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.

In the next two hours:

➤ National Community of Practice
➤ Concept of “ALL”
➤ Foundational beliefs of the LifeCourse Framework
➤ LifeCourse tools (with exercises)
➤ Next steps for PA
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"

What do we know?

- Expectations are formed early and over time.
- Expectations shape experiences.
- Experiences also shape expectations.
- Expectations are influenced by opportunities and support.

Where should we go?

- We must connect families with ordinary examples of what is possible.
- We must invest in expectations.
- We must catch and communicate a collective vision.
- Finally, professionals must let parent expectations challenge their own.
EXERCISE!

"God, we...now the paradigm is shifting."

WINGSPREAD REPORT, 2011
RECOMMENDATION 1:
Design the structure and functions of state service systems to include a focus on supporting families reflective of the fact that most people with I/DD are living with their families in the community.
Wingspread report, 2011

- Identify strategies for collaboration and support with local and statewide family-focused organizations or networks that can assist in the development, implementation and evaluation of strategies for supporting families.

- Establish mechanisms to maintain ongoing dialogue with families, services system representatives and other key stakeholders involved in supporting families.

Wingspread report, 2011

- Increase opportunities for self/family directed service options.

- Build the capacity of supports coordinators to support and plan with people with autism or intellectual disability within the family unit.

Wingspread report, 2011

- Identify and fund strategies for assisting individuals with I/DD and their families to navigate both disability and community services and supports, including informal or natural supports.

- Provide training to all stakeholders on supporting persons with I/DD within their natural homes and communities, accessing community services along with disability supports as needed.
the national community of practice

- Grant from AIDD in 2012
- 5 states plus Missouri as mentor state
- 5 year initiative, now in 4th year
- Expansion to more states starting July 1, 2016
- PA accepted in February to join national Community of Practice
- What joining will mean for PA

12 more states joining as of 7/1/16

![Map of the United States showing states highlighted for the national community of practice.]

type of change that is needed

- Transitional Change
  - "Rethinking" the system and its practices to fit the new model
  - Merges, consolidations, reorganization, revising systematic payment structures.
  - Creating new services, processes, systems and products to replace the traditional one

- Transformation Change
  - Fundamental reordering of thinking, beliefs, culture, relationships, and behavior
  - Tense assumptions inside out and disrupt familiar habits and structures
  - Rejects command and control relationships in favor of co-creative partnerships

Creating Blue Space, Hans Metzner, 2013
Developing innovative strategies for transformation within and outside DD system

- Family and Self-Advocacy Networks
- Simplify the front doors
- Give families a different, positive narrative
- Inclusive education with supports
- Adaptive equipment
- Problem Solving and Life Navigation
- Inclusively designed and affordable homes
- HIIT and fitness knowledgeable and supportive
- Strong families and friends share their lives.
- Inclusive and accepting spiritual and recreational opportunities
- Changes public opinion that work for ALL
- And much more...

Foundational Beliefs

Core Belief:
All people and their families should be able to live, love, work, play and pursue their dreams and aspirations in their communities.
All of us exist within the context of family

- Family is defined by the individual
- Individuals and their family may need supports that adjust as roles and needs of all members change
- Not dependent upon where the person lives

lifecourse framework basics

A Good Life for All

- The individual will achieve self-determination, interdependence, productivity, integration, and inclusion in all facets of community life.
- Families will be supported in ways that maximize their capacity, strengths, and unique abilities to best nurture, love, and support all family members to achieve their goals.

Services and Supports are Evolving

- Everyone exists within the context of family and community
- Traditional Disability Services
- Integrated Services and Supports within context of person, family, and community
Reciprocal Roles Between all Family Members

- Caring About
  - Affection & Self-Esteem
  - Repository of knowledge
  - Lifetime commitment
- Caring For
  - Provider of day-to-day care
  - Material/financial
  - Facilitator of inclusion and membership
  - Advocate for support

*Adapted from Rigby & Yaffe (2012), Daily (1998), Turbott et al. (2011)

The LifeCourse Tools

- Trajectory Toward a Good Life
- Life Domains: Outcomes and Possibilities
- Three Buckets of Support
- Integrated Supports Star

These tools are:

- Conversation starters
- Problem solvers
- Valuing about the future
- Empowering ownership of a vision
- Can be used by anyone in any setting
- Focused on all stages of the lifespan
Life Trajectory:
Experiences and Life Stages

Vision for a Good Life

The future is not something we enter. The future is something that we create. And creating that future requires us to make choices and decisions that begin with a dream.

> Leonard Sweet

Life Stages and Trajectory Toward the Good Life

What would that good life look like?

What do we know we don't want to see happen?
Achieving Outcomes for Connected Life Domains

- Daily Life and Employment (school/education, employment, volunteering, routines, life skills)
- Healthy Living (medical, behavioral, nutrition, wellness, affordable care)
- Community Living (housing, living options, home populations and settings, community access, transportation)
- Safety and Security (emergencies, well-being, legal rights & issues, guardianship options & alternatives)
- Citizenship and Advocacy (voted roles, making choices, setting goals, responsibility, leadership, peer support)
- Social and Spirituality (friends, worship, leisure activities, personal networks, faith community)

Looking at Life Possibilities

| Innovative | Very new or undiscovered |
| Island of Innovation | Exists in a lot of places but not everywhere |
| Traditional Options | Services that have existed for a long time |

THREE BUCKETS

- Discovery & Navigation (information and referral)
- Connecting & Networking (getting to know someone who has "been there")
- Goods & Services (plan to daily support of home, work, and in the community)
INTEGRATED SUPPORTS

A USEFUL TOOL FOR:
- Problem-solving
- Identifying strengths
- Exploring options
- Seeing opportunities

EXERCISE!

next steps for PA
The PA Family Network

- Coordinated by Vision for Equality
- Curricula to be developed jointly with ODP
- Content for families will be centered around envisioning a good life, using lifespan tools, and seeing supports and services in a new way
- Family Advisors across the state will help families to connect with each other, support mentoring relationships, and help to identify community resources.

Person-Centered Thinking Trainers

- Ten family members across the state were selected and are engaged now in becoming fully-credential PCT Trainers

Self-Advocates United as One

- Launching July 1 with a plan to support self-advocate training and mentoring across the state, and will work in parallel efforts with PA Family Network
6-8 Regional Collaboratives

- Counties, SCOs, ASERT and ODP staff (ID and autism, regional and central office staff), self-advocates and families, providers, as well as community partners working together to build commitment, strength and new approaches in local areas to better support real lives.

Putting the Lifecourse Framework Together

www.supporttofamilies.org
www.lifecoursetools.com

Thank you!
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