



July 18, 2017

FSSA Division on Aging
402 W. Washington Street
Room W454
Indianapolis, IN 46204

Re: Comments on Home and Community-Based Services

To Whom It May Concern,

On behalf of Seniorlink, the parent organization of Caregiver Homes of Indiana, we are pleased to submit this testimony to contribute to the Administration's evaluation of Indiana's current long-term services and supports delivery system. We appreciate the opportunity to offer our perspective regarding how the State can best ensure meaningful access to community-based supports that provide a real alternative to costly and restrictive institutional care. As the leading provider of Structured Family Caregiving to elders and adults with physical disabilities in Indiana, and an organization that has focused, for more than 16 years, on supporting family caregivers to keep care at home, our comments specifically address the value of Structured Family Caregiving in rebalancing the LTSS delivery system, and make recommendations regarding expanded family caregiver supports that could be deployed to meet the needs of consumers and families statewide.

We deliver Structured Family Caregiving services to more than 4,200 adults of all ages and disabilities and their families across six States (CT, IN, LA, MA, OH and RI). In Indiana, we have provided Structured Family Caregiving since 2013 and now proudly serve more than 900 consumers. 73% of the consumers and 76% of the caregivers we support in Indiana are women. The average age of the consumers served is 66.8 and the average age of caregivers is 47.7. More than 70% of consumers need physical assistance with more than three activities of daily living. Prevalent diagnoses include hypertension, COPD, and diabetes. More than 38% of consumers have at least one diagnosed psychiatric condition and 29% of consumers served have Alzheimer's disease or dementia.

Structured Family Caregiving is successful because it is flexible and person and family-centered, because it seeks to provide the resources necessary to be sufficiently supportive of individuals with complex medical and behavioral health conditions in the community, and because it specifically focuses on engaging and enabling committed lay caregivers to provide such care. The model includes:

- Professional care teams that extend the reach and impact of existing AAA case management services – Structured Family Caregiving care teams coach caregivers during frequent face-to-face visits and technology-enabled "check-ins" providing family members with the skills, confidence, and support they need to manage complex medical conditions and behaviors.
- Live-in caregivers who provide around-the-clock support to consumers – caregivers promote independent living and improved health outcomes by assisting with personal care, ensuring adherence to medical appointments with primary care providers and specialists, helping with medication management, and intervening to manage disruptive behaviors. Whenever possible, caregivers also help consumers to participate in social activities in the community. