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Deputy Secretary

Office of Developmental Programs
Oct. 14th, 2016

Then and Now

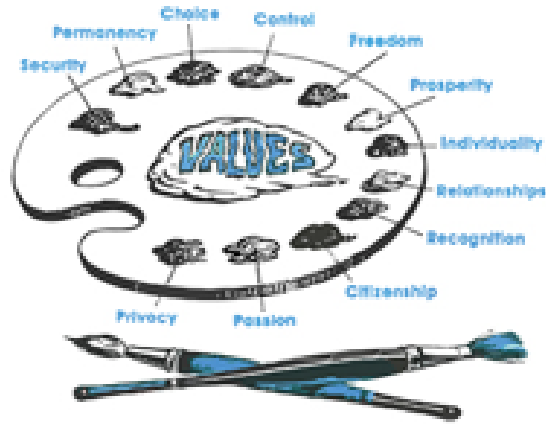
EVERYDAY LIVES, 1991

In 1989, the Pennsylvania Office of Developmental Programs (ODP) invited people with disabilities, families, advocates, governmental officials, and service providers to think about what the future should look like for all people with disabilities. Pennsylvania had been a national leader in creating community services as an alternative to institutional services, but it was time to think more deeply about what the purpose of community services should be — what kinds of experiences and opportunities people should have and what the overall outcome should be.

For months, participants conducted research about best practices and discussed their findings. Most importantly, the planning group asked people with intellectual disabilities what was important to them. The result was a list of *Everyday Lives* principles that has guided ODP and the service system since *Everyday Lives* was published in 1991.

Deeply rooted in the concept of self-determination, *Everyday Lives* promotes the belief that, with the support of family and friends, people with disabilities can and should decide how to live their lives.

The original *Everyday Lives* told us what was important to people with disabilities and made



An illustration from the 1991 *Everyday Lives* publication shows what people with disabilities value in their lives.

recommendations about how the service system should increase opportunities for full community participation, provide individuals with more control over services, and improve the system's accountability for assuring health, safety, and positive outcomes.



CREATING *EVERYDAY LIVES*, 2016

In November 2014, ODP formed the Information Sharing and Advisory Committee (ISAC), an ongoing committee to discuss policies and practices and make recommendations to ODP.

More than 265 stakeholders conducted research and evaluated best practices to determine the most important steps for ODP to take to improve system delivery.

Recommendations were submitted by the Futures Planning Work Group and were further developed and explored by ISAC members, resulting in this edition of *Everyday Lives*.



EVERYDAY LIVES: VALUES IN ACTION

The foundation of *Everyday Lives: Values in Action* is two statements:

1. We value what is important to people with disabilities and their families, who are striving for an everyday life. An everyday life is about opportunities, relationships, rights, and responsibilities. It is about being a member of the community, having a valued role, making a contribution to society, and having one's rights as a citizen fully respected. It is a vision that we should all be working toward together.

2. People with disabilities have a right to an everyday life; a life that is no different than that of all other citizens. This continues to be the truest statement on which we can build our work.

Everyday Lives will be a guide to ODP as it develops policy and designs programs. Providers of services will use the recommendations of *Everyday Lives* to support individuals and



their families to achieve an everyday life. *Everyday Lives* will guide everyone toward the possibility of an everyday life.

History



HISTORY

Accomplishments of the past raise expectations for the future

1940s

- Families across the commonwealth formalized their support and advocacy network with incorporation of the Pennsylvania Association for Retarded and Handicapped Children, 1949

1960s

- The Mental Retardation Facilities and Community Mental Health Centers Construction Act (P.L. 88-164) provided money to build community facilities, 1963
- Social Security Act Amendments (P.L. 88-97) established Medicare and Medicaid, 1965
- The Pennsylvania MH/MR Act established a system of community services, 1966

1970s

- PARC vs. Commonwealth established the right to education with due process in Pennsylvania, 1971
- Pennsylvania funded Family Support Services for the first time, 1971
- Pennsylvania began funding Community Living Arrangements for the first time, 1971
- The Federal Education for All Handicapped Children Act (94-142) mandated free, appropriate, and individualized education for all children in the least restrictive environment, 1975
- Protection and Advocacy system was mandated (P.L. 94-103), 1975
- Federal court rules that institutionalization is a violation of constitutional rights to equal protection in the case of PARC vs. The Pennhurst State School and Hospital, 1977



1980s

- Lifesharing program began, 1982
- Self advocates in Pennsylvania formalized their peer support group and incorporate as *Speaking for Ourselves*, 1982
- Federal Fair Housing Act added disability as a protected class, 1988

1990s

- Americans with Disabilities Act (ADA) was passed, 1990
- Early Intervention Services System Act was signed by Gov. Robert P. Casey, 1990
- *Everyday Lives* was published by Gov. Casey, 1991
- Waiting list campaign: Individuals and families advocated for services for people and families who have been waiting for a long time, 1998
- *Multi-Year Plan* for Pennsylvania's system of services for people with disabilities and their families was published by Gov. Tom Ridge, 1997
- Pennsylvania included post-secondary education options in waiver services, 1997



Cover of the 2001 publication, *Everyday Lives: Making It Happen*.

