



Blueprint for Change

Next Steps in the Journey

- *The “First Conversation”*
- *Building a Workforce*
- *Establishing Shared Living*
- *Developing a System for People with Challenging Behaviors & Mental Health Needs*
- *Navigating Managed Care*

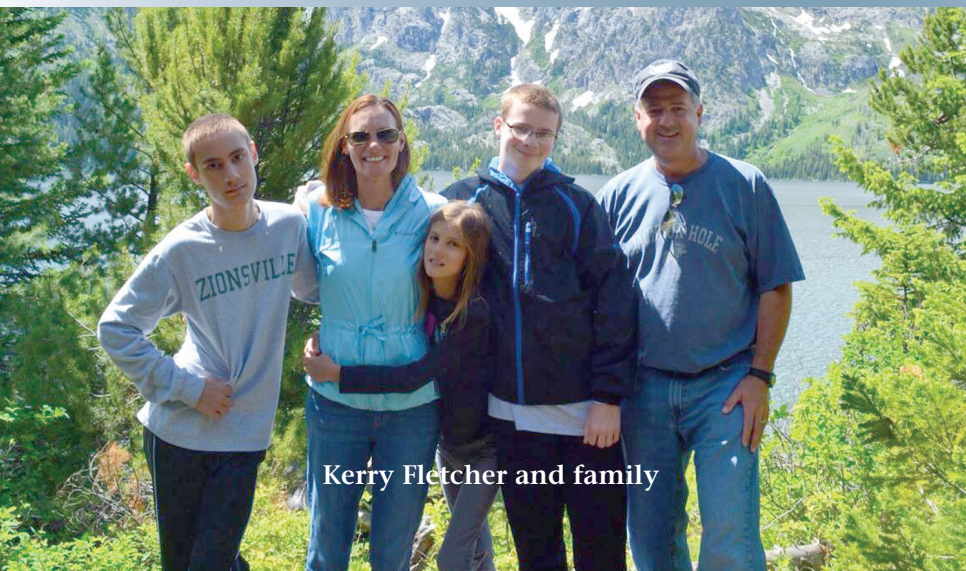
The Arc of Indiana developed the initial Blueprint for Change back in 2010 as a guide to improve not only the wellbeing of individuals with developmental disabilities, our family members, but also to improve the quality of life for citizens of Indiana. It not only communicated the hope of what life for our loved ones could be in the future, but also offered a plan that everyone—legislators, government officials, service providers, families, and self-advocates— could rally behind and use as a starting point to impact change.

As we begin the “Next Steps in the Journey,” it is important to pause and reflect on the progress that has been made. The Blueprint lead to several accomplishments highlighted in the beginning of this report. However, it is also important to not pause too long and to remember that the journey is not done. This ever-changing continuation of the Blueprint highlights the next stage of that journey into the future we, as family members, see for our loved ones. It also offers hope and a plan as the dynamics of the world are changing. Ultimately, both of these documents communicate a common purpose of inclusion and support for those we love now and into the future.

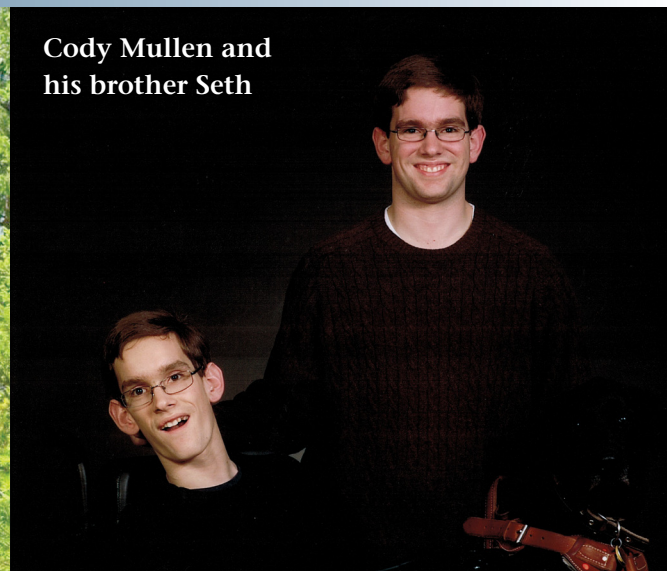
Please join us on this vital journey for so many Hoosiers.

Kerry Fletcher
President, The Arc of Indiana

Cody Mullen
Chairman, Blueprint for Change Steering Committee



Kerry Fletcher and family



Cody Mullen and
his brother Seth



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Blueprint for Change Next Steps in the Journey



In 2010, The Arc of Indiana created the **Blueprint for Change**, which laid out a new path for Hoosiers with intellectual and development disabilities (I/DD) and the system that provides them with supports and services.

