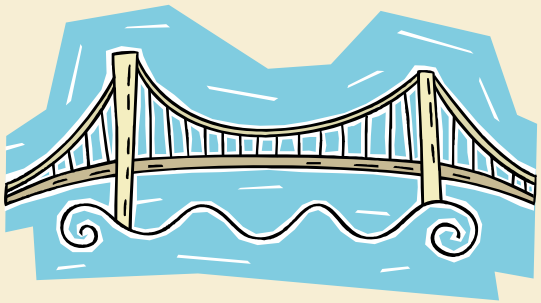


Development of a Transition Program

Building your vision and strategic plan

Riley Hospital for Children
Indiana University Health

SCHOOL OF MEDICINE
INDIANA UNIVERSITY

Mary Ciccarelli, MD

NMPRA

May 2012

Process of Program Development

IU Needs assessment

- Dyson Community Pediatric Training Initiative
  - 2003 - Dept of Pediatrics and parent-to-parent inquiries around transition, assessment and pilot
- CATCH resident grant
  - Parent conversations at clinic visits
- Indiana MCH needs assessment pilot
  - 2004 - Semi-structured interviews with parents and young adults at independent living centers and with academic adult and pediatric subspecialists

Constructing the IU Team

- Faculty
- Department of Medicine and Pediatrics leaders
- Children's Hospital
- Maternal Child Health
- Parent to parent champion
- Collaborators
  - parent to parent, independent living center
  - Bureau DD, State Council on DD (GPCPD)
  - UCEDD (IIDC), LEND (RCDC)
  - Medicaid, Dept of Education, Voc Rehab
  - Autism Center, ARC
  - Cystic Fibrosis Center, Developmental Peds Clinics, Rheumatology, PMR

Creating the IU mission and values

- Retreat
  - 2-day facilitated retreat with broad range of potential stakeholders
  - Develop missions /values and pilot suggestions
- *MISSION: "Steering YSHCN toward successful adult life"*
- *VALUES: Youth as a whole person, family-centered, strength-focused, self-advocacy, community inclusion, interprofessional team – academic/community, promote system change*