- *Five Year Plan to Address the Waiting List* was adopted, Gov. Ridge, 1998
- *Self Determination* grant was awarded by the Robert Wood Johnson Foundation, 1999



- The Person/Family Directed Support Waiver was implemented, 1999
- U.S. Supreme Court ruled in *Olmstead vs. L.C.* that integration is for everyone, 1999

2000s

- Independent Monitoring for Quality (IM4Q) was established, 2000
- *Everyday Lives: Making It Happen*, was published by Gov. Ed Rendell, 2001
- Autism Task Force produced a report, 2004
- PA Act 62, Autism Insurance Act was established, 2008
- ODP initiated services to adults with autism, 2008

2010s

- Pennsylvania State Senate Bill No. 458 was passed amending the Mental Health and Mental Retardation Act

of 1966 by renaming it the Mental Health and Intellectual Disability Act, 2011

- Futures Planning Work Group met, 2013-15
- Home and Community-Based Services (HCBS) Final Rule mandated inclusive settings and person-centered practices, 2015
- PA was accepted into the National Community of Practice: Supporting Families throughout the Lifespan, 2016
- Gov. Tom Wolf signed the Employment First Executive Order to increase competitive, integrated employment among people with disabilities, 2016
- Pennsylvania Department of Human Services officially updated language to remove outdated or offensive terms in 24 chapters of regulations, 2016
- Gov. Wolf signed into law the Pennsylvania Achieving a Better Life Experience (ABLE) Act so people with qualified disabilities and their families can open tax-exempt savings accounts to be used for disability-related expenses, 2016

What is Important to People with Disabilities

EVERYDAY LIVES IN ACTION: MY LIFE, MY WAY
CONTROL: I have control over all areas of my life. My family, supporters, and community know these are my decisions and work with me to achieve greater control.
CHOICE: I decide everything about my life. My family, supporters, and community help me learn about opportunities and together we make them happen.
FREEDOM: I have the same rights as all other members of the community and I can fully use them. My family, supporters, and community respect my rights.

EVERYDAY LIVES IN ACTION: MY LIFE, MY WAY	
STABILITY: Changes to my life are made only with my permission and input. My family, supporters, and community do “nothing about me without me.” They plan with me to meet my needs, now and for the future.	EMPLOYMENT/MEANINGFUL CONTRIBUTION: I want to work and/or have other ways to contribute to my community. My family, supporters, and community support me to find and keep a real job that I like with good wages and benefits or start and run my own business, and/or volunteer the way I want in my community.
HEALTH AND SAFETY: I am healthy and safe in all areas of my life. I, my family, supporters, and community balance health, safety, and risk according to my wants and needs.	INDIVIDUALITY: I am respected and valued for who I am and want to be. My family, supporters, and community treat me with dignity and support me in a person-centered way.
CONNECTED: I am a full member of my community with respect, dignity, and status. My family, supporters, and community know me as a person, welcome and accept me.	RELATIONSHIPS : I decide who is in my life: friends, family, partners, neighbors, pets, and others in the community. My family, supporters, and community respect the relationships I choose and support me to form new relationships.
RESPONSIBILITY: I am dependable and honor my commitments. I keep my word. My family, supporters, and community are honest and fair, do what they’re supposed to do, and keep their word.	PARTNERSHIP: I need people in my life who will honor my life’s journey. My family, supporters, and community work together with me to build bridges.
COMMUNICATION: I am listened to and understood; my input is valued. My family, supporters, and community listen to me and communicate in ways that work for me.	QUALITY: I want my life my way. I, my family, supporters, and the community make sure the services I choose are proved to be of high quality.
SUCCESS: I am the best I can be in the goals that I decide. My family, supporters, and community learn how to support me to achieve my goals.	ADVOCACY: I am the best person to let others know what I want and need. My family, supporters, and community listen to me and understand what I want and need, and assist me to be heard by others.

What is Important to Families?

Family is integral to an everyday life. We are born into families and we choose families. Families are the foundation of our early development and often our achievements as adults.

If people with disabilities are to enjoy the everyday life that all citizens should enjoy, families will play a key role beginning in the earliest years by having a positive and promising vision for their child. Families can do this by knowing how to facilitate their child's full inclusion into the school and community, by ensuring

their child has all the experiences and opportunity needed to learn and grow toward independence, by having good advocacy skills, and by preparing for all of life's transitions into adulthood.

Families need support. Families need information, advocacy skills, and connections to other families. The realization of *Everyday Lives* is dependent on the service system successfully partnering with families to achieve the hopes and dreams of their family members.

EVERYDAY LIVES IN ACTION: WHAT FAMILIES VALUE

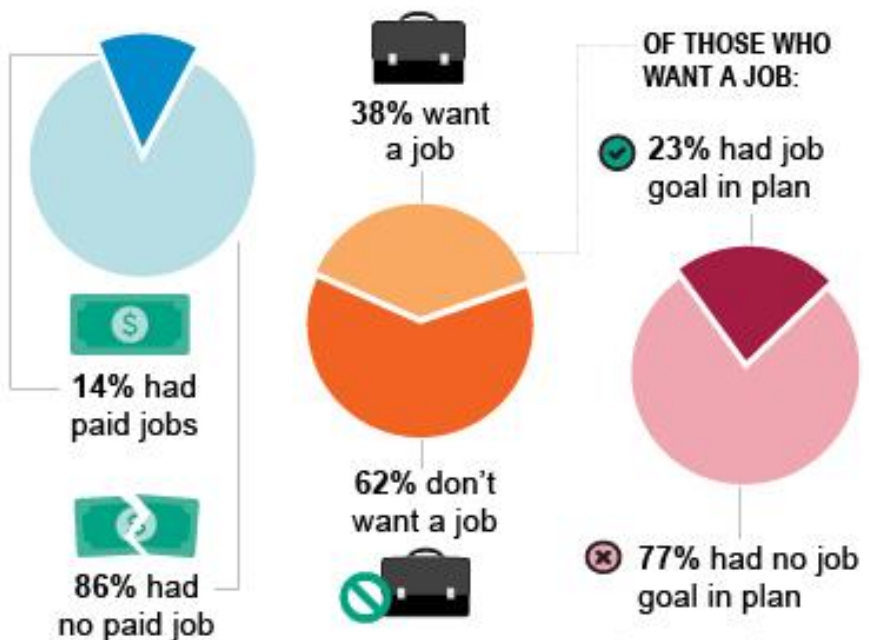
<p>THE UNIQUE ROLE OF FAMILY: Families represent the very heart of life throughout the lifespan.</p>	<p>CHOICE AND CONTROL: Families seek freedom, on behalf of their family members, to make responsible and personal choices in all aspects of life.</p>
<p>SUPPORTING FAMILIES THROUGHOUT THE LIFESPAN: Our families must be encouraged and supported early on in their children's lives to hope, dream, and reach for the future.</p>	<p>HEALTH AND SAFETY: People should be safe at home, work, school, and in the community.</p>
<p>KNOWLEDGE AND RESOURCES: Families want to feel strong so they can provide for and support their loved ones.</p>	<p>SIMPLICITY AND FLEXIBILITY: Families value a simplified and transparent system that is easy to access, understand, and navigate.</p>
<p>MENTORING: Families value mentoring as a strong component to informing and supporting families.</p>	<p>QUALITY AND STABILITY: Families value quality supports and services that enable people to live everyday lives.</p>
<p>COMMUNICATION: Good communication involves everyone working toward common goals, respecting one another in partnership.</p>	<p>COLLABORATION: Along with self advocates, family members must be part of the discussion, planning, and creation of every element of the service system.</p>
<p>RESPECT AND TRUST: Respect must be granted to families, their values and beliefs, homes, and privacy.</p>	<p>OPPORTUNITY FOR INNOVATION: Families support innovative, creative approaches that can be the key to truly person-centered solutions and often offer the most cost-efficient solutions.</p>