In that groundbreaking work, our five major goals were to **build** career pathways for all; **discover** and **realize** individual gifts; **support** resourcefulness of individuals, families and communities; **use** what you need; and **shift** the power to what works.

Since then, we've witnessed remarkable change. The state of Indiana has embraced different approaches and implemented key endeavors to provide a way to measure how Indiana's system of services is developing.

Blueprint for Change – What We Accomplished

The Blueprint for Change was designed to be a collaborative effort, focused not on just what The Arc would do, but what we as Hoosiers would do together. Following are just some of the significant changes that have taken place:

Waiting List – Out of the Blueprint came a new approach to addressing the years long waiting lists for Medicaid Waiver services. The Family Supports Waiver was created to focus on providing supports and services to those on the waiting list and young adults leaving high school. The state budget passed in the 2015 session of the General Assembly provides funding for fiscal years 2016-2017 that should result in the elimination of the Medicaid Waiver waiting list.

Emergency Supports – The Community Integration and Habilitation Waiver was established as a “needs based” waiver to provide immediate services to individuals meeting critical needs criteria – including having a caregiver over the age of 80, loss of a caregiver, and emergency health or safety needs.

*We must
continue to
reinvest savings
from models
that don't work
into models
that do.*



The Erskine Green Training Institute and Teaching Hotel – the boldest undertaking that came from the Blueprint is the establishment of the Erskine Green Training Institute and Teaching Hotel in Muncie, Indiana.

When the Blueprint was developed, the hope was that it would inspire, challenge and lead us in to new territories. Little did we imagine how much that would be true.



Jeff Huffman, chairman of The Arc's Education Committee and parent to a son with Down syndrome, brought the Blueprint to life when he had a vision of creating a training institute for people with disabilities that would be embedded in a fully functioning, tax paying hotel.

Today, the Erskine Green Training Institute is located within the Courtyard Muncie at Horizon Convention Center, and will provide training in the hospitality, food service, and healthcare fields.



*Left to right;
Huffman Family
Erskine Family
Green Family*



Over the last five years, we have made some great progress ... but in other areas, we still have a lot of work to do.

Measuring Progress

A recent report also measured the state's progress in serving its residents with I/DD. Every four years since 1999, David Braddock, Ph.D., of the University of Colorado has analyzed services in Indiana. He produced his most recent update in June 2014. This report is especially important, as it chronicles Indiana's economic recovery since 2009, as well as its recovered momentum in expanding and improving services for people with I/DD.

Of particular note in the 2014 report:

- Indiana closed all its state operated institutions for people with I/DD as of 2013.
- From 2010 to 2013, adjusted community services in Indiana have increased by \$109 million.
- The state continues to rely too heavily on residential settings for 16 or more people, as well as settings of 7 to 15 individuals. In contrast, Indiana too seldom uses smaller settings for six and fewer individuals.
- Indiana Home & Community-Based Services (HCBS) Waiver recipients grew rapidly between 2004 and 2014, increasing from 3,820 to 13,727 individuals, primarily due to the creation of the Family Supports Waiver.
- Indiana is one of 14 states with Medicaid Waivers emphasizing employment, case managers, and person directed services. The number of people with I/DD in supported employment has begun to recover but remains below the national average.
- While family support services have grown since 2009, they continue to lag behind the national average and comparison states.
- Residential support waivers have increased, but 72 percent of people live with their family, meaning that families are the primary source of support for people with I/DD.

To read the full report, visit: www.StateoftheStates.org

To review accomplishments from the original Blueprint for Change initiative, visit: www.arcind.org/about-the-arc/blueprint-for-change.

Blueprint for Change: Next Steps in the Journey.

Over the last five years, great progress has been made ... but in other areas, much work remains to be done. To evaluate the achievements in the past five years and lay out the next actions Indiana needs to take, we've created ***Blueprint for Change: Next Steps in the Journey***.

In it, we identify five critical areas:

- ◆ Starting your journey with the 'First Conversation'
- ◆ Building a workforce for I/DD services and supports
- ◆ Establishing 'Shared Living' for residential supports
- ◆ Developing a statewide system for people with I/DD with challenging behaviors and mental health needs
- ◆ Navigating Managed Care

For each topic, we've created a position paper that explains in more depth the critical nature of what stakeholders need to accomplish.

As with the original Blueprint, we know that resources are not endless. We must continue to reinvest savings from models that don't work into models that do. The following papers contain detailed concepts to explore and develop as we take the next steps in our shared journey.



Starting the Waiver Journey with the 'First Conversation'

As families begin the process of accessing services through the Medicaid Waiver for a child with an intellectual or developmental disability (I/DD), it's crucial to begin by obtaining reliable information. This first step will help ensure that families are comfortable and knowledgeable about the process and ready to start down the path that leads to the outcome they want.



