2018 Pennsylvania Community on Transition Webinar Series

Webinar 4
Planning for the LifeCourse-Independent Living

Charting the LifeCourse for Everyday Lives
Today:

- National Community of Practice: Supporting Families throughout the Lifespan – Focusing on: Independent Living
- Foundational beliefs of the LifeCourse Framework and how they support Independent Living.
- LifeCourse Tools – Applicability when helping a students and families envision and plan for their post-secondary dreams and goals in the context of the Life Domains.
- Resources

What comes Next?
Core Belief:
All people and their families have the right to live, love, work, play and pursue their life aspirations in their community.

Everyday Lives
VALUES IN ACTION
Everyday Lives: our framework for change

1. Assure Effective Communication
2. Promote Self-Direction, Choice and Control
3. Increase Employment
4. Support Families throughout the Lifespan
5. Promote Health, Wellness, and Safety
6. Support People with Complex Needs
7. Develop and Support Qualified Staff
8. Simplify the System
9. Improve Quality
10. Expand Options for Community Living
11. Increase Community Participation
12. Provide Community Services to Everyone

Supporting Families

4. SUPPORT FAMILIES THROUGHOUT THE LIFESPAN

The vast majority of people with disabilities in Pennsylvania live with their families. Families need support in order to make an everyday life possible. Families need information, resources, and training. They need connections with other families and support services. Listening to people with disabilities and their families is key to providing supports that help them achieve an everyday life.
Community Supports

10. EXPAND OPTIONS FOR COMMUNITY LIVING

Expand the range of housing options in the community so all people can live where and with whom they want to live. Listening to people with disabilities and their families, providers, and support coordinators will help people locate affordable and accessible housing, find housemates, and identify housing resources/supports and other government benefits that, when blended with natural supports, will promote an everyday life.

11. INCREASE COMMUNITY PARTICIPATION

Being involved in community life creates opportunities for new experiences and interests, the potential to develop friendships, and the ability to make a contribution to the community. An interdependent life, where people with and without disabilities are connected, enriches all of our lives.

Level of Choice and Relationships

<table>
<thead>
<tr>
<th>LEVEL OF CHOICE WHERE PEOPLE LIVE MATTERS</th>
<th>RELATIONSHIPS PEOPLE HAVE FRIENDS</th>
</tr>
</thead>
<tbody>
<tr>
<td>The choice scale runs from zero to 100. A higher score indicates a greater level of choice-making. The statewide average score is 48.</td>
<td>In a National Core Indicators study:</td>
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<tr>
<td></td>
<td>78% of people from Pennsylvania who have an intellectual disability or autism said they have friends who are not family or staff</td>
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<tr>
<td>STATE INTERMEDIATE CARE FACILITY (ICF)</td>
<td>76%</td>
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<tr>
<td>LIFESHARE</td>
<td>78%</td>
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<td>OWN HOME</td>
<td>76%</td>
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<td>RELATIVE’S HOME</td>
<td>78%</td>
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<tr>
<td>PRIVATE ICF</td>
<td>78%</td>
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<tr>
<td>COMMUNITY HOME (1-4 PEOPLE)</td>
<td>78%</td>
</tr>
<tr>
<td>COMMUNITY HOME (5+ PEOPLE)</td>
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<tr>
<td>Source: 2014 Independent Monitoring for Quality; Institute on Disabilities, Temple University</td>
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<tr>
<td>Source: National Core Indicators (NCI) and Pennsylvania IMQ, 2013-14</td>
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</table>
The Life Course Principals

The most powerful force in changing transition outcomes for young people with significant disabilities is not ultimately found in the transition plans we craft, the educational services we offer, the instruction we provide, or the systems we build, but rather in the expectations and aspirations individual parents hold for their sons and daughters. All of these other efforts are no doubt essential, but absent families equipped with a clear and compelling vision for a “good life” after high school, we are missing something utterly essential.

- Erik Carter
  “What Matters Most: Research on Elevating Parent Expectations”

The importance of having a vision of a good life

Having a vision sets the dream, the positive expectation for the future.

But without a vision, there is no expectation of what the future might look like.

Life Stages and Trajectory
Toward the Good Life

What is my vision of an everyday life?

