



Imagine *Different* ... Achieve *Different* Coalition

We believe all children should grow up in families, and with the right supports, this can happen for all children with disabilities.

www.imaginedifferent.org

WHO WE ARE

The Imagine Different Coalition, formed in May of 2014, is a group of parents, advocates, professionals, and allies from across the state that has come together because of a shared concern about the number of children with disabilities growing up in facilities. The Coalition's mission is to champion systemic change and the development of community support to ensure that every child in Pennsylvania with disabilities who lives in or is at risk of being placed in a facility can alternatively grow up in a well-supported and loving family.

FISA Grant: Expanding Lifesharing Opportunities for Children

- Purpose: to promote the development of Lifesharing family options as alternatives to facility placements for children with complex disabilities and families of Allegheny County
- What we've done so far
 - Convened relevant stakeholders in Allegheny county
 - Engaged in guided dialogues
- What we have yet to do
 - Develop recommendations
 - Write final report

Introductions of Team

- Imagine Different Coalition presenters
- Allegheny Office of Developmental Supports
Promising Practice Team
- Allegheny families



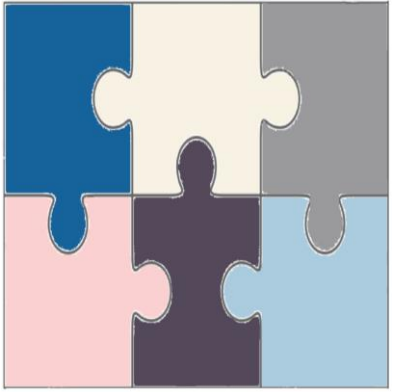
Our purpose today

*To share what we've
learned from stakeholders
and provide requested
information*



Our starting assumptions based on research and experience

1. Family life is a developmental need for children.
2. All children can live with families *with the right support*.
3. Lifesharing can provide support for families or a way to provide family life for children who cannot live at home.
4. Lifesharing is do-able based on experience in other states.
5. Lifesharing can work in Pennsylvania.



Lessons from experience in other states with lifesharing for children with disabilities

Six necessary elements

1. Understanding needs of children
2. Understanding families' experiences and perspectives
3. Finding good Lifesharing families
4. Matching children and Lifesharing families for children who can't stay at home
5. Transition planning
6. Supporting Lifesharing families



Who we talked to about Lifesharing for children in PA

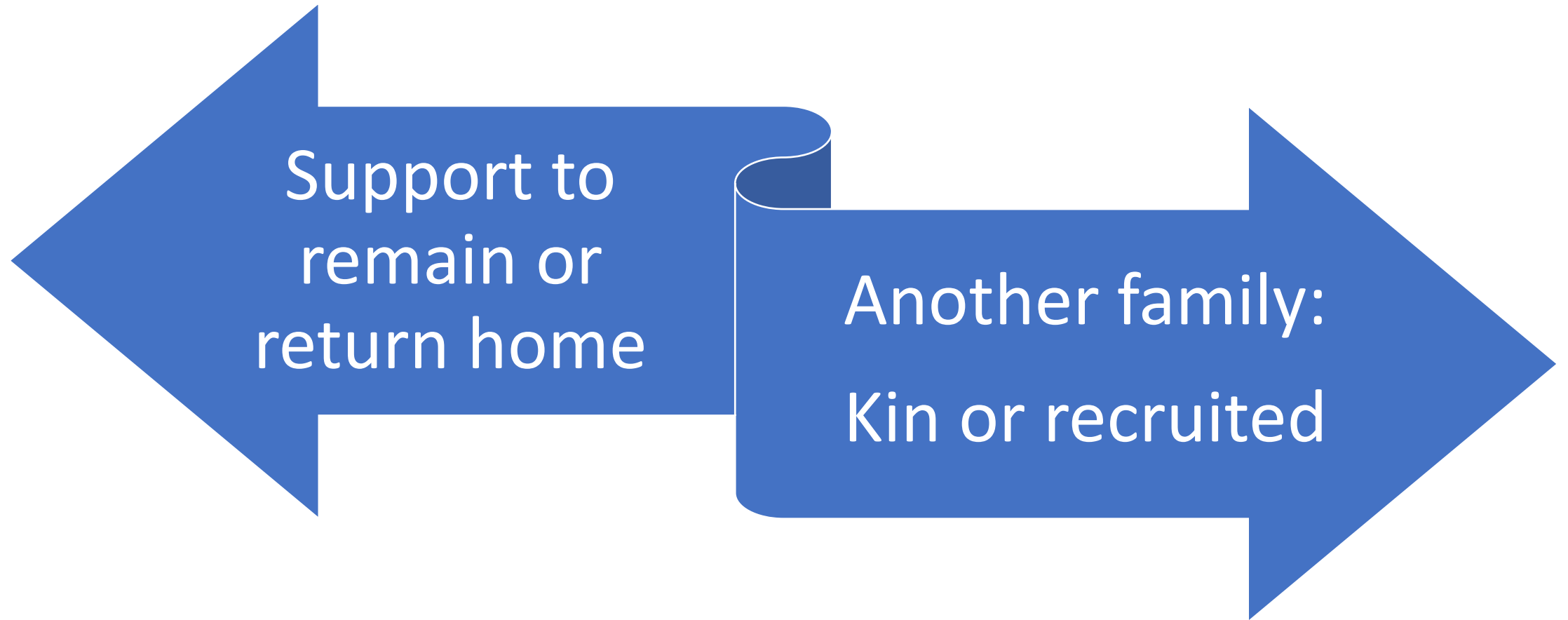
- Lifesharing Providers
- Supports Coordinators
- Managed Care Organizations
- Families