The Arc of Indiana recommends that the state of Indiana provide a “First Conversation” as a Medicaid Waiver service. During this conversation, new families would learn about the choices they will need to make and the acronyms they’ll need to learn from others who have taken this journey.

Following is an overview of issues families may want to think about and discuss with someone who has experience with the Medicaid Waiver, including Family Advocates within The Arc’s Advocacy Network.

Components of the First Conversation

The Medicaid Waiver is an investment—not a program—that gives families a resource that they can use wisely over the long term. As of 2015, families can receive up to \$16,545 per year to invest in their loved ones. As part of the First Conversation, you’ll start thinking about how you’ll use those resources to achieve your goals and your loved ones goals. Be sure to:

Daydream a little. Paint a picture in your mind of what you would eventually like your child to accomplish. Give thought to:

- Where he’ll be living
- What sorts of activities he will be doing
- Who her friends will be
- What important connections she’ll have in her community

What does your family want the future to hold for your child?

A guidebook to help you and your loved one reach goals

Picture what your child has to offer. Think about who your child is. What are her greatest gifts? What are her greatest needs? What are his dreams – and yours? What does your family want the future to hold for your child?

Dive into the Medicaid Waiver process. Start developing a thorough understanding of the details that come with participating in the Waiver, such as:

- What does a case manager do?
- What is a provider, and how do you pick one?
- What is the pick list, and why is it not alphabetized?
- What are the available services, and how can I use them?
- What does the annual budget mean?
- Where do I find out what things cost?
- How do I get what I need and want?
- What if I'm not happy with how things are going?
- Do I need to spend all of the money?
- What is Family and Caregiver Training?

Understand other sources of financial support for your loved one. You may be able to tap into other benefits for your child. As part of your First Conversation, discuss how your insurance and Medicaid can work together for better health care, and how SSI or SSDI can fit into the picture.

Give thought to other people who can offer assistance. Your First Conversation may lead you to other community supports. In fact, the family or individual joining you in this conversation may be able to make a personal introduction. In addition, think about *natural supports* you can draw upon for help. This includes the people you might turn to in other situations when you need a hand, like friends, family and worship congregations.

We envision collaborating with other advocacy organizations to create a Medicaid Waiver funded service that would be open to every new family on the waiver. Families would receive a guide that helps walk them through the First Conversation topics. This guide would be useful in helping families develop a vision for their child—whether infant, youth, teen or adult.

We also support a training program to teach families and self-advocates how to walk newcomers through this guide and share information on how to achieve their vision using not only Medicaid Waiver supports, but also other programs and services, including community and natural supports.

Building a Workforce for I/DD Services and Supports

Nearly 80 percent of DSPs say they want to stay in the field, but would need to earn more money to do so.

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Many experts in the field believe we will not reach a stable workforce until DSPs make at least \$15 hourly, which would allow them to develop their jobs into a long-term career.



Direct Support Professionals (DSPs) who work with individuals with intellectual and developmental disabilities (I/DD) often act as the glue that helps hold a family or a small group of adults together.

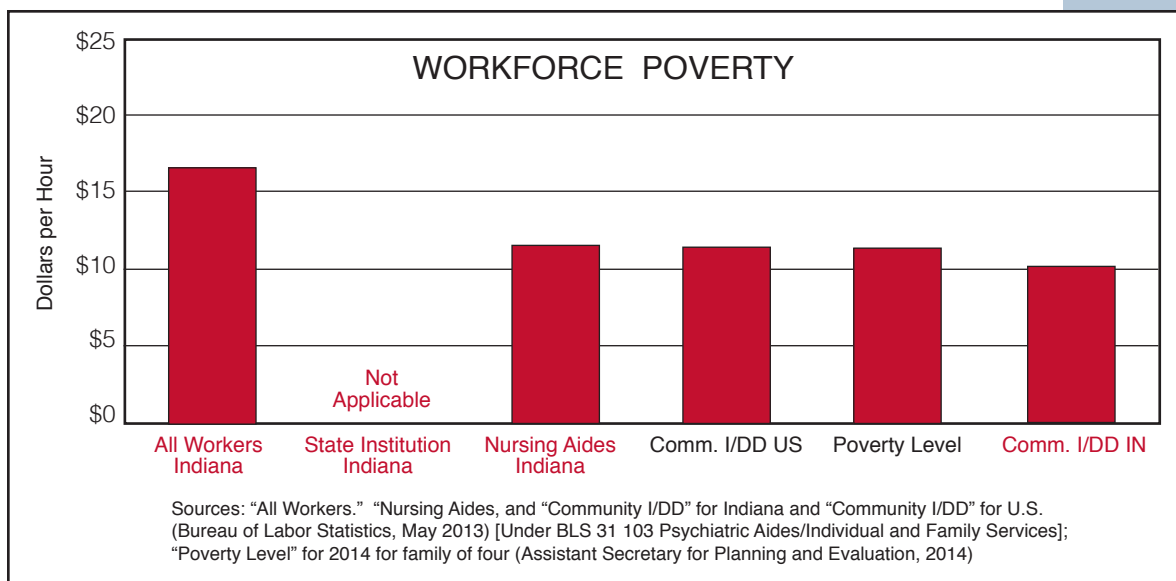
It's time to strengthen that bond in Indiana. By raising compensation for these professionals and developing a more diverse network of support, we can better serve the needs of Hoosiers with I/DD.