What do I know I DON'T want?
Life Experiences and Life Transitions

Getting New Diagnosis
Parents Turn 65
Medicare & SSDI
Leaving Early Childhood/enter school
Transition planning
Turning 18. Leaving school at 18 or 21
Living Adult Life
Enjoying friends and family
Volunteering
Finding a job
Making Mistakes
Learning to say “no”
Scouts, 4H, faith groups
Playing sports or an instrument
Birthday parties with friends
Giving up on your goal because of one setback is like slashing your other three tires because you got one flat.
Toby McKeehan
“Anticipatory Guidance for Life Experiences”

Trajectory Isn’t Always Straight
Getting back on track
Incidents shouldn’t become life sentences
Mykayla’s Story

LifeCourse can help us have **high expectations** and envision the kind of life that will be fulfilling and where we can make a difference.

**Barriers**
- Historically, people with disabilities did not have many chances to work in their communities.
- Low expectations and focus on limitations rather than strengths.
- Low employer expectations – subminimum wage.

**Moving Forward**
- The LifeCourse framework and tools breakdown these barriers – beginning with a **dream**.
- Empowering the person and their family.
The Lifecourse Framework:

- Starts with the LifeCourse principles
- Conversation starters
- Problem solvers
- Encouraging creation and ownership of a vision for an everyday life
- Can be used by anyone in any setting
- Focused on all stages of the lifespan

Life Experiences and Life Transitions

- Getting New Diagnosis
- Parents Turn 65
- Medicare & SSDI
- Leaving Early Childhood/enter school
- Turning 18
- Leaving school at 18 or 21
- Living Adult Life
- Getting a home
- Finding a job
- Volunteering
- Enjoying friends and family
- Chores and allowance
- Making Mistakes
- Learning to say “no”
- Scouts, 4H, faith groups
- Playing sports or an instrument
- Birthday parties with friends
- "Anticipatory Guidance for Life Experiences"
Everyday Lives: Recommendation 4

The vast majority of people with disabilities in Pennsylvania live with their families. Families need support in order to make an everyday life possible throughout the person’s lifetime.

Families need information, resources and training.

Discovery & Navigation (Info and Training)

Families need connections and peer support opportunities with other families.

Connecting & Networking (Talking to someone that has been there)

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

Goods & Services (Day to Day, Medical, Financial Supports)

Everyday Life Domains

Daily Life and Employment (school/education, employment, volunteering, routines, life skills)

Community Living (housing, living options, home adaptations and modifications, community access, transportation)

Social and Spirituality (friends, relationships, leisure activities, personal networks, faith community)

Healthy Living (medical, behavioral, nutrition, wellness, affordable care)

Safety and Security (emergencies, well-being, legal rights & issues, guardianship options & alternatives)

Citizenship and Advocacy (valued roles, making choices, setting goals, responsibility, leadership, peer support)
# Daily Life and Employment

**Daily Life**

- School/education, employment, volunteering, routines, life skills

**Education**

- Can I look at ways to continue learning and education?
- Is there something I’ve already learned that I would like to explore or develop?

**Employment**

- What will I do doing the day now that I am an adult?
- What are the things I really like or don’t like?

**Volunteering**

- Can I find or volunteer opportunity that matches my interest or abilities?

**Routines**

- Are there any changes in my daily routine that I would like to try?

**Life Skills**

- Can I learn or improve in any skill that I really want to do?

**Engagement**

- Does my transition plan include work or volunteer experience, and providing time to look for, get, and keep a job?

**Continuity**

- How can I plan to plan for success?

**Rituals**

- Are there any rituals that I would like to continue or try something new?

**Stress Management**

- Can I learn or improve in any stress management technique that would help me stay calm and focused?

**Communication**

- Are there any communication plans for adults?

**Health**

- Can I learn or improve in any health management techniques that would help me stay healthy and fit?

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**Resources**

- Your IEP for Transition
- Office of Vocational Rehabilitation
- Employment services – job coaching, job finding, Discovery (ADEPT)
- Career Link
- Works for Me
- Post secondary school – College, technical schools
- Home and Community Based Waivers
- Centers for Independent Living
- Social Security Administration: SSI and SSDI
- PA Family Network - Workshops and Mentoring

**Daily Life & Employment**

What a person does as part of everyday life – school, employment, volunteering, routines, & life skills.