What we heard

- Families face challenges now and fear for the future
- Very few children are using or referred to Lifesharing
- Lack of awareness or misunderstanding of availability/eligibility for children's services that are different from adult services
- Lack of awareness or understanding of possibilities of Lifesharing for children
- Concerns about system issues (e.g., rates, staff shortages, multiple coordinators and turnover, processes)
- Concerns about recruiting and competency of potential LS families
- Concerns about trust and trustworthiness of support staff and potential LS families
- Wariness but also excitement about Lifesharing possibilities

Lifesharing opportunities



Families' thoughts about Lifesharing

We've asked families to address three things

1. Tell us about your family
2. What challenges are you dealing with?
3. What are your thoughts about the potential of Lifesharing
 - As support at home?
 - Use of an alternate family?

Topics we'll cover today

PART I

1. Imaginable possibilities of Lifesharing
2. Building trust and trustworthiness of Lifesharing
3. Finding Lifesharing families for children
4. Matching and transition planning to assure a well-prepared Lifesharing family

PART II

1. Children's services under Medicaid
2. Medicaid waivers
3. Recent changes

Imagine different: achieve different

- Imagine shared parenting and partner family possibilities
- Imagine family perspectives
 - Before: Wariness
 - Experience after: Feeling of kinship
- Imagine tailoring
 - Full-time or part-time
 - Shared parenting agreement
- Incorporate LS possibilities in Lifecourse planning



Past Life Experiences

List past life experiences and events that have prepared or supported my family member to move towards a vision for a good life

List past life experiences that pushed my family member's trajectory toward things they did not want or I did not want for them

Moving Forward

List current or future life experiences or goals that will continue to support my family member to move towards a vision for a good life

List barriers or things to avoid that might get in the way of my family member taking steps to reach their goals

