



Imagine Different...

Achieve Different!

*A Workbook
for Families*

from PEAL Center and
EveryChild, Inc.

Acknowledgements

This series of three workbooks has been developed through collaboration between the PEAL Center and EveryChild, Inc.

PEAL (Parent Education and Advocacy Leadership) Center

The Parent Education and Advocacy Leadership Center (PEAL Center) is a non-profit organization of parents of children with special healthcare needs and disabilities reaching out to assist other parents and professionals across the state of Pennsylvania. Established in 2005, its mission is to ensure that children, youth, and adults with disabilities and special health care needs lead rich, active lives and participate as full members of their schools and communities. Integral to this goal of true inclusion is to work towards creating a system in Pennsylvania where all children and youth, including those with disabilities and special health care needs, are able to grow up as members of loving families.



EveryChild, Inc.

A non-profit organization based in Texas whose mission is to create a system that ensures that children with disabilities grow up in families instead of institutions. EveryChild was created in 2002 by families and child advocates who were concerned about the number of children with developmental disabilities who were growing up in institutions. EveryChild works to assist in the development of a system of family-based alternatives to congregate care. Over the course of the past ten years, Texas has dramatically reduced the use of congregate care by children with developmental disabilities who were able to return to family life.



Project Advisory Committee

The workbooks have been informed by the active participation of members of the Project Advisory Committee. Members include adults with disabilities and experience living in congregate care facilities as children; parents of children with developmental disabilities, mental health needs, and complex medical needs; and system representatives and advocates who have contributed to improving services and supports for children with disabilities.

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Introduction

This workbook is one of series of three workbooks written to help imagine and achieve the possibility of a family life for children with developmental disabilities living in facilities in Pennsylvania.

The workbooks were developed with input from people with disabilities, families of children with disabilities, and people who have worked in Pennsylvania's service system. The content is based on thirty years of experience in other states working with several hundred families whose children moved from congregate care facilities to family homes.

Three key lessons learned in the course of working with families to help children move from congregate care have shaped these workbooks.

Lesson 1: Systems need to reach out to families of children living in facilities. It was only through active and respectful engagement that movement to a family became the preferred choice of families. Respect sometimes involved presenting alternatives families might not have sought or initially welcomed.

Lesson 2: Families need a facilitator to help them to consider different options. The assistance of someone who a family saw as knowledgeable and trustworthy was pivotal in achieving a family-based alternative to congregate care. Families whose children lived in facilities often saw no realistic alternative. The lack of imaginable alternatives was not simply the result of a lack of information, but rather the lack of someone to help them explore possibilities and then work with them to bring a different vision of the future it into reality.

Lesson 3: Systems need to devote energy to system change to enable alternatives. It took a lot to build and sustain a system that enabled children living in facilities to move to families. It required the time, energy, focus, and action of many people but it was possible.

Experience showed that moves to family homes became the preferred living arrangement under three conditions:

- a. Families** were offered adequate support.
- b. Facilitators** were available to assist families to consider and implement a different alternative.
- c. System representatives** collaborated to improve services and supports and remove barriers.

Based on these lessons, the workbooks are much more than a listing of resources and contacts. The content recognizes that families, facilitators, and system representatives all play a role in making family life possible.

Separate workbooks are therefore specifically targeted to these three parties:

Families—the first workbook is designed for birth parents, adoptive parents, extended kin, and unrelated individuals with close-as-kin relationships with children with disabilities living in congregate care facilities.

Facilitators—the second workbook is designed for individuals interested in effectively assisting children to move from facilities to family life by helping their families to consider and accomplish a family-based alternative.

System representatives—the third workbook is designed for facility and community service providers, policy-makers and decision-makers.

The workbooks are based on the premise that each of these parties must engage in **imagining different** as a prerequisite to **achieving different**.



A message to families

This workbook is an invitation to families of children with developmental disabilities who are living in facilities. If you're reading this as a parent of a child living in a facility, you have an interest, however tentative, in knowing about other options for your child.

You might want a change for your child and your family but not see how it's possible. You may be deeply worried about giving up what certainty you feel you have with your child's current situation. The workbook has been designed by people who have worked with many families who felt that way but found hope and help to consider something else and subsequently found a better solution for their child and family.

The workbook recognizes that the decision you made to place your child in a facility was likely very difficult and emotionally painful. You may feel like the facility solved problems that were otherwise unsolvable with your child living at home.

The workbook understands that a decision to change will be based on what you think is best for your child and your family. It assumes you will choose an alternative only if you believe it will be better than your current situation.

Consider the workbook as a chance to look at different services and supports or to look at services and supports differently. We hope it offers ideas to help you see the real possibility of your child being able to once again enjoy the benefits of family life. At the end of the day, it will be your decision whether to make a change. We hope by using these tools you will find a path to family life that's right for your child and your family.

Using the workbook

It's your workbook—you don't need to show it to anyone else. It includes space for you to write. Don't worry about what you say or how you say it. Use it to capture your thoughts and help you process them. Use it as a starting place and add to it as you go.

As you move through the workbook, you will see that it moves through four stages:

Taking stock—thinking about what is important to you and your child taking into account your current situation and past history

Exploring—learning about different family options you might consider

Setting a new direction—using what you learn to consider whether to make a change

Achieving—seeing a change through to completion

Although the process is described in stages, as the graphic on the next page suggests, the process may “circle around.” Sometimes you may go back to an earlier stage for reconsideration.

The idea of considering an alternative to your child's current living arrangement may seem overwhelming. You might want help. In fact, the workbook assumes you will probably need help. In this workbook, this person is called a “facilitator.” The workbook will describe the role of a facilitator and how you might find one. You can go through the book on your own or with a facilitator.

The focus of the workbook is on minor children (under age 18) but the material may also be applied to young adults for whom family life may be a desirable alternative to congregate care. The materials are not designed to be used by children and youth with disabilities, but it is expected that their views will be taken into account.

Imagine different: Achieve different!

1. Taking stock:

Understanding previous experience, current situation, and needs

2. Exploring:

Considering alternatives

3. Setting a new direction:

Deciding whether to pursue an alternative

4. Achieving:

Deciding whether to pursue an alternative through to completion



The workbook has had input from people with disabilities and families with children with disabilities. It was designed by people with thirty years of experience working with hundreds of children with intellectual and developmental disabilities and complex medical, physical, behavioral, or mental health needs who successfully moved from congregate facilities to families. You will hear their stories throughout the workbook:

RANDY, a young boy who uses a ventilator to breath 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 but 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 it is emotional or may be frustrating because of gaps and barriers in the current service system. But we believe it can also be hopeful. It will probably require a lot of work and many other people.

By working together we hope you can imagine the possibility of family life again for your child and then achieve it.



Stage 1. Taking stock

The *first* step is taking stock of your situation considering both what led to you to seek out-of-home services and what your child and family need now. The first exercise is intended to help you step back and think about what's important for you and your child. Your answers can serve as the foundation to refer back to as you begin to weigh what an alternative might offer.

TAKING STOCK: Think about what is important to you	INSTRUCTIONS: Identify positive things you want to maintain and concerns you want to resolve
What does your child need to be happy? What's important to your child?	
What does your child need to be healthy and safe?	
When you placed your child in a facility, what problems did it solve for you?	
When you placed your child in a facility, did it raise any new problems?	
What are the best things about your child's current situation? What's working?	
What are you not satisfied with? What's not working?	
What are your greatest worries or fears about your child's future?	
Before you placed your child, what would have helped you to keep your child at home?	
What would be most important for your child to be at home now?	
If you had unlimited money and power, what would an ideal living arrangement look like for your child?	
What are the most important characteristics a living arrangement for your child needs to have?	

Rate how close your child's current living arrangement comes to your ideal?	Rating scale: 10 = high 1 = low	COMMENTS
Overall happiness with my child's current living arrangement		
Concerns about my child's current living arrangement		
Likelihood that my concerns can be resolved		
Trust that the future is secure for my child in this facility		
Confidence that a better alternative is possible		

Think about what is important to your child	INSTRUCTIONS: Identify positive things you want to maintain and concerns you want to resolve
What makes your child happy?	
Who makes your child happy?	
What are the most important things to your child about his or her living arrangement?	
What kind of living arrangement would your child prefer?	

Rate how close your child's current living arrangement come to your child's ideal?	Rating scale: 10 = high 1 = low	COMMENTS
My child's happiness in his or her current living arrangement		
My child's dislikes about his or her current living arrangement		
Likelihood that my child's concerns can be resolved		
My child feels like he/she is living with people who love him/her		

Your answers above are the starting place for comparing alternatives.



Stage 2. Exploring

The *second* stage will help you learn about ways to achieve family life as an alternative to a facility. They may include things you considered in the past which you might revisit. Or they might include things you haven't considered or haven't known about. The information and exercises that follow might guide you to new ideas about family-based alternatives to a facility for your child.

What is a family-based alternative?