**Agency Involvement: IEP Process**

<table>
<thead>
<tr>
<th>PROVIDER/AGENCY</th>
<th>WHEN</th>
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<tbody>
<tr>
<td><strong>Special Education Transition Planning</strong> - Assessments: Interest/Preference, Academics Activities to Support, Postsecondary Education, Employment, Independent Living</td>
<td>Before, During, and After High School</td>
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<tr>
<td><strong>OMHSAS – County-Based Mental Health Services (Child)</strong></td>
<td>Before, During, and After High School</td>
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<tr>
<td><strong>OVR - Early Reach Initiative Pre-Employment Transition Services (beginning age 14)</strong></td>
<td>Before High School and early High School career</td>
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<tr>
<td><strong>OVR – Pre-Employment Transition Services and Individual Cases [beginning at age 16]</strong></td>
<td>During High School</td>
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<tr>
<td><strong>OVR – Individual Cases</strong></td>
<td>After High School</td>
</tr>
<tr>
<td><strong>ODP – ID/A Waivers – Based on capacity and eligibility</strong></td>
<td>Before, During, and After High School</td>
</tr>
<tr>
<td><strong>ODP - Adult Autism Waiver (AAW) and Adult Community Autism Program (ACAP) – Age 21 and older</strong></td>
<td>After High School</td>
</tr>
<tr>
<td><strong>OMHSAS – County-Based Mental Health Services (Adult)</strong></td>
<td>After High School</td>
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Pennsylvania Office of Vocational Rehabilitation

OVR Services

Services available to OVR Customers:

- Diagnostic Services
- Vocational Evaluation
- Counseling & Guidance
- Pre-Employment Transition Services
- Restoration Services
- Placement Services
- Supported Employment
- Financial Aid for Training
- Assistive Technology
- Business Services
The Required Five PETS Include:

Under the Workforce Innovation & Opportunity Act (WIOA) of 2014, OVR is required to provide:

- Job Exploration Counseling
- Work Based Learning (WBL)
- Counseling on Opportunities for Enrollment in Comprehensive Transition or Post-Secondary Education Programs at Institutions of Higher Education
- **Workplace Readiness Training to Develop Social Skills and Independent Living**
- **Instruction in Self-Advocacy**

Independent Living Skills Instruction:

Group instruction that gives Students with Disabilities skills to access and use community services and supports to increase self-reliance and self-confidence in the workplace.
Independent Living Skills Examples:

- Budgeting and Finances as they relate to employment
- Housing options
- How to obtain a photo ID and other vital records
- Internet Usage and the impact of Social Media
- Transportation Methods
- Laundry and Hygiene
- Safety
- Nutrition for Employment
- Navigating Social Services
- Managing Health Needs

Pennsylvania Office of Vocational Rehabilitation

We can help students and their families feel empowered, heard and learn in a supportive inclusive environment together. All students should feel like they not only belong but have value... because it’s the path to a good life.
Community Living (housing, living options, home adaptations and modifications, community access, transportation)

<table>
<thead>
<tr>
<th>Transition</th>
<th>Adulthood</th>
<th>Aging</th>
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<tbody>
<tr>
<td><strong>Living Options</strong></td>
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<tr>
<td>What living options are available to me?</td>
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<td>Which living option will work best for me?</td>
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<td>What will I need to consider when choosing a living option?</td>
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<td>Accommodations and Access</td>
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<td>Transportation</td>
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<td><strong>Future Planning</strong></td>
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Resources

- IEP for Transition – Independent Living supports
- Centers for Independent Living
- Home and Community Based Waiver Services - own a home, LifeSharing, Group Homes, Home modifications
- Housing Authority – HUD: Section 8, Vouchers, etc.
- Self Determination Housing Project of PA
- Transportation services
- PA Family Network- Workshops and Mentoring

Community Living

Where and how someone lives – housing and living options, community access, transportation, home adaptations and modifications.
Lifesharing

*Lifesharing* refers to a manner of living where individuals with and without intellectual distinctions share life experiences, explore personal growth, and pursue individual goals by living together in common household.

