Transition to Adulthood for Youth with Traumatic Brain Injury and Intellectual/Developmental Disabilities

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Learning Objectives

• To recognize the value and importance of addressing transition from a holistic perspective for youth 14 to 22: Person Centered Planning

• Compare short and long term program models

• Develop transition initiatives that can take place in healthcare and community settings
Why is it important?

Transition happens everywhere and sometimes *at* the same time
Rationale

• 15 to 19 year olds are at highest for TBI
• Appropriate identification, screening and intervention could result in better outcomes
• Specific training is needed for youth with a TBI with IDD and their caregivers
• Recognition the TBI can reoccur, especially for youth with unsteady gait
Youth Transition Program

• Funded by TBI Implementation Grant #H21MC17232 from the U.S. Department of Health and Human Services Health Resources and Services Administration (HRSA).

• Program 4/1/10-3/31/14
Program Consultant

• School
  – Trouble concentrating
  – Too many distractions
  – Not getting school work done
  – Requested accommodations, but did not get them
    • Extended time to do work
    • Take book home
    • Stay after class to do the work

• No one to help (no BrainSTEPS)
  – Failed class and took summer school to graduate
Program Consultant

• Became a CHOP employee March 7, 2011
• Created resource list for youth and families
• Contributed to Bucks County REACH
• Offers support to program participants
• Works in CHOP Emergency Department
Graduation = Success!
Direct Service Plan

- Request and review healthcare and school records
- Provide:
  - Intensive Care Coordination - Point person to provide navigation and support individuals and families
  - Health Care Transition
    - Care Binder: comprehensive healthcare plan
      www.chop.edu type in Care Coordination.
    - Pages in English, Spanish and Arabic
    - Medical Summary
Direct Service Plan

- Needs assessment with youth and parents/caregivers
- Referrals to community resources
  - BrainSTEPS  [www.brainsteps.net](http://www.brainsteps.net)
  - Behavioral health
  - Neuro-psychological testing
  - Office of Vocational Rehabilitation
  - Communication with schools and agencies
  - Collaboration with the youth’s medical team
  - Advocacy groups
BrainSTEPS

- Strategies
- Teaching
- Educators
- Parents
- Students
Additional Services for Youth

- CHOP Career Path: Pediatric Comprehensive Rehabilitation Outpatient Evaluation - P-CORE
- Neuro-Rehab Follow-up
- Neurology
- Neuro-psychological evaluation
- Further medical assessment
- REACH for Work
- REACH for College
- REACH for TBI
- Community Resources: BrainSTEPS, Home Care, Elks Nurses, Liberty Resources, Office of Vocational Rehabilitation
Healthcare Transition

- Start addressing transition to adult care as long as medically stable
- Person needs to learn to care for own health needs as soon as possible
- Find qualified adult providers to meet specific needs
  - Recognize the lack of multi and inter-disciplinary care in adult world
  - Find adult services to meet psychosocial needs
Medications

- Take medications independently and correctly
- Know the names of medications and what they do
- Fill prescriptions when needed
- Reorder medications before they run out
- Know the side effects of each medication
- Know what to do if you are having a bad reaction
Supplies and Equipment

• Independently use and take care of medical equipment and supplies

• Order medical equipment before they run out, know how to pay for them

• Call the suppliers when there is a problem with the equipment
Insurance

• Know what kinds of medical insurance you have

• Continue or know how to apply for health insurance

• Use community support services and advocacy services (legal services – Disability Rights Network, insurance - MAWD), when needed
Youth Transition Program

- Develop mechanisms to support youth transitioning from **pediatric** to **adult-oriented health and social service systems**
  - www.chop.edu/transition
  - www.gottransition.org
  - www.chop.edu/concussion

- Identify resources and collaborative linkages of service providers at the local, regional, and national levels who can support youth with TBI and their family.
  - Community Resources for Families: www.chop.edu/crf
REACH

Rapport, Empowerment, Advocacy through Connections and Health

A program for teens and young adults (ages 14 to 22) with special healthcare needs created by teens and young adults with special healthcare needs.