My Vision for My Family Member's Good Life

What I Don't Want

LifeCourse Good Life Trajectory tool

Past life
experience

Moving
forward

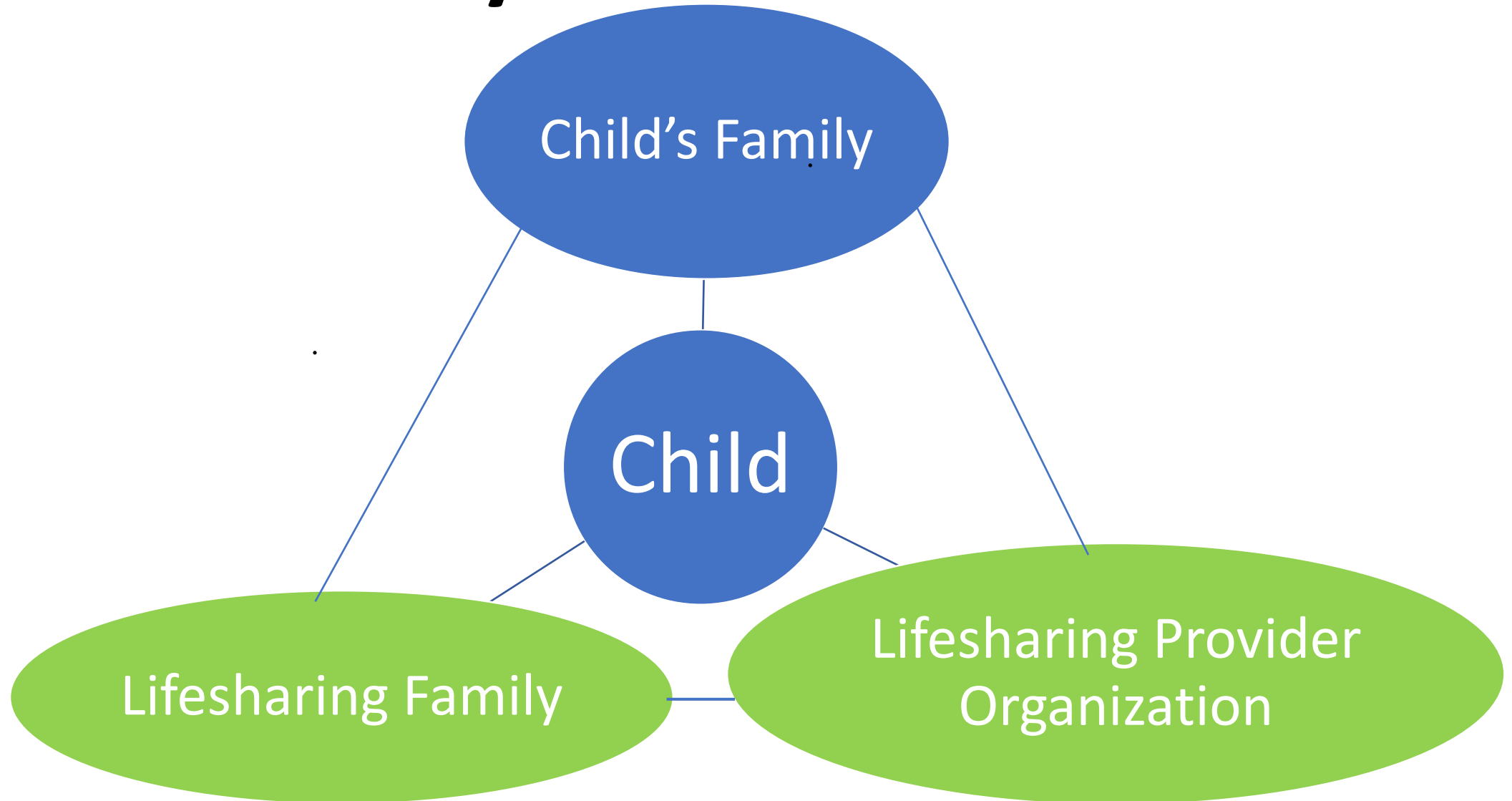
Vision for good life

What don't want

Conditions for building family trust and acceptance of Lifesharing for their child

1. Child's family retains decisions about whether to use Lifesharing and which Lifesharing family to use
2. Relationship with a trusted guide to explore the possibilities of Lifesharing
3. High quality, well-supported Lifesharing families readily available
4. Time, exposure, and experience

Relationships in Lifesharing with another family



Elements of trust

- Relationship/connection
- Longevity and continuity
- Competence
- Experience > earned trustworthiness
- Engagement > time and energy

Family	Past history and experience	Present situation	Future hopes and fears
<ul style="list-style-type: none">• Support coordinators• Support staff• Lifesharing families	<ul style="list-style-type: none">• Listen• Imagine	<ul style="list-style-type: none">• Understand• Acknowledge	<ul style="list-style-type: none">• Imagine• Anticipate