In the Lifesharing Model, a provider agency enrolled with ODP contracts with people who wish to share their lives to serve as host homes. An individual with an intellectual distinction is then matched with the host home. The host home provides the Life Sharing HCBS Waiver services to the individual, and the provider pays the host home in the manner specified by their contract. The provider then submits a claim in PROMISSe for payment to the agency.

One of the fundamental goals of Lifesharing is to forge enduring and permanent relationships as the foundation for learning life skills, developing self-esteem and learning to exist in interdependence with others. To achieve this and other goals requires proximity and integration. For this reason, Lifesharing homes are limited to **no more than two** individuals.

The Benefits of Lifesharing

- Allows for more one-on-one attention to individuals’ needs and desires

- Lifesharing participants are integrated into all aspects of the host home household, just as they would be in a private home.

- As active members of the host home household, both individuals and Lifesharers benefit from their shared life experiences. The relationships established through Lifesharing are symbiotic in nature; everyone achieves personal growth through their interactions with one another.

- By learning how to live as a member of a household, Lifesharing participants acquire the life skills necessary for independent living, such as personal finance, social interaction, and household maintenance.
**SAVE THE DATE**

Monday, October 21 &
Tuesday, October 22, 2019
Kalahari Resort & Conventions
Mt. Pocono, PA

Pennsylvania's Lifesharing Coalition Presents...

**7th Annual Lifesharing Conference**

Family Friendly, Training Hours, Sponsorship Opportunities, Excellence in Lifesharing Award Ceremony, Large Venue and so much more!

**Look for more details April 2019!**

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**Healthy Living**

(medical, behavioral, nutrition, wellness, affordable care)
Resources

- PA Secondary Transition Guide
- Got Transition
- National Youth Transition Center
- PA Medical Home Project:
  - Transition Healthcare Checklist: (search for Transition to Adult Living in PA)
- Your Local Hospitals and Medical Community
- PA Family Network- Workshops and Mentoring
- PA Health Care Qualify Units (HCQUs)
Health Care Quality Units

The Health Care Quality Units (HCQUs) work to support and improve the health information and knowledge for the intellectual disabilities community service system by building capacity and competency within the physical and behavioral health care systems as well as the stakeholders of the ID system.

There are eight HCQUs across Pennsylvania. See Map:

- PA Office of Developmental Programs Health Care Quality Units
- Northwestern PA HCQU (Milestone HCQU Northwest)
- Northeastern PA HCQU (Advocacy Alliance)
- Central PA HCQU (Geisinger)
- Eastern PA HCQU (Advocacy Alliance)
- Philadelphia Coordinated Health Care (PCHCQI, Inc.)
- South Central PA HCQU (Advocacy Alliance)
- Southwestern PA HCQU (Kephos)
# Safety and Security

**Emergencies, well-being, legal rights & issues, guardianship options & alternatives**

**Public Safety**
- Do you know a number to call for help if you are in danger or need immediate assistance?
- Do you know who to call if you see suspicious activity on your property or in your community?
- Are you familiar with community resources that can help in emergencies?

**Emotional Health**
- If you are feeling sad or anxious, do you know how to access support services?
- Do you have a support system in place that you can rely on during tough times?

**Safety & Security**
- Do you have a plan in place in case of emergencies?
- Are you familiar with the emergency procedures in your building or neighborhood?

**Legal and Financial Planning**
- Do you have a will or a living will in place that outlines your end-of-life wishes?
- Do you have a power of attorney that appoints someone to make decisions on your behalf if you are unable to do so?

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**Safety & Security**

<table>
<thead>
<tr>
<th>Personal Safety</th>
<th>Legal and Financial Planning</th>
</tr>
</thead>
<tbody>
<tr>
<td>If I live in my own home or apartment, what measures should I have in place to ensure my safety?</td>
<td>If I have a will or a power of attorney in place, what does this mean?</td>
</tr>
<tr>
<td>Do I understand who should be notified if I am unable to communicate my wishes to others?</td>
<td>Do I have a plan in place to ensure that my wishes are carried out after my death?</td>
</tr>
<tr>
<td>What steps should I take to prepare for any legal or financial issues that might arise?</td>
<td>How can I ensure that my financial affairs are in order?</td>
</tr>
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**Aging**