A family-based alternative is simply a living arrangement in a family home where a child is a loved member and the family has the supports they need to meet the needs of that child. There are two kinds of family-based alternatives to a facility:

1. Return home.

The first kind of family-based alternative to think about is the possibility of returning home. You may dearly want your child to return home but you may also be very skeptical about the possibility. Even if return home seems unlikely, remember this stage is just exploring.

The first section below (pp. 6-16) may help you to consider if there is anything that would enable your child to return home.

2. Move to another family home.

The second kind of family-based alternative to think about is the possibility of another family caring for your child in their home. You may be very wary of this alternative, but again, this stage is just exploring, so try to keep an open mind to see if there is a family living arrangement that you could become comfortable with for your child.

The second section below (pp. 17-35) will help you think about the possibility of another family caring for your child with your continued close involvement.

Help from a facilitator

If you are finding it difficult to imagine family life for your child, the information and exercises that follow may help you. In addition, you may find that you would like to talk with someone who can work with you to look at possible options. When you decided on your child's current living arrangement, you may not have been provided with information about family based alternatives to congregate care. This may be in part because there weren't many options available at the time. However, there may be more information or different options available now.

A first place to start is to contact your child's supports coordinator, case manager, or care manager. Most children living in facilities have someone assigned who is responsible for identifying and coordinating services for your child. You may not know this coordinator or you might find they are not familiar with the alternatives described in this workbook. You may need to find a "facilitator." A facilitator as described in this workbook may work differently than this assigned coordinator.

In this workbook, a facilitator is someone whose specific purpose is to help children living in congregate care facilities by helping their families to find solutions to problems that prevent their child from living in a family. Facilitators do more than just provide information and coordinate services. They are

someone who has the skills, time and energy to work with you, is willing to do whatever it takes to help you imagine the possibility of your child returning to family life, and will help you figure out how to achieve it.

They may or may not be assigned or paid to work as a facilitator. The facilitator role is not yet clearly established in Pennsylvania. However, there are people and organizations that can help you try to find someone to act as a facilitator for your child. For help in finding a facilitator, you can contact one of the following agencies.

PEAL Center

www.pealcenter.org

412-281-4404

Ask to speak to a Parent Advisor

Education Law Center

www.elc-pa.org

215-238-6970

PA Health Law Project

www.phlp.org

Philadelphia: (215) 625-3990

Pittsburgh: (412) 434 5779

Harrisburg: (717) 236-6310

PA Elks Home Service Program

www.paelkshomeservice.org

814-781-7860

Parent to Parent of PA

www.parenttoparent.org

1-888-727-2706

Vision for Equality

www.visionforequality.org

215-923-3349

Considering return home

Let's first explore the possibility of your child returning home. This section is intended to help you imagine this possibility.

You may be reluctant to consider your child returning home after the experiences that led you to place your child. Or you may be interested but feel like you don't know where to get support or how to start, especially if your child has lived away from home for a long time. This section may give you a clearer picture of what might help you to be able to bring your child home.

The work of this stage is to visualize possibilities. At this stage you don't need to make a decision, so try not to close off any ideas yet. Later stages in the workbook will help with decision-making.

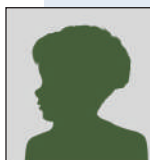
The first task is to look at what you need, before you look at how to get it.

This section is intended to help you clarify what you would need for your child to come home. Try not to think about "services" but rather focus on needs. In addition to your child's needs, you'll want to identify family needs, circumstances, or issues that would be affected by your child's return home.

It might help to think about the kind of support you would need as either **people**, or **things**, or **arrangements**. The following table and stories give some examples. The examples are not meant to include every possibility, but rather to offer some ideas that might help you picture your own needs. You might find going through this process is an area where a facilitator could be helpful.

EXPLORING: Imagining successful return home	Examples of needs	Examples of support
<p>PEOPLE Think about what kind of support you would need from other people.</p> <p>Consider good days and bad days. Think about people to help you at home and in the community. Think about people with particular kinds of expertise.</p>	To provide hands-on help	Someone to assist with our care at home Someone to do care for us when we're not home Someone to help our child in the community Someone to help with household tasks
	Expert knowledge	Someone to advise us what to do Someone to come to our house to show us what to do Someone to provide treatments or therapies for our child
	Social relationships	Friendships for my child Support for us Support to maintain existing relationships Connections to new relationships
	Problem-solving	Someone to help us figure things out Someone to connect us to others or to resources
	Advocacy	Someone to go to bat for us
<p>THINGS Think about what kind of things you would need. Think about things for your child and things for your home.</p>	Equipment, devices, and supplies	Medical supplies Medical equipment Physical care equipment for lifting or bathing Personal hygiene supplies Adaptive devices: to help in getting around (like a wheelchair or walker) to help with communicating (like a voice synthesizer)
	Household	Modifications to our home Goods Furnishings
	Vehicle	Having a reliable vehicle Adapting our vehicle
<p>ARRANGEMENTS Think about arrangements you would need.</p>	Financial	Ways to pay for what we need
	Agreements for future use	Somewhere our child can go to give us a break An on-call system in case of a crisis
	Housing	Finding different housing
	Transportation	Transportation to school Transportation for recreation for our child other than us
Think about anything else you would need.	Other	

The stories below provide examples of supports that enabled children to return home.



RANDY was born with a severe neurological impairment. He uses a ventilator for breathing, is fed by a gastrostomy tube, and requires monitoring by various kinds of medical equipment. His mother was single, had a limited personal network of support, no steady income, no reliable housing, and no car. She was overwhelmed by his condition and her unstable personal situation. Randy was placed in a pediatric nursing home but his mother hoped that he would be able to return home one day.

EXPLORING: Return home	Randy's family's support needs
People	Nurses to come to the home to help with Randy's daily care Training for Randy's mother from home-care nurses Someone to help find and coordinate resources
Things	Medical equipment and supplies A vehicle that could accommodate Randy's wheelchair and equipment
Arrangements	Income assistance Coverage for Randy's medical expenses Finding affordable accessible housing

Randy's return home

A facilitator worked with Randy's mother to consider options. The facilitator worked with a pediatric home care organization, an equipment provider, and a support coordinator to develop a plan. The plan involved finding subsidized housing, arranging in-home nursing, finding a used vehicle, arranging medical equipment and supplies, training Randy's mother in his care, and obtaining SSI and Medicaid. The plan was implemented and Randy was able to return home.



SETH is an active 13 year old with an intellectual disability and autism. He needs constant supervision and assistance with daily living skills. He has a diagnosis of Intermittent Explosive Disorder. He has two siblings. Seth was placed in a large Intensive Care Facility at age eight when his family was struggling with his care and a psychiatrist recommended placement. After two years, the facility closed. His parents moved him to three group homes over the next two years. They were unhappy with the turnover of staff in the group homes.

EXPLORING: Return home	Seth's family's support needs
People	Someone who understands challenging behavior and dual diagnoses to come to the home and work with Seth and to take him out into the community
Things	A fence for the backyard
Arrangements	Payment for trained supporters to come to the home Coordination between the trained supporters, psychologist, psychiatrist, and school Occasional opportunities for Seth to spend time away from home overnight somewhere he feels comfortable and is safe

Seth's return home

Since his initial admission, Seth's siblings had grown older and his family was able to reconsider the possibility of his return home. They worked with a support coordinator and were able to arrange for staff who were trained to work with individuals with challenging behavior to come to their home to assist with his care. They got help with the cost of the fence, coordination, and making arrangements for respite. Seth was able to move home with the support his family needed.

Now consider your own situation and use the exercise below to identify your needs. As you go through the exercise, for each section think about filling in the blanks in this statement:

“In an ideal world, our family would have _____
 [someone or something or some arrangement]
 to help with _____.”
 [the purpose of the support]

EXPLORING: Return home	INSTRUCTIONS: Identify your family’s support needs
Think about what you would need from other people .	People
Think about what kind of things you would need.	Things
Think about arrangements you would need.	Arrangements
Identify any other kinds of support you would need.	Other

The next task is to think about resources for your support needs. This is where a facilitator can help.

Generally support will come from some combination of:

1. Your personal network
2. Your community
3. The formal service system

1. Personal network. You may be able to rely on family and friends for some part of the support you need.

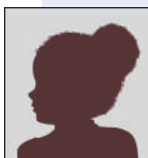
2. Community. If you have needs beyond what your personal network can handle, you may need to look to the community for support. Community resources may be available formally or informally. Informal community resources include assistance from individuals or from groups such as churches, neighborhood groups, or civic groups. Formal resources include organized community programs such as child care, recreational programs, or after school programs.

3. Service system. If personal and community resources are not sufficient, you may need support from the formal service system. This would include disability services. Getting services will usually involve identifying programs and following an application process and being determined eligible. Two potential resources of particular importance are the Medical Assistance Program and Medicaid Home and Community-Based Services Waivers.