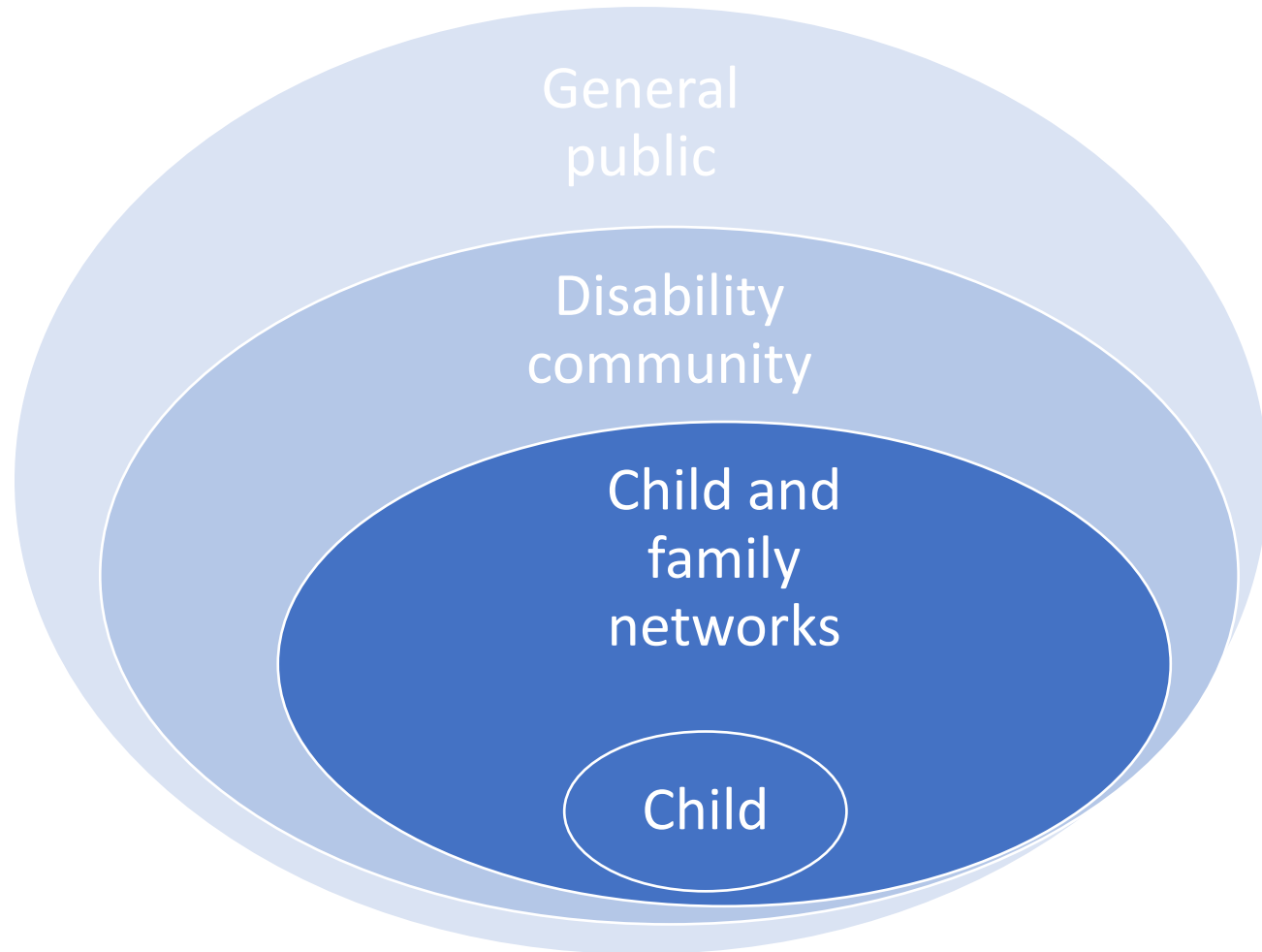
Finding good LS families

Myth: You can't find Lifesharing families for children with complex needs.

Availability of good Lifesharing families is directly related to:

1. The energy put into seeking and preparing them
2. The support available to sustaining them

Successful recruitment strategies



- 1. Child-specific**
 - Child's personal network
 - Family's personal network
- 2. Disability community**
 - Provider network
 - Word-of-mouth
- 3. General public**
 - Exposure
 - "Incubation period"

Recruitment strategies



Network: Use of
Lifecourse tools



LS provider:
Ongoing
recruitment of
pool



MAPPING RELATIONSHIPS

 CARING ABOUT	Who serves in this role now?	Looking Ahead	Next Steps
Shares Love, Affection and Trust			
Spends Time and Creates Memories Together			
Knows about Personal Interest, Traditions, Cultures			

 CARING FOR	Who serves in this role now?	Looking Ahead	Next Steps
Supports Day-to-Day Needs			
Ensures Material and Financial Needs are Met			
Connects to Meaningful Relationships and Roles			
Advocates and Supports Life Decisions			



LifeCourse Mapping Relationships tool

	Who now?	Looking ahead	Next steps
Caring about			
Caring for			

Matching and Transition

- Facilitator lead
- Team-based expertise
- Time and energy
- Phased
 - Get to know child's needs
 - Exposure > learning about > child specific training
 - Increasing time together
 - Visits in child's residence
 - Supervised caregiving in child's residence
 - Shorter increasing to longer caregiving in Lifesharing family's home
 - Detailed pre-move team-based plan





Building Lifesharing for children with disabilities in Pennsylvania

1. Expand imagination of LS possibilities
2. Expand Family Facilitator model for all children with disabilities in facilities
3. Expand LS provider capacity
4. Fully using existing resources



PART II

Children's Resources Explained

Children's Services are Not Enough

Though children have access to additional service systems including education and child welfare, and expanded Medicaid entitlements...

