

Lifesharing for Children

Lifesharing Conference

October 18, 2016

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Purpose

- Follow up general session this morning
- Introduce the Imagine Different Coalition
 - Working on behalf of PA children with disabilities growing up in facilities or at risk of admission
- Enlist the Lifesharing community to offer opportunities for family life

CHILDREN NEEDING FAMILY LIFE

3000+ children and youth with developmental disabilities growing up in facilities

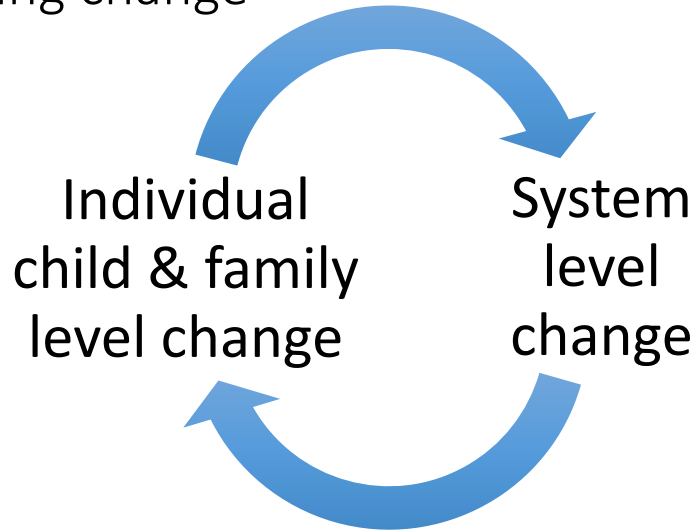
- 1800 under child welfare system
- 1400 under various offices not involving child welfare
 - Intermediate Care Facilities
 - Pediatric Specialty Care Homes
 - Residential Treatment Facilities
 - Inpatient Facility-Based LTC Facilities
 - Other kinds of long-term care facilities
- Admissions continue

WORKING FOR CHANGE:

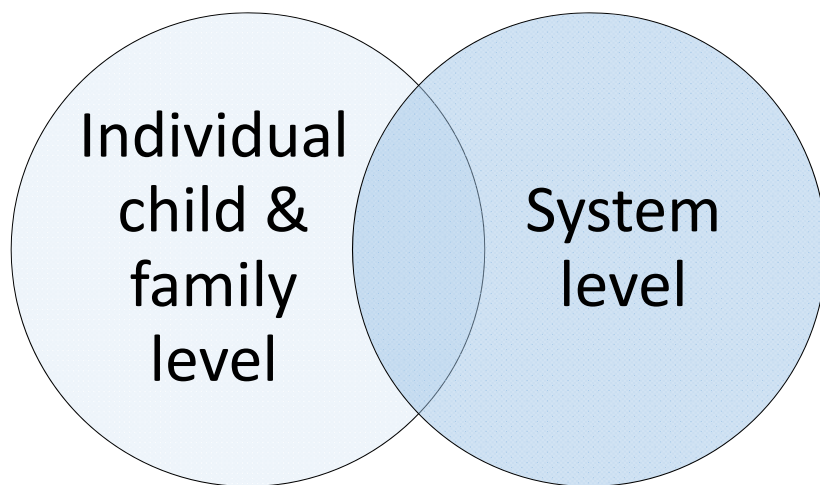
Imagine Different Coalition

- Dedicated to ensuring children with disabilities have the opportunity for family life instead of facility life
- Families, individuals with disabilities, advocates, organization representatives organized in 2014
- Informational materials
 - *Position on Children with Disabilities Growing Up in Congregate Care Facilities*
 - 3 toolkits: Families, System Representatives, Facilitators
 - Imagine Different Website