BY THE NUMBERS: *EVERYDAY LIVES* TODAY

EMPLOYMENT

Of people interviewed by Independent Monitoring for Quality:

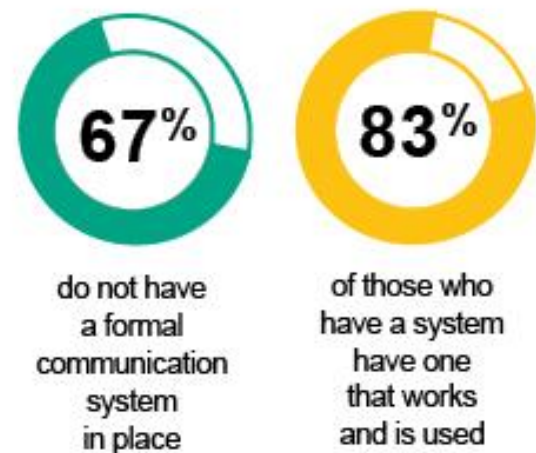


Source: National Core Indicators, 2012-13

COMMUNICATION

PEOPLE NEED TO BE HEARD

For people who don't communicate effectively through speech:



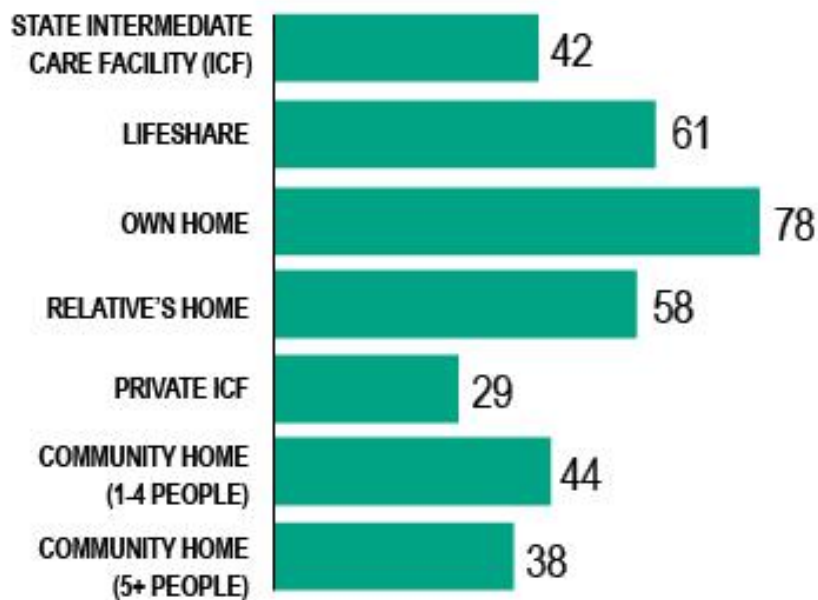
Source: 2014 Independent Monitoring for Quality, Institute on Disabilities, Temple University



LEVEL OF CHOICE

WHERE PEOPLE LIVE MATTERS

The choice scale runs from zero to 100. A higher score indicates a greater level of choice-making. The statewide average score is 48.

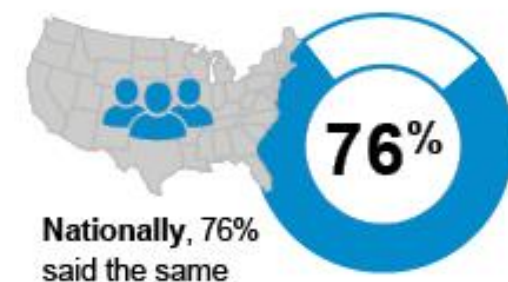
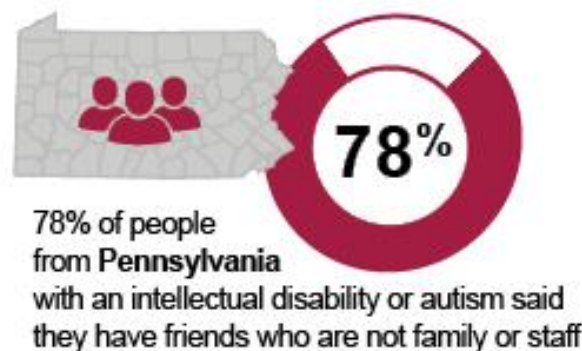


Source: 2014 Independent Monitoring for Quality, Institute on Disabilities, Temple University

RELATIONSHIPS

PEOPLE HAVE FRIENDS

In a National Core Indicators study:



Source: National Core Indicators (NCI) and Pennsylvania IM4Q, 2013-14

VALUES IN ACTION: RECOMMENDATIONS

I SAC recommendations for *Values in Action* are built on the values, goals, expectations, and aspirations of people with disabilities and their families. The recommendations are a guide for ODP to develop policy and design programs for people with disabilities, families, providers of service, and advocates who support people to have an everyday life.