THE MEDICAL ASSISTANCE PROGRAM (MA) (also called Medicaid or ACCESS) Medical Assistance (MA) provides free medical and behavioral health coverage to people with low incomes or with disabilities. Early Periodic Screening Diagnosis Treatment (EPSDT) is a program for all children under 21 on Medical Assistance that entitles them to all medically necessary health services and treatment.

HOME AND COMMUNITY-BASED SERVICES WAIVERS (HCBS)
 The Pennsylvania Department of Public Welfare administers service packages known as “Medicaid waivers” which provide a variety of supports to help individuals live at home or in the community. Three HCBS waivers provide supports and services for eligible children under age 18 and three waivers provide supports and services for eligible young adults age 18-20. Details about eligibility requirements and covered services for each waiver will be described later in the workbook.

Often family support arrangements involve personal, community, and service system supports at the same time. Here are some examples of different ways to arrange support.



JAMIE and KARLY are 14-year-olds who both have tracheostomies for breathing. They both need specialized care and monitoring at all times by someone with medical expertise. Their families need help with this care and monitoring.

Jamie's family support arrangement	Karly's family support arrangement
Jamie's family uses a home care agency that hires and schedules nurses who come to their home. The agency is paid by Medical Assistance.	Karly's family has a neighbor who is a nurse. They hire her to come to their home on a flexible schedule they work out together. She is paid directly by Medical Assistance.



MARC, KIM, and CHRIS are 8 year olds who have intellectual disabilities and autism. They need help with personal care like bathing, grooming, and dressing. They need close supervision because they are very active and easily upset when their routines are disrupted. Disruptions can occur multiple times a day and sometimes result in damage to household furnishings or injuries if not dealt with by someone who is skilled and trained in positive behavior support.

Marc's family support arrangement	Kim's family support arrangement	Chris's family support arrangement
Marc's family chose a provider organization that sends trained staff to their home to assist with his care. The provider is paid through a waiver.	Kim's family hired and trained a family friend to help them at home after school and on weekends. They submit paperwork to the waiver program to authorize payment to the aide.	Chris's family hired his favorite aide at school to help him go to a gym after school and on weekends. They pay the gym membership and submit paperwork to the waiver program to authorize payment to the aide.

These examples show two general ways that supports can be managed.

1. Provider-managed method
2. Family-directed method

In the provider-managed method, you identify agencies that offer a needed service. The provider you choose uses their resources on your behalf. In the examples above, Jamie's and Marc's families use this method. In the family-directed method, you identify people or things or arrangements that could help you. You control and authorize designated resources to pay for individuals, things, or arrangements that suit your situation. In the examples above, Karly's, Kim's, and Chris's families use this method.

Your choice of methods affects how much responsibility you assume for making arrangements and keeping records.

Which method would you generally prefer?

- Provider-managed
- Family-directed

The material covered so far provides a lot to think about.

You can use the following exercise to reflect on your thoughts so far about your child returning home.

Imagining your child returning home

	INSTRUCTIONS: ✓ Check all that apply			
	This makes sense for my child to return home from a facility	I am familiar with positive examples of this	I want to learn more	This is outside my experience
Support from other people				
Having things you need				
Having arrangements you need				
The concept of family-driven supports				
A facilitator to help with finding and getting support for your child to return home				

Consider the work you've done so far as an introduction to possibilities. The next section will help you think through whether you're ready to further consider the possibility of your child returning home.



Stage 3. Setting a new direction: Return home

The *third* stage is about considering whether to move in the direction of your child returning home. Setting a new direction will depend on (1) your comfort with making a change, and (2) whether you can imagine services and supports that might work. The exercise below is intended to help you sort out whether to proceed with planning to bring your child home.

Factors to consider in determining whether to go forward with planning to return home

		INSTRUCTIONS: ✓ Check the boxes that best apply		
		A	B	C
INSTRUCTIONS: <i>Summarize below (from your earlier exercise) what you would need for your child to return home</i>		We can see how to get what we need	We would consider return home if we could figure out how to get this	Even with this kind of help we would not consider our child returning home
PEOPLE				
THINGS				
ARRANGEMENTS				
OTHER				

If most of the boxes you checked were in column A or B, you might be ready to move on to the fourth stage which is designed to help plan specific steps to achieve your child's successful return home.

If you had checks in column C for supports that would be essential for your child to come home, you might want to consider the possibility of another family caring for your child. Exploring this alternative is covered later in the workbook. Even if you're reluctant, give yourself the chance to work through that section of the workbook.

Remember, setting a new direction is not a final decision. Nor is it a decision to make the move immediately. Your decision will depend on working out all the specific arrangements to assure your child's return home will be successful which is covered in the next stage.



Stage 4. Achieving: Return home

Now that you have a general idea about the supports and services you need, the next task is to figure out how to get them. The *fourth* stage outlines concrete activities for your child to return home.

Achieving return home depends on working out many details. Your decision is not final until all of the resources you need are lined up.

Two kinds of activities are described to accomplish return home: (1) planning activities and (2) transition activities. *Planning* is about finding ways to meet your needs. *Transition* is about making arrangements to actually set up specific services and supports for your child to be able to move home.

Depending on your situation, moving home may require a lot of support and a lot of work to arrange. You will need accurate information and you may need help in figuring out how supports and services can be put together to meet your specific needs. Given the complexity of the task, you may find you need the help of a facilitator. (See the section on page 5 for help in finding a facilitator.)

*Below is a list of
(1) planning activities
followed by a list of
(2) transition activities.*

1. Planning activities for return home

Identify a team to help you in planning for the possibility of your child returning home.

Identify and get commitment of people who can work as a team to assist you in coordinating your child's return home. In addition to you and other family members, team members could include a support coordinator, community services providers (such as nursing agencies, behavior support specialists, or medical equipment providers), current facility staff, and/or a facilitator.

Clarify your support needs for return home. The exercises you did earlier are a good place to start to assure your team understands what you need. It may be necessary to arrange for additional assessments of your child's support needs in your home. Your team can help you pull together additional needed information.

Identify resources for identified needs. This is a key part of the planning process. You will need to figure out who can provide support and whether it can

be provided at the level or intensity your child and family need. This requires knowledge of community resources and the service system and is an area where it is likely you may need help from a support coordinator and/or a facilitator. A good support coordinator or facilitator will know where to go or how to find out about resources.

Many informational resources are available to help in locating resources. While no one resource may have everything you need to know, a good starting place is:

Disability Rights Network

www.drnpa.org

Harrisburg Office: 1-800-692-7443
(717) 236-8110

Philadelphia Office: (215) 238-8070

Pittsburgh Office: (412) 391-5225

The organizations listed on p. 5 may also be helpful.

Two resources that may be particularly helpful are the Medical Assistance Program and the Home and Community-Based Services Waivers that were mentioned earlier.

The chart on the next page indicates some of the supports and services covered by these programs. Some additional services are also provided which are not listed. In addition to program eligibility criteria, each service also has specific eligibility criteria and limits. Taking full advantage of these programs requires understanding complex details. You will need a support coordinator or facilitator who really understands how they work.

For more information about waivers:

<http://www.dpw.state.pa.us/forchildren/healthcaremedicalassistance/homeandcommunitybasedservices/index.htm>

For more information about Medical Assistance:

Allegheny County Family

Resource Guide: www.familyresourceguide.org/medical-ins/

[familyresourceguide.org/medical-ins/medical-assistance.aspx](http://www.familyresourceguide.org/medical-ins/medical-assistance.aspx)

Pennsylvania Health Law Project:

www.phlp.org/wp-content/uploads/2012/08/HCBS-Waivers-BasicFactSheet-2012.pdf

Services for children under age 21	MEDICAL ASSISTANCE PROGRAM	MEDICAID HOME & COMMUNITY-BASED SERVICES WAIVERS					
		Person/Family Directed Support Waiver	Consolidated Waiver	Infant, Toddlers, and Families Waiver	Independence Waiver	OBRA Waiver	Attendant Care Waiver
ELIGIBILITY							
Age	0-21	3+	3+	Birth to 3	18+	18+	18+
Disability	Yes	Intellectual Disability	Intellectual Disability	Early Intervention	Physical Disability	Developmental Physical Disability	Physical Disability
Meets need for institutional level of care		ICF/MR	ICF/MR	ICF/MR ICF/ORC	Nursing facility	ICF/ORC	Nursing facility
Income	Child's income is considered. Parental income is waived.						
SERVICES	Note: Each service has specific conditions and limits to coverage.						
Habilitation (skill development)		✓	✓	✓		✓	
Personal assistance	✓				✓	✓	✓
Community integration					✓	✓	
Respite		✓	✓		✓	✓	
Home modifications		✓	✓		✓	✓	
Vehicle modifications		✓	✓		✓	✓	
Assistive technology Adaptive equipment	✓	✓	✓		✓	✓	
Nursing	✓	✓	✓		✓	✓	
Home health	✓	✓	✓		✓	✓	
Behavioral support/ therapy	✓	✓	✓		✓	✓	
Medical equipment/ supplies	✓				✓	✓	
Transportation	✓	✓	✓		✓	✓	
Community transition						✓	✓
Homemaker	✓	✓	✓				
Service coordination		✓	✓		✓	✓	✓

Your task now is to get down to the details of putting together a package of supports that will work for your child and your family.