Better pay can encourage a more consistent workforce

Roughly 50,000 full- and part-time DSPs work for Indiana agencies to assist individuals through the Medicaid Waiver system. Nearly 80 percent of these workers serve in residential settings. They provide:

- respite care
- 24-hour support
- assistance with mealtime, bathing, dressing and community activities
- support for individuals in the workplace

However, these vital workers are typically paid a wage that leaves them struggling – which in turn adds more burdens to Indiana's support system.



As the chart above notes, these workers make an average of \$10.20 per hour. This compensation puts them substantially behind many other occupations, and even below the poverty level. More than half say they are the primary wage earner in their household, and nearly 30 percent must work a second job.*

Nearly 80 percent of DSPs say they want to stay in the field, but would need to earn more money to do so. The amount of compensation that agencies can offer is directly related to the level that the state pays providers in Medicaid Waiver rates.* Families and people with I/DD across the state report high worker turnover, especially with night staff, as well as shortages on critical shifts.

Many experts in the field believe we will not reach a stable workforce until DSPs make at least \$15 hourly, which would allow them to develop their jobs into a long-term career. Since labor represents nearly 80 percent of Medicaid Waiver costs, that is a challenging number to achieve.

However, other states are addressing this need. In Ohio, officials recently announced a three-year plan to modernize services, move residents from institutional settings, implement a shared living plan and raise the average DSP wage to \$19 an hour. It should be noted that this plan is proceeding in a state led by a fiscally conservative governor.

Indiana needs better compensated DSPs, but this should only be the start of the improvements to our support network.

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They've noted that their visibility has given them inspiration to become leaders in their own communities.

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The Arc of Indiana believes this is a great path forward for people with I/DD who want to build a career in serving others.

*Direct Support Professionals Survey, Spring 2014



**Develop a workforce
capacity building
program**

**Implement a major
shared living
program**

**Implement a self-
directed care model**

**Reinstate the INTRAIN
program**

**Add two new Medicaid
Waiver services**

**Implement a study
documenting use of
parents and direct
family workers as
DSPs**

**Invest dollars that were
previously cut**

The system needs support professionals who have I/DD

People with I/DD provide a valuable resource for meeting the growing need for direct support professionals.

Who better to train a person to ride public transportation than someone who rides it every day? Who can be a better job coach in navigating challenging social settings than someone who has done that successfully?

People with I/DD have often mentioned the significance of seeing two women with disabilities, Betty Williams and Melody Cooper, in leadership roles with The Arc of Indiana. They've noted that their visibility has given them inspiration to become leaders in their own communities.

The service and support system should look to people with I/DD to fill a number of existing and new roles. This will require addressing current staffing rules that may preclude hiring people with a disability, such as degree requirements.

Several states are considering adding a new peer support role to their Medicaid Waiver menu. This model would provide funding to recruit, train and hire people with disabilities. They would participate in team meetings with other individuals with disabilities who lack a role model to show them how to advocate for themselves. Ideally, this would help ensure that case managers and staff work to build waiver supports to help individuals achieve their goals. Peers would also provide a bridge to self-advocacy groups and other natural supports in the community.

The Arc of Indiana believes this is a great path forward for people with I/DD who want to build a career in serving others.

Family Members as Direct Support Workers

Another option that appears to be growing in popularity is using family members as paid supports for their sons and daughters. Some estimates indicate that as many as 15 to 20 percent of the staff supporting people on waivers may be parents.

In some cases, family members may have accepted this position after growing frustrated by the lack of reliable staff during necessary hours, or the inability to receive certain services due to insufficient staff. In other cases, families specifically select an agency that specializes in using relatives as paid supports.

The Arc of Indiana encourages this important option for families. However, it shouldn't be the only choice, particularly for adults with I/DD who at some point may want to leave their family home. Nor should the system depend on family members to the point that we fail to act on addressing the wage and benefit problems that hamper DSP recruitment and retention.

We call on the state to gather data on the number of family members providing direct support, along with the reason they chose this option. Procedures for these staffing situations should be carefully reviewed to ensure that safeguards and protections remain in place for individuals receiving services.

