

Rosie Benford Miller
UPMC Children's Hospital

TRANSITION: CREATING A BRIDGE FROM PEDIATRIC TO ADULT HEALTH CARE

MY CONNECTION TO CHP ADOLESCENT MEDICINE

- National Health Corps member
 - Branch of AmeriCorps
- Youth Engagement Program Coordinator
- Health Educator
- Why am I passionate about transition healthcare?

WHAT IS IT LIKE TO BE A TEEN?

- Reflect on your teenage years:
 - What excited you about independence?
 - What intimidated you about independence?

WHAT IS IT LIKE TO BE A TEEN?

WITHOUT DISABILITY

- Decreased parental/adult attention → independence
- More social outings and increased importance of friendships and peer support
- Emphasis on “fitting in”
- Physical changes and self-image
- Considering future goals and life
- Develop identity and ideals
- Feelings of love and changing relationships
- Experimentation

WITH DISABILITY

- Increased parental/adult attention → dependence
- Feelings of isolations due to lack of peer support
- Emphasis on “fitting in”
- Physical changes and self-image
 - Heavily impacted by ability
- Difficulty envisioning future goals and life
- Difficulty gaining independent thoughts from those of adult support
- Feelings of love and changing relationships
- Experimentation (increased risks)

OUR CLINIC'S
APPROACH TO
TRANSITION

Transition vs. transfer

Reproductive health

Asking what you don't know

Navigating legal changes

Supportive

Independent

Time for teens to be heard

Informative and confidential

Opportunity to discuss mental health

No judgement

WHAT IS TRANSITION?

- “Transition is the purposeful planned movement of adolescents and young adults with chronic medical conditions and disabilities from pediatric (child-centered) to adult-oriented providers and facilities.” (Blum et al, 1993)
- Transition is a long process
- Transfer is a planned moment: the transfer of care

WHY DOES TRANSITION MATTER?

- 90% of youth with Special Healthcare Needs survives into adulthood¹
 - Life expectancies grow as healthcare improves
 - Negative health outcomes occur when young adults are poorly prepared for the transfer
- About half a million of these youth become adults each year in the US²
- Primary specialty care provider teams are tasked with facilitating the transition process
 - Parents, guardians, and other support systems can support youth during this process


¹Blum, 1995; ²Newacheck et al, 1994

GETTING FROM HERE... TO THERE



HOW TO AVOID GAPS

- Use a holistic approach: attend to medical but also psychosocial, vocational, and educational needs
- Goals:
 - Help patient develop skills in managing their own healthcare and other needs independently
 - Allow for comprehensive, uninterrupted care that is developmentally appropriate

Age	Health Care Provider	Parent/Family	Young Person
Birth  Adulthood	Major Responsibility	Provides Care	Receives Care
	Support to parent/family & child/youth	Manages	Participates
	Consultant	Supervisor	Manages
	Resource	Consultant	Supervisor/CEO

Good2Go Transition Program Resource Manual

Sick Kids Toronto

MOVEMENT TOWARDS INCREASED SELF-MANAGEMENT OF A CHRONIC ILLNESS

HOW IS OUR CLINIC SUPPORTING TRANSITIONING YOUTH?

- Bridges Transition Clinic: Integrated Healthcare
 - Director
 - Transition Care Coordinator
 - Psy.D. student
 - Pitt Health Law Clinic
- Transition Task Force
 - Subcommittees
- CHANGE
 - Community Partnerships