1. ASSURE EFFECTIVE COMMUNICATION



Every person has an effective way to communicate in order to express choice and ensure their health and safety. All forms of communication should consider and include the individual's language preferences and use of current technology.

living, and how to have fun all are key choices in life, as are seemingly small choices, such as what to eat, what to wear, when to wake up in the morning, and when to go to bed. It is important to be able to trust the people who provide assistance, to feel confident that they respect you and your right to manage your life, and to enjoy each other's company.

2. PROMOTE SELF-DIRECTION, CHOICE, & CONTROL



Personal choice and control over all aspects of life must be supported for every person. Choice about where to live, whom to live with, what to do for a

Self-direction works when individuals have clear and understandable information, opportunities to exercise choice, and assistance with making decisions when needed. Self-direction is only possible when family, friends, and people who provide supports respect the individual's preferences and their right to make mistakes and facilitate the implementation of the individual's decisions.



3. INCREASE EMPLOYMENT

Employment is a centerpiece of adulthood and must be available for every person. The benefits of employment for people with disabilities are significant and are the same as for people without disabilities.

EMPLOYMENT IS:

- Feeling proud
- Having self-confidence
- Getting a paycheck
- Meeting new people
- Building new skills
- Paying taxes

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.

5. PROMOTE HEALTH, WELLNESS, AND SAFETY



Promote physical and mental health, wellness, and personal safety for every individual and their family. Promoting physical and mental health means providing information about health and wellness, emotional support, and encouragement. Tools that help every individual adopt a healthy lifestyle — including good nutrition, healthy diets, physical activity, and strategies to reduce and manage stress and protect oneself from all types of abuse and exploitation — must be provided.

6. SUPPORT PEOPLE WITH COMPLEX NEEDS



People with disabilities who have both physical and behavioral health needs receive the medical treatment and supports needed throughout their lifespans. When individuals, families, and providers plan and modify supports as people's needs change to meet these challenges, people are more able to live an everyday life. Opportunities for a full community life are dependent on adequate supports and the commitment to build capacity within the larger human service delivery system.



7. DEVELOP AND SUPPORT QUALIFIED STAFF



People with disabilities receiving services benefit when staff who support them are well trained. Values, ethics, and person-centered decision-making can be learned and used in daily practice through mentorship and training. Providing professional training that strengthens relationships and partnerships between individuals, families, and direct support professionals will improve the quality of support.

8. SIMPLIFY THE SYSTEM



The system of supports and funding of those supports must be as straightforward and uncomplicated as possible. This will allow for greater understanding and use of the system by everyone — most importantly the individual needing and receiving supports.

9. IMPROVE QUALITY



Together we must plan and deliver services and supports that adhere to our values, measure person-centered outcomes, and continuously improve an individual's quality of life. All stakeholders must be engaged in the process of measuring how well services assist people in achieving an everyday life.

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.



12. PROVIDE COMMUNITY SERVICES TO EVERYONE

Some people with disabilities — whether living on their own, with families, or in institutions — are waiting for community services. The goal is to build a system that has the capacity to provide services in a timely fashion for all people who need supports.

13. EVALUATE FUTURE INNOVATIONS BASED ON *EVERYDAY LIVES* PRINCIPLES



Future consideration of service models and reimbursement strategies must be based on the principles of person-centered planning, individual choice, control over who provides services and where, and full engagement in community life.

Innovative approaches should be evaluated based on the recommendations of *Everyday Lives*, including: employment, recognizing and supporting the role of families, and meeting the diverse needs of all individuals. Stakeholders should be fully engaged in designing, implementing, and monitoring the outcomes and effectiveness of innovative service models and service delivery systems.

April



Pamela



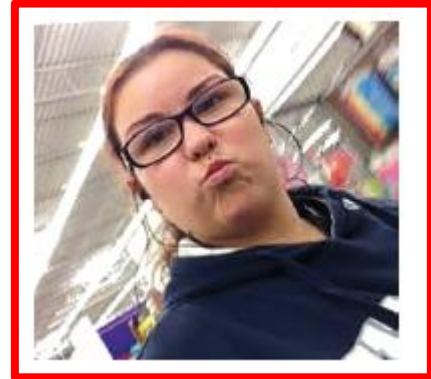
Alina and her family



Michael



Elysia



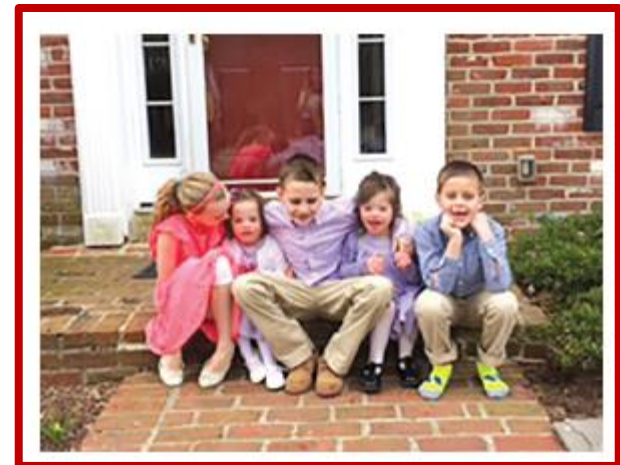
Austin and his sister Tiffany



Naomi and Justin, Mom and Dad



Susan, Meredith and Siblings





SUPPORTING FAMILIES

of individuals with intellectual & developmental disabilities
THE NATIONAL COMMUNITY OF PRACTICE • FUNDED BY THE ADMINISTRATION ON INTELLECTUAL & DEVELOPMENTAL DISABILITIES

Taking a Life Course Perspective





SUPPORTING FAMILIES

of individuals with intellectual & developmental disabilities

THE NATIONAL COMMUNITY OF PRACTICE • FUNDED BY THE ADMINISTRATION ON INTELLECTUAL & DEVELOPMENTAL DISABILITIES

Individual with Disability:
achievement of self-determination,
interdependence, productivity, integration
and inclusion in all facets of community life.

