



# Dear Family

Introducing Lifesharing—a way to support family life for children with developmental disabilities

Brought to  
you by the  
Imagine  
Different  
Coalition

The *The Imagine Different . . . Achieve Different Coalition* is a volunteer organization made up of parents and family members and people who want to find ways to support children with disabilities in family life.



Are you  
struggling  
to care for  
your child  
at home?

Do you wonder if you're  
getting all the support  
that might be possible?

Lifesharing may be an  
option you're not aware  
of.

Is your child  
living in a  
facility?

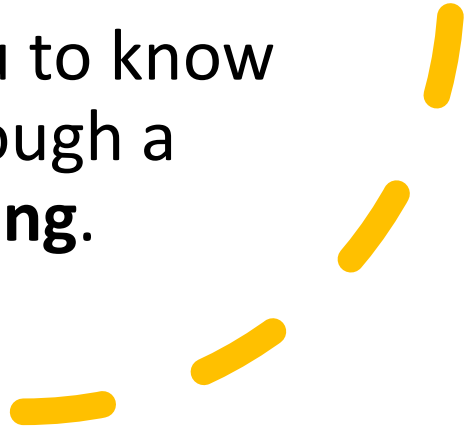
Do you wonder if  
there is an  
alternative?

Lifesharing may be  
an option you're  
unaware of.

We get it!

From our Imagine Different Coalition family members and our members' contacts with families, we have heard about experiences of many families. We know how hard it can be to raise children with complex health care needs and developmental disabilities without enough support. We also know how hard it can be to find supports.

Through this webinar we want you to know about support that is possible through a particular program called **Lifesharing**.



# What we'll cover


- What is Lifesharing?
- How can Lifesharing potentially help support family life for children with disabilities?
- Who qualifies for Lifesharing?
- Who to contact to explore Lifesharing.

You'll hear examples of how Lifesharing has helped other families






First,  
imagine.

