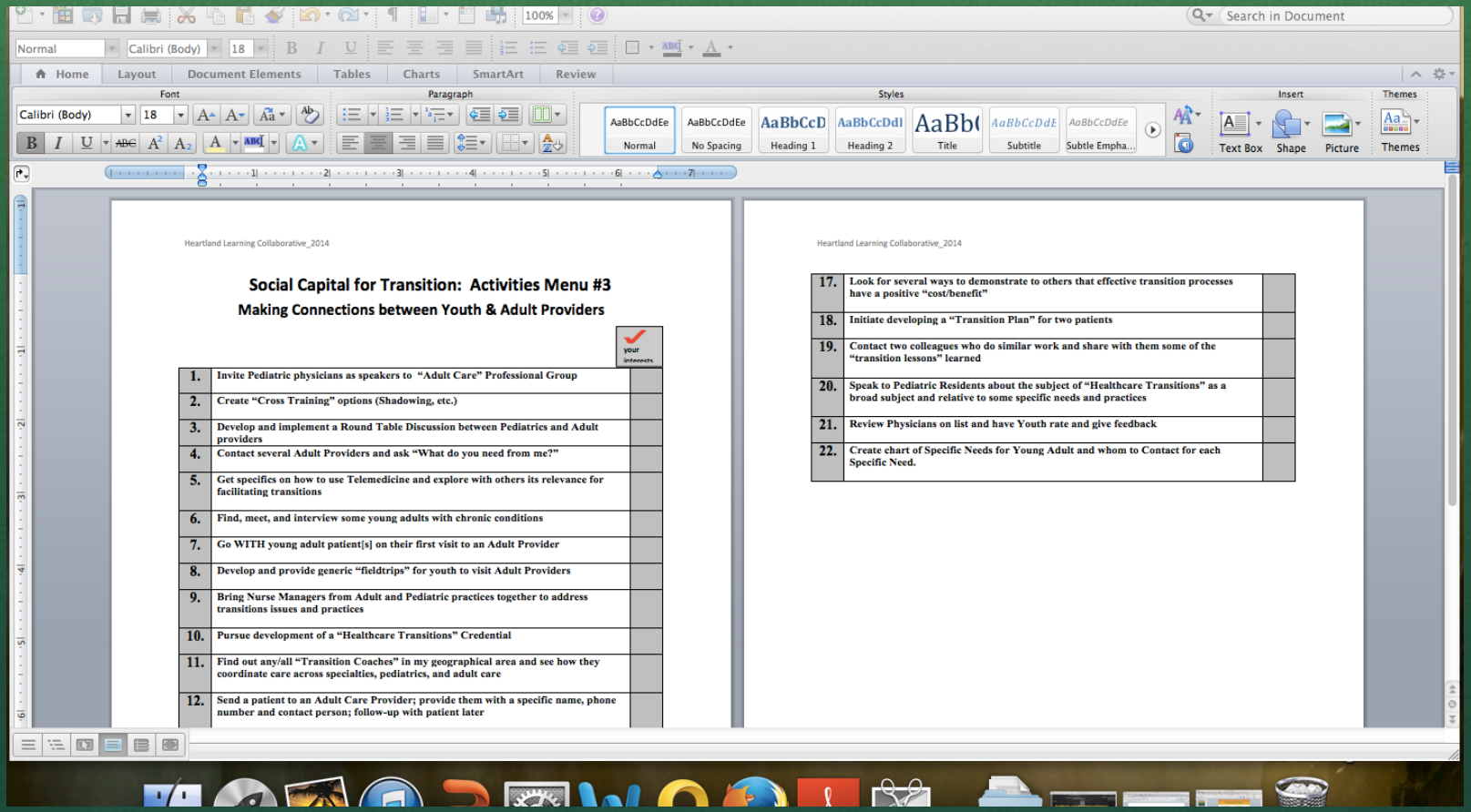
19.	Create easy Access to Records—so that youth and Adult have access to all key records	
20.	Develop Guidelines re: What to Expect with Adult Care! What are the differences between Pediatric and Adult Care?	
21.	Review Summary with Patient—So they "Know What to Expect"	
22.	Arrange one visit with Adult Provider and then come back to Pediatric Provider	
23.	Conduct mini Workshops for youth	
24.	Review Physicians on list and have Youth rate and give feedback	
25.	Create chart of Specific Needs for Young Adult and whom to Contact for each Specific Need.	

Social Capital: Connection Activities Menu



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Social Capital for Transition: Activities Menu #3

Making Connections between Youth & Adult Providers

		your interests
1.	Invite Pediatric physicians as speakers to "Adult Care" Professional Group	
2.	Create "Cross Training" options (Shadowing, etc.)	
3.	Develop and implement a Round Table Discussion between Pediatrics and Adult providers	
4.	Contact several Adult Providers and ask "What do you need from me?"	
5.	Get specifics on how to use Telemedicine and explore with others its relevance for facilitating transitions	
6.	Find, meet, and interview some young adults with chronic conditions	
7.	Go WITH young adult patient[s] on their first visit to an Adult Provider	
8.	Develop and provide generic "fieldtrips" for youth to visit Adult Providers	
9.	Bring Nurse Managers from Adult and Pediatric practices together to address transitions issues and practices	
10.	Pursue development of a "Healthcare Transitions" Credential	
11.	Find out any/all "Transition Coaches" in my geographical area and see how they coordinate care across specialties, pediatrics, and adult care	
12.	Send a patient to an Adult Care Provider; provide them with a specific name, phone number and contact person; follow-up with patient later	

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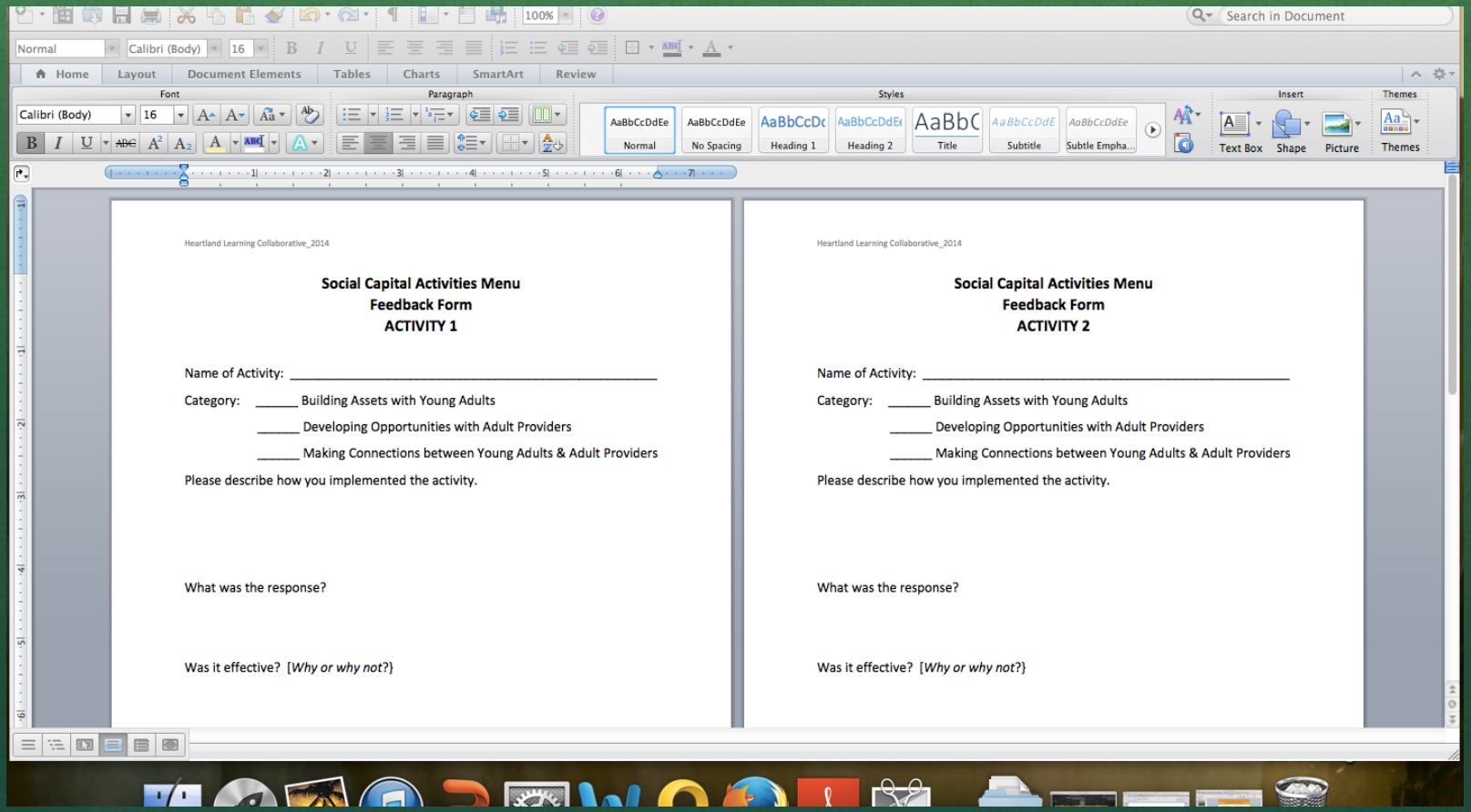
17.	Look for several ways to demonstrate to others that effective transition processes have a positive "cost/benefit"	
18.	Initiate developing a "Transition Plan" for two patients	
19.	Contact two colleagues who do similar work and share with them some of the "transition lessons" learned	
20.	Speak to Pediatric Residents about the subject of "Healthcare Transitions" as a broad subject and relative to some specific needs and practices	
21.	Review Physicians on list and have Youth rate and give feedback	
22.	Create chart of Specific Needs for Young Adult and whom to Contact for each Specific Need.	

Social Capital Activities: Feedback Form



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Social Capital Activities Menu
Feedback Form
ACTIVITY 1

Name of Activity: _____

Category: _____ Building Assets with Young Adults

_____ Developing Opportunities with Adult Providers

_____ Making Connections between Young Adults & Adult Providers

Please describe how you implemented the activity.

What was the response?

Was it effective? [*Why or why not?*]

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Social Capital Activities Menu
Feedback Form
ACTIVITY 2

Name of Activity: _____

Category: _____ Building Assets with Young Adults

_____ Developing Opportunities with Adult Providers

_____ Making Connections between Young Adults & Adult Providers

Please describe how you implemented the activity.

What was the response?

Was it effective? [*Why or why not?*]

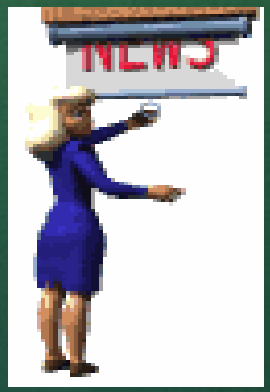
What are the Next Steps?

- Determine integration of activities
- Formulate “how to” strategies
- Compile an implementation process
- Contributing to…
  - Finalizing activity menu tools
  - Initiating a draft protocol
  - Disseminating information

Where Do We Go From Here?

Considerations…

- Conduct an adult provider study
- Investigate current practices in medical education related to health care transition
- Implement Activities Menu
- Create products and resources
- Facilitate a national Think Tank



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