Supported by a grant from the Dept. of Health & Human Services, Health Resources & Services Administration, Maternal Child Health Bureau, MCH Grant T73MC00051,
Mission

To prepare teens and young adults with special healthcare needs for a successful transition into adulthood by providing peer support, guidance and resources.
Vision - 2003

REACH will locate, help to develop, and establish comprehensive, collaborative adult-oriented healthcare and community services for young adults with special healthcare needs that encourages and supports independence and well-being.
REACH

Workshops include:

- Self Care
- Self Advocacy
- Care Coordination
- Wellness
- Relationships
  - Sexual health
- Eligibility for insurance and Federal programs
- Navigating the medical system
- Advocating for support services

Opportunity for young people and their parents
Bucks County REACH Program

2 Night program for teens (14 y/o to 19 y/o) and their parents

– Each night 1 ½ hours long
– Have an acquired brain injury
– Are transitioning to adulthood (work force, college, etc.)
Planning Process

• 5 months prior to event
  – Conference call with CHOP and BCIU #22
  – Identify resources, needs, past strengths and weaknesses with program
  – Identified roles of community partners

• Roles:
  – CHOP: Flyer, activities, and outreach
  – BCIU: identify students that would benefit from program, activities, and facility
Planning Process

• 4 Months Prior to Event:
  – Site visit to CHOP to meet face to face
    • Clear agenda in place
    • Logistics discussed
    • Jobs delegated to appropriate partners
Planning Process

• 1 Month Prior to Event
  – Site visit to BCIU #22
  • Met and discussed finalizing the schedule, participants, food, binders, and content
Planning Process

• 1 Day Before Event
  – Finalized first night’s schedule & participants
  – Finalized materials & food needed

– Materials included:
  • Care Binders
  • Hello my name is tags
  • Brain Injury Board and tags for teens to fill out about brain injury
  • Pads and pens for parents and teens to take notes
  • Sign in sheets
  • Pens/markers
  • Checklists for 2nd night materials
Bucks County REACH Kick OFF!

• Agenda Night 1:
  – Introduction
  – How TBI Effects Me
    • TRAQ form
    • Chalk Talk board (Youth writes on big post it What Brain Injury means to Me)
Bucks County REACH Kick OFF!

Break Out Sessions Night 1:

- **Teens**: Art Activity
- **Parents: Group Discussion**
  - Brain Injury 101
    - Mild/moderate/severe
    - Hidden disability
  - Stress Management
    - Emotional, irritable, etc
  - Relationships
    - Peer, Family, School
- **Care Binder Introduction Night 1**
  - Checklist of forms to bring for second night
  - Bring pages from the care binder website that you want to use
  - Provided Emergency Information Sheet
Chalk Talk: What Brain Injury Means To Me...

I can’t wear the clothes I want to wear.

My mom treats me like a baby.

It’s Harder to complete my work.

Can’t use the hand I used to write with.

I can’t wear flip flops anymore.

I don’t have any friends.
TRAQ:
Transition Readiness Assessment Questionnaire

• Self report validated measure
• Assess the youth’s level of independence in health care
• Assess the parent’s perception of their child’s level of independence in health care
• Covers medications, supplies, insurance
Bucks County REACH Day 2

• **Group Discussion:**
  – Reflections from week 1

• **Break Out Session**
  – Physical Activity

• **Group Discussion:**
  – Community Supports
  – Learning how to do it on my own: Trisha Ali
  – OVR, BIAPA and other resources
  – Going to college with a TBI

• **Health Care**
  • Care Binders
  • Medical follow-up
  • Program Evaluation
Outcomes

Immediate

• Parents and teens were able to ask questions that will effect their future

• Both medical and academic professionals in the same room discussing with families services and supports available in their community
Outcomes

Short term

• In follow up meetings with local school districts parents and teens brought care binders that contained their medical and academic information
Outcomes

Long Term:

• Follow up in 6 months with TRAQ forms via BCIU #22 BrainSTEPS Team

• Continued support and communication with parents and teens with both academic and medical communities through transition to adulthood
Take Home Points