- The Coalition operates on the premise that building a good life for children and families begins by being able to imagine it, then working through service systems to find supports to achieve it.
  - We hope you will find some inspiration here to imagine possibilities you hadn't considered and learn how to achieve them.
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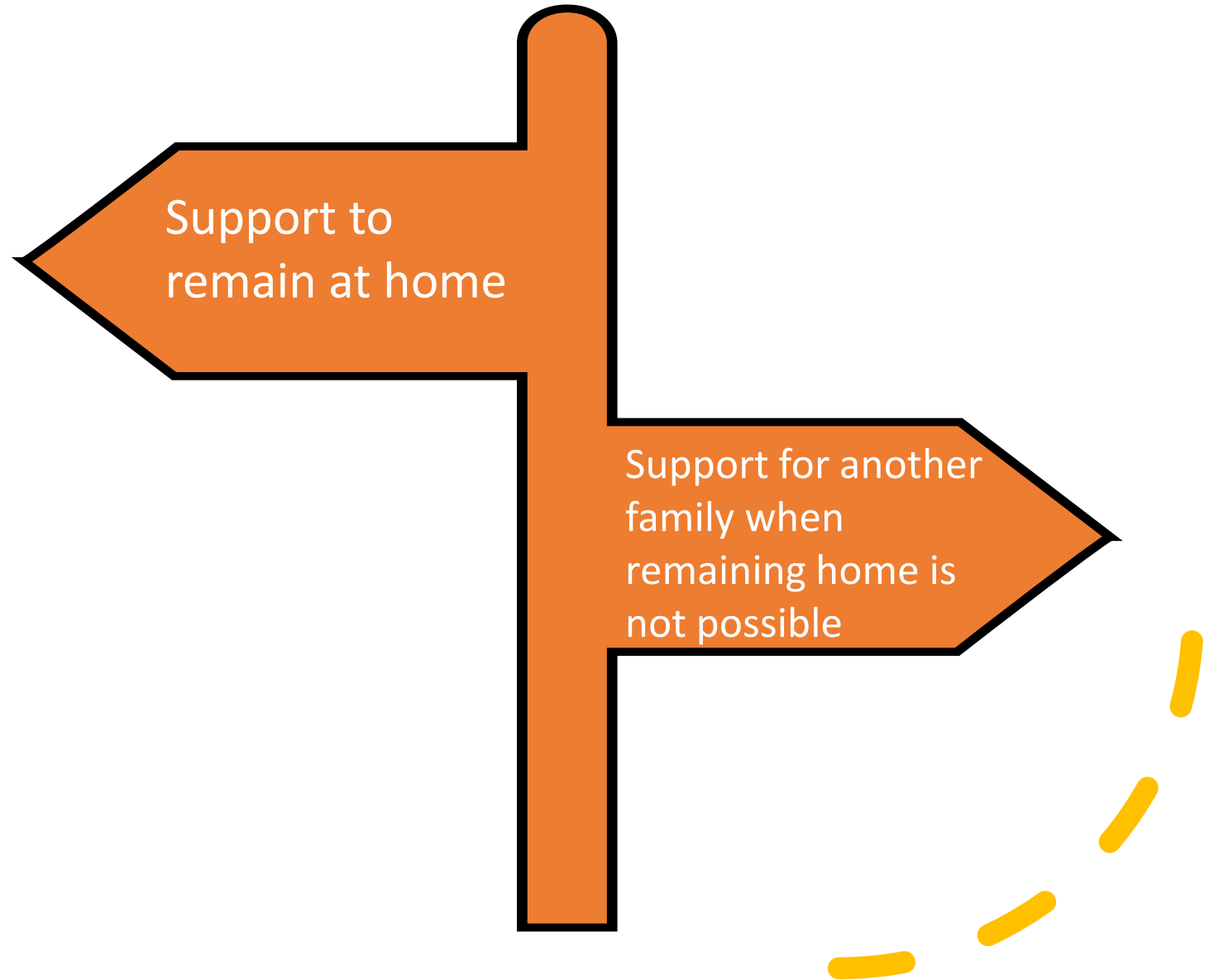


# Things to know about Lifesharing

1. How Lifesharing may support your family in caring for your child at home.
  2. How Lifesharing may support extended family members to care for your child in their home.
  3. How Lifesharing can be a way for your child to enjoy the benefits of family life if not in your home or a relative's home.
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# What is Lifesharing?




Support that  
can help  
your child  
live at home

## Lifesharing

- Payment to families for care provided
- Program specialist to support families

## Related support available with Lifesharing

- In-home nurses and aides
  - Intensive behavior supports
  - Home modifications
  - Respite
  - Coordination of services and supports
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Imagine  
different to  
achieve  
different

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While every family is different, it may be helpful to hear about the experiences of other families who have children like yours.

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Hearing how other families have used Lifesharing may give you ideas about how it might work for your family.

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*Following are the stories of families who used Lifesharing to support their children with significant disabilities to thrive in their family home.*



# Behind the scenes

- For each story, you'll see how Lifesharing and related supports were arranged to fit the unique situations of each child and family.



# Meet Randy

- Born with severe neurological impairment led to an extended NICU stay.
- Complex medical needs: ventilator, gastrostomy tube, monitoring by various kinds of medical equipment.
- Single mother, limited personal network of support, no reliable housing, and no car. Overwhelmed by his condition and her unstable personal situation.
- Placed in a pediatric care facility, but his mother hoped that he would be able to return home one day.
  - Lifesharing enabled Randy to return home. Randy's mother was paid a stipend that provided income so she didn't have to work outside the home. A Lifesharing specialist worked with Randy's mother to help her organize her daily life, go with her to doctor appointments, and be readily available for calls and visits and problem solving.

