Development of a Transition Program

Building your vision and strategic plan

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NMPRA

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Process of Program Development

Transition Program Development

- Internal Assessment
- External Assessment

Strengths, Weaknesses, Opportunities, Threats

VISION
MISSION
VALUES

Goals & Objectives

- Service Delivery Plan
- Manpower Needs
- Marketing
- Facility/system needs
- Human resource plan
- Funding
- Budget

Action Plan
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
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.
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.
If you answer yes to:

- I know my height, weight, birth date, and social security number.  
- I know the name of my condition and can explain my special health care needs.  
- I know who to call in the case of an emergency.  
- I ask questions during my medical appointments.  
- I respond to questions from my health care providers.  
- I know what kind of medical insurance I have.  
- I know the names of my medications and what they do.  
- I know how to get my prescriptions refilled.  
- I know where to find my medical records.  
- I know how the use of tobacco, alcohol, and drugs will affect my health and my ability to make decisions.  
- I know how to get birth control and protection from sexually transmitted diseases if I need it.  
- I know how to schedule a medical appointment.  
- I keep a schedule of my medical appointments on a calendar.  
- I can get myself to my medical appointments.

www.youngwomenshealth.org/bostonleah/PDF/transitions_questions.pdf
<table>
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<th>CYACC provider transition flowsheet</th>
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<tr>
<td><strong>ASSESS</strong></td>
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<td>Diagnosis/Treatment - Youth Training/ Understanding</td>
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<td>Creation of Portable Medical Summary</td>
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<td>Mental Health/Coping</td>
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<td>Activities of Daily Living/ Self-care skills/special needs</td>
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<td>Healthy eating/ Physical activity</td>
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<td>Risk screens – safety, smoking, alcohol, drugs, violence</td>
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<td>Puberty/ Sexuality/ Reproduction</td>
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<td>Teen Immunizations/ Routine Screening</td>
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<td>Condition-specific Screening</td>
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<td>Parent to Parent Support / Guide in Letting Go</td>
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<td>Peer Involvement/ Social supports</td>
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<tr>
<td>Future goal setting/ Creation of Transition Plan</td>
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<td>Independent living and/or Caregiver issues</td>
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<td>School/ Higher Ed</td>
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<td>Job prep/ Voc Rehab</td>
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<td>Medicaid Waiver Status</td>
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<td>Assent as minor/ Consent at 18</td>
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<td>Decision-making Supports/ Guardianship needs</td>
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<td>Adult Health Care Financing Plan</td>
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<td>Transportation/ Driving Needs</td>
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<td>Advances Directives/ Health Care Rep</td>
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<td>Financial issues/ Budgeting skills</td>
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<td>Transfer to Adult Subspecialists</td>
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<td>Transfer to Adult Primary Care</td>
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**Portable Medical Summary**

**Legal Name**
- Address, City, State, Zip
- Phone, cell, email

**Insurance**
- Company Name
- Certificate # / BC Plan
- Group # / BS Plan
- Rx BIN

**Legal/Health POA**
- Name
- Relationship
- Cell
- Work

**Advance Directives**
- YES NO
- DNR: YES NO
- Organ Donor: YES NO

**Allergy**
- Health Issues
  - ADD Name of Health Issue, age onset
  - Body System
    - ADD Name of Health Issue, age 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**
- Diagnosis?
- Age on onset
- Age next episode
- Body System
- What treatment?
- Age on onset
- Age next episode
- Surgery
- Diagnosis?
- Age on onset
- Age next episode
- What treatment?
- Age on onset
- Age next episode

**Medical Tests**
- Test Type
- Month/Year
- Pos./Neg.
- Summary results

**Immunizations**
- Hepatitis 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
  - Phone
  - Address
- Name
  - Phone
  - Address

**Other**
- Dentist
  - Name
  - Phone
  - Address
- Rx-Pharmacy
  - Name
  - Phone
  - Address
Emergency plan

PRIMARY DIAGNOSIS:

BASELINE DATA:
- vital signs: BP __ HR __ RR __ Wt. __ Ht. __ O2 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:
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<td>Primary Care:</td>
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<td>Health knowledge/understanding/self-care:</td>
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<td>Teen health/preventive care:</td>
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<td>Health habits/physical activity/nutrition:</td>
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<td>9.</td>
<td>Mental health/stress management:</td>
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<td>10.</td>
<td>Clinic accommodations/accessibility:</td>
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<td>11.</td>
<td>Condition specific:</td>
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<td>12.</td>
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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


• 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

• 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
• 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