Workforce Proposal

Hoosiers with I/DD require a consistent and comprehensive workforce, which will require the state to simultaneously address the following issues:

Develop a workforce capacity building program that enhances DSP wages through a number of strategies to reach a goal of an average hourly DSP wage of \$17.50 within five years. This plan will also address enhanced training and retention quality measures for DSPs.

Implement a major shared living program to allow people to choose who they live with in one-to-one settings. The savings such a program can provide (See Page 11) must be plowed back into raising the quality of the workforce through training and wages.

Implement a self-directed care model for individuals to convert their shift model to a version that allows them to hire people they choose via a fiscal intermediary. Savings in this program, while not as dramatic as shared living, can be substantial. These savings can also support higher wages with less administrative costs for the program.

Reinstate the INTRAIN program to enhance the education of the DSP workforce through Ivy Tech. DSPs would see wage increases for each educational block they complete, and agencies with a more highly trained workforce might receive higher reimbursement.

Add two new Medicaid Waiver services—peer support professionals and peer support network administration—to bring people with I/DD into the workforce.

Implement a study to identify and continue documenting the system's use of parents and direct family workers as DSPs in order to understand and utilize this critical resource effectively.

Invest dollars that were previously cut from the program into a new workforce development effort to raise wages. Over the past several years Indiana has developed a surplus. Much of this came from sustained cuts to the Medicaid Waiver program. These dollars should be reinvested back into a growing economy. Much of the money added to the pay of Hoosier DSPs is spent within the state. The 2015 General Assembly took an important step forward in this effort by restoring key Medicaid Waiver rates to 2010 levels, but more than \$100 million remains cut from the program, and it should be restored and invested in workforce development.

This will not be a small program or an easy one to implement. But a failure to take action will put even greater stress on thousands of Hoosier families and lead to more difficult decisions in the future.

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Establishing Shared Living for Residential Supports

“Shared living is not about beds, slots or facilities,” the National Association of State Directors of Developmental Disabilities Services (NASDDDS) notes. “It is about creating the opportunity for people with developmental disabilities to have a home and people to share everyday life with ... It is about being a member of the community.”



The Shared Living approach for people with intellectual and developmental disabilities (I/DD) is gaining praise nationwide. This community residential concept is cost-effective, and it allows individuals with I/DD to create more enduring connections with their caregivers.

In a Shared Living program, providers—who can be a family, a couple or an individual—live in a home with a person with I/DD. Typically, a single person with I/DD lives in the caregiver’s home, though in rare cases the home may serve multiple residents, such as siblings.

“Shared Living is not about beds, slots or facilities,” the National Association of State Directors of Developmental Disabilities Services (NASDDDS) notes. “It is about creating the opportunity for people with developmental disabilities to have a home and people to share everyday life with ... It is about being a member of the community.”

The Arc of Indiana strongly believes that our state should adopt shared living as a service option in the Medicaid Waiver program.

One factor driving our interest is the potential for cost savings. Even though shared living utilizes paid caregivers, the cost can be roughly 40 percent less expensive for a state compared to a traditional shift model.

In addition, Colorado and Rhode Island’s experience with shared living demonstrates the many benefits that this arrangement can provide for community members and individuals with I/DD.

Other states have observed the positives of Shared Living

As shared by NASDDDS, disability experts in Colorado and Rhode Island have noted that Shared Living provides a number of advantages in terms of resident safety and caregiver satisfaction.

For example, ample training and oversight for the caregivers is built into this concept:

- Caregivers are classified as independent contractors of a licensed and approved provider agency. They are monitored and subject to the same review as any other provider service.
- Caregiver training emphasizes that the program is about relationships, not just a placement.
- Case managers and provider agencies have very clear responsibilities for staying in close contact with the caregiver, with the expectation that they will visit regularly and have full access to the home.
- Incidents and accidents are reported like in any other setting.

The reimbursement rates are high enough to recruit and retain quality caregivers, which helps support long-term relationships with the residents. In Colorado, only 10 percent of caregiving applicants were accepted into the program. For caregivers, benefits include these factors:

- Caregivers receive a monthly rate that is exempt from federal income taxes. States reported payments ranging from just over \$2,500 per month to as high as \$5,000 per month, depending on the recipient's need.
- Caregivers are paid for full-time support, including transportation to and from the resident's workplace, doctor appointments, social activities and classes. They also receive paid respite.
- In some cases, caregivers' partners are allowed to have outside jobs.

People with I/DD participate in interviews with caregivers and visit the home before making their decision. The introduction process may involve a weekend or overnight stay. Individuals with more severe disabilities have demonstrated that they do equally as well under this model as people with fewer needs. Residents have reported that they particularly enjoy the enduring interaction with their caregivers, who don't change from shift to shift, or even year to year:

- "... people don't leave me anymore. I always thought I did something wrong when I had people leave and go to another job."
- "... I really liked my apartment with two other guys, but people were always coming and going. Just when you got to know someone it changed."
- "... I like saying good night to the same people that I say good morning to!"