INSTRUCTIONS: Using the exercise you did earlier, identify people, things, and arrangements you need.						
Needs	Supports People/Things/ Arrangements	Family Resources	Community Resources	Service System Resources	Funding Sources	Service Providers
Personal assistance	In-home In the community Other					
Personal equipment or supplies	Communication aides Adaptive equipment Hygiene supplies Other					
Health support	Primary care physician Nursing expertise In-home nursing Specialized therapy Medications Medical treatments Specialist expertise Medical equipment Medical supplies Respite Other					
Behavioral support	Specialized expertise In-home guidance In-home assistance Respite Other					
Mobility support	Home modifications Transportation Vehicle modifications Specialized equipment Other					
Homemaker support	Cooking Cleaning Shopping Other					
Household support	Housing assistance Household goods Relocation assistance Income assistance Respite Other					
Social support	Connections to supportive relationships					
Education support	Regular school day Extended school day Extended school year Other					
Support coordination	On-going Crisis prevention Crisis intervention Other					

✓ Contact resources. It can take a great deal of work to understand eligibility rules and access procedures for community and service system resources. You may want help from a support coordinator or facilitator.

✓ Determine whether to proceed. Deciding whether to go ahead with your child’s return home will depend on whether adequate resources are available to meet needs which are essential to you and your family. After making contacts

and learning what resources are available, you will need to determine how closely those resources fit your needs. The following tool may help with that assessment.

Supports needed

INSTRUCTIONS: Summarize your identified needs below	Support availability: ✓ Check the boxes that best describe the fit between needs and support to meet them		
	A	B	C
	GOOD FIT support available	POSSIBLE FIT dependent on something*	POOR FIT unavailable, unlikely to change
People			
Things			
Arrangements			
Other			
*Describe conditions to be met to obtain needed support			
Overall assessment of goodness-of-fit between needs & supports			



If most of your check marks are in Column A, you may be ready to proceed with transition activities below.

Where you checked Column B you will need to decide what has to be done and the conditions and time-table for when to proceed.

Where you checked Column C, it may be that changes in the service system will be required for you to

get what you need for your child to return home.

If that is the case, you may want to consider working with other families and advocates who are working for system improvements. Some of the groups listed on p. 5 are working for change to improve supports for families.

If you’re ready, the next activities will help you with the transition home.

2. Transition activities for return home

☑ Consider the need for transition visits. It will be important for you to have whatever time and/or guidance you need to become comfortable in resuming care for your child. Visits home prior to moving can provide you and your team with critical information that may not be evident in a facility setting. Visits home should include people who will be supporting you after the move to identify any additional training or support needs.

☑ Arrange services and supports. For each type of support or service you will need:

1. Develop a schedule for what you need and when you need it
2. Follow procedures for obtaining funding
 - a. Complete applications or eligibility determinations
 - b. Obtain authorizations or approvals
3. Confirm arrangements with people who will be supporting you
4. Confirm arrangements with providers
 - a. Exchange information
 - b. Obtain additional assessments if needed

☑ Address financial issues. Resolve any eligibility or enrollment problems. You might need assistance from a facilitator or an advocate. Apply for benefits or provide notices of a change of address to the Social Security Administration and Medical Assistance Program. Check with the facility to see if there is money remaining in your child's personal account and request that it is sent to you.

☑ Arrange for training. Identify what training you or the people who support you need, who should do

the training, and when and where the training should occur. Most children who live at home don't have access to 24/7 paid support staff. In addition, sometimes paid staff are unable to work their assigned schedule. You need to feel comfortable, competent, and confident in meeting your child's needs in the absence of support staff.

☑ Arrange for transfer to a new school. If your child will be changing schools, assure the new school is aware of your child's pending enrollment and potential start date. Assure an Individual Educational Plan meeting is scheduled. Assure the transfer of the Individual Education Plan and documentation from the former school.

☑ Confirm ongoing support coordination. Identify a support coordinator who will be responsible for following up to assure the support you need continues or can be changed if needed.

☑ Confirm back-up caregivers/contingency plan. Develop a contingency plan that identifies back-up for bad days and anticipates the unexpected. Identify what would happen if something happens that prevents you from caring for your child. Confirm people who could step in if you need them. Contingency plans may include your extended family but should not rely on them unless they are willing and able. A provider agency could be part of your back-up plan. Expectations should be clearly spelled out including contact arrangements and preparation of the back-up caregivers.

☑ Arrange for personal/household needs. Arrange for delivery of needed personal/household items such as supplies, appliances, equipment, or furniture.

☑ Coordinate moving day. Make sure everyone is prepared for the day of discharge. Arrange transportation. Arrange for medications, prescriptions, physician's orders, and your child's personal belongings or equipment. Make plans for your child to say good-bye.

☑ Celebrate your child's return. Plan something special for your family to mark this homecoming.

☑ Follow up. Be clear about who and when someone will be checking in with you to be sure things are going well or helping if changes are needed.

CONSIDERING YOUR CHILD RETURNING HOME

If successful, this section has helped you think through the possibility of your child being able to once again live with your family. The path home may be challenging but hopefully this section of the workbook has contributed some useful ideas that will enable you to imagine the possibility of your child returning home and some tangible strategies that may enable you to achieve it.



If you're not ready for your child to return home, consider going on to the next section which returns to Stage 2 to explore the possibility of another family caring for your child.

Even if you're skeptical about this option, give yourself a chance to work through that section.

Stage 2. Exploring: Another family caring for your child

While having your child at home may be your dearest desire, you may not feel it is possible even with additional support. If so, you might consider another family who you could trust to care for your child with your close and continued involvement. You may know someone who you think could play that role, like a relative or friend. If not, the idea of someone else caring for your child may not seem appealing or feasible. Remember this stage is exploratory so keep an open mind and try not to rule out the possibility.

When you think about another family caring for your child, you might think of foster care where children are placed after abuse or neglect. But this is only one kind of family living alternative and is only relevant in limited situations. You might not have imagined other family living arrangements where you can *voluntarily* choose another family to care for your child while you continue to be closely involved and maintain your parental rights.

Imagine the possibility, what if...?

1. *What if one of your relatives was willing to care for your child if they could get extra support?*
2. *What if your best friend was willing to care for your child if they could get extra support?*
3. *What if the staff member you most trust at the facility was willing to care for your child in their home if they could be supported?*
4. *What if you could find someone you could trust as much as your favorite staff member whose career was caring for children with disabilities in their own home instead of working a shift in a facility?*

In this workbook such a family is called a “**partner family**” and the arrangement is called “**life-sharing.**” Because this arrangement may be hard for you to imagine, we will devote a lot of time to describing this possibility.

The work of this stage is to more carefully explore possibilities. The exercises and information that follow are intended to help you learn about and imagine possible options. You may find it would be helpful to have a facilitator assist you with this exploratory process.

The following exercise is a place to start. As you fill it out, think about the kind of family you would trust to care for your child.

EXPLORING: Another family	COMMENTS
<p>Is there anyone you already know who you would trust to care for your child in their home?</p> <ul style="list-style-type: none"> • a relative • a good friend • a staff person at the facility 	
<p>What is it about the families you considered that leads you to consider or reject your child living with them?</p> <ul style="list-style-type: none"> • Personal attributes • Experience • Location • Relationship with you • Access to support • Something else 	

There are generally two ways to find another family to care for your child:

1. The first way is finding someone within your personal network.
2. The second way is recruiting a community family.

More details are provided later in the workbook.

Below are examples of families who used someone from within their personal network.



JOSH is a friendly 20 year old young man who has a moderate intellectual disability and cerebral palsy. He uses a power wheelchair and an augmentative communication device and needs assistance for all activities. His single mother struggled financially. She needed to work but her son's care needs conflicted with her work obligations.

CONGREGATE CARE

Josh was placed in a large ICF facility at the age of 15.

FAMILY-BASED ALTERNATIVE –Extended family

A facilitator helped Josh's mother to fully explore options. Josh's mother felt she could not resume care for him on her own and she was not interested in considering an unknown family. The facilitator helped her see an option she hadn't considered possible. Josh's mother learned how her extended family could be supported to care for Josh in their home. Josh was able to go to live with his uncle's family near his mother.



RONNA was born with a congenital brain deformity with the strong likelihood of future severe impairments. Ronna's parents were overwhelmed by her condition and fearful of taking her home.

CONGREGATE CARE

Ronna's parents were advised to place her. She was placed in a pediatric nursing facility where she remained for five years where she got assistance with all her daily care and close monitoring of her health and physical condition.