***Families:**
will be supported in ways that
maximizes their capacity,
strengths and unique abilities
**so they can best support,
nurture, love and facilitate.....**

Vision for a Good Life

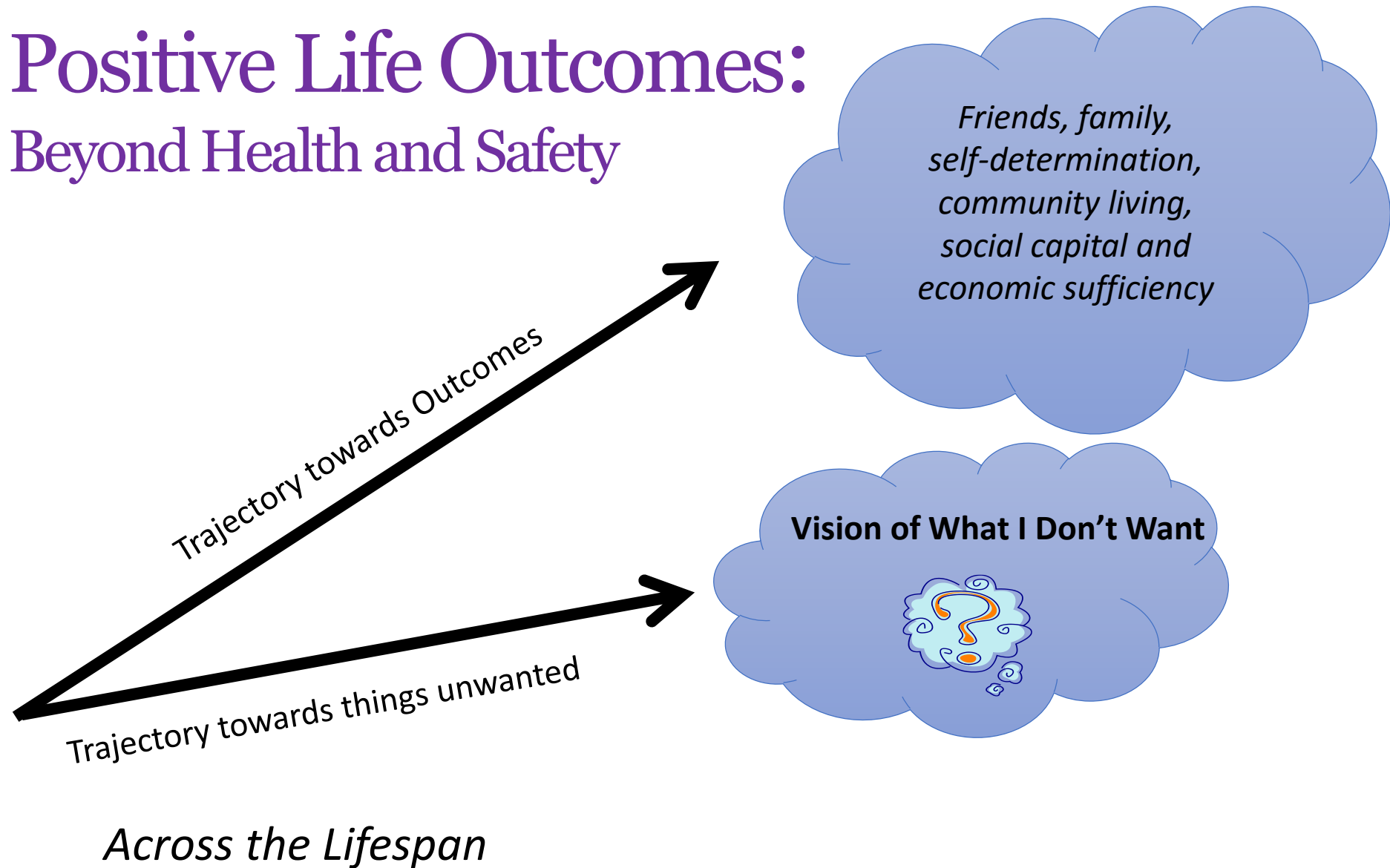


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*The future is not something we enter.
The future is something that we
create. And creating that future
requires us to make choices and
decisions that begin with a dream.*

- -Leonard L. Sweet

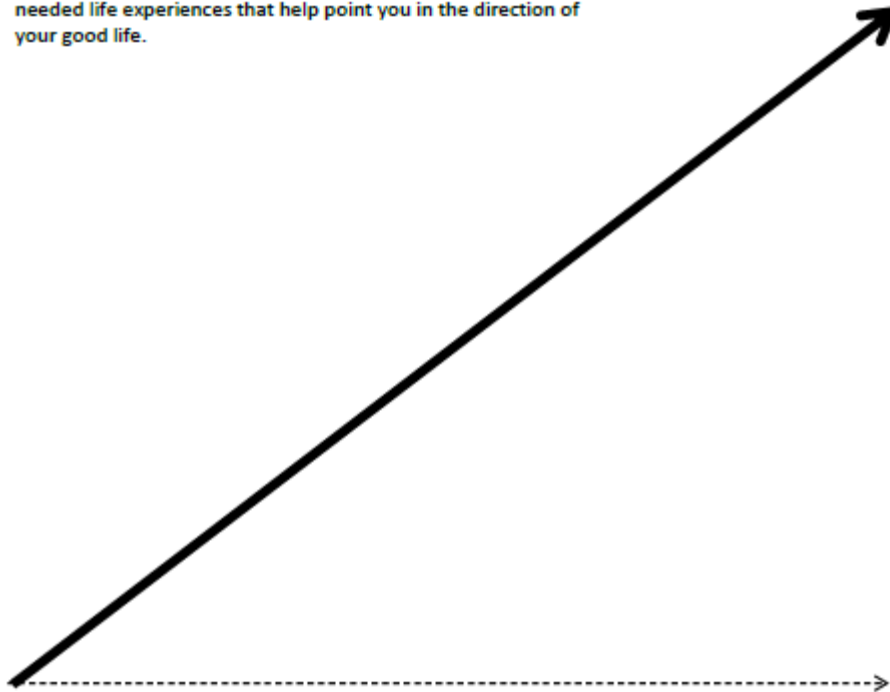
Trajectory towards Positive Life Outcomes: Beyond Health and Safety



CHARTING the life course

Life Trajectory Worksheet: Family

Everyone wants a good life. The bubbles on the right will help you think about what a good life means for you or your family member, and identifying what you know you don't want. You can use the space around the arrows to think about current or needed life experiences that help point you in the direction of your good life.