IU goals

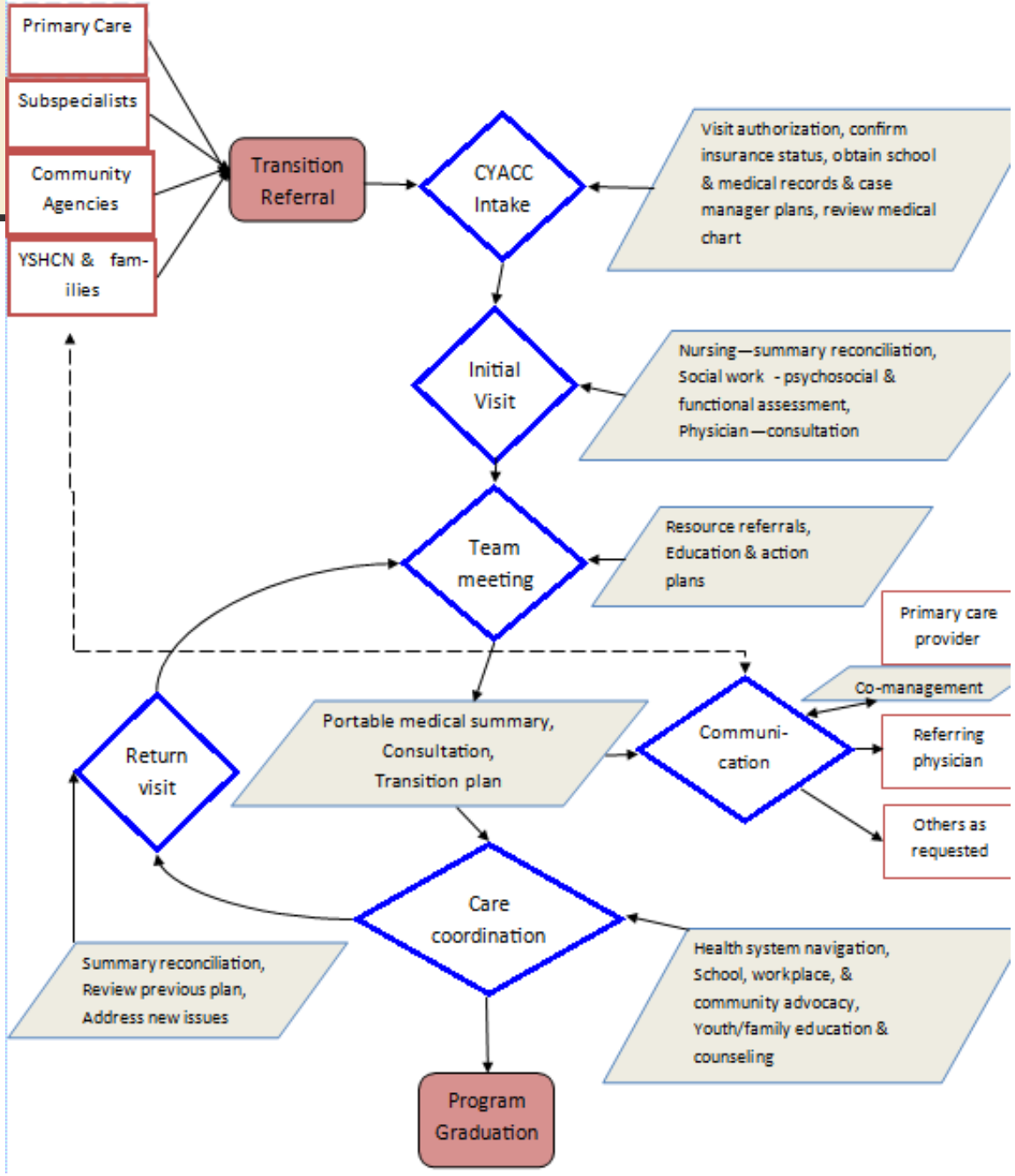
- Create transdisciplinary team
- Provide statewide consults to youth with special needs ages 11-22
- Address health, education, employment, independent living, and recreation
- Prepare for transition and support through transition
- Educate others – physicians, other professionals
  - Local, statewide, national
- Collect research data

IU Funding

- Clinical revenue inadequate
  - Unable to support the planned scope of work
- Indiana Maternal Child Health
- Matching funds
  - Dept of Pediatrics, primary care practice plan, county hospital
- Additional grants – state agencies
  - MCH CISS, Dept of Education, Medicaid, Division of Disabilities

IU Service Delivery Model

- Center for Youth and Adults with Conditions of Childhood
  - 2006 - consultation & care coordination
  - YSHCN ages 11-22
  - Chronic illness, physical and intellectual disabilities
- Trans-disciplinary team
  - Social workers, Nurses, Physicians
  - Community advocates, Parent liaisons



IU systems change plan

- Expand team
  - Transition steering committee
- Education
  - Pediatric and Internal Medicine residencies
  - Medical students, other residencies
  - CME – faculty, community providers
  - Medical home learning collaborative
- Research
  - Outcome survey
  - Medicaid costs
  - Self-management curriculum
  - Simulation curriculum

Transition outcomes

- Satisfaction
- Self-efficacy
- Achievement of transition tasks
  - Transfer, summaries, insurance
- Prevent adverse health outcomes
- Prevent gaps in services
- Health care utilization
- Costs
- Health status

IU Evaluation

- AAP-AAFP-ACP transition report - face validity
- Medical home support feedback
- MCH grant measures - MCH core outcomes
  - Family satisfaction surveys
  - Team meeting “what we did”
- Annual outcome survey
- Logging of team activity and lessons learned

SAMPLE TRANSITION POLICY:

www.pediatricmedhome.org/pdfs/1_Brochure_Sample.pdf

Indiana Pediatrics Medical Home

- Our office strives to provide a standard of care which is family-centered, accessible, continuous, comprehensive, coordinated, compassionate and culturally effective.
- As your medical home, we will:
  - Take care of your child when he/she is sick or well from birth to age _____
  - Discuss with you any treatments and testing your child may need
  - Work with you and other providers to coordinate care
  - Help you plan your child's care, setting goals for now and the future as your child grows towards becoming an adult
  - As our patients becomes teens, we work together to plan and teach skills so they learn to manage their own health care and prepare for a transition to adult services at age _____.
  - At age 18, youth become able to consent for their own care and must decide if they want to share their personal health information, unless there is a legal reason to create a different plan.

