An Overview: Charting the LifeCourse for Everyday Lives

February 24, 2020

Webinar Goals

• Introduce the Concept of Family Support

• Introduce the LifeCourse Approach to Working with Families
  • Anticipatory Guidance – The Foundation of the LifeCourse
  • The LifeCourse approach and the LifeCourse Tools

• Demonstrate the application of the LifeCourse Tools in the Healthcare Environment
Why Do We Focus On Families?

1. All families have the right to live, love, work, play and pursue their life aspirations in their community.

2. “The most powerful force in achieving a good life for people with disabilities is found in the expectations and aspirations individual parents hold for their sons and daughters.” Eric Carter

3. Two daily realities faced by families with children with disabilities are:
   - There is a focus on what their children and their family can’t do, not what they can do.
   - Each day is complicated which makes it hard to focus on planning for the future.
What is Anticipatory Guidance?

The Foundation of the Life Course
Anticipatory Guidance “consists of the information that clinicians give families about what they should expect in their child’s development, what they should do to promote this development, and the benefits of these healthy lifestyles and practices.”


❖ Center for Disease Control: Anticipatory Guidance is given by the health care provider to assist parents to understand the expected growth and development of their children. It is specific to the age of the patient and includes information about the benefits of healthy lifestyles and injury and disease prevention.

❖ American Psychological Association: Anticipatory Guidance consists of counseling and educational services provided to individuals before they reach a turning point or significant developmental change in their lives. Examples include parental guidance before a child enters school and counseling employees who will soon reach retirement age.

❖ Health Resources and Services Administration (HRSA) Maternal& Child Health Program: The life course approach, also known as the life course perspective or life course theory, refers to an approach developed in the 1960s for analyzing people’s lives within structural, social and cultural contexts.
Anticipatory Guidance: Anticipating and Planning for the Future

Plan the Future
- What is my vision of an everyday life?
- What do I know I DON'T want?

Plan for Life’s Transitions
- Enjoying friends and family
- Getting a home
- Volunteering
- Chores and allowance
- Learning to say “no”
- Making Mistakes
- Scouts, 4H, faith groups
- Playing sports or an instrument
- Birthday parties with friends

“Anticipatory Guidance for Life Experiences”

The LifeCourse Building Blocks

Supporting Families

Thinking about the Future
- What is my vision of an everyday life?
- What do I know I DON'T want?
Families need connections and peer support opportunities with other families.

Listening to people with disabilities and their families is key to providing supports that help them achieve an everyday life.

_Discovery & Navigation_
Info and Training

_Connecting & Networking_
Talking to someone that has been there

_Goods & Services_
Day to Day, Medical, Financial Supports

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**How Can MCOs/SNUs Support Families?**

**Provide information that is responsive to the family about the disability, local school system, local community resources & assist them to access the information.**

**Keep materials about family support groups, advocacy groups & disability support groups in your offices.**

**Provide services & supports that will enable the child to live a typical life in their family and community.**
Planning for the Future

What is my vision of an everyday life?

What do I know I DON'T want?

How Can MCOs/SNUs Help Families Think About the Future?

- What are other people the child’s age doing?
- Does my family plan what a day will look like?
- Where and with whom do I think my child will live in his/her adult life?
- What will our family need to support him/her to live a quality life as an adult?
Life Stages and Transitions

Enjoying friends and family
Volunteering
Getting a home
Finding a job
Learning to say “no”
Making Mistakes
Scouts, 4H, faith groups
Playing sports or an instrument
Birthday parties with friends

Getting new diagnosis
Transition planning
Leaving early childhood / enter school
Living adult life

“Anticipatory Guidance for Life Experiences”

How Can MCOs/SNUs Prepare Families for Transitions?

