SHARED LIVING

TABLE OF CONTENTS

I. **Introduction to Shared Living** 2

- What is Shared Living?
- The match
- Participant Benefits
- Economic Benefits on the Caregiver
- Respite
- Incidents of Abuse and neglect

II. **Service Overview** 4

- Indiana's Current Model: Structured Family Caregiving
- Updated Model Overview

III. **Conclusion** .... Error! Bookmark not defined.

INTRODUCTION TO SHARED LIVING

To meet the growing demand and assure sustainable, and cost-effective programs, States are turning to Shared Living as an alternative to providing residential services and supports. In many ways Shared Living is different when compared to other programs in HCBS waivers as it builds the service around the relationship between the consumer and the host family. It is a quality of life program, which is built on the participant choosing whom they live with and where they live as well. Relationships are at the heart of Shared Living, including relationships, which reach beyond the Shared Living provider to friends, extended family members, and neighbors. Almost every State in the country has a version of Shared Living available. The overview of the service is based upon a review of successful programs in Pennsylvania, Colorado, Massachusetts, and Iowa.

WHAT IS SHARED LIVING?

Shared Living is an option in which an individual in the community and a person with an intellectual or developmental disability choose to live together and share life's experiences. The approach is designed to enable people with support needs to experience a community life; one that is not controlled by the formal service delivery system. The model supports the development of natural supports and helps the individual attain maximum independence. Shared Living does not refer to a place, nor a "facility," or a group home. Shared Living is not a "residential program" or a supported program with multiple staff working in shifts.

The individual is an independent contractor who is typically a non-family member or a family member who is not the participant's spouse or the parent of the participant who is a minor. The number of participants in a Shared Living setting typically do not exceed two, with exceptions requiring approval from the placement authority and the Individual Support Team. Necessary support services are provided by the independent contractor as part of Shared Living. Home providers typically have twenty-four hour a day/seven day a week responsibility for the individuals who live with them, though individuals typically receive other supports during a day (e.g., employment services, school, day services) through their waiver budget.

Only agencies may be Shared Living providers, with the independent contractors and settings being approved and monitored by the agency provider. The agency provider will conduct at least one visit per month to the home or more if determined by the Individual Support Team to assure services are provided and the needs of the participant are met. Independent contractors are trained and paid by the approved agency provider. Home providers operate under contract with local services agencies and are not considered agency staff or employees. As independent contractors, they are not subject to wage and hour laws, worker's compensation or unemployment insurance. Shared Living in many States falls into a section of the federal tax code which permits provider reimbursements, called "difficulty of care" payments, to be exempt from taxation. Respite support for the independent contractor is provided through provider agency approved respite workers.

THE MATCH

One of the most important components of Shared Living is the "match." The success of Shared Living depends on the careful process of introducing people to each other and assuring the

relationships work. This match is mutual: both the person providing support and the individual supported must have time and opportunity to get to know each other and to explore if the relationship will work. Opportunities to meet and spend time together before deciding to share lives are critical to assuring the match is right for both parties. The service system needs to be flexible enough to permit the development of relationships and, in fact, encourage relationships which might lead to Shared Living. Recognizing this, the system must include a clear process driven by the Individual Support Team and support the process of building the right match.

PARTICIPANT BENEFITS

The most important benefit of Shared Living is the quality of life people enjoy from having chosen the people with home they live. As stated previously, relationships are at the heart of Shared Living. Participants in Shared Living experience more robust social networks that are meaningful. The natural support networks stretch outside the participant's personal network to include the host family's community connections. People are actively connected to their community. Many States report Shared Living arrangements that are continued for more than 10 and even 20 years. Compare this to the constant turnover experienced in shift staff models.

ECONOMIC IMPACT ON THE CAREGIVER

There are several desirable unintended outcomes as well. Shared Living will be less costly for many individuals when compared to shift-staffed situations; particularly when some individual needs more "customized" supports or one-to-one staffing, to be successful in the community. Shared Living may also provide a measure of stability for the independent contractor. Compensation rates are significantly higher for the independent contractor as compared to hourly shift staff rates. For Example, In Colorado reimbursement for independent contractors can range between $30,000 to over $40,000 annually.

Shared Living payments made to independent contractors are tax exempt. Payments made to Shared Living providers are considered Difficulty of Care Payments by the Internal Revenue Service. It is important each independent contractor is familiar with the rules pertaining to difficulty of care payments under § 131(c).

For the person with a disability, stability, and permanence are additional benefits. Living in a home, seeing the same people every day, and enjoying predictable holiday rituals provide a constancy that is difficult to sustain in a group home or residential setting. The issue of individual staff coming in and out of the person's life is minimized. For example, Pennsylvania reports out of 842 individuals in Shared Living, the length of relationships is remarkably stable, particularly as compared to staff turnover rates in other residential settings.

RESPITE

One ongoing concern is providing a break for Shared Living Providers. Respite in a Shared Living setting can cover a range of circumstances. Here are a couple of examples:

1. A Shared Living provider leaves for a week-long vacation.

2. A Shared Living provider has a personal appointment and will be unavailable to provider support for 12 hours.
3. A Shared Living provider is running up to the grocery store and a family member stays behind with the person in services while the provider runs the errand.

In each case, the parameters of respite should be determined by the Interdisciplinary Team. Respite is best provided by people who know the person receiving services well and can meet the needs of the person in services. Ultimately, the service provider should assure the person providing the respite has completed required criminal background checks and meet training requirements. Respite is not typically a service paid by States, rather, respite payments are carved out of the Shared Living rate.