FAMILY-BASED ALTERNATIVE—Partner family

A facilitator contacted Ronna's parents to encourage them to reconsider family life for their daughter. Never having cared for her, they felt ill-equipped to have her live with them. They were also skeptical about another family of strangers caring for her. The facilitator learned that Ronna's parents trusted Sharon, the aide who worked with Ronna at the nursing home. The facilitator approached Sharon about the idea of becoming a partner family for Ronna. She was interested but neither her apartment or car would accommodate Ronna's wheelchair and she needed a source of income. The facilitator connected Sharon to a provider agency that assisted her to find accessible housing, provided a lift for the van she traded in for her car, arranged for nursing staff to assist her and to be available in the event of an emergency, and provided a monthly subsidy payment similar to her income from the nursing home job. Ronna's family agreed for her to live with Sharon because they knew she loved their daughter and understood her needs and they trusted her.

The **second way** to find another family to care for your child is to be introduced to a family recruited by a provider for you to consider. (More details are provided later in

the workbook.) If you don't already know a family you trust, it's probably hard to picture another family caring for your child. Many parents who have been in your situation were

equally doubtful but subsequently found a successful family situation.

Below are examples of families who chose a recruited family for their child.



JAMAL is an eight year old with a severe intellectual impairment and ADHD. He's a very active boy and sometimes his exuberance inadvertently led to injuries to his younger siblings. When his mother felt she couldn't protect his younger siblings she sought an out-of-home placement.

CONGREGATE CARE

The only placement available was a large ICF facility several hours from his family home. JaMal was one of only a few children in a facility of 100 beds.

FAMILY-BASED ALTERNATIVE—Partner family

A facilitator contacted JaMal's mother to explore family-based alternatives. His mother was skeptical about another family caring for him, but the opportunity to have him closer to home was appealing so she agreed to meet some potential families. She was introduced to Chandra who lives within fifteen minutes of her. Chandra had worked in group homes with individuals with intellectual disabilities before she became certified as a partner family. JaMal's mother and Chandra clicked immediately. JaMal moved to Chandra's home. JaMal's mother says, "She's like a sister." Now the two extended families socialize together and JaMal moves back and forth between his two loving families.



TIM is a twelve year old with autism and a severe intellectual disability. He is very active and needs constant vigilant supervision because of his lack of safety skills. His parents struggled with his need for constant supervision while also caring for his four siblings.

CONGREGATE CARE

Tim was placed at age four in a large facility. His parents believed the facility was the only setting that could serve their son.

FAMILY-BASED ALTERNATIVE –Partner family

Tim's family met with a support coordinator who was familiar with alternatives to facility care who offered to introduce them to some partner families. Though reluctant, they agreed. They met a partner family they had not imagined. The partner family had experience in caring for children just like Tim. The support coordinator facilitated careful transition planning and Tim was able to move from the facility to the partner family's home. His family remains active in his life.

How does a partner family arrangement work?

A partner family is a family you chose to care for your child while you continue to be closely involved and maintain your parental rights. Children can live with a partner family and yet remain an integral part of their own family's life. Partnering with another family is a way to provide practical assistance to you while enabling your child to enjoy the benefits of family life.

Partner families are people with unique attributes who have made a personal commitment to a child's daily welfare and who have the means, time, personal qualities and support they need to provide a family home.

- A partner family may be a family you already know and trust.
- A partner family may be a family who is recruited for your child.

- Partner families are licensed and supervised by a provider organization to assure their ability to provide for the welfare of children in their care.
- Partner families are evaluated, prepared, monitored, and paid by a provider agency to care for a child with a disability in their home.

- Partner families offer the reliability of trained and supervised caregivers within the nurturing environment of family life.
 - Partner families provide:
 - Physical security through a stable, safe living arrangement.
 - Emotional security through a nurturing relationship.
 - Partner families receive:
 - Guidance
 - In-home support
 - On-going monitoring
 - Provider agencies that are responsible for partner families are licensed and regulated by the state to assure the safety and well-being of children entrusted to them.
- Provider agencies do this by:
- Evaluating potential partner families
 - Conducting criminal and child abuse background checks
 - Inspecting partner families' homes
 - Providing training and supervision
 - Undergoing inspections by the state of their oversight of partner families

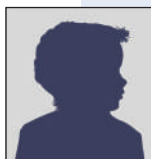
What is life-sharing?

Life-sharing recognizes that a partner family living arrangement involves a relationship between a child and partner family, but also between the child's parents and the partner family. A child often lives with a partner family full-time but sometimes the child's family might provide care in their home for part of the week.

A successful life-sharing arrangement will require finding a good match between your child, a partner family, and your family. Your child's needs will be best met when you and the partner family develop a trusting relationship and work together on your child's behalf. Life-sharing requires developing a workable agreement about your mutual expectations.

Other parents who have used partner families report that the experience of having another family who loves and values their child has been tremendously supportive to them as well as their child. They report a partner family can become like extended family.

Following are examples of three children whose families chose a life-sharing arrangement.



RAMÓN is an eight year old Latino boy. He has a pervasive developmental disorder, a moderate intellectual disability, and challenging behavior. He was the second child of his 18-year-old parents who subsequently had two more children.

CONGREGATE CARE

Ramón was admitted to a large ICF at age seven when his parents could no longer manage his behavior. After his admission, Ramón's parents divorced and his father moved out-of-state. Ramón's mother had to work to support her children so she felt she was unable to care for Ramón at home.

FAMILY-BASED ALTERNATIVE –Partner family

A support coordinator contacted Ramón's mother to explore alternatives. The support coordinator introduced the idea of a partner family. She worked with several provider agencies and was able to identify three potential partner families. When Ramón's mother met the partner families, she connected with one of the families who spoke Spanish and also had a son with autism. Ramón was able to move to the partner family's home and his family sees him more than they could in the facility.



AARON'S mother was in a bind. Her health was deteriorating while her son's care needs were growing. Aaron has significant developmental disabilities and Hepatitis C. At nine years of age Aaron was unable to walk, talk, or meet his daily needs. His mother had been caring for him alone since her husband's death but then she was diagnosed with a degenerative physical health condition. She turned to the system for help.

CONGREGATE CARE

Aaron's mother accepted the only option she was offered—an ICF facility located about two hours away which provided "specialized treatment" for 120 adults and children with needs similar to Aaron's. He lived there for several years.

FAMILY-BASED ALTERNATIVE—Partner family

A facilitator learned about Aaron and sought out his mother to talk about alternatives. The facilitator described a partner family option. Aaron's mother's thoughts about the arrangement? "I think it's great. Nobody told me there were families who would do this. If he can't live with me, I would rather have him with a family." Her conditions were that she wanted a black family who lived near her and understood Aaron's disability needs. Working with a provider organization, an African American family was found who lived about five minutes from her who had experience with children with developmental disabilities and was willing to have Aaron become a part of their home while also helping his mother to remain active in his life. The partner family understands her situation and takes Aaron to spend time at her home when her health prevents her from getting out.



BINH is a beautiful nine year old Vietnamese boy with a fabulous smile. He has physical and intellectual disabilities and complex medical needs. He has a tracheostomy for breathing, a gastrostomy tube for nourishment, and a wheelchair for mobility. At birth his teenage mother was encouraged to let go of any relationship with her son because of his short life expectancy.

CONGREGATE CARE

After a lengthy hospitalization, Binh was transferred to a nursing home. Binh's mother maintained contact with her son, though visits were infrequent due to distance. She wished he could be closer.

FAMILY-BASED ALTERNATIVE –Partner family

A facilitator met with Binh's mother and her extended family to explore alternatives. Binh's mother felt she couldn't bring him home but indicated willingness to consider a partner family. Working with provider agencies, the facilitator identified a potential partner family with experience with children with complex medical needs near Binh's extended family. After facilitating visits and transition planning including nursing support for the partner family, Binh was able to move from the facility to the partner family.

When parents first hear about partner families, they often have concerns:

1. How is another family better than the specialized care offered in a facility?
2. How could another family do what we couldn't?
3. How do I know another family will be safe and trustworthy?

1. How is another family better than the facility?

Understanding the benefits of a partner family will be key to whether you choose one. In the exercises you did earlier you identified what you want for your child and the qualities you would look for in another family. Consider those qualities when you think about the facility where your child lives.

The facility's qualities are made up of the building and the people who work there. If you think about the building, you might see how a family home offers a smaller more intimate setting with fewer rooms and roommates. If you think about what's most important about the facility, you might find that the issues that really concern you are related to the people who care for your child.

It might be helpful to look more closely at the attributes of caregivers in a facility compared to a partner family home.

Similarities in expectations of caregivers	Facility staff	Partner family
Care is delegated by you to qualified substitute caregivers	X	X
Caregivers undergo background checks	X	X
Caregivers have specialized training to care for children with disabilities	X	X
Caregivers are always available because it's their job and they are paid to provide services	X	X
The caregiving arrangement is licensed, regulated, and subject to periodic inspections	X	X
Professional guidance and specialized services are available to help caregivers	X	X

Differences in expectations of caregivers	Facility staff	Partner family
Responsibilities	Assigned to a group of equally needy residents	Child is a member of a household
	Duties delegated by the employer	Duties developed in partnership with parents
Relationships	Expected to be affectionate but not to get emotionally involved with children	Expected to get emotionally involved with a child as part of the family
	Expected to be respectful but not have personal relationships with parents	Expected to have a personal relationship with parents
Duration of responsibility	While on duty	As long as the child is a member of the family and potentially life long

Think about caregiving arrangements in concrete terms:

- Does your child have a primary caregiver?
- Is your child's primary caregiver someone you chose?
- Is your child tucked in at night by the same loving person every night?
- Is the caregiver at night the same person your child wakes up to?
- Can your child expect the same caregivers to be there next week? Next month? Next year?