<table>
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<th>Legal and Financial Planning</th>
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<tr>
<td>If there are legal or financial issues that arise, who will be responsible for making decisions on my behalf?</td>
<td>If I have or do not have a will in place, who will inherit my property?</td>
</tr>
<tr>
<td>How can I ensure that my wishes are known and respected?</td>
<td>How can I ensure that my affairs are managed in accordance with my wishes?</td>
</tr>
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</table>
Resources

- Special Needs Registry – emergency responders
- Yellow Dot – information notice to look in the glove compartment
- PA Assistive Technology Foundation
- APPs and other GPS technology
- Legal Decision Making – Power of Attorney, Guardianship and Supported Decision Making
- Self Advocacy Skill development – IEP goals and other resources
- PA Family Network - Workshops and Mentoring
- PA Health Care Quality Units (HCQUs)

Safety and Security

Staying safe and secure – emergencies, well-being, guardianship options, legal rights & issues.

People with disabilities are sexually assaulted 7x more than people without disabilities.
A Person with a Disability is More Likely to Suffer from Police Brutality Partially because the manifestation of their Disability can be Misunderstood as Defiant Behavior

Victimization Risk Continued

- May Need to Learn Safety Skills and Ways to Protect Themselves
- May Not have Anyone to Advocate for them!
Recognize the Signs...

- Memory Loss
- Breaks/Bruises
- Personality Changes/Behavioral Changes
- Social Isolation
- Giving Away Assets/Belongings
- Banking Changes
- Weight Loss

Report Abuse...

- 1-800-932-0313
- 1-800-490-8505
- 1-800-490-8505
Make A Plan

- Learn the Signs of Abuse/Victimization
- Know the Tools (Registries/Yellow Dot)
- Prepare For A Wandering Incident
- Teach Self-Advocacy & Disclosure
- Consider ID Options
- Build Safety Life Skills
- Be known in Your Community
Social and Spirituality (friends, relationships, leisure activities, personal networks, faith community)
Social and Spirituality

Resources

- Community Centers
- Volunteer groups
- Social Media
- Library
- Faith Communities
- Fire Department
- Hobbies and Clubs
- Friendship Circle
- Meet Up, a social website to find others with similar interests.
- Home and Community Based Waivers
- PA Family Network- Workshops and Mentoring
Time Banking

What is time banking?

- A network of people using time as currency to exchange services
- Person A does something for Person B, B pays A using time credits and Person A can spend these time credits on recruiting the services of Person B or any other person using the time bank
Citizenship and Advocacy (valued roles, making choices, setting goals, responsibility, leadership, peer support)
### Citizenship and Advocacy Resources

- Participate in your Transition IEP and your other planning meetings
- Register to Vote, Carry a state ID
- Join local Civic Associations
- Neighborhood Watch groups
- Volunteering, Involved in local politics
- Self Advocacy groups – PYLN, SAU1, Speaking for Ourselves
- Centers for Independent Living
- Arc of PA and their chapters
- Disability advocacy groups
- PA Family Network - Workshops and Mentoring

### Building valued roles, making choices, setting goals, assuming responsibility, and driving how one’s own life is lived.
Self-Advocacy is Expressing

Thoughts & Ideas
What You Need
How You Feel

Self-Advocacy Skills

Speaking Up
Learning
Choice
**Self-Advocacy Training:**

Group instruction that gives Students with Disabilities the skills to effectively communicate, convey, negotiate or assert their own interest and/or desires. The goal is for students to take responsibility for communicating their needs and desires in a straightforward and respectful manner to others.

**Self-Advocacy Examples:**

- Disability Awareness
- Setting Goals
- Self-Determination
- IEP and Transition
- Decision Making
- Relationships and Boundaries
- Self-Care and Wellness
- Disability Disclosure
- Assistive Technology and Accommodations
- Community Resources
THE LIFECOURSE TOOLS

ENVISIONING YOUR EVERYDAY LIFE IN ACTION
LifeCourse tools

Transition Planning and Resources

LifeTrajectory Worksheet

Transition Planning and Resources

Charting the LifeCourse

Life Domain: Transition to Adulthood

Charting the LifeCourse, which was created to help individuals and families address common issues throughout life.
## CHARTING the LifeCourse

### Tool for Developing a Vision - Individual

Forming a vision and beginning to plan for the future in each of the life domains helps plot a trajectory for a full, inclusive, quality life in the community. This tool is to help individuals with disabilities of all ages think about a specific vision in each life domain for how they want to live their adult life, and prioritize what they want to work on right now that will help move toward the life vision.