INCIDENTS OF ABUSE AND NEGLECT

Although a there is no evidence identified supporting abuse and neglect occurring at a decreased rate in Shared Living settings, there is ample evidence to support people experience it at an alarming rate in congregate settings where multiple staff are required to provide services such as group homes, ICF/IDs, mulit-bed supported living homes. Violence towards people with intellectual and developmental disabilities can be attributed to a disparity of power between direct support professionals and people supported. Additionally, abuse of people in service is also related to Direct Support Professionals being overworked, underpaid, and placed in stressful situations. Shared Living provides a living arrangement opposite of a congregate living model. By assuring proper matching with a Shared Living provider, routine oversight and support by the provider, maintaining individualized care settings, adequate reimbursement and a customer service model, incidents of abuse and neglect are anticipated to occur at a lower rate than current alternative supported living models.

SERVICE OVERVIEW

Given the robust benefits associated with the Shared Living model, Indiana's current model requires an update to incentivize people with intellectual and developmental disabilities, their families and providers to engage in participating in and providing the service.

INDIANA'S CURRENT MODEL: STRUCTURED FAMILY CAREGIVING

Indiana calls its Shared Living program "Structured Family Caregiving." The program is poorly structured, inadequately reimbursed and underutilized by people with disabilities compared to other states. Structured Family Caregiving does have some of the same basic qualities as described above: an independent contractor is sharing the home with the waiver recipients, the provider agency is required to submit to background checks, home inspections, and provide training as required by BDDS. The BDDS approved agency provider is responsible for independent contractor recruitment and approval, matching, training, oversight of services, documentation reviews, and emergency support. The provider is also responsible for conducting visits to the home to monitor the ongoing success of the match.

Currently, the Structured Family Caregiving service is widely underutilized. According to the *In-Home and Residential Supports for Persons with Intellectual or Developmental Disabilities: Status and Trends Through 2015 Residential Information Systems Project Report* published by the National Residential Information Systems

Project An estimated 12% of LTSS recipients with IDD (61,715 people) in non-family settings lived in a host or foster family home. Disproportionately, less than 3% of people supported utilize this service in Indiana.

Structured Family Caregiving does not permit the utilization of day services and does require a monthly nursing visit. It does not provide direction on the number of people in the home. Structured Family Caregiving does not embrace the use of the "day services bucket" or the "behavioral support" bucket consistently to give a full range of support possibilities to people.

Less than 300 people with intellectual and developmental disabilities use the service in Indiana.

UPDATED MODEL OVERVIEW

Although Indiana's Structured Family Caregiving model has the framework of a successful program, there are changes required to expand the service's utilization throughout the state. The Shared Living service delivery model will build on the current model, while making the service a more desirable and viable option for individuals receiving waiver services as well as approved provider agencies.

To ensure Shared Living participants receive the level of service needed to ensure their health, safety, well-being and success, Shared Living service levels needs to reflect the 7 tiers of service as opposed to the current three. There are currently three service levels of Structured Family Caregiving available to participants, which effectively prevent individuals with higher acuity levels from being served in the model due to very low rates for the higher Algo levels. The Shared Living service delivery model must offer a service tailored more to an individual's needs rather than what is offered by the existing model. By utilizing seven levels as opposed to three, the model allows the level of service to address the individual's needs more effectively and correlates with their Algo level. This level system is consistent with other successful state models. The levels are determined by the individual's Algo level.

Additionally, for Shared Living to be a more likely choice for consumers, the following changes to the current service delivery system are need to be implemented:

1. Due to the lack of understanding of how the service supports people, training and education on Shared Living needs to be provided to case managers, providers, service coordinators, and self-advocates / families so there is public and individual awareness and understanding on the benefits of the service.
2. Limit the number of participants in a Shared Living setting, with exceptions determined by the individual, the Individual Support Team and the Bureau of Developmental Disabilities. The preferred setting size in a Shared Living setting is no more than two. Settings with more than two participants will require the approval of BDDS and the Individual Support Team. Limiting the setting size will help in assuring people receive quality supports and that independent contractors do not over-extend themselves. Existing settings more than 2 will be grandfathered in and reviewed by the Individual Support Team.
3. Allow utilization of all other available waiver services, except for Residential Habilitation and Support (RHS), Respite, and Transportation, by Shared Living participants. This includes access to the buckets of reserved funding for all CIHW recipients. Transportation

is a service that will be provided to the participant within the scope of the Shared Living service delivery, and Respite will continue to be a service funded through the Shared Living reimbursement. This will allow service participants the opportunities to benefit from employment and community opportunities funded through the waiver.

4. Remove the requirement of the managing provider agency to conduct nursing visits to the Shared Living setting monthly. Adding the Wellness Coordination service to all plans of participants that choose the Shared Living service regardless of Algo/Raw Health Score would allow for the proper oversight of health, safety and wellness of participants.
5. Continue requiring agency providers conduct at least one visit monthly to the service setting to ensure health, safety and quality of care. The frequency of these visits may be higher if determined by the Individual Support Team, individual and independent contractor.
6. Continue requiring a daily dated entry be completed by the Shared Living independent contractor, as well as consider requiring an entry at least monthly by the Shared Living provider agency when required visits are conducted

CONCLUSION

Shared Living dramatically increases positive outcomes for participants; while reduces costs for DDRS and providers by reducing the staffing burden. With a focus on building independence and choice for the consumer, while have a dramatic economic impact on the caregiver, Shared Living services have the opportunity to improve the lives of thousands of Hoosiers with intellectual and developmental disabilities.