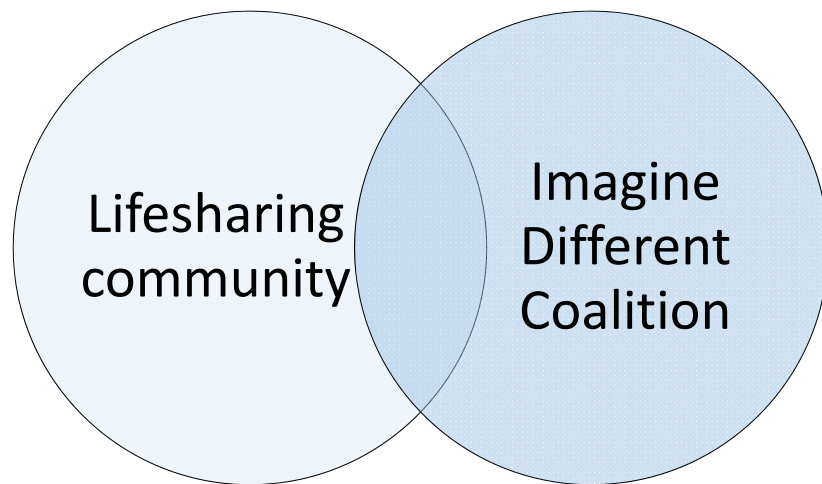
Achieving change



Need for Lifesharing community involvement



Working together



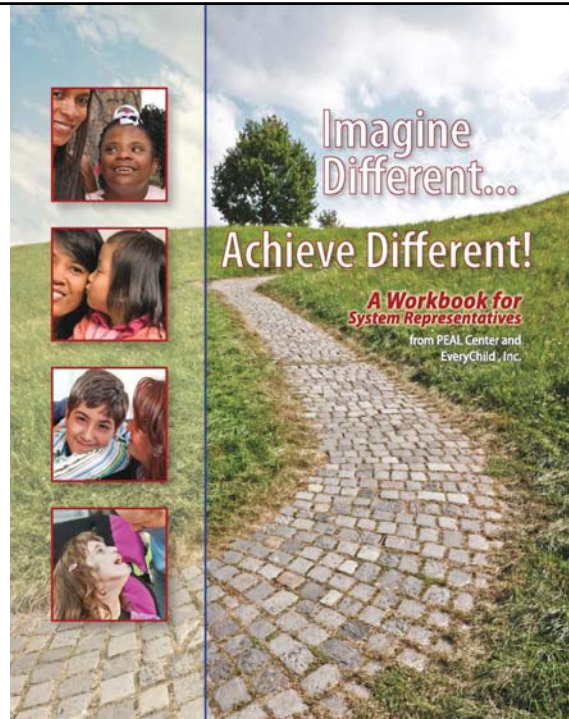
Increasing opportunities for Lifesharing for children who cannot return to or remain at home

Individual child and family level	System level
Become a Lifesharing family	Increase awareness of Lifesharing
Share stories to show potential benefits	Participate in system change forums and public comment requests
Encourage others to become Lifesharing families	Identify children in need of Lifesharing
Help a child's family/guardian to imagine different	Help in matching children and Lifesharing families
Participate in transition planning from facility to family life	Join system change initiatives

Imagine Different
Coalition resources

***Imagine Different . . .
Achieve Different!***

1. A Workbook for System Representatives
2. A Workbook for Families
3. A Workbook for Facilitators



Review key concepts from morning session

- Family-based alternatives
- Partner family
- Facilitator

Imagine different: Achieve different!

2. Exploring:
learning about
different family-based
alternatives

**3. Setting a
new direction:**
considering the need for systemic
changes to better support family-
based alternatives

1. Taking stock:
thinking about the system's
past and current capacity
to achieve family-based
alternatives to congregate
care

4. Achieving:
identifying strategies to
implement changes to make
family-based alternatives
feasible and sustainable



The workbook is grounded in real life experiences. You will hear stories throughout the workbook about children who moved from facilities to families.

RANDY, a young boy who uses a ventilator to breathe was able to return home from a nursing facility.

SETH, a teenager with autism, challenging behavior, and a mental health diagnosis was able to return home from a large facility.

JOSH, a twelve year old with severe physical disabilities was able to move from a nursing home to his uncle's home.

AARON, a boy with a severe intellectual disability, whose mother could not care for him due to her own health condition, was able to move from a facility to a family when his mother chose another family to care for her son.

RONNA, a young girl with complex medical needs was able to move from a nursing home when her parents chose for her to live with her favorite staff person from the facility.

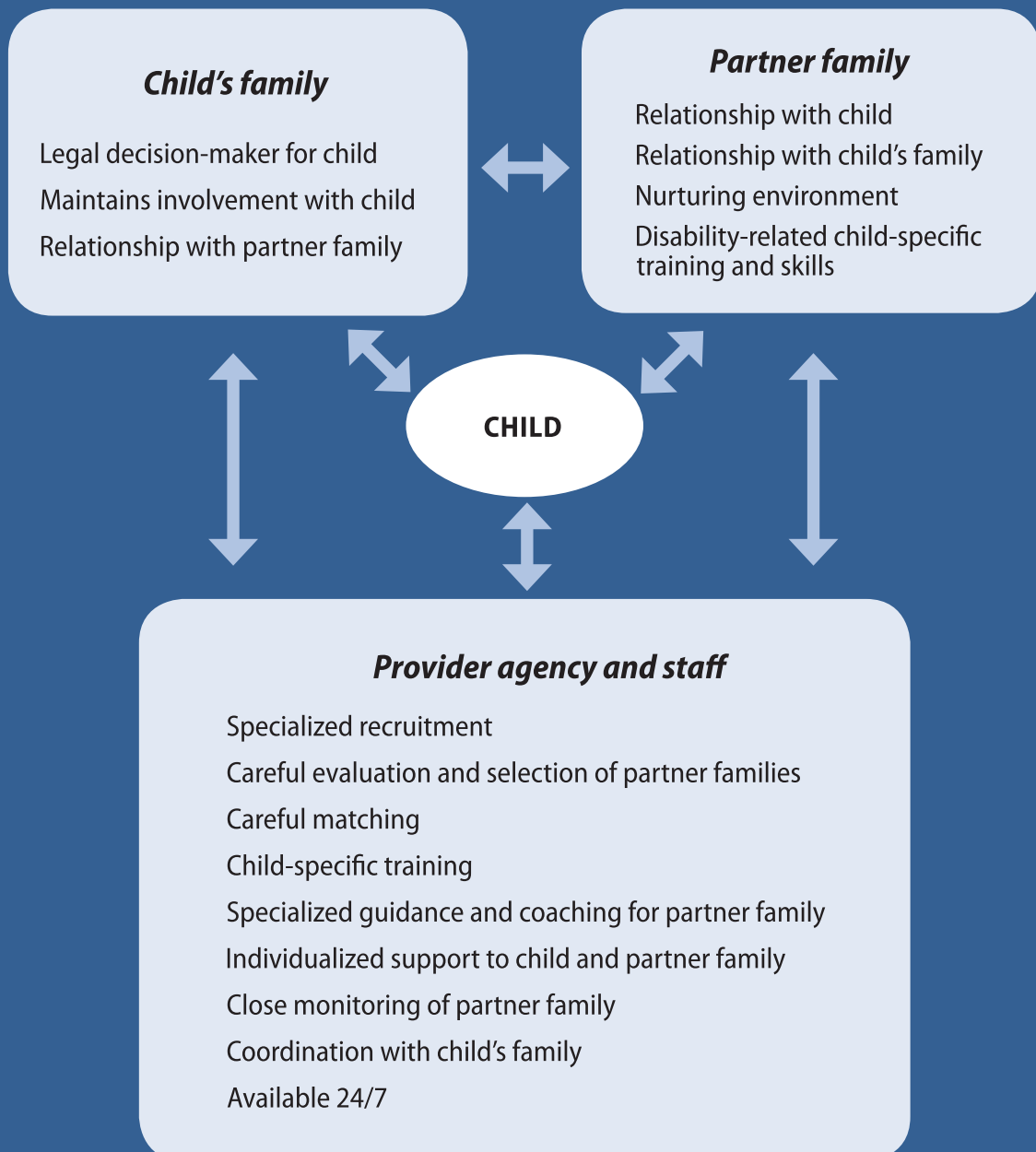
JAMAL, an eight year old with a developmental disability, ADHD, and challenging behavior was able to move to a family recruited to share care with his parents.