Many families of people with I/DD are recognizing the benefits of Shared Living after learning more about the concept. At first, many wonder why this "other

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... people don't leave me anymore. I always thought I did something wrong when I had people leave and go to another job.

... I like saying good night to the same people that I say good morning to!

... I have less worries about the future now than ever before. I truly believe this family has become part of John's future, regardless of what the system does.

”

Shared Living is an option for young and old that Indiana should adopt

The NASDDDS provides some examples of people who are enjoying the advantages of this residential approach:

- • • **Ralph**, 63, lives on a farm with Tom, a 65-year old retired widower. They both love to play golf and fish.
- • • **Ellen**, a 35-year-old with a full-time job, shares a home with a couple and their 4-year-old twins.
- • • **Jim**, 48, lives with a married couple. Though the wife still works, the husband is retired with lots of spare time.
- • • **Lynne**, who at 27 has left her home for the first time, shares her apartment with Sarah, a 28-year-old single professional.
- • • **Susie**, a 10-year-old with a degenerative illness, lives with a couple and their three children, who range in age from 2 to 15.

family or caregiver” should step in to provide care. This can be a difficult idea for people who have been taking care of their loved one for decades.

They may also mistakenly assume that this program is a form of foster care. However, families often realize that shared living provides not just a shelter, but a long-term relationship with someone their son or daughter chose. Families have noted that:

- “... I have less worries about the future now than ever before. I truly believe this family has become part of John’s future, regardless of what the system does.”
- “... we really had to look carefully at this option. When we spent some time looking at shared living, we realized how much support the caregivers receive, and there really are a lot of people looking out for our son. That meant alot.”
- “... One of the hardest things ever was to consider our daughter moving away from home. We knew it was time; it was no longer possible for us to care for her at home. For Laura it really has made all the difference in the world.”

Shared Living proves popular, but requires planning

Colorado officials noted that more than half of the state’s residents with I/DD who need round-the-clock support are opting for shared living over a group home or a shift staff model.

With Shared Living providing substantial savings over a traditional shift model, Colorado is able to move more resources to other needs within the state. Shared Living also provides time savings. As one official noted, “We no longer were constantly trying to find roommates for people in a shift staff model. People worked hard on the match between individual and caregiver, and it works.”

However, our counterparts in Colorado emphasized that shared living—like any service—requires careful planning, education for the public, training and support.

“Consumer satisfaction with this program is very high. The selection of this model has surpassed what we thought it would ever do,” one noted.

A neighboring state is eyeing shared living, and so should Indiana

Recently, Gov. John Kasich of Ohio announced a three-year plan to change the landscape in the state for people with I/DD. Key to his plan was moving them from institutional settings, giving raises to direct support professionals and implementing a shared living program throughout the state. Nearly every

conference of state agency personnel around the country is exploring Shared Living, as well.

The Arc of Indiana believes we need to adapt Colorado's Shared Living program for Hoosiers, and replace the term "structured family caregiving" (SFC) in the current waiver. SFC is based more on a foster care model, and it often involves multiple individuals living with one caregiver.

Indiana should offer the program to people in Medicaid funded group homes, those living in community residential programs funded by the Community Integration and Habilitation (CIH) Waiver, and those currently living with family who need 24 hour residential supports.

We will need to start an education and outreach program to help people understand how shared living is different from foster care. We'll also need to grow support for the program from self-advocates, families, case managers and provider agencies.

With the savings that shared living provides, the state would ideally address critical issues in the rest of the system, including:

- Wages for direct support professionals (see page 8 for more about this urgent issue)
- Gaps in the system that threaten people with I/DD and mental health needs
- System infrastructure

We feel that a Division of Disability and Rehabilitative Services (DDRS) Shared Living Task Force of all key stakeholders needs to begin work immediately to make the program a viable option and choice for Hoosiers.

With the savings that shared living provides, the state would ideally address critical issues in the rest of the system, including:

- Wages for direct support professionals
- Gaps in the system that threaten people with I/DD and mental health needs
- System infrastructure

To learn more about Shared Living, we recommend *The Shared Living Guide* by Robin Cooper, Kara LeBeau and Nancy Thaler of the NASDDDS. You can purchase a copy at the NASDDSS website: <http://www.nasddds.org/>

Developing a statewide system for people with challenging behaviors and mental health needs

Too often, these situations lead to heartbreaking outcomes that could be prevented. As a result, one of our most critical needs is a support program for these individuals.

Too often, families of individuals with I/DD and behavioral problems face a fragmented and disjointed system that can provide little primary response to help prevent situations from escalating.



The Arc of Indiana receives many calls that illustrate the system's shortcomings in helping people who have both intellectual and development disabilities (I/DD) and challenging behaviors.