<table>
<thead>
<tr>
<th>LIFE DOMAIN</th>
<th>My Vision for My Future</th>
<th>priority</th>
<th>Current Situation/Things to Work On</th>
</tr>
</thead>
<tbody>
<tr>
<td>Daily Life Employment</td>
<td>What do I think I will do/want to do during the day in my adult life? What kind of job/career might I like?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Community Living</td>
<td>Where would I like to live in my adult life? Will I live alone or with someone else?</td>
<td></td>
<td></td>
</tr>
<tr>
<td>Social &amp; Spirituality</td>
<td>How will I connect with spiritual and leisure activities, and have friendships and relationships in my adult life?</td>
<td></td>
<td></td>
</tr>
</tbody>
</table>

### Exploring Life Possibilities

There are many options for living, working, and playing in the community. What might have been great 30 years ago, may not work for today's vision of a quality life in the community. This tool is to help individuals and families look at a variety of life options in each of the life domains, some of which are traditional or historic and no longer preferred by many, some that are known and tried, but not necessarily the norm, and others that are new or unfamiliar to individuals, families, and professionals.

<table>
<thead>
<tr>
<th>Innovative Life Options</th>
<th>Traditional Life Options</th>
</tr>
</thead>
<tbody>
<tr>
<td>- Micro-enterprise</td>
<td>- Sheltered workshops</td>
</tr>
<tr>
<td>- Careers</td>
<td>- Day Institution</td>
</tr>
<tr>
<td>- Competitive employment</td>
<td>- Community Living</td>
</tr>
<tr>
<td>- College or tech school</td>
<td>- Social &amp; Spirituality</td>
</tr>
<tr>
<td>- Supported employment</td>
<td>- Healthy Living</td>
</tr>
<tr>
<td>- Work sites or services</td>
<td>- Safety &amp; Security</td>
</tr>
<tr>
<td>- Job coaches</td>
<td>- Citizenship &amp; Advocacy</td>
</tr>
<tr>
<td>- Volunteering</td>
<td>- Supports for Family</td>
</tr>
<tr>
<td>- Special college programs</td>
<td>- Support Services</td>
</tr>
</tbody>
</table>

New ideas things that someone has tried, and you replicate or adapt for your own needs: things that haven't been thought of yet or tried.
Charting the LifeCourse
Experiences and Questions Booklet
A Guide for Individuals, Families, and Professionals

Throughout our lives, we face questions and search for answers that will help us on our journey to a full and meaningful life. This is true for anyone, especially when you or someone you care about experiences a disability or special health care need.

Charting the LifeCourse is a tool to assist you in creating a vision for the future. It is designed to help you think about the questions to ask as well as the choices, options, and life experiences to consider as you “plot a course” to a full and meaningful life. It is intended to be a starting point, no matter where you are in your life journey.

We hope this LifeCourse Experiences and Questions booklet helps you realize that even when your child is very young, and whenever you are on the journey as a parent and grow into adulthood, their life experiences and environment can shape how they will live life in the future.
LifeCourse Focuses on **day-to-day** experiences, relationships, supports, and resources that will **keep us moving toward our vision**.

- What happens everyday is important. Questions to consider:
  - Are the experiences we are having today following the trajectory toward our dreams?
  - What relationships and opportunities can help make this happen?
  - Where can we be involved in community and build those contacts and experiences?
  - What skills or training may be helpful in keeping me moving toward my vision of an everyday life?

The LifeCourse Tools lead people to think creatively and anticipate what’s next.
MY ODP

SUPPORTING FAMILIES
COMMUNITY OF PRACTICE
Visit the National Community of Practice website

Welcome to the Office of Developmental Programs Resource Center

Questions?
Reach out we can help!

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Office of Vocational Rehabilitation

Pennsylvania Youth Leadership Network

Family Network
Supporting Families Throughout the Lifespan

Pennsylvania Department of Education

Pennsylvania Community of Practice for Supporting Families

Support Families
Life Course Tools
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