# Behind the scenes

How Randy's support was arranged:

1. A facilitator reached out to Randy's mother to help her consider options. Randy's mother chose Lifesharing.
2. The facilitator brought in a Supports Coordinator and other people to help develop a plan to find housing and arrange services and supports.
3. In-home nursing was provided through a home health agency, paid for by Medicaid. Also provided mother ongoing training.
4. Medical equipment and supplies were provided through a durable medical equipment company, paid for by Medicaid.
5. Randy's mother found a used vehicle. Modifications for a wheelchair lift were paid for by a Medicaid waiver.

# Meet Seth


- Active 13-year-old with an intellectual disability and autism.
- Needs constant supervision and assistance with daily living skills.
- Has challenging behavior and a diagnosis of Intermittent Explosive Disorder.
- Parents feared they would have to place Seth in a facility.
  - Lifesharing enabled Seth to remain home. Parents paid a stipend which supplements their income. A Lifesharing specialist regularly visits in their home, provides assurance that they have someone they can call, and helps them manage stress.
  - Also
    - One-to-one aide trained to work with individuals with challenging behavior comes to Seth's home to assist with his care.
    - Respite enables Seth's parents a weekend away or occasional breaks.



# Behind the scenes

How Seth's support was arranged:

A Supports Coordinator assisted Seth's family.

- Helped them apply for the Medicaid waiver to get services and supports.
  - Coordinates and monitors services and supports.
  - Connected family to a Behavioral Supports organization that arranged a Behavioral Specialist to come to their home, paid for by Medicaid.
  - Connected the family to another family who could provide respite, paid for by waiver.
- 



# Meet Josh

- Friendly 20-year-old young man.
  - Moderate intellectual disability and cerebral palsy.
  - Uses power wheelchair and an augmentative communication device.
  - Needs assistance for all activities of daily living.
  - Single mother struggled to meet his care needs on her own, placed Josh in a group home at age 15.
- Lifesharing enabled Josh to move from the group home to live with his uncle's family near his mother.

# Behind the scenes

How Josh's supports was arranged:

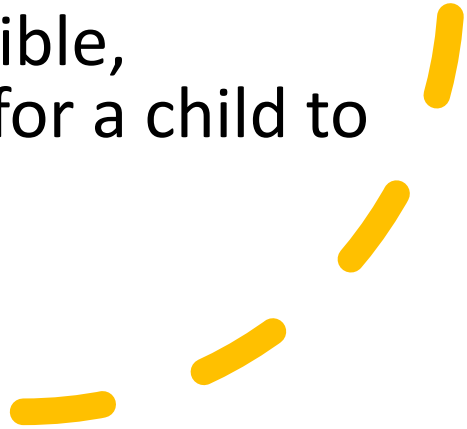
1. A Supports Coordinator knowledgeable about ways Josh could be supported to live in a family home worked closely with Josh's mother and his extended family to fully explore family-based options.
2. Josh's mother felt she could not resume care for him at home. The Supports Coordinator helped her see an option she hadn't considered possible: how an extended family member could care for Josh in their home through Lifesharing.
3. Josh's uncle agreed to become a Lifesharing family for him. He was introduced to a Lifesharing provider agency who assessed his home and ability to care for Josh.
4. Josh's uncle is paid and provided support as a Lifesharing family through a Medicaid Waiver. He is able to continue his job which allows him to work from home.

# When support at home is not enough

Parents of children with complex health care and/or developmental disabilities sometimes find they can't continue their care at home, especially when they face a combination of factors:

1. A child's extraordinary and complex needs.
2. Family issues like housing, financial burdens, health and needs of other family members.
3. Service system inadequacy, complexity, fragmentation, and delays.

When remaining home is not possible, Lifesharing can offer another way for a child to enjoy the benefits of family life.



# Things to know about Lifesharing with another family

- “Lifesharing” is a way for your child to live with another family of your choosing.
- A Lifesharing family cares for your child in their home and supports your continued relationship.
- You don’t have to give up your rights. You share parenting with the family you choose.
- Your child can live full-time with a Lifesharing family and have regular contact with you, or your child can share time between your home and the Lifesharing family.
- Other families who have used Lifesharing say it is like having extended kin.