2. How could another family do what we couldn't?

There are a number of ways that your family and a partner family differ.

Partner families choose whether, how, when, and under what circumstances to provide a home for a child with disabilities while you likely didn't have these choices. Partner families have these choices as a condition of their acceptance of a child as a family member.

- Choice to care for a child with a disability in their home
- Choice about the type of disability they feel comfortable with

- Choice to adapt their lifestyle to accommodate a child's needs

When you became the parent of a child with a disability, you likely faced an emotional struggle and situation that you hadn't imagined or prepared for. When you placed your child in a facility, you likely didn't feel you had the support you needed to care for your child at home. By comparison, partner families have support you may not have had. They assume responsibilities:

- When they are emotionally prepared

- When they are prepared for a child's disability needs
- When they have the supports they need *before* a child comes to live with them
- When they can expect supports to continue

When you think about these differences, you may begin to see how partner families may have circumstances which you didn't have that enable them to be successful.

3. How do I know the family will be good?

Of course you will be concerned about your child's welfare if you entrust his or her care to another family. You need to be assured that safeguards are at least as good in a partner family home as they are in the facility. You can think about judging protection for your child in two ways: (1) systemic safeguards and (2) personal experience.

Systemic safeguards

You should understand the multiple ways in which partner families are monitored:

- Partner homes are licensed based on:
 - Home inspections
 - Background checks
 - Home studies
- Partner homes are supervised and monitored by provider agencies that are licensed by the state.
 - Provider agencies are required to make monthly home visits
 - Provider agencies are subject to state inspections

Personal experience

You should consider others' direct experience as well as your own views from direct experience.

- You will want to hear from other people who know the partner family.
- You will want to hear from the provider agency staff who are responsible for monitoring the partner family identified for your child.
- You may want to hear about the experience of other families who have used partner families.
- You will want to get to know the proposed partner family before deciding.
- You will want to be sure about your ongoing involvement after your child moves.

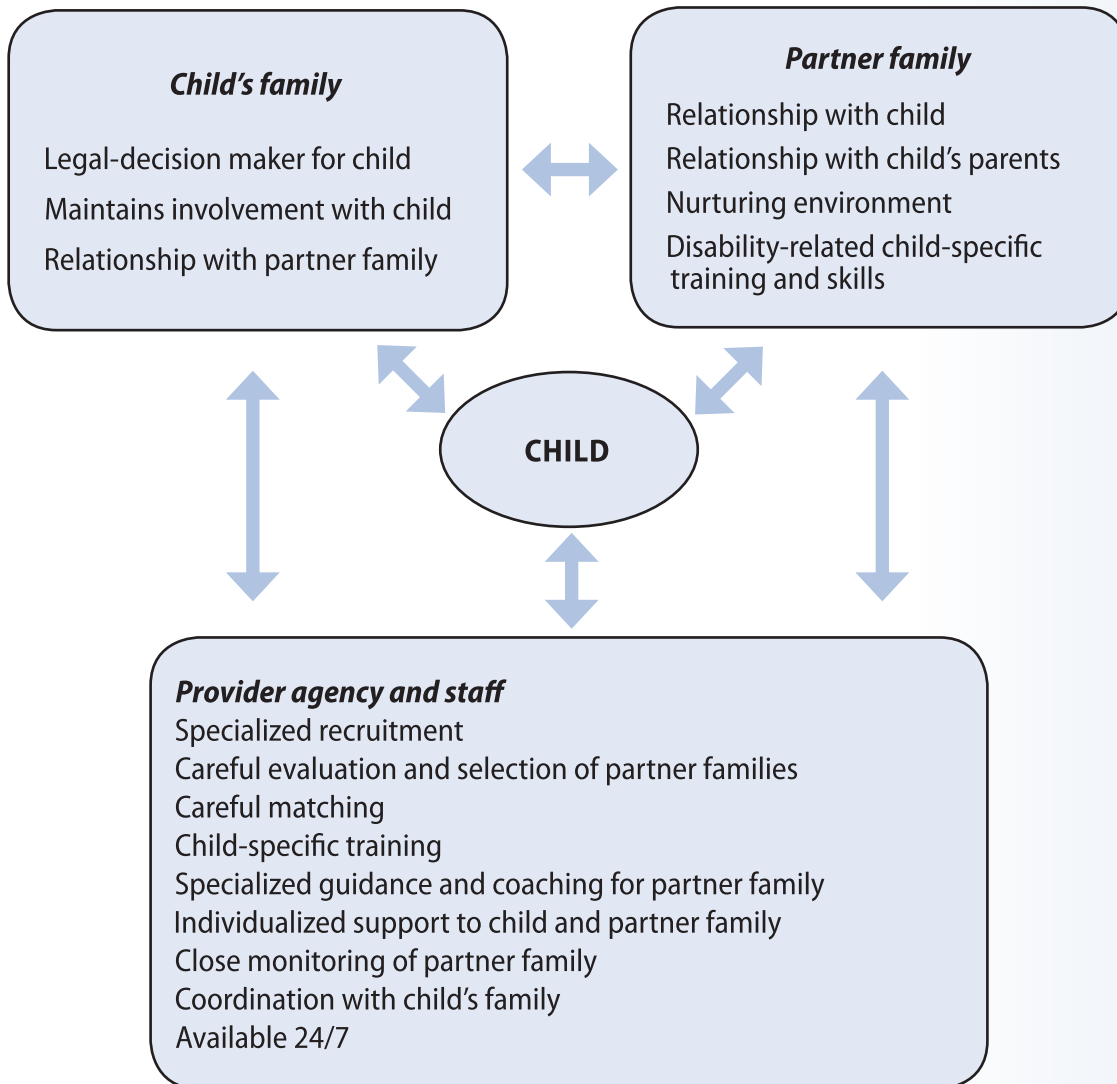
Ultimately your decision will be based on your trust in systemic safeguards coupled with the trust you come to feel for the particular partner family. At the end of the day, your sense of trust will develop from personal knowledge through interactions with the partner family. You should take as much time and as many opportunities as you need to decide about a potential partner family.



Characteristics of a system of life-sharing

The diagram below describes the elements of successful life-sharing and how they relate to each other.

Attributes of partner family / Life-sharing arrangement



Pennsylvania Life-sharing

Lifesharing through Family Living is a program of The Pennsylvania Department of Public Welfare, Office of Developmental Programs. Lifesharing offers opportunities for individuals with intellectual disabilities to live with an unrelated family who is licensed to care for a maximum of two individuals with disabilities in their home. Most lifesharing arrangements are funded through the Consolidated Waiver. You can learn more about PA Lifesharing at the website: www.palifesharing.com

Success of partner families

In thinking about life-sharing, it might help you to know how successful partner family arrangements have been in Pennsylvania and elsewhere.

A significant amount of research and experience in Pennsylvania and other states shows the feasibility of specialized partner family arrangements to assist children and youth with complex needs including developmental disabilities, behavioral challenges, mental health needs, and juvenile justice involvement to move from residential treatment facilities to family care.

Research has demonstrated better outcomes in well-supported family care than residential care. Of note, research suggests one of the factors that most contributes to better outcomes is the parent-child relationship that is unique to a family setting.

See the references for some additional information about successful systems developed in Michigan and Texas and Pennsylvania.

There is a lot to think about.

You can use the following exercise to reflect on your thoughts about partner families and life-sharing so far.



Imagining another family caring for your child

	INSTRUCTIONS: ✓ Check all that apply			
	This makes sense for my child to be able to move from a facility	I am familiar with positive examples of this	I want to learn more	This is outside my experience
The concept of a partner family and life-sharing arrangement				
Importance of careful selection and preparation of partner families				
Importance of matching				
Importance of adequate support for partner families				
A facilitator to help with finding a life-sharing arrangement				

Consider the work you've done so far as an introduction to possibilities you may want to explore further. If you decide to proceed with a partner family/life-sharing arrangement, you will need to learn a great deal more about what will work for your particular situation. The next section will help you think through whether you're ready to further consider the possibility of your child living with another family.

Stage 3. **Setting a new direction:** **Find a life-sharing arrangement**

The *third* stage is about considering moving toward a partner family living arrangement. Setting a new direction will depend on (1) your motivation to make a change, and (2) whether you can envision the possibility of a partner family fitting your particular situation. The exercise below is intended to help you sort out whether to proceed with trying to find a partner family.