1. Provide care binders to help students organize themselves
   • Extremely beneficial and successful
   • Students have continued to use the binders and individualize them
   • BrainSTEPS will be training all teams in the use of Care Binders with students
Take Home Points

1. Expectations of the parents
   • Parents began to have higher expectations of their children

2. Recognition of behavioral pieces
   • Brain chemistry versus loss of friends, sense of self
CHOP Career Path Vision Statement

- To provide occupationally skilled workers with academic, vocational, technical and workplace competencies that will make them responsive to socioeconomic, technological, and environmental challenges in a complex and changing society, regardless of disability.
A “Unique” Model

- Youth with most significant challenges who have not had access to social, volunteer and/or vocational experiences

- Population of students preparing to graduate and young adults who have graduated high school. Ages 18+.

- Those transitioning to adulthood with Special Health Care Needs, including TBI and/or Intellectual Disabilities

- Not employed or under-employed
A “Unique” Model

- Comprehensive assessment for community transition including evaluation by a multidisciplinary team.

- Social work and counseling support to guide youth through process of preparing for competitive work.

- Chance for total work immersion and networking during internships

- Trans-disciplinary approach to preparing adolescents for work
Our Partners

- The PA Office of Developmental Programs (Waiver)
- External Community Agencies: JFCS & local Schools
- The PA Office of Vocational Rehabilitation (Dept. Labor and Industry)
- The PA Office of Developmental Programs (Waiver) Rehabilitation Clinics Physicians Social Work
- LEND: Research Based Community Project
- D&I, AARG & Transition Special Interest
- Department Directors, Managers & Staff
- PA State Leadership Community on Transition & Local Transition Council

The Children’s Hospital of Philadelphia®
Hope lives here.
Our Roles

Assisting the patient and family through the process of transition as it is a period or time, with a series of steps, not just a single transaction.

• Providing Education
• Open dialogue and discussion- respecting the person becoming an adult
• Resources for the patient and family
• Thorough evaluation and documentation
• Correspondence with providers and agencies
Skills We Can Teach

• The same skills we want the person to have during medical transition:
  – Taking charge of appointments: Responsibility
  – Transference of accountability: from parent to youth
    • Arriving on time, having vital information, planning for follow-up and medications
  – Learning self-advocacy and self care skills
  – Understanding how their disability can or will impact them in the future
The Message: The Feelings
Transition From School

• Not all students have comprehensive transition coordination services
• Not all students have an IEP (if applicable)
  • Decisions about post-secondary schooling needs to be addressed early on.
• For those with IEP’s: Discussions of 12+ programs (up to age 21) can be beneficial for some students and might be the right choice
• Current level of functioning in a community setting are often not known:
  • Safety
  • Transportation
  • Handling money
• Outdated data: Neuropsychological Testing, re-evaluations or transition goals in and IEP
Transition From School

• Interests are often not explored: prefixed menu of “jobs”
• Community based experiences are often most helpful rather than classroom based exploration
• Customized school transition programs can be developed
  • Often developed for school environments only
• Referrals to community based agencies are sometimes not completed when recommended
• Students and families do not understand that there services are not “offered” to them
• Public benefits can change at 18
Welcome to Adult Systems

• When seeking support services after high school the benefits change significantly:
  – Entitlements no longer exist after graduation
  – Regardless of diagnosis or disabilities
• You must apply for services: You must be deemed eligible
• You are considered an adult at 18 regardless of functioning.
• There are no specific “youth” models
• They will not seek out youth to apply for services
The Attitudes
What is Supported Employment?

• For those with the most severe disabilities,
• who need intensive or ongoing job support
• who have traditionally been excluded from competitive work settings, or
• whose work skills have been underdeveloped, interrupted or intermittent because of their disabilities.
Program: Accessing Work

Bridging the gap between high school and the world of work:

An transdisciplinary program that assists young adults with chronic illnesses and/or disabilities transition from a school based setting to a competitive work environment utilizing rehabilitation and supported employment approaches.
What We Do:

Transdisciplinary approach to transition

Competitive Employment

Medical, Social, Educational, Business & Community Based
How We Do It:

1. Referrals from Clinics/Clinicians & Community Agencies
2. OVR/DVRS Involvement for Funding and Support
3. Evaluation and Program Acceptance - Funding in place
Vocational Readiness Assessment

A cooperative assessment is completed to assess an individual’s strengths and challenges as they present in a situational work environment.
Evaluation

**Physical Therapy Eval.**
- Functional endurance/strength
- Physical tasks (cleaning/delivery)
- Safety

**Occupational Therapy Eval.**
- Self management skills
- Money management
- Executive functioning skills

**Speech Therapy Eval.**
- Memory
- Problem solving
- Organization

**Career Path Team Functional Assessment**
- Battery of Clerical Tasks, hands on tasks, cognitive functioning & work ethic

**PCORE via Health Insurance & State Funds**
# Evaluation Components

<table>
<thead>
<tr>
<th>Interest Inventories</th>
<th>Functional Assessments</th>
<th>Situational Work Assessments</th>
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<tbody>
<tr>
<td>• COPS System</td>
<td>• Situational problem solving/safety</td>
<td>• Mail delivery, Linens, storeroom, cashier</td>
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<tr>
<td>• Department Visits</td>
<td>• Interaction with staff/peers</td>
<td>• Computer tasks</td>
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<td>• Done with in mock tasks</td>
<td>• Done in real &amp; mock tasks</td>
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= One Comprehensive Report
Training

Internships- Skill Development (6-8 months)

Group and Organizational Work

Intern Site 1

Intern Site 2

Professional

Personal

Individual Treatment

Counseling

Social Work
Training - Internships

- **Linen Attendant**
  - Support staff responsible for folding and organizing linens

- **Materials Distribution**
  - Receiving/delivery clerk
  - Storeroom inventory control assistant

- **Division of Gastroenterology**
  - Technician assistant in Procedure suite
  - File clerk in Administrative suites

- **Division of Quality and Patient Safety**
  - Clerical assistant and data entry clerk

- **Research Administration and Finance**
  - Clerical support staff

- **Central Processing/ sterilization**

- **Reach Out and Read**
  - Organizing donations, letters and books at primary care sites.

- **Connelly Center**
  - Library duties and book cart to rooms
  - Stock and inventory of family supplies and rooms

- **Karabots Primary Care Center**
  - Assistant to secretary and PSR
  - Data entry

- **Human Resources**
  - Receptionist

- **Lab Services**
  - Blood bank data base
  - Administrative tasks

- **Family Health Care Coverage Programs**
Strategy Development

- Task analysis
- Creation of visual strategies
  - Task monitoring / tracking sheets
  - Memory sheets
- Procedural strategies
  - Process of steps
  - Task definition
  - Training manual

- Communication strategies
  - Scripts
  - Common issues

- Use of Technology
  - Basic computer skills
  - Microsoft office
  - Email
  - Dept. assigned software
Personal Development

- **Group Sessions**
  - Interviewing skills
  - Employer relations
  - Expectations
  - Personal issues vs. Work issues
  - Communication skills

- **Individual Sessions**
  - Resume writing
  - Planning and organization skills
  - One on one interviewing
  - Work ethic and behavior feedback
  - Performance feedback
Job Placements

- Quality & Patient Safety
- GI Endoscopy Suite
- GI Admin Offices
- Supply Chain
- Environmental Services
- ED Patient Services
- Hospital Billing (PARC)
- Nursing Support
- OR Preoperative Core Tech
- Occupational Therapy
- Linens Department
Placement

Each individual works with the CCP team and the departments

Networking-internally/externally

Each individual creates a profile
• weekly searches with staff
• internally and externally

External job development occurs in the community

Interviewing preparation and support
After Placement

• Each individual receives Job Coaching
• Coaching differs for each individual based on needs
• Support with learning both skills and organizational operations. I.e. Learning Links, benefits, computer based systems.
• Gradual independence over a 90 day period with decreased support ongoing as needed.
• Support to supervisor/manager for the individuals learning style and communication.
Recognition & Success

31 = number of paid positions obtained through Career Path services

28 = number employed @CHOP

2014: Director, Symme Trachtenberg, nominated for “Disability Employment Champions of Change” at the White House on October 14, 2014 for expanding employment opportunities for people with disabilities.