- Taking their children home
  - Establish normal family routines
  - Address child’s need for developmental stimulation
  - Apply for Community Based Services
- Future medical interventions – what to expect
- Starting school
  - Enrollment
  - Preparing for the IEP
- Adolescence and sexuality
- Graduating from public school
- Moving to adulthood
- The loss of family members
Example

- Personal Safety – Sexual Health

The Trajectory Isn’t Always Straight

Getting back on track

Incidents shouldn’t become life sentences
Meet Jimmy

Integrated Supports

www.dpw.state.pa.us

www.dhs.pa.gov

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Integrated Services and Supports

Personal Strengths & Assets

Technology

Relationships

Community Based

Eligibility Specific

- Life experiences, personal knowledge, personality traits, belongings, social skills, education and training
- Pad/smartphone, "apps", remote monitoring, cognitive accessibility, adaptive equipment
- Family, friends, neighbors, co-workers, community members, church members
- Schools, public transportation, businesses, churches, public safety, hospitals, parks & recreation
- Developmental disability services, special education, Medicaid, food stamps, Section 8 housing, Vocational Rehabilitation

Charting the life course

Meet Jimmy

www.dhs.pa.gov
How Can MCOs/SNUs Utilize Integrated Supports?

Personal Strengths & Assets

Relationships

Eligibility Specific

Community Based

Technology

MCO’s - Develop Policies and Practices to Support Families

Every program, organization, system and policy maker must always think about a person in the context of family.

A Family Map
The LifeCourse Tools:

- Conversation starters
- Problem solvers
- Visioning about the future
- Empowering ownership of a vision
- Can be used by anyone in any setting
- Focused on all stages of the lifespan

The One Page Profile

One family’s story shows that this can be useful in the Doctor’s Office, for both doctors and nurses:

Count to 5

Include me in the process

Do not try to put a Band-aid on me
A Tool for Starting a Conversation


### FIGURE 3: LifeCourse Legend

<table>
<thead>
<tr>
<th>LIFE DOMAINS</th>
<th>LIFE STAGE</th>
</tr>
</thead>
<tbody>
<tr>
<td>Daily Life &amp; Employment</td>
<td>Promotional/Info: Early years, wellness or meeting developmental milestones</td>
</tr>
<tr>
<td>Community Living</td>
<td>Early Childhood: Preschool age, getting a diagnosis</td>
</tr>
<tr>
<td>Safety &amp; Security</td>
<td>School Age: Everyday life during school years</td>
</tr>
<tr>
<td>Healthy Living</td>
<td>Transition: Transitions from school to adult life</td>
</tr>
<tr>
<td>Social &amp; Spirituality</td>
<td>Adulthood: Living life as an adult</td>
</tr>
<tr>
<td>Citizenship and Advocacy</td>
<td>Aging: Getting older and preparing for end of life (parent/family/individual)</td>
</tr>
</tbody>
</table>

Promotes self-determination
A Tool for Starting a Conversation

Healthcare
- Are you keeping me healthy with well-baby visits and taking me to the doctor when I am sick?
- Do your parent/child instincts tell you something isn’t going quite right with my health, growth or development?
- Do you know if I am hitting my developmental milestones on time?
- Do you know what red flags to watch for?
- If I need testing or assessment, will insurance pay for it, or are there other funding sources?

Disability/Diagnosis Specific
- Are you expressing your concern about my health or development to my pediatrician?
- Where are you taking me to find out about my health or development; what kind of testing do I need?
- Has anyone else mentioned concerns about my health or development to you?
- What are you doing to get the help I need while waiting for a diagnosis and/or services?

Fitness and Nutrition
- Are you taking me to activities such as babysitting, Mommy and Me classes, etc.?
- Do I have opportunities at home to get stronger, such as tummy time or a playpen?
- Are you introducing a variety of healthy foods in my diet?

Next steps

Integrated Services and Supports

where do we go from here?

www.dhs.pa.gov
Resources

• For information about Charting the LifeCourse and the National Community of Practice visit:
  – https://www.lifecoursetools.com/
  – http://supportstofamilies.org/

• For information about how the PA’s Office of Developmental Programs is using Charting the LifeCourse and PA’s Supporting Families Statewide Initiative visit:

• For guidance and support that can be provided directly to individuals and their families contact:
  – http://sau1.org/ (Self Advocates United as One)
  – https://www.visionforequality.org/pa-family-network/ (PA Family Network)

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