... without access to LifeSharing waiver services, many are growing up in facilities.

MA for Children in PA

- The MA benefit package for children (EPSDT) is much more comprehensive than that for adults.
- In PA, children with significant disabilities are eligible without regard to their parents' income.

Child Benefit Package - EPSDT

- Early and Periodic Screening, Diagnostic and Treatment services
- All children on MA under the age of 21 are entitled to EPSDT. This includes **virtually all medical services** that are necessary to treat an illness, condition or disability.
- Most, but not all, disability services are considered “medical”

Examples of EPSDT Services

- Services of any state-licensed health practitioner, e.g., Physical Therapy, OT, Speech
- Hearing Aids
- Wheelchairs and eyeglasses w/o limits on replacement
- Stairglides and wheelchair lifts
- Intensive Behavioral Health Services (IBHS) – 1/1 behavioral services at home, in school or in the community, including Applied Behavior Analysis (ABA); **AND**



Home Health Coverage

Shift nursing, home health aide or personal care services - **for as many hours as deemed medically necessary.**

State only considers nursing and home health aide services to be medically necessary when parents are unable (e.g., due to physical or mental limitations) or unavailable to provide the care – i.e., **when they are working, sleeping, or engaging in other responsibilities.**

--Foster parents have been treated the same way, and it is expected that LifeSharing parents will be as well.

At all other times, nurse or aide services are considered to be respite care and are NOT covered by EPSDT.

Non-Covered Services

Services **NOT** covered under EPSDT are few but include:

- Purely educational/vocational services, (e.g., tutoring, job coach)
- Home and vehicle modifications (e.g., widened doorways, accessible bathrooms, decks for wheelchair lifts to land on)
- Respite – nurses/aides when parents are available but need a vacation or break (unlike adults, waivers fund respite with a nurse for children)
- Room and board outside of congregate settings
- LifeSharing

HealthChoices – Physical Health

- Most children on MA are required to choose a physical health managed care plan (MCO) or will be assigned to one. A few children may remain in DHS's fee-for-service (no MCO) MA program.
- Every physical health MCO has a Special Needs Unit (SNU) to assist with issues related to, among others, children with disabilities. Children with disabilities can have MCO caseworkers assigned from the SNU or, in some cases, from a shift nursing unit.

Service Requests

- Generally, children must use providers in their physical MCOs' networks and they must get prior authorization for most services. Note: MCOs must use MA-enrolled out-of-network providers when they do not have in-network providers available.
- Most physical health services require a prescription and many require a treating professional to write a letter to the MCO explaining why the service or item is medically necessary. Healthcare providers generally know how to submit these requests, but you can always call the MCO SNU for help.
- Denials of requests can be appealed, and current services cannot be terminated or reduced pending the outcome of an appeal filed within 10 days.

HealthChoices- Behavioral Health

- Children on MA, like adults on MA, are automatically enrolled in their county's single behavioral health managed care plan.
- Most behavioral health services can be accessed by going directly to a participating provider or by contacting the behavioral health MCO for assistance.

Why Families Place Children in Facilities

Lack of adequate home-based physical and/or behavioral support

- MA authorizes nurses and home health aides for all needed hours when parents are working, sleeping, or attending to other responsibilities, but not for respite –
- Critical shortages of nurses and aides for *authorized* hours result in parents losing sleep and/or jobs, which in turn can put the child at risk and/or leave the family impoverished.
- Behavioral aides are also in short supply, leaving parents exhausted.

Lack of safe, accessible, and appropriate housing

- MA does not cover home modifications, waiting lists for public housing are years long.

To prevent a transfer of custody to child welfare which could deprive them of parental rights unnecessarily.

Child Welfare

- Too many children with disabilities end up in the child welfare system -not due to abuse or intentional neglect -but simply because their parents do not have the support and wherewithal to meet their extraordinary needs on their own.
- Once in child welfare custody, these children are often placed in facilities due to lack of medical foster homes.