VISION for a GOOD LIFE

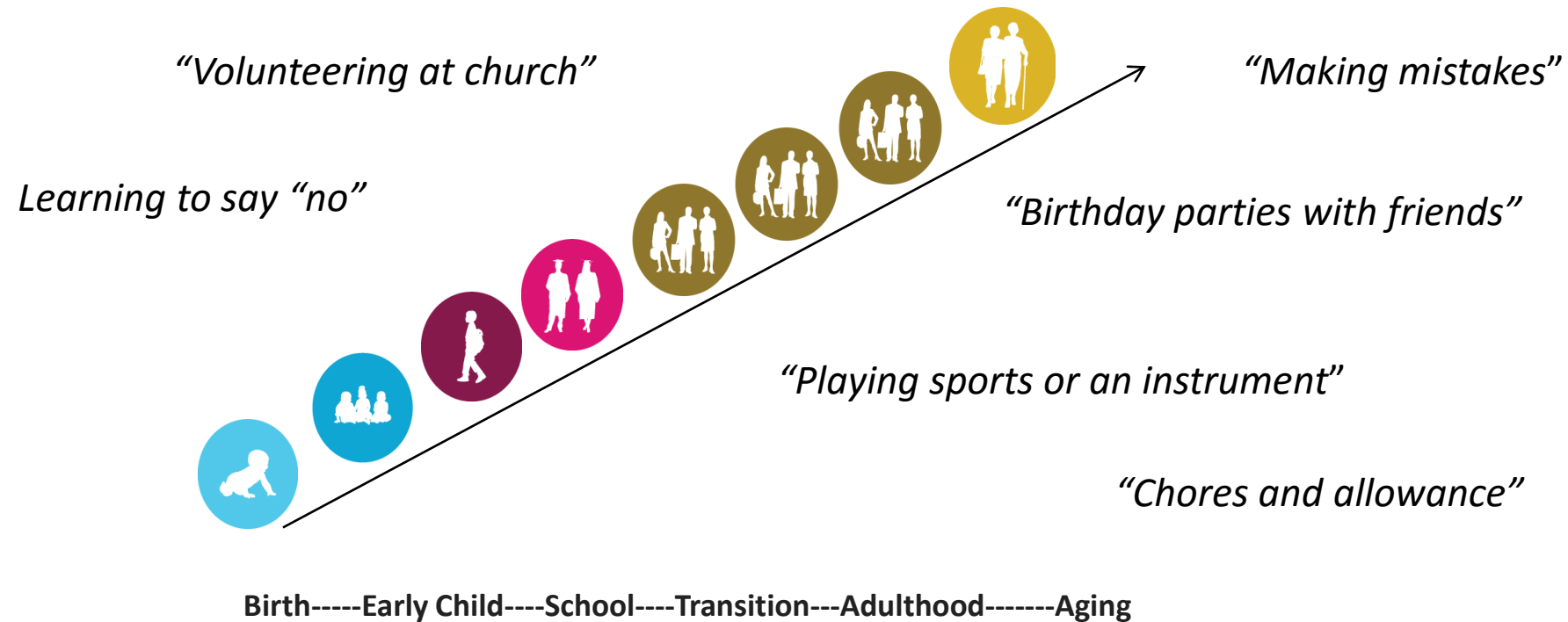
Family & Friends
Education
Career
Job of Choice
Economic Sufficiency
\$ for Home & Fun

What I DON'T Want

Poverty
Isolation/Loneliness
No opportunities
Sheltered Employment
Dependence on Gov't



Focusing on Life Experiences Across the Generations



“Anticipatory Guidance for Life Experiences”

Thinking Across All 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 adaptations and modifications, community access, transportation)



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



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



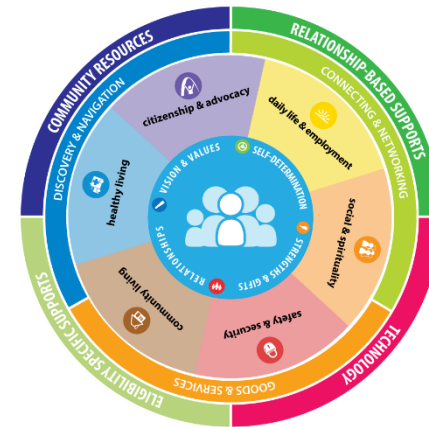
Citizenship and Advocacy
(valued roles, making choices, setting goals, responsibility, leadership, peer support)