Whether and when children move from facilities to family life depends on many variables including family circumstances and the adequacy of support available to enable them to thrive. The workbook takes these many variables into account.

The process of considering change may be challenging because of gaps and barriers in the current service system. But it can also be hopeful. Change will require a lot of work and many other people. By working together we hope you can **imagine** the possibility of family life again for children with disabilities growing up in facilities and then work to **achieve** it.

The diagram below describes the relationship between the three parties to a life-sharing arrangement: the child's family, the partner family, and the provider organization responsible for the partner family.

ATTRIBUTES OF PARTNER FAMILY/LIFE-SHARING ARRANGEMENTS



Taking stock

Think about your familiarity with family-based alternatives to congregate care	Rating scale from 1=low to 1=high
Rate your familiarity with the experiences of children with disabilities living in congregate care	
Rate your familiarity with families' experience in placing their children in congregate care	
Rate your familiarity with family-based alternatives in PA	
Rate your confidence in helping a family consider a family-based alternative	

Issues	Comments
To what extent does the system currently make resources available to support family-based alternatives to congregate care?	
How does the system encourage families of children in congregate care to consider family-based alternatives?	

Exploring

Imagining a partner family life-sharing arrangement	INSTRUCTIONS: Check all that fit for you			
	A key feature to help a child move from a facility	Familiar with positive examples	Open to learning more	Skeptical about this or its feasibility
The idea of life-sharing				
The idea of a partner family				
Evidence that life-sharing can work				
The role of facilitators to help families imagine the possibility of a partner family				
A mechanism for matching partner families with children and their families				
Ongoing supports to partner families				

Setting a new direction

Factors to consider in determining whether to go forward in a new direction	INSTRUCTIONS: Check all that fit for you		
	I see change as needed and in progress	I see change as needed and possible but insufficient effort currently being directed to change	I see little need for change
The extent to which lifesharing alternatives should be increased			
The pace at which the system is shifting away from facilities toward family-based alternatives			
The extent to which I or my organization could offer to expand lifesharing opportunities			
The extent of my interest or my organization's interest in working collaboratively with others to increase family-based alternatives			

Achieving

Achieving change	Comments
What areas of change would you like to work on?	
What areas of change are within your sphere of influence?	
What groups do you or your organization have membership that supports development of family-based alternatives?	
What planning activities currently underway could you join to effect change?	
Who could you enlist to join in working for change?	

Ideas for working together--group activity

What I/we could do right now

Identify

What I/we could do with small changes

Identify

What I/we could do with more significant changes

Identify

Take-away's

- What can we do to increase opportunities for Lifesharing/partner families for children with disabilities who are growing up in facilities or at-risk of admission?
 - Individually
 - Collectively

JOIN US

Imagine Different Coalition

- Visit website www.imaginedifferent.org
- Fill-out handout interest in membership
 - Leave with us
 - Mail in

Resources

- Available on website www.imaginedifferent.org
- Position on Children with Disabilities Growing Up in Congregate Care Facilities
- Imagine Different ... Achieve Different!
 - *A Workbook for System Representatives*
 - *A Workbook for Families*
 - *A Workbook for Facilitators*