# How Lifesharing with another family works

Lifesharing involves both a caring family relationship and a place to live.

Lifesharing families are carefully matched with a child and the child's family.

Individual plans address the unique needs of each child and the continuing involvement of the child's family.

Lifesharing provider agencies

1. Find and evaluate potential Lifesharing families.
2. Provide or arrange support and training for Lifesharing families.
3. Monitor Lifesharing families.

# Lifesharing is not foster care

Lifesharing is a disability-related service for children with developmental and intellectual disabilities or complex health care needs—it is *not* part of the child welfare/protection system.

- Parents choose whether to use Lifesharing and which Lifesharing family to provide care for their child.
- Choosing a Lifesharing family does *not* require parents to give up their rights.

# Safeguards

Your child's safety and well-being are overseen by state monitoring of Lifesharing provider agencies.

The Office of Developmental Programs inspects and licenses unrelated families. Children in Lifesharing are monitored by an assigned Supports Coordinator.

Agencies that provide Lifesharing:

- Must be approved by the state
- Are responsible for selecting, preparing, supporting, paying, and monitoring the Lifesharing family.
- Work with families in choosing a Lifesharing family for their child
- Work to address any issues or concerns.

Meet some families who chose Lifesharing with another family

*Following are the stories of families who chose a Lifesharing family when they couldn't care for their children with significant disabilities in their own homes.*





# Meet Ronna

- Born with a brain malformation and the strong likelihood of future severe impairments.
- Parents overwhelmed by her condition and fearful of taking her home from the hospital. On doctors' advice, placed her in a pediatric care facility where she remained for five years.
- Ronna's family agreed to Lifesharing with Sharon, the aide who worked with Ronna in the facility. Ronna's family chose her because they already knew and trusted her, and they knew she loved their daughter and understood her needs.

# Behind the scenes

How Ronna's support was arranged:

1. A facilitator contacted Ronna's parents to encourage them to reconsider family life for their daughter. They were skeptical about her coming home but also skeptical of another family they didn't know caring for her.
2. The facilitator learned about the special relationship Ronna had with the aide who worked with her at the facility. The facilitator approached Sharon about becoming a Lifesharing family.
3. The facilitator connected Sharon to a Lifesharing provider agency that:
  - Evaluated her
  - Inspected her home
  - Worked with Ronna's Supports Coordinator to:
    - Arrange a lift, paid for by Medicaid, for a van Sharon traded in for her car
    - Arrange for nursing staff, paid for by Medicaid, to assist Sharon and be available in the event of an emergency
  - Provided Sharon with a stipend payment, paid through a Medicaid waiver, which enabled her to reduce her hours at the pediatric care facility to be home with Ronna, working only when she was in school.

# Meet Jamal

- Eight-year-old with a severe intellectual disability and ADHD.
  - Very active boy, sometimes his exuberance inadvertently led to injuries of his younger siblings.
  - Mother felt she couldn't protect his siblings, placed him in a residential facility.
- Jamal was able to move from the facility to live with Chandra as a Lifesharing family. The two extended families socialize together and Jamal moves back and forth between his two loving families. His mother says, "*Chandra is like a sister.*"

# Behind the scenes

How Jamal' supports were arranged:

1. A Supports Coordinator helped Jamal's mother understand what options for family life were possible. His mother was skeptical about another family caring for him, but the opportunity to have him closer to home was appealing. She tentatively agreed to meet potential Lifesharing families through a Lifesharing provider. When she met Chandra, they clicked immediately. She appreciated her previous experience with individuals with intellectual disabilities and challenging behavior.
2. Chandra had enjoyed her experience as a group home staff working with individuals with disabilities. She became a Lifesharing family because it would allow her to work with a child with a disability on a one-to-one basis. With the income from Lifesharing, she was able to continue the work she loved but while working at home.

