Creating and Operating Services to Support Youth in Transitioning to Adult Health Care: Teaching the Importance of Health and Wellness and Medical Homes

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Presenter:
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What is a MEDICAL HOME?

First and Foremost – a place where a person feels **safe** and **at home** with the physician, the nursing staff and the administrative staff
What is a MEDICAL HOME, cont’d.

• A **partnership** between the youth and their primary care clinic or physician

• A **relationship** based on mutual trust

• Connections to supports and services to meet the needs

• **Respect** for the youth’s cultural and religious beliefs

• After hours and weekend access to medical **consultation** about their care

• Feeling **supported** in their care

• Primary care physician **working with a team** of other care providers.
Benefits of Having a Medical Home

Youth regularly see the same primary care physician and office staff who know them and:

- Who **partner** with them in coordinating their care
- **Exchange information** with the youth honestly and respectfully as they learn from each other.
- **Supports youth** in finding resources, for all stages of growth and development

Adapted from the brochure *Medical Home: Families and Providers Working Together* - developed by the Washington Medical Home Leadership Network.
Benefits of Having a Medical Home, cont’d.

• Youth are **connected** to information and family support organizations

• The medical home partnership **promotes health and quality of life** as youth grow and develop into an adult

Adapted from the brochure *Medical Home: Families and Providers Working Together* - developed by the Washington Medical Home Leadership Network.
Tips for Youth and/or Family: Building Medical Home Partnerships

When youth visit their primary care physician’s office they/family should:

– Bring a list of questions or concerns to discuss
– Share information on changes occurring
– Ask about resources that may help the youth
– Ask to meet the office staff that will be working with them
– Show appreciation

For more medical home information for families, tools, brochures, and presentations, go to: http://www.medicalhomeinfo.org/tools/familyindex.html
What works in Mississippi?
PARTNERSHIPS!
Title VII, Part C funding

- Establishes LIFE as a center for independent living
- Requires that we provide the four core services of independent living as well as other IL services the Board of Trustees chooses (in Mississippi, that’s most of them)
- Eligibility is simply anyone with a significant disability, of any age and any type of disability
- In an effort to serve individuals “of any age and any type of disability” we seek other sources of funding
Specific needs within disability community have emerged
  – The need to provide IL services to children and youth
  – The need to provide IL services to parents or caregivers

Funding was sought to address the needs

Funds led to the establishment of programs that provide independent living services to children, youth and parents

Additional staff were hired

The Assistant Director serves as Project Manager to provide oversight and guidance to the staff
How to Develop Partnerships

• Find the entities in your state providing Title V Maternal and Child Health Services Block Grants Programs (often state health departments) http://mchb.hrsa.gov/programs/titlevgrants/index.html

• Find the entities in your state operating the Family to Family Center http://www.fv-ncfpp.org/
How to Develop Partnerships, cont’d.

- These entities are required to provide Health Resources and Services Administration (HRSA) with state data on their outreach and service efforts to children with special health care needs. How are they reaching families in rural areas? How are they providing IL services to children and youth? Do they need you & your network of centers? Find out!
LIFE partners with the Children’s Medical Program (CMP) under the Bureau of Maternal and Child Health through the Mississippi State Department of Health. Our roles and responsibilities under this contract are:

- To provide Independent Living Services to youth with disabilities between the ages of 5 and 21 who are referred to us from CMP clinic staff as well as other referral sources (such as schools, IL staff, etc.)
State Department of Health Partnership (Title V program in MS), cont’d.

- Assign an IL Transition Specialist to participate in weekly CMP clinics offered to children and their families.
- Assist CMP staff to ensure that families are receiving information regarding the resources available to them through the schools, the Division of Medicaid, and others.
- Advocate on behalf of the consumers and their families to ensure that appropriate services are provided in a timely manner.
This Partnership is Known as:

HEALTHY OPPORTUNITIES FOR TRANSITION in Mississippi or HOT!

Established in 2004 because the Title V entity knew our reputation for service, knew LIFE had a network of offices that reached rural areas and knew we provided services to children and youth w/disabilities. They needed us to reach their goals!
Family to Family Center (F2FC) Partnership

Mississippi's Family-to-Family Health Information and Education Center is a family-focused, family-managed resource center that EMPOWERS families of children with special health care needs to be partners in decisions concerning the health of their children.
The F2F Center is...