LifeSharing Can Make All the Difference

While the waiver cannot provide the absent nurse or aide:

- Paying parents as the LifeSharing provider (or possibly community habilitation provider) could enable them to replace their lost income due to inadequate staffing. (Home/vehicle modifications and respite could also be made available.)
- A shared parenting arrangement through LifeSharing can give parents the time they need to recuperate, care for the rest of the family, keep their jobs, and avoid institutional placement for the child.
- For families whose circumstances make caring for their child at home impossible, LifeSharing would keep the child out of the child welfare system, allow them to maintain the relationship and parental rights, and provide a home beyond the 21st birthday.

LifeSharing and MA Waivers

- In the regular Medicaid/Medical Assistance (MA) program, every MA eligible person who needs a “covered” service within their benefit package is entitled to get it.
- Home and Community Based Service (HCBS) programs “waive” regular MA rules and offer additional services to a limited number of people at risk for institutional placement.
- While these waiver services cannot duplicate services available to children through EPSDT, they can provide certain vital disability services that are not MA-covered – such as respite, home/vehicle modifications, and **LifeSharing**.

WHAT HAS CHANGED?

DHS is actively trying to reduce facility placements for children with medical complexity and has come to see LifeSharing as an important tool to do so. To that end they have:

- **Expanded HCBS waiver eligibility and access for children**
- **Amended and added waiver services and rates for children (and adults) with medical complexity**
- **Created an inter-office Transition Home Team**
- **Contracted for a Family Facilitator to assist in the discharge of children from Pediatric Care facilities to families**

Home and Community Based Service Waivers Serving Children

- PA has numerous HCBS waiver programs, but only 3 serve children (excluding Early Intervention for ages 0-3)
- They are:
 - Consolidated (unlimited service cost)
 - Community Living, and
 - PFDS (Person, Family, Directed Service)





Waiver Eligibility for Children

These three waivers are available to children, from birth, who:

- have Intellectual Disability or Autism; or
 - are Likely to be diagnosed with ID or Autism by age 9; or
 - have a multisystem medical condition that requires nursing to assist with medical technology (medically complex)**
- and
- Meet an Intermediate Care Facility (ICF/ID or ICF/ORC) level of need; and
 - Meet financial eligibility criteria, which virtually all such children do because their parents' income doesn't count.



Enrollment of Children

Waivers currently have long waiting lists and children have historically been a low priority due to a misconception that their needs can be met elsewhere
...BUT:

- Children who need LifeSharing – i.e., that are currently in facility placements, are at risk of facility placement within 6 months, or whose health and safety is at risk, fall into the “emergency” category in the priority system (the PUNS);
and
- For those children who are registered as medically complex (tech dependent), the state has reserved waiver slots specifically for them.
- For eligible children without medical complexity, we urge you to consider the developmental imperative for family life when assessing priority within the emergency waiting list.

New Services and Rates

- State has added new nurse oversight requirements for LifeSharing for people with medical complexity
- State has increased LS provider agency rates beyond SIS Level 4 for “Medically Complex Life Sharing”
- As a result of parent input, we’ve recently sought more information from the state on LS parent stipends and related questions
- Apart from LS, the state has added a new service: Family Medical Support Assistance, which includes nurse oversight and assistance with care management (e.g., making appointments, etc..)

How You Can Help

The State has embraced LifeSharing for children, especially those with medical complexity.

Whatever your role in the system, please do your part to make family life a reality for all children with disabilities.

If you are:

El Service Coordinator, county/private Child Welfare agency, MCO-SNU, or county MH/BH staff - refer the family (with consent) to the county ID/A office – See DHS Bulletin ODP 00-22-04 (July 12, 2022)

County ID/A - register the child and arrange for Targeted Service Management (TSM) – See ODP Bulletin 00-22-01 (March 1, 2022) - then, obtain a waiver from the state (with consent) if they have medical complexity or otherwise reach the top of the emergency list

TSM - place them on the emergency waiting list if they are in or at risk of facility placement or their health and safety is at risk, - see PUNS Manuel, pp. 16-17

SC - explain LifeSharing and other options to their families and help them obtain services

LifeSharing Provider - expand and adapt your program to serve them.



Lifesharing opportunities

Lifesharing could offer family life to many children with disabilities.

We can work together to expand opportunities for Lifesharing.

We invite recommendations for expanding LS opportunities

- Send suggestions now to Sallie Lynagh, slynagh@pealcenter.org
- Save the date May 31 for initial draft of recommendations