Brian had two on one staffing in his Medicaid Waiver setting. A trip to the emergency room changed his medication plan, and his behaviors escalated. When he got angry one evening he threw food at a staff member and walked out of the home. Police were called, and he was found walking around the block. He was arrested on several felony charges of assaulting a police officer and he went to jail.

When Chris completed high school, he could not find employment or day program services. His mother had to quit her job in order to stay home with Chris, who was becoming increasingly difficult. Her depression and exhaustion led her doctor to strongly recommend that she take a break from caring for Chris. She found no options for Chris to receive extended out-of-home respite care. Finally, she had to seek psychiatric care herself, and Chris was placed in a CIH Medicaid Waiver home. Had she received the extended respite care she sought—along with a long-term solution to give Chris employment, day program and behavioral supports—the cost to the state would be significantly less and Chris would still be living in his family home.

Too often, these situations lead to heartbreaking outcomes that could be prevented. As a result, one of our most critical needs is a support program for these individuals.

In 2013, the Indiana General Assembly directed the Family and Social Services Administration (FSSA) to evaluate Indiana's services for Hoosiers with I/DD and challenging behavior or mental illness. The Arc of Indiana, working with our partners at FSSA, INARF and the Indiana Association of Behavior Consultants, brought in Joan Beasley, PhD, from the University of New Hampshire to study the issue.

Staff from the University of New Hampshire met with key state leaders and providers of crisis services that are no longer available. They also conducted more than 50 personal interviews, held focus groups and collected 1,000 online surveys from families, self-advocates and professionals in the state.

Their study included some remarkable findings on a cost-effective way to improve the system: "... [C]onsiderable cost savings could occur if the current dependence on staffing as the remedy to challenging behavior/mental illness could be replaced by improved capacity in treatment and services. **With just a 10 percent reduction in the use of enhanced staffing, a savings of \$22 million dollars would be possible.** While this cannot occur without improvements in services as described in this report, it makes a compelling argument for the need to put considerable effort into improving capacity within the system..."

Excess staffing occurs in Medicaid Waiver and Group Home settings when the system provides more workers to try to contain people's behavior rather than treating underlying behavioral or mental health issues. The consultants' recommendations were presented to the state and included in legislation that did not make it through the legislative process.

State has resources to meet this challenge

Too often, families of individuals with I/DD and behavioral problems face a fragmented and disjointed system that can provide little primary response to help prevent situations from escalating.

The consequences of the current arrangement go beyond excess staffing costs. These include:

- A significant number of individuals who request inpatient psychiatric services
- A large number of 911 calls from providers and families, which can lead to dangerous outcomes for the individual, staff and families.
- A waiting list for Extensive Support Needs (ESN) group homes, which are specialized residences for people with pronounced behavioral needs.

[C]onsiderable cost savings could occur if the current dependence on staffing as the remedy to challenging behavior/mental illness could be replaced by improved capacity in treatment and services. **With just a 10 percent reduction in the use of enhanced staffing, a savings of \$22 million dollars would be possible.**

The Arc of Indiana recommends that we develop a statewide program that begins with one regional single point of entry. FSSA should begin soliciting a request for proposal from regions of the state to begin what would become a statewide model.

Contracts should be awarded to single points of entry for the system that include 24 hour crisis response and network partnerships between DD providers, Community Mental Health Centers, schools, hospitals and psychiatric care.

As the study notes, there is a lot of work ahead of us. However, Indiana does have important strengths that can be used in this process:

Commitment. Stakeholders across the system have a strong degree of dedication to making these improvements.

Some existing expertise. The study highlighted a shortage of expertise in addressing individuals with I/DD and challenging behaviors. However, several providers in Indiana have had significant success in serving the target population – including Community Developmental Disability Agencies and Community Mental Health Centers.

We're ready to meet the challenge. While all groups across the state acknowledged that the current system has significant gaps, they've shown a strong desire to work together toward solutions.

A plan that could quickly lead to better results

The Arc of Indiana recommends that we develop a statewide program that begins with one regional single point of entry, much like the First Steps model for infants and preschoolers with developmental delays. FSSA should begin soliciting a request for proposal from regions of the state to begin what would become a statewide model.

Contracts should be awarded to single points of entry for the system that include 24 hour crisis response and network partnerships between DD providers, Community Mental Health Centers, schools, hospitals and psychiatric care.

Each pilot must have trained navigators to help educate providers and coordinate services across the system for high-risk individuals until they are stable and have a clear care plan to follow.

Pilot programs would:

- Establish a standardized cross-systems crisis intervention planning process that includes three levels of intervention, beginning with what can occur at home; who to call for help and advice; and how to access emergency assistance immediately. The process should include a focus on increasing successful home-based remedies.
- Mentor direct support residential and vocational support providers through ongoing outreach to program sites, so they can become better able to effectively support individuals and reduce dependence on enhanced staffing.
- Train I/DD providers on multidisciplinary approaches including wellness and positive psychology. Training must be easy to access and primarily web-based, and it must focus on evidence-based approaches.