Families Need Support

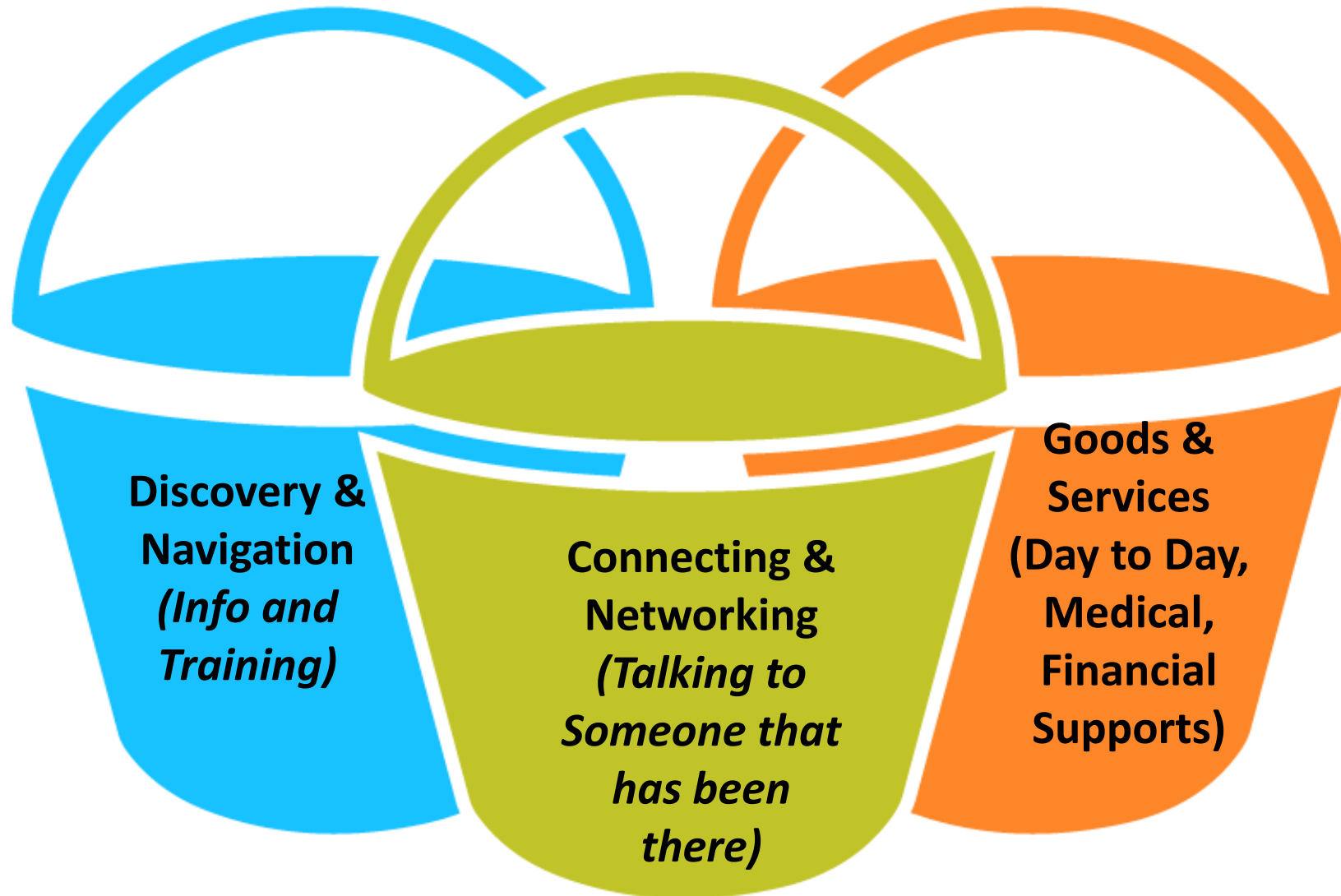
People with disabilities and their families...

have access to resources and supports, that are person and family centered and directed, that enhance individual lives and maintain the family well-being.