# Meet Aaron

- Nine-year-old African American boy.
- Intellectual and physical disabilities, unable to walk or talk or meet his daily needs.
- Mother had been caring for him alone after her husband's death. When she was diagnosed with a degenerative physical health condition, she could no longer care for him. She accepted the only option she was offered—a facility. Nobody told her about Lifesharing.
  - Aaron's mother liked the idea of him living with a family. When she learned about Lifesharing, she chose a family with experience with children with disabilities to care for Aaron. They understand her situation and take Aaron to spend time in her home when her health prevents her from getting out.

# Behind the scenes

How Aaron's supports were arranged:

1. A Supports Coordinator reached out to Aaron's mother to talk about alternatives to the facility. She described Lifesharing. She helped Aaron's mother to understand how Aaron could live with a Lifesharing family and she could continue her relationship with him.
2. Aaron's mother was introduced to a Lifesharing provider agency. She was offered several Lifesharing families. She chose a family who was African American like her.

# Meet Ramon

- Ten-year-old Latino boy.
- Pervasive developmental disorder, intellectual disability, and challenging behavior.
- One of four children of divorced parents. Father moved out-of-state. Mother had to work to support her children and felt she was unable to care for Ramon at home. He was placed in a large residential facility with other boys with behavioral challenges.
  - Ramon was able to move to a Hispanic Lifesharing family who spoke Spanish and had a son with autism. His mother and brothers see him regularly.

# Behind the scenes


How Ramon's supports were arranged:

1. A Supports Coordinator was key to helping Ramon's mother understand options, including Lifesharing, that would allow him to live with a family.
2. The Supports Coordinator worked with several provider agencies and was able to identify potential Lifesharing families.
3. The Lifesharing family that Ramon's mother chose was experienced with children with autism and challenging behavior, shared her Hispanic culture, and was bilingual.





# Making Lifesharing work

- Medicaid
  - Medicaid waiver
  - Supports coordination
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# MEDICAID

- Also known as Medical Assistance (MA)
- Federal health care program for people who have low income or have disabilities
- For enrolled children under the age of 21, covers medically necessary services including, but not limited to:
  - Doctors
  - Medications
  - Therapies (e.g., OT, PT, ST)
  - In-home nurses and aides
  - Medical equipment and supplies
  - Intensive behavior supports

# MEDICAID WAIVERS

- Also called Home and Community Based Services (HCBS), offer additional Medicaid-funded services to avoid institutional placement. These services may include, but are not limited to:
  - LifeSharing – support in the home of parents or relatives or another family chosen by the child’s parents or guardian
  - Home modifications like widening doorways and expanding bathrooms
  - Respite care to provide relief and breaks to caregivers

Eligibility criteria for waivers:

1. Intellectual Disability, Autism, or likelihood of being diagnosed with either by age nine, or complex medical needs; and
2. Risk of institutionalization.

# SUPPORTS COORDINATORS

- Supports Coordinators are available through enrollment with your county's office of intellectual/developmental disabilities.
- Supports Coordinators will
  - Talk with you about what kinds of supports and services would be helpful
  - Help you talk with community agencies that could support you and your choices
  - Coordinate and monitor services and supports
  - Help with enrollment in a Medicaid waiver
- Note: waivers have waiting lists so be sure to get on the list.

Imagine  
different!

Learn more

LEARN MORE

*Visit*

*[www.imaginedifferent.org](http://www.imaginedifferent.org)*

Achieve  
different!

Connect with  
others who  
can help

## WAYS TO GET STARTED

Register your child with your  
county intellectual disability office

Register your child with your  
county Medical Assistance office

Talk to a Supports Coordinator

Reach out to family and disability  
advocacy organizations



Best wishes!

We hope you have found inspiration to imagine a life with the support your child needs to live with a family.

Please take heart and reach out to the contacts offered on the Imagine Different website.