- Train and mentor mental health teams on diagnosing and treating people with dual diagnosis, including all forms of mental health care including psychotherapy. Training must be easy to access and primary web-based, and it should focus on evidence-based approaches.
- Collect and review data, including family and caregiver satisfaction, and compare results with non-piloted areas.
- Study the impact in the regional area on excess staffing, hospitalization and incarcerations, then report that data.
- Conduct statewide training for target populations of providers – Community Developmental Disabilities Agencies, Community Mental Health Centers, Case Managers and Families

FSSA should immediately put out a request for proposal seeking innovative and collaborative proposals to develop this first pilot in the next two years, then expand throughout the state as other regions of the state are selected and funds become available.

Based upon the success of the first pilot, The Arc of Indiana believes the remaining areas of the state would develop faster, and we could achieve a statewide model program in 4 to 6 years.

This program can be funded with existing resources, utilizing the savings that will be generated in the coming years. We believe these will exceed the 10 percent quoted by the study. It's imperative that all savings be invested back into the system over that time period.

The initial estimate is \$2.5 million for the first two years of the pilot project. This will be matched with available federal dollars for an expenditure in the \$5 million range.

To read the University of New Hampshire report, "Indiana Service System Analysis, University of New Hampshire," visit: www.arcind.org/supports-services/helpful-resources-links and search under "Reports."

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Navigating Managed Care

As states collect and report on new managed care approaches, it will be important to monitor the impact of these programs for people with I/DD and their families. Indiana should also engage disability stakeholders – including people with I/DD, families, advocacy groups, community providers and health care providers – in the design, implementation and monitoring of any new managed care or systems redesign.



Several factors have recently encouraged nearly all states to examine using managed care for Long-Term Services and Supports (LTSS).

State governments, providers and advocates are giving more attention to improving the overall health and wellness of people with intellectual and developmental disabilities (I/DD). However, states are facing limited revenues and increasing Medicaid costs.

Managed care usually introduces an entity between the state and provider organizations to manage the costs of either acute care (healthcare and hospitalizations) or long term services and supports (such as the Family Support Waiver, Community Integration and Habilitation Waiver and Group Homes). This entity is charged with both improving quality through greater coordination and saving money for the system. A common criticism of managed care is that the contract with the new entity is more focused on saving money than improving quality.

Several states are doing more than just investigating – they’ve already begun to implement managed care for people with I/DD. The Arc of Indiana is not opposed to this approach across the board – but we think the state should proceed with care before adopting it.

As states collect and report on new managed care approaches, it will be important to monitor the impact of these programs for people with I/DD and their families. Indiana should also engage disability stakeholders – including people with I/DD, families, advocacy groups, community providers and health care providers – in the design, implementation and monitoring of any new managed care or systems redesign.

In 2014, Indiana began the effort to better coordinate care for people with I/DD through a new Health and Wellness Coordination Service for some people who are receiving services under the Community Integration and Habilitation (CIH) Waiver. This first step—in which nurses provide care coordination and oversight—can be expanded to ensure more integrated care from community providers, acute care and long-term services and supports. While not a managed care program, this service begins to address the acute care and wellness issues of people with disabilities.

Given federal initiatives to ensure that states are providing Home and Community Based Services (HCBS) in the most integrated setting, we have a great opportunity in Indiana to change and improve our systems of care. Some paths we can take moving forward include:

Conducting regional pilot projects to include acute care coordination/management for people with I/DD. This can be the next step for the Health and Wellness Coordination Service as attempts are made to help people with I/DD enjoy improved health and longer lives. Efforts could include working with community providers to develop more formal relationships with health care providers to ensure more integrated care coordination.

Developing and implementing better care transitions for people with I/DD. Even for the general public, a trip through the health care system – perhaps involving the ER, a hospital stay and a visit to rehab – can result in a lot of expense but poor outcomes for the individual.

For people with I/DD, care transitions can be further complicated, given that they may include direct support professionals, as well as problems associated with payment starts and stops for medical versus community supports. We believe the system could achieve cost savings and better outcomes by putting more focus on care transitions with the various stakeholders.

The Arc of Indiana can provide assistance as the state considers managed care. We can:

- Convene experts from different states to discuss ideas that might work here.
- Provide individuals with I/DD, families, legislators and policymakers with opportunities to jointly engage in designing, implementing and monitoring pilot projects.
- Facilitate stakeholder input in developing outcomes, priorities and cost-saving ideas.

The Arc of Indiana has a long track record of working to help stakeholders develop a shared purpose. We believe managed care, no matter what form it may take, will require this sense of shared purpose.



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