The Adolescent in Transition:

Bridging the Gaps in Health Care for the Youth with Developmental Disabilities (YDD)
GAPS
Background

• Children with developmental disabilities increasingly survive into adulthood.
Objectives:

• Identify gaps and issues in the health care for YDDs
• Discuss Health Care Models for Transitioning the YDD
• Share the PGH experience: Transition Clinic for YDDs
• Propose an individualized approach for measuring outcomes
Transition Needs of the YDD

- Adult health care
- Post secondary education
- Integrated/inclusive employment
- Community participation
- Leisure and recreation
- Social support
Transition Issues for the YDD

1. Lack of understanding of the YDD’s needs
2. Complexity of medical problems
3. Difficulty facilitating referrals to appropriate specialists
4. Difficulty communicating with the patient or their caregivers
5. Limited time for visits
Transition Issues for the YDD

6. Lack of knowledge of and difficulty coordinating resources
7. Difficulty accessing services
8. Lack of structured activities once out of high school transition program
9. Absence of long-term goals for the individual
A Frightening Trend*

AUTISM DIAGNOSES RISING
Almost 1.5% of US children are now diagnosed with autism, according to data from 11 regions in the United States.

Prevalence of autism in US children (%)

Study publication date

1 in 5,000 1 in 2,500 1 in 150 1 in 110 1 in 166 1 in 500 1 in 68
• Experts in adult medicine, may not have the same experience with autism as pediatricians.

• In a survey of 346 physicians in Connecticut, almost two-thirds said they did not receive any training in the care of adults with autism.

ARE YOU READY?

“TRANSITION is the purposeful, planned movement of adolescents and young adults with chronic physical and medical conditions from child-centred to adult-orientated health care systems.”

(Blum et al, 1993)
Health Care Transition (HCT)
“HCT is intended to ensure continuity of developmental and age-appropriate care for all patients, including children with special health care needs (CSHCN)”
Health Problems in Adults

![Chart showing health problems in adults with and without ASD.](chart)

Based on data from "Psychiatric and Medical Conditions Among Adults with ASD" (Croen et al. 2014).

Models of HCT

A. Transitioning Youth to Adult Care Providers
   - Change of health providers (PGH model)

B. Transitioning to an *Adult* Approach to Health Care
   - Without change of providers
WHO IS RESPONSIBLE?
UP-PGH
Transition Clinic for the YDD
OPD Census for Section of Developmental and Behavioral Pediatrics

• 7.8 to 10% are ages 16 and up.

• Top Diagnoses:
  1. Intellectual Disability
  2. Autism Spectrum Disorder
  3. Cerebral Palsy
History of the TC-YDD

- Transition Workshop – February 26, 2014
- Planning Meeting – November 17, 2014
- Pilot Clinic – January 22, 2015
Vision

• “We envision our youth with developmental disability with optimum health, living a full life, with meaningful activities, nurturing relationships, and community participation, regardless of their ability.”
Mission

• to provide a pathway into the adult sector for young adults with disabilities
• to consolidate and further develop expertise in developmental disabilities within the adult sector
Mission

• to provide holistic service for patients and their families
• to develop resource materials and guidelines for patients, families and relevant health professionals
Philosophy

• Transition is a **PROCESS**.
• It is **dynamic** and **gradual**.
• It should be **coordinated** and planned well in **advance**
• It should be in close consultation with the young **person** *(self-determination)*
Incorporate medical, vocational, psychosocial, educational, cultural and equipment needs of the young adult.

The timing of the transition process is unique to each individual.
Philosophy

• Aim is to optimize the health of the individual and their ability to adapt to adult roles, promoting his capacity for self-management.