DYLAN'S STORY

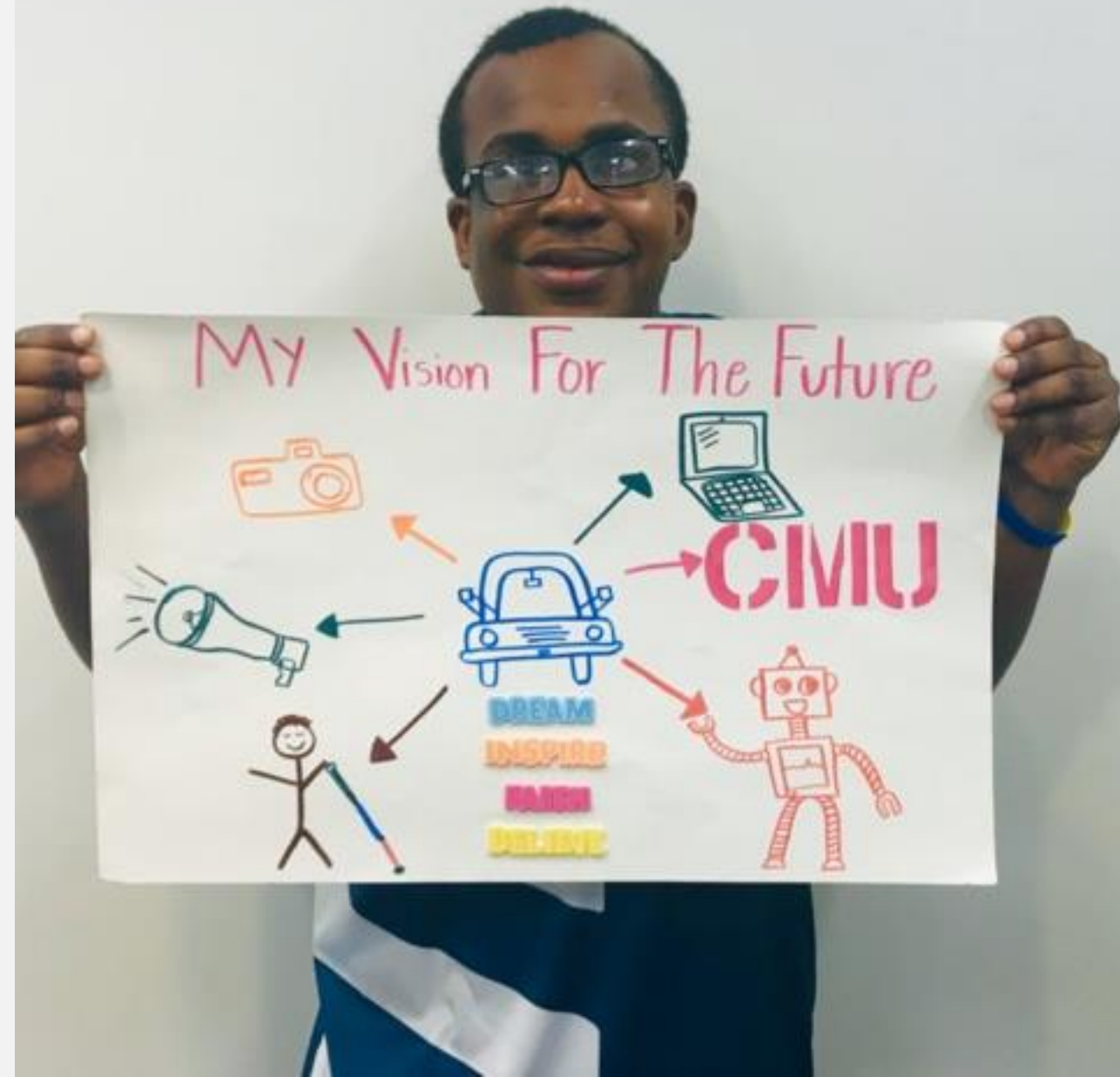
- Struggles as a youth with a disability:
 - Social isolation
 - Poor self-image/lack of self-confidence
 - Heightened sense of disability
- Dylan highlights the importance of:
 - Self-advocacy
 - Education
 - Representation/peer support

CHANGE

- **CHANGE:** Children's Hospital Advisory Network for Guidance and Empowerment is a cross-disability and chronic illness youth group focused on increasing self-advocacy and building life skills
- Open to all 14-26-year-old individuals who identify as having a chronic illness or disability
- We help youth:
 - Claim their voice to grow as advocates
 - Find support as they transition from adolescent health care to adult medicine
 - Host educational events for other young people and their support systems
 - Encourage medical providers to embrace and incorporate youth development, advocacy, and empowerment in their practices
 - Positively affect the policies, procedures, and processes at Children's Hospital to better serve the needs of adolescents and young adults
 - Be empowered to make important and educated decisions in healthcare and other aspects of life

CHANGE

- Monthly meetings:
 - Self-advocacy and how to advocate for oneself
 - Goal setting and peer support
- Independent Projects
 - Based on member's interests and experiences
- Additional support:
 - HCPD: Health Committee for People with Disabilities
 - Barriers to My Belonging
 - Letters-to-the-Editor
 - Other community partners



CHANGE BENEFITS

- Why join CHANGE?
 - Environment to foster peer support
 - Learn how to be a self-advocate
 - Learn about transition healthcare
 - Connect and network with the chronic illness/disability community in PGH
 - Financial compensation



WHAT DO OUR MEMBERS THINK?

- “Through CHANGE, I have been able to exchange perspectives with providers and other youth, and in turn, gain a greater appreciation for my own experiences.”
–Richelle DeBlasio
- “With CHANGE I have met people who I know I would never have met otherwise, and their lives and understanding of the world have taught me about a world wider than my own. My time in CHANGE has been about growth and understanding, and it is an inspiration to me about the power of advocacy and agency in our community.” – Anupama Jayachandran





HOW CAN WE SUPPORT TRANSITIONING YOUTH?

- Educate ourselves and youth
- Praise them for their strengths
- Support and listen to our youth's needs
- Advocate for them and encourage them to be self-advocates
- Create a comfortable, nonjudgmental setting
- Share your concerns while involving the youth
- Encourage them to find peer support

ADDITIONAL RESOURCES

- Achieva Family Trust
- CHANGE
- City Connections
- LEND Clinic
- Office of Vocational Rehabilitation
- PA Able Accounts
- PA Assistive Technology Foundation
- PEAL Center
- Pitt Health Law Clinic
- Start on Success

CONTACTS

ROSIE BENFORD MILLER

- Youth Engagement Program Coordinator
- Email: BenfordMR@UPMC.edu
- Phone: (412)692-8025

CAITLIN THORNBURGH, LSW

- Transition Care Coordinator
- Phone: (412)692-6677, option 4