Life Course



Three Types of Supports



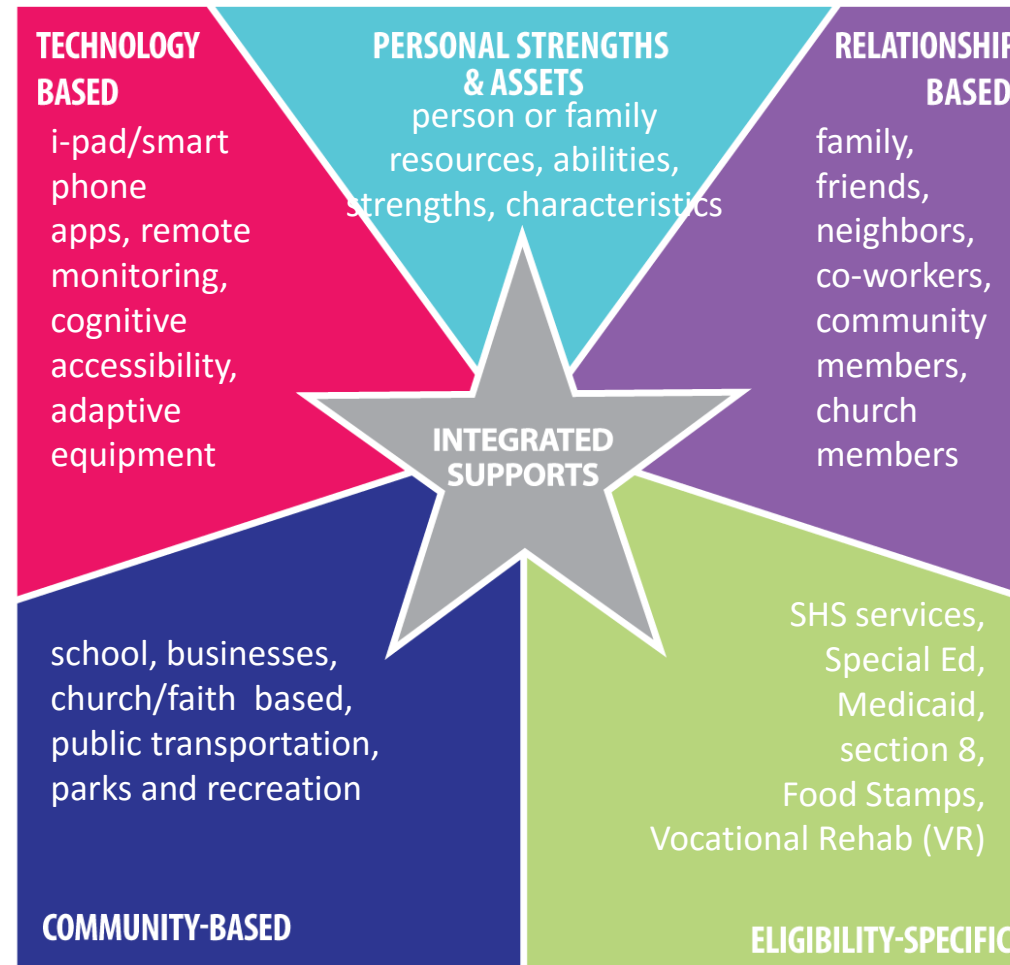


Types of Supports

Discovery & Navigation: Knowledge & Skills	Connecting & Networking Mental Health & Self-efficacy	Day-to-Day Services Instrumental Supports
<ul style="list-style-type: none">• Information on disability• Knowledge about best practices and values• Skills to navigate and access services• Ability to advocate for services and policy change	<ul style="list-style-type: none">• Parent-to-Parent Support• Self-Advocacy Organizations• Family Organizations• Sib-shops• Support Groups• Professional Counseling• Non-disability community support	<ul style="list-style-type: none">• Self/Family-Directed services• Transportation• Respite/Childcare• Adaptive equipment• Home modifications• Financial assistance• Cash Subsidies• Short/Long term planning• Caregiver supports & training

Families Need Assistance in Identifying, Developing and Integrating Supports & Services

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The Next Steps

- **Implement ISAC Recommendations**
- **Renewing Our Waivers ***
 - Incentivize employment
 - Promote full inclusion in the community
 - Greater supports for families
 - More independent living options
- **New Service Rates***
- **Implement New Federal HCBS Rule**
 - Employment; inclusion and rights
- **Training**
- **New 6100 Regulations ***
 - Promote full inclusion
 - Reflect the HCBS Rule
- **Rollout Supporting Families Community of Practice**
- **ISAC serve as Quality Council and measure progress on Everyday Lives**

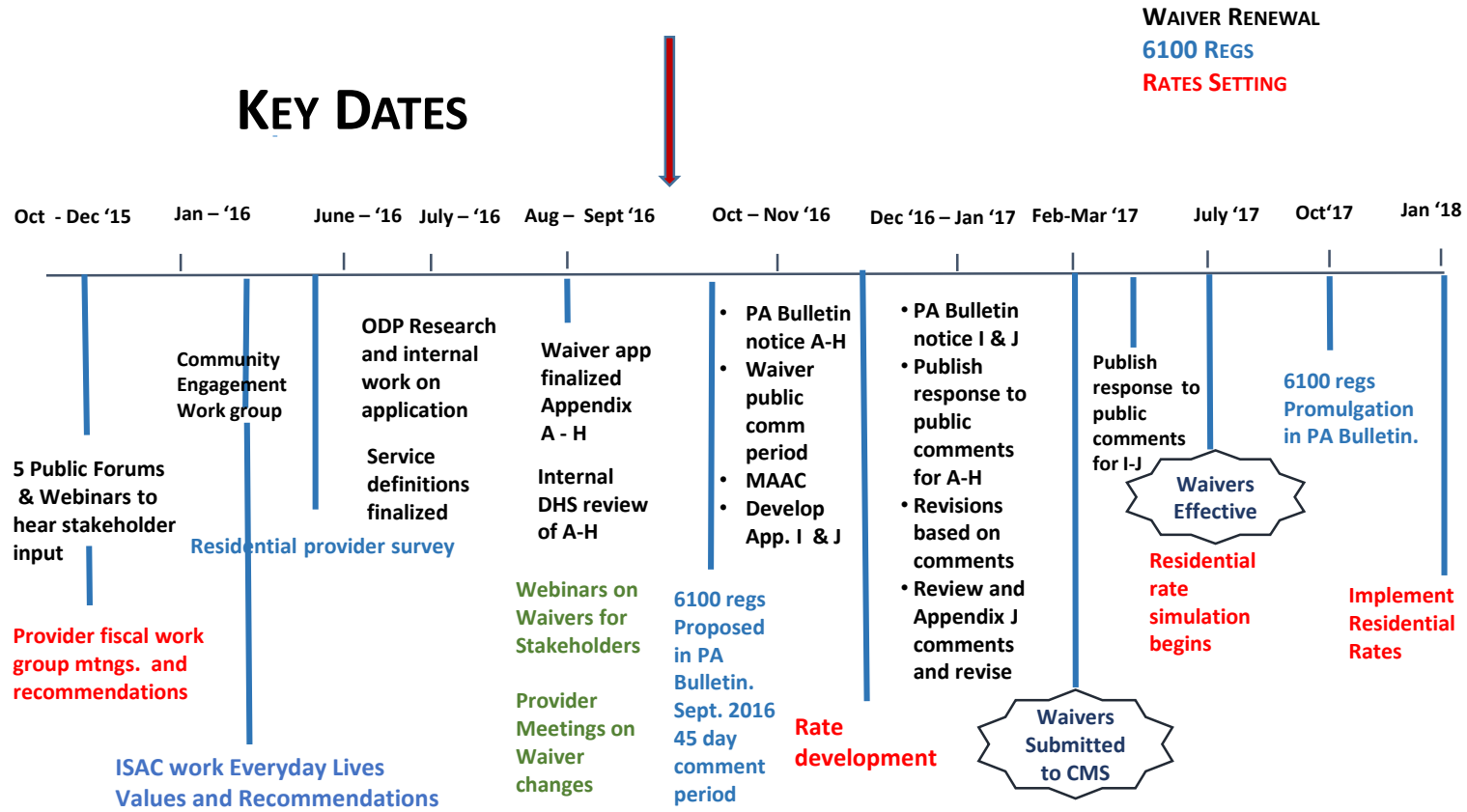
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PFDS and Consolidated Waiver Renewal Development Time Line





The End