• Care should be both patient and family-centered.
Clinic Schedule

- Monthly (last Thursday)
- 4 pts for team conference (half day)
Transition Team

- Clinic Coordinator
- Section of Developmental Pediatrics
- Section of Adolescent Medicine
- Department of Family Medicine
- Department of Psychiatry
- UP-CAMP
- Other specialty clinics (as needed basis)
Interdisciplinary Team
with the patient at the center

Allied Medical Services
Psychiatry
Developmental Pediatrics
Family Medicine
Adolescent Medicine
Health Care Transition Phases

12-14 years: PREPARATION
- Introduce teen and family to transitioning
- Patient education

15-18 years: ACTIVE TRANSITION

19-22 years: TRANSFER

http://www.gottransition.org/providers/index.cfm
Health Care Model: Medical Home

- Comprehensive
- Patient & Family Centered
- Coordinated
- Continuous
- Accessible
- Accountable
**Process**

**INCLUSION CRITERIA**
- Patient at least 16 years old
- Initial evaluation at the Dev Clinic
- Consent from caregiver/family member

**EXCLUSION CRITERIA**
- Patient with severe disability
- Patients with other chronic/complex medical conditions

**Dev OPD**
- Needs assessment
- Medical and Mental Health
- Life Skills Inventory
- Adaptive Functioning
- Vocational and Career Exploration

**Eval**
- Evaluation by other specialties
- Disability
- Chronic/complex conditions

**Entry**

**Follow-up**
- Discharge
- A discharge is formalized in writing and given to family and adult care partners with details for continuing plan for care

**Re-evaluation**

**Evaluation**
Team Conference

I. Introduction of Patient and current profile
   – Weaknesses
   – Strengths

II. Present management
   – Health
   – Education
   – Other services

III. Identified needs
   – Medical
   – Educational/Vocational

IV. Plans
   – Behavioral
   – Others (ex. legal)

V. Referrals

VI. Follow-up
Services

• Developmental Evaluation
• Medical Evaluation
• Immunization
• Counseling
• Screening for mental health issues
• Psychosocial Risk Assessment

• Parent and Patient Education
• Referral/linkage to other services
Census of the TC-YDD (PGH)

- **Jan 2015 to Aug 2017** (Total of 48 patients)
  - 58% - Autism
  - 29% - Intellectual Disability
  - 13% - Down Syndrome
Education

PATIENT:

FAMILY:
Families have their own “special needs”
Parent Training

May 27, 2015

RAISING TEENS WITH SPECIAL NEEDS: SAFETY AND SEXUALITY ISSUES

• Normal Adolescent Growth and Development
• Social Development and Sexuality Across the Lifespan
• Socio-emotional and Reproductive Issues and Rights
• Safeguarding the YDD from Sexual Abuse
Parent Training
August 27, 2015

FAMILY MATTERS: CARING FOR THE YDD’s AND THEIR FAMILIES

- Parenting Issues and Communicating with the YDD
- Optimizing Outcomes
- Legal Issues
- Case discussions
- Stress management for the caregivers
Seminar
December 1, 2016

HELPING THE YOUTH WITH DEVELOPMENTAL DISABILITIES (YDDS) FIND EMPLOYMENT AND ACHIEVE INCREASED INDEPENDENCE IN THE WORKPLACE

- Assessments for Vocational Potential and Readiness
- Educational Programs for the YDD
- Preparing the YDD for Vocational Placement (Guidance, counselling, coaching)
- Employment & Workplace Inclusion for YDDs
Grand Rounds with the Philippine Society of Developmental and Behavioral Pediatrics – Dec. 1, 1016
Measuring Outcomes
“When is a good outcome actually good?”

Source: Lounds, TJ. When is a good outcome actually good? Autism. 2017 Aug 1
• Outcomes should not be measured at a single point in time.
• Growth target vs. Proficiency target
Hybrid of:

1) Standardized
2) personalized approach.
Defining good outcomes

• Objective indicators:
  – Employment
  – Independent living
  – relationships

• Subjective indicators:
  – Quality of life
  – Happiness
Indicators of Progress and Outcomes for Measurement:

- Anxiety
- Distress
- Hypersensitivity
- Sleep problems
- Happiness
- Relationships
- Parent stress

Goals Begin With The End in Mind

- Stephen R. Covey