2014: Access Achievement Award from the Mayor’s Commission on People with Disabilities from the City of Philadelphia.

2012: PA OVR Recognized CHOP in their Annual Report as an Exemplary Employer for Youth with Disabilities.

2011: vendor for Home and Community base Waiver services through IDS

2009: vendor for the Office of Vocational Rehabilitation

2007: Grant from OVR to start

Joni Rittler, VP of Supply Chain, Jarell Smith, supply chain employee with Career Path Director, Symme Trachtenberg, Manager; Jamie Dianni, Social worker; Natalie Stollon and Job Coach; Allison Simms.

AUCD's Andy Imparato, Symme Trachtenberg from Philadelphia LEND and Bill Kiernan from UCEDD in Boston at The White House.
Accomplishments

OVR Exemplary Employer
Children’s Hospital of Philadelphia

As recently as five years ago, young adults with chronic health conditions such as sickle cell disease, metabolic disorders and spina bifida found it difficult to compete in the local labor market. A secure job with a salary above minimum wage, benefits and the potential for advancement seemed out of reach for individuals who had endurance issues or required non-traditional schedules to accommodate medical treatment or participation in support programs. These young adults, lacking the training and experience of their peers, need innovative programming to enable them to enter the workforce. Now, thanks to Career Path, an innovative internship at the Children’s Hospital of Philadelphia (CHOP), 11 young adults with special health care needs have accepted competitive, full- and part-time positions, many offering paid time off and medical benefits.

Charles Rawlings, a full-time employee who capitalizes on the speed of his power wheelchair, provided by OVR, has become the “go to” person for critical deliveries. Patty McLean scans documents for the patient quality and safety department. Nora Crawford is a file clerk in the gastrointestinal suite. Jerome Smith has just been hired as the first paid employee in the newly created transport/equipment delivery department.

A Perfect Fit
Job Training Program Helps Young Adults with Disabilities or Chronic Illnesses Find Their Passions

By the time he was in his early 20s, Justin Naylor had held seven different jobs but didn’t find the right job until he participated in CHOP’s Career Path program.

The program, now in its third year, places Philadelphia-area young adults with disabilities or chronic illnesses in unpaid internships at Children’s Hospital. The interns work closely with a CHOP job coach, who helps them find the best use of their skills and, when they’re ready, apply for jobs both within and outside of the Hospital.

Key to the program’s success is the comprehensive, multifaceted assessment all interns complete before they are placed in a CHOP department. The assessment helps program coordinators identify each intern’s strengths — knowledge they use to find a placement that fits.

Naylor, who has completed a three-month internship in the Endoscopy Suite, where he was responsible for cleaning and restocking the endoscopes. His supervisor, Anna Pem, R.N., M.S.N., respiratory nurse manager, says he was ideally suited for the clinical environment. “He’s so patient. For the safety of the patients, he has something inside, the urge to do it — he definitely understands how what he’s doing is important for our patients.”

Naylor’s job coach, Jamie Dissani, M.S., C.I.L.S., vocational support coordinator in the Department of Community Education, says the main challenge for the young adults she works with is finding a job to fit their abilities — it’s a lack of experience.

“Because of their disability or medical condition, many of them have never experienced what a typical teenager has experienced. They’ve never volunteered, they’ve never babysat,” says Dissani.

Naylor completed his Career Path internship this past spring and accepted a permanent position as a C.I.L.S. Assistant in the Endoscopy Suite shortly thereafter.

“This is a job I’m really interested in keeping for awhile,” he says.

For more information about the Career Path program contact Jamie Dissani at ext. 4-0674 or dissani@phillychop.org.
Core Benefits

- Growth from within the organization
- Ability to pilot positions (customize)
- Support from other departments

**Business**
- Inclusive workplace
- Seasoned entry level staff

**Person**
- Self reliance
- Sustainability
- Decreased public assistance
- Preparation for college or career
- Self Efficacy
- Independence

**Growth from within the organization**
**Ability to pilot positions (customize)**
**Support from other departments**
For More Information

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