Factors to consider in determining whether to go forward with planning for a partner family

	INSTRUCTIONS: ✓ Check the boxes that best apply		
	A	B	C
Your level of comfort in considering a partner family for your child	<input type="checkbox"/> We are ready to find a partner family	<input type="checkbox"/> We might consider if we could find the right partner family	<input type="checkbox"/> We are very skeptical about our child moving to a partner family
Your ideas about a possible partner family	<input type="checkbox"/> We have a family in mind	<input type="checkbox"/> We would need help to find the right partner family	<input type="checkbox"/> We are not ready to consider potential partner families
Your time frame for pursuing a partner family	<input type="checkbox"/> We want to move forward as soon as possible	<input type="checkbox"/> We want to take our time but are ready to begin	<input type="checkbox"/> We want to wait—we're not ready to move ahead

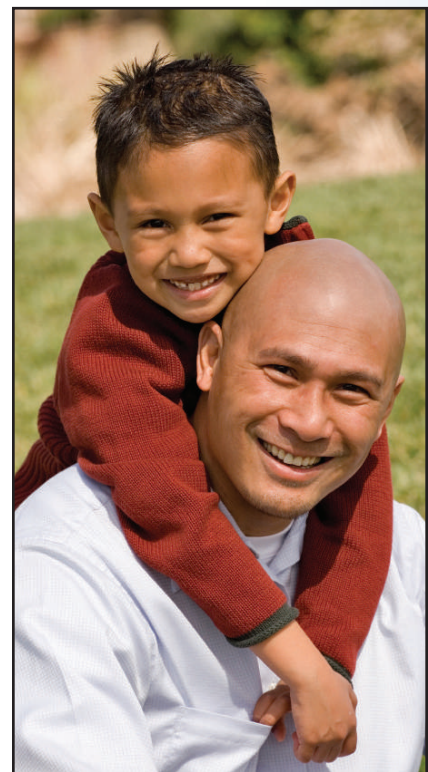
If most boxes you checked were in column A and B, you might be ready to proceed to the fourth stage which is designed to help plan specific steps to achieve a partner family living arrangement.

If your checks were mostly in Column C, you might want to take more time or consider seeking the views of other families and/or help from a facilitator to become more comfortable.

Remember, setting a new direction is not a final decision.

Nor is it a decision to do so immediately. Ultimately your willingness to consider a partner family will be based on the qualities of a specific partner family offers. You will have to move from an imagined family to consideration of a real family caring for your child. What other parents found who successfully moved their children to partner families was that their decision became clear when they met an actual family.

Your decision will depend on finding the right partner family and working out specific arrangements to assure they will be successful. That is the work of the fourth stage.



Stage 4. **Achieving: A life-sharing arrangement**

The fourth stage identifies concrete activities to find the right family with the right attributes and supports to fit your child's needs and your preferences.

This is a complex undertaking. It requires a variety of activities and a lot of support and work to arrange. Given the complexity of the task, you will likely need the help of a support coordinator or facilitator.

Before you can achieve a partner family, it will be important to understand funding for partner families and the supports they need to meet your child's needs. Funding for the life-sharing arrangement is limited as of the writing of this workbook. It is primarily funded through the Consolidated Waiver for children and youth under age 21

coupled with Medical Assistance (*describe earlier on p. 8*). Only individuals over age three who have an intellectual disability are eligible for the Consolidated waiver and there may be a waiting list for the waiver. Life-sharing is sometimes funded through county discretionary funds. A goal of the workbook is to stimulate interest in system change to ensure more access to family-based alternatives to congregate care for children, in particular, for partner family arrangements.

Assuming there is funding for a life-sharing arrangement, below is a list of the activities which will likely be necessary.

Four types of activities are needed to achieve a life-sharing arrangement:

- 1. Recruiting**—finding a potential family
- 2. Matching**—considering whether a potential family is a good fit
- 3. Planning**—determining what supports and services are needed
- 4. Transition**—setting up what is needed

These activities will help determine whether the imagined partner family living arrangement can be achieved.

1. Recruitment activities

As mentioned earlier, there are two potential ways to find a partner family:

1. Personal network search
2. Provider-based search

Below are more details about each method.

Personal network search

The strategy of the personal network search is to think about people who have a connection to your child and your family to see if there is someone who might be approached about caring for your child. The strategy also involves thinking about people you know who might in turn know other people you don't know who might be approached.

The following exercise will help you think about someone you know or someone who knows your child who

might be a possible partner family. People who know your child's daily routines may help in identifying families who might be interested in becoming a partner family for your child. The first step is brainstorming. In the exercise below, include as many people as you can think of. At this point, you don't need to know if they would be willing—the matching process later will help you narrow the list.



Finding a partner family from your personal network	INSTRUCTIONS: Identify possible leads
<p>Relationships</p> <ol style="list-style-type: none"> 1. Is there anyone you know who you would trust to care for your child in their home? <ul style="list-style-type: none"> A relative? A good friend? A staff person at the facility? 2. Who are the important people in your child's life? 3. Who has a special relationship to your child? <ul style="list-style-type: none"> Someone at the facility? Someone at your child's school? 	
<p>Community connections</p> <ol style="list-style-type: none"> 1. Of places your child goes in the community, is there someone who shows an interest in or connection to her or him? 2. Is there someone from the community who visits the facility and shows an interest in or connection with your child? 3. Is there someone you know from a community group, church, or organization you belong to that might provide a lead to a possible family? 	

If this exercise leads you to identify any families, the section on matching can help you with the process of pursuing these leads.

The planning steps later in the workbook can then help with thinking about what supports and services might help an interested family to become willing and able.

Remember, a promising family would need to get connected to a provider for background checks and a home study to become licensed and fully prepared.

Provider-based search

The provider-based search involves engaging provider agencies that are licensed to recruit and support partner families.

Think about what you would like a provider agency to know about your preferences in a potential partner family.

Finding a potential partner family through a provider agency	INSTRUCTIONS: Identify your preferences regarding a potential partner family
<p>Family characteristics race/ethnicity family composition experience</p>	
<p>Location geographic area distance from your home</p>	
<p>Expectations your level of involvement your relationship with the partner family</p>	

The next step is to identify provider agencies and determine which agencies have partner families in your desired geographical area with experience with children with disabilities similar to your child. You may try to find provider agencies on your own, but it will likely be more effective to get help from a support coordinator or a facilitator who

knows the provider network. You can find providers in your region at the PA Lifesharing website:

<http://www.palifesharing.com>

The next step is to contact provider agencies to learn about their partner families who might be a good match for your child. This will involve exchanging information about your

child and the agency's potential families and arranging for agency staff to meet your child to identify leads worth exploring further.

The matching process below will help you figure out whether a recruited family might be a good fit.

2. Matching activities

Either recruitment method (personal network or provider-based) can lead to identification of a potential partner family. The next step is determining if the potential family is a good match. Matching is about finding a “good fit” between your child, your family, and a particular partner family.

A good fit is determined by weighing multiple factors:

- Your child's needs
- Your family's preferences
- The partner family's abilities and characteristics
- The partner family's preferences

Fit is also determined by feelings—whether you feel good about the partner family and whether they show positive feelings toward your child.

Fit can sometimes involve negotiations. Some of each family's preferences will be non-negotiable but others may be open to compromise. Fit is determined by the degree to which both families can negotiate mutually acceptable compromises.

Matching is a process of discovery. It takes time. When a potential match is identified, it is essential to take the time to explore it thoroughly. Sometimes matches are clear right away. Sometimes matches that look good initially might not work out because it becomes clearer along the way that the fit is not good enough.

Other matches that are not clear right away may look better as you get to know the potential family.

You will need to know how supports to the partner family can be arranged to meet your child's specific needs so you can be confident the partner family can succeed.

You should understand that the match is tentative until you give final approval.

The following activities can help you in considering fit.

☑ Identify a team of individuals to help you in considering a proposed family. In addition to your family members and others who you trust, team members could include a support coordinator, staff from community services providers and the current facility, and a facilitator.

☑ Assure team members have a thorough understanding of your child's support needs. Team members should meet your child, review important records, and talk with current caregivers and professional staff who interact with your child. Facility staff and care plans will have important information, but it may be necessary to arrange for community-based assessments in order to get a complete picture of what your child would need to live successfully in a partner family home.

☑ Explore promising family leads. Look more closely at potential partner families. The booklet *A Guide to Choosing a Support Family* gives helpful advice to consider in deciding about a particular family. See the references to obtain the booklet.

- Identify potential matches that merit further exploration.
- Exchange information—provide information about your child to the partner family and get information about the partner family.
- Meet a potential partner family and visit their home.
- Arrange initial visits between your child and a potential partner family, typically at the facility where your child lives.
- Determine additional facility visits, home visits, and other activities to give your child and the partner family time to get to know each other.
 - Visits should be frequent enough and long enough to allow relationships to grow and to discover any additional support issues that need to be addressed prior to moving.
 - Arrange any child-specific training or preparation the partner family needs before visits in their home.