• A collaboration of The University of Southern Mississippi Institute for Disability Studies, the Children’s Medical Program of the Mississippi State Department of Health, and LIFE of Mississippi, Inc.

• Funded by the Institute for Disability Studies

• Located at the Resource Library at the Jackson Medical Mall in the Title V funded Children’s Medical Program clinic

• Managed by the parent of a child with special health care needs who is an employee of LIFE
The F2F Center

• Through project activities, the F2F Center works to enable families to be knowledgeable, comfortable and competent in addressing the Title V system with regard to their child’s unique health care needs as well as advocating for ongoing and continuous quality improvement.

• As with the HOT program – the Institute for Disability Studies knew our reputation for providing services to children and youth w/ special health care needs, knew we were statewide and knew we had a network of parents they could benefit from!
Title V Block Grant Program and F2F

- The Title V Block Grant Program and Family to Family Center sponsor in MS needed LIFE and our system of independent living services!

- They sub-contracted federal funding to us to provide direct IL services to children & youth with special health care needs and their families – rather than hiring new staff within their own system.

- We operate as a center for independent living, following our own guidelines but we also maintain specific data they request from us.

- They provide the data management system

- They submit the data to their federal funding source

- We use it on our 704 report as well
Key Measure of Performance

One of the six Maternal and Child Health Bureaus identified key measures of performance as:

Children and youth with special health care needs receive coordinated ongoing comprehensive care within a medical home

Who has a more coordinated system of care than an independent living center?!
Tying Partnerships Together in MS

Tying Partnerships Together in Mississippi to increase a family’s knowledge of medical homes:

- LIFE staff attend CMP clinics with the F2F Parent Coordinator
- Working together in the clinics, they provide the four core services of independent living to children & youth and parents/caregivers
Peer Support

- Primary Service provided
- HOT Transition Specialist talks with the consumer and determines their transition goals
- Parent Coordinator talks with the parents/caregiver and determines their goals for the consumer’s transition
Peer Support, cont’d.

- Transition Specialist and Parent Coordinator work together with consumer and family to provide services designed to ensure successful transition – peer support is coordinated
- Occurs in the clinic, at a consumer’s home, in the school and at special events
Outreach and Information to Families regarding Medical Homes

Besides visits in the CMP clinics, LIFE staff also:

• Provide information one-on-one with consumers and family members during peer support encounters
• Conduct workshops at group gatherings such as the annual Youth/Parent Retreat and annual parent conferences
• The LIFE Director shares her own personal experience with the LACK of a medical home when she no longer could attend CMP clinics after turning 21 - and her current positive experience of having a medical home
Importance of Outreach and Information to Physicians Regarding Medical Homes

Finding a doctor to serve as a medical home for both pediatric/adult health care can be difficult for several reasons:

1) Many families do not have private comprehensive medical coverage due to cost
2) Many individuals and families therefore rely on Medicaid as their only form of health care coverage
3) Many doctors in private practice will not accept Medicaid only
4) This often leaves health care groups and/or hospitals as the only available source for medical treatment. Meaning, the individual may not see the same physician every time.
Mississippi Outreach to Physicians

The Family to Family Center in Mississippi, the American Academy of Pediatrics/Mississippi Chapter and the State Department of Health all work toward increasing the number of physicians willing to serve as medical homes in our state.

These entities promote medical homes by:

– Publishing and distributing information to pediatricians and pediatric dentists
– Offering information through continuing education training
Get Real! Tips for Youth

- From a Consumer and Advocate standpoint, medical homes are **imperative** to promote health and wellness.

- Understanding your body and how your disability affects you individually is **critical**.

- **No One** knows your body as well as you do!

- **YOU** are your own best advocate!

- Sticking with the same physician allows them the opportunity to **really** get to know you and your disability.
A good medical home ensures…

- That you have an advocate in your doctor!
- Timely and appropriate referrals to specialists
- A central location for ALL medical records and information
- *Less* likelihood of drug interactions
- *More* likelihood of good health and wellness
Purpose of the Project

This program is part of a series of trainings and other activities provided to the IL field by the New Community Opportunities Center at ILRU. The project’s purpose is to assist CILs in developing self-sustaining programs that support community alternatives to institutionalization for individuals of any age, and youth transition from school to post-secondary education, employment, and community living.
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