Language about adult model of care: privacy & confidentiality

Your doctor…

- **Respects your privacy.** Discuss any privacy concerns about communicating by e-mail or phone. Ask your doctor who has access to your medical records and if your records are secure.
- **Has answered all kinds of questions from other teens and young adults.** Ask your doctor whatever questions you have.
- **Will want to ask you private questions about your health to help you make healthy decisions.** Develop a style of trusting communication between you and your doctor so you can answer questions honestly and openly.
- **Can help you find a way to talk about your concerns with your parents or other important people in your life.** Tell your doctor if things you talk about can be shared with a specified other person.

How well do I manage my own health care? Please circle Yes or No

1. I know my height, weight, birth date, and social security number. Yes No
2. I know the name of my condition and can explain my special health care needs. Yes No
3. I know who to call in the case of an emergency. Yes No
4. I ask questions during my medical appointments. Yes No
5. I respond to questions from my health care providers. Yes No
6. I know what kind of medical insurance I have. Yes No
7. I know the names of my medications and what they do. Yes No
8. I know how to get my prescriptions refilled. Yes No
9. I know where to find my medical records. Yes No
10. I know how the use of tobacco, alcohol, and drugs will affect my health and my ability to make decisions. Yes No
11. I know how to get birth control and protection from sexually transmitted diseases if I need it. Yes No
12. I know how to schedule a medical appointment. Yes No
13. I keep a schedule of my medical appointments on a calendar. Yes No
14. I can get myself to my medical appointments. Yes No

If you answer yes to:

11-15 Statements
Super! You are already taking on adult responsibilities. You are ready to transition your health care and should speak with your health care providers about a transition plan.

6-10 Statements
You are on your way. You are actively taking on many responsibilities in your health care. Pick a few more responsibilities from the checklist to do for your next appointment. Also, start talking about transitions with your health care providers.

5 or Lower Statements
Now is a good time to start taking on more responsibility in your health care. Pick one new responsibility from the checklist and practice it at your next appointment. If you need help, ask a friend, parent, nurse, social worker, or doctor.

www.youngwomenshealth.org/bostonleah/PDF/transitions_questions.pdf

CYACC provider transition flowsheet

ASSESS	11-12 Yrs	13-14 Yrs	15-16 Yrs	17-18 Yrs	19-21 Yrs	> 21 Yrs
Diagnosis/Treatment - Youth Training/ Understanding						
Creation of Portable Medical Summary						
Mental Health/Coping						
Activities of Daily Living/ Self-care skills/special needs						
Healthy eating/ Physical activity						
Risk screens – safety, smoking, alcohol, drugs, violence						
Puberty/ Sexuality/ Reproduction						
Teen Immunizations/ Routine Screening						
Condition-specific Screening						
Parent to Parent Support / Guide in Letting Go						
Peer Involvement/ Social supports						
Future goal setting/ Creation of Transition Plan						
Independent living and/or Caregiver issues						
School/ Higher Ed						
Job prep/ Voc Rehab						
Medicaid Waiver Status						
Assent as minor/ Consent at 18						
Decision-making Supports/ Guardianship needs						
Adult Health Care Financing Plan						
Transportation/ Driving Needs						
Advances Directives/ Health Care Rep						
Financial issues/ Budgeting skills						
Transfer to Adult Subspecialists						
Transfer to Adult Primary Care						

LEGAL NAME Address, City, State, Zip Phone, cell, email

INSURANCE	Company Name	Certificate #	BC Plan / BS Plan	Rx BIN
		Group #	/ 800-XXX-XXXX	

Legal/ Health POA *	Name	Relationship	Cell	Work

DOB xx-xx-xxxx **ADVANCE DIRECTIVES: YES NO** **DNR: YES NO** **ORGAN DONOR: YES NO**

ALLERGY:

HEALTH ISSUES		
Body system	ADD Name of Health Issue	age on onset
Body system	ADD Name of Health Issue	age on onset

MEDICATIONS		
Rx	What for?	Name of Drug, Dosage x ? how many times a day, ADD RX #
OTC		List any over the counter Drug –indicate daily or PRN

MEDICAL HISTORY				
Body System	Diagnosis?	age on onset	age next episode	age next episode
	Diagnosis?	age on onset	age next episode	age next episode
	Diagnosis?	age on onset	age next episode	age next episode
	SURGERIES			
	What treatment?	age on onset	age next episode	age next episode
	What treatment?	age on onset		
Body System	Diagnosis?	age on onset	age next episode	
	Diagnosis?	age on onset	age next episode	

MEDICAL TESTS			
Test type	Month/Year	Pos./Neg.	Summary results
Test type	Month/Year	Pos./Neg.	

IMMUNIZATIONS							
Tentanus	YR	TB	YR	Pneumococcal vaccine YR			

FAMILY HISTORY		
Father	Alive/Deceased Age?	Health Issues, Cause of Death
Mother	Alive/Deceased Age?	Health Issues, Cause of Death
Other	Alive/Deceased Age?	Health Issues, Cause of Death

PHYSICIANS			
Primary Care Name	Name	Phone	Address
	Name	Phone	Address

OTHER			
Dental	Name	Phone	Address
Rx –Pharmacy	Name	Phone	Address

Portable Medical Summary

Emergency plan

PRIMARY DIAGNOSIS:

BASELINE DATA:

- vital signs: BP __ HR __ RR __ Wt. __ Ht. __ 02 sat. __
- Physical findings: Neuro exam:
- Devices: Lab/diagnostic test findings:

MANAGEMENT SUGGESTIONS:

- Allergies/medications & foods to avoid/rationale
- Procedures to avoid/rationale
- Common presenting issues/findings & specific diagnostic/management considerations:
- Management-related specialty physician info:

Health Transition Plan

1. Primary Care:
2. Subspecialty Care:
3. Health care financing:
4. Health care decision making:
5. Heath knowledge/understanding/self-care:
6. Advance planning:
7. Teen health/preventive care:
8. Health habits/physical activity/nutrition:
9. Mental health/stress management:
10. Clinic accommodations/accessibility :
11. Condition specific:
12.
13.

Important information in transfer

- Baseline functional and neurologic status
- Cognitive status, formal test results, date of administration
- Condition-specific emergency treatment plans and contacts
- Patient's health education history and understanding, including procreation potential and genetic information
- Information about advance directives
  - Identification of the decision-maker proxy or guardian
  - History of advance-directive planning
- Communication preferences and anticipated needs for clinical accommodations
  - use of sign language interpreter, augmentative communication, need for conscious sedation, etc.

Sources of Chronic Condition Info

- Diagnosis specific organizations
  - i.e. Spina Bifida Association www.sbaa.org
- Genetics Home Reference http://ghr.nlm.nih.gov/condition
- National Institute of Neurological Disorders and Stroke www.ninds.nih.gov/disorders
- National Dissemination Center for Children with Disabilities http://nichcy.org/disability/specific
- Order of Mendelian Inheritance in Man www.ncbi.nlm.nih.gov/omim
- Family Village www.familyvillage.wisc.edu

Conclusions from IU

- Patient and family centered approach
  - Team members, youth and parents
- Stakeholders and advisory groups
  - New collaborations, funding sources and ongoing service delivery improvements
- Proof of effectiveness
  - Short term – numbers seen, satisfaction
  - Longitudinal outcome measures
- Sustained attention
  - To identified needs, funding, functionality, effectiveness of service delivery model

Center for Youth and Adults with Conditions of Childhood

- Steering youth with special needs ages 11-22 y.o. to adult life
  - Family-centered
  - Maximize quality of life
  - Promote community inclusion
- Consultative service
- Care coordination
- Self-management training
- Support for medical home

CYACC

- Office

- Riley Hospital, Room 5833, 705 Riley Hospital Drive, Indianapolis, IN 46202
  - 317-948-0061
  - cyacc@iupui.edu
  - Fax 317-948-7577

- Clinic
  - Wishard Primary Care Center, 1st floor