☑ Determine if a match is a good fit. A match is a good fit when you, the partner family, and the provider agency are in agreement that it meets your child’s needs and each family’s preferences and all parties are ready to work toward transition from the facility. A Goodness of Fit Assessment tool has been developed to assist in this assessment. See the references to obtain a copy.

Following is a short summary of the tool.

Summary of “Goodness of Fit” considerations	INSTRUCTIONS: Identify partner family attributes		
	Strength	Amendable to change or would be acceptable with additional support or activities*	Poor fit—unlikely to change even with supports
Characteristics of partner family			
Relationship with child and child’s family			
Housing			
Location			
Partner family experience			
Certification and training			
Preparation relevant to child’s needs			
Supervising provider agency supports			
*Activity or support that would make factor acceptable			
Match assessment			

If you feel a match is good, it is still not a final decision. Your final decision will depend on working out specific arrangements to assure it will be successful. The next two steps involve (1) planning and (2) transition activities. The provider agency and service coordinator will play important roles in these activities. You may also benefit from a facilitator’s help with these activities.

The planning activities that follow will help you figure out what needs to be done next.

3. Planning activities

Clarify the partner family's support needs. You and the facility staff will have important information about your child. The provider agency will have important information about the partner family. It may be necessary to arrange additional assessments of your child's support needs in a partner family's home.

In addition to your child's needs, the partner family's needs include circumstances or issues that will be affected when your child joins their family. Examples include work or other family obligations (such as other children or grandparents), housing issues (such as space or accessibility), and the availability or absence of an informal support network.

Partner family needs	INSTRUCTIONS: Identify support needs
What kind of help will the partner family need from other people? On a good day On a bad day In the community From people with particular kinds of expertise	People
What kind of things will the partner family need? Equipment Supplies Home modifications Other things	Things
What arrangements will the partner family need? Coordination Transportation Respite Income Crisis back-up Other arrangements	Arrangements
Identify any other needs.	Other

☑ Identify resources for identified needs. The crux of the planning process is figuring out who can provide needed support and whether it can be provided at the level or intensity your child and the partner family need. This requires knowledge of the partner family's personal resources, community resources, and the service system. This is generally the responsibility of the support coordinator and the provider agency. The following tool may help in this process.

INSTRUCTIONS: Identify resources to meet your needs						
Needs	Supports People/things/ arrangements	Partner family resources	Provider agency resources	Community resources	Other resources	Funding sources
Personal assistance	In-home In the community Respite Other					
Health	Primary care physician Specialist expertise Nursing expertise In-home nursing Specialized therapy Medications Treatments Medical equipment Medical supplies Other					
Behavioral support	Specialized expertise In-home guidance In-home assistance Respite Other					
Mobility	Home modifications Transportation Vehicle modifications Specialized equipment Other					
Homemaker	Cooking Housekeeping Shopping Other					
Household	Income Household goods Other					
Education	Regular school day Extended school day Extended school year Other					
Coordination	On-going Crisis prevention Crisis intervention Other					

Determine whether to proceed to transition. Whether to go ahead with your child's move to the partner family will depend on whether adequate resources are available to meet essential needs. Testing how good the fit is between needs and available supports will involve judgment as what is essential and how closely the available resources come to meeting that. The following tool may help with that assessment.

Supports needed

INSTRUCTIONS: Summarize your identified needs below	Support availability: ✓ Check the boxes that best describe the fit between needs and support to meet them		
	A	B	C
	GOOD FIT support available	POSSIBLE FIT dependent on something*	POOR FIT unavailable, unlikely to change
People			
Things			
Living arrangements			
Other			
*Condition to be met to obtain needed support			
Overall assessment of goodness-of-fit between needs and supports			

If Column C is checked, this particular partner family may not be a good fit. Where Column B is checked, you will need to decide with your team what needs to be done and the conditions and timetable to proceed. If most of the check marks are in Column A, you may be ready to proceed with the transition activities.



The transition activities that follow will help you in figuring out the final steps for your child to move to a partner family.

4. Transition activities

A transition plan details what tasks need to be completed prior to your child moving to the partner family's home. The transition process requires working with everyone involved to ensure a successful transition by establishing who is responsible for necessary activities and dates for completion.

Overall transition activities involve:

1. Identifying and securing the **supports and services** your child will need to live successfully in the partner family's home
2. Arranging for additional child-specific **training and preparation** for the partner family to ensure they can meet your child's needs
3. Building and strengthening the **relationships** between your child and the partner family and between your family and the partner family
4. Continuously **evaluating** the match and making adjustments as necessary

Many of these activities will be done by the provider agency and a support coordinator or a facilitator.

Arrange visits while other transition activities are occurring.

Continuing partner family visits with your child during this period will enable them to become more comfortable and to build a relationship. Visits should include staff from the provider organization to guide the partner family and observe their care and interaction with your child in order to identify any additional training or support needs.

Secure services and supports.

For each type of needed support or service, the following activities need to be coordinated with the partner family and community providers:

1. Confirm arrangements with identified providers

2. Follow procedures for obtaining funding
 - a. Complete eligibility determination and enrollment procedures
 - b. Obtain authorizations or approvals
3. Obtain additional assessments if needed
4. Arrange training as needed for people who will support the partner family
5. Develop a schedule for supports or service delivery

Arrange partner family training. Identify what training is needed, who should do the training, and when training should occur so that the partner family feels comfortable, competent, and confident in meeting your child's needs.

Arrange for enrollment in new school. Assure the new school is aware of your child's pending enrollment and potential start date. Assure an Individual Education Planning (IEP) meeting is scheduled. Assure the transfer of the IEP and all other documentation from the former school.

Identify back-up caregivers/contingency plan. Develop a back-up plan that identifies caregivers who could step in if necessary. Back-up and contingency plans may include your family but should not be expected unless you are willing and able. The provider agency is responsible for the back-up plan. Expectations should be clearly spelled out including contact arrangements and preparation of the back-up caregivers.

Negotiate a life-sharing agreement. It can be valuable to clarify understandings with the partner family in writing. A written life-sharing agreement signed by both families and the provider can

confirm roles, responsibilities, and expectations. A provider agency's co-signature on the agreement assures that they understand the agreement and can assist in assuring it is followed or renegotiated. See the references to obtain an example of a life-sharing agreement. Generally items in the agreement include:

- Acknowledgment of the legal status and authority of each family
- Identification of the supervising provider organization
- Identification of how the agreement can be modified
- Specific details about responsibilities:
 - Daily care*
 - Medical care*
 - Educational arrangements*
 - Respite care*
 - Service planning*
 - Family interactions*
 - Emergency arrangements*
 - Financial arrangements*
 - Religious and cultural expression*
 - Future expectations*

Coordinate moving day.

Decide how you will be involved and who will transport your child to the partner family home. Make sure that all parties are prepared for the day of discharge. Assure medications, prescriptions, and physician's orders are obtained and your child's belongings and equipment are transferred. Assure forwarding addresses and contacts are shared. Plan how to let your child say good-bye.

Celebrate: Decide how to join the partner family in welcoming your child to their home.

Follow-up: Clarify who will be checking in with you to see how the arrangement is going and whether any changes are needed.

CONSIDERING A PARTNER FAMILY

If successful, this section has stimulated your interest in considering the possibility of your child being able to live with another family. The path to life-sharing as described in this workbook may be challenging, but hopefully this section has offered some useful ideas that may allow you to imagine the possibility of your child living with a partner family and some tangible strategies to achieve it.



REFERENCES AND ADDITIONAL MATERIALS

Materials are available from the PEAL Center or from EveryChild, Inc.

PEAL Center

1119 Penn Avenue, Suite 400
Pittsburgh, PA 15222
412-281-4404
Toll Free 866.950.1040
TTY 412.281.4409
www.pealcenter.org

EveryChild, Inc.,

8400 N. MoPac, #201
Austin, TX 78759
512-342-8844
www.everychildtexas.org

Guide to Choosing a Support Family

Partner family Goodness-of-Fit Assessment

Life-Sharing Agreement

Characteristics of successful systems of family-based alternatives

IN CLOSING

This workbook invited you to think about a change in your child's living arrangement. Now that you've completed the workbook, we hope it has helped you imagine the possibility of your child again enjoying family life.

You have had a chance to **take stock** of your current situation and what you really want for your child. You have had a chance to **explore** possibilities of well-supported family life. Perhaps you can now imagine family life that you hadn't thought possible. Part of imagining family life is also imagining the journey to get there. You have had a chance to see how the system currently works and also how it could work differently. You have had a chance to see how to use what works and how to link with others to change what doesn't. Hopefully the workbook has helped you to **set a new direction** for your child and family. You may now be ready to work to **achieve** the family life the workbook has helped you to imagine.

The process of achieving change may be challenging because of gaps and barriers in the current service system. It will require a lot of work and other people like a facilitator but also others like representatives of the system who coordinate programs, or work for provider organizations, or make policies. By working together with others, we hope you can **imagine** the possibility of family life again and how to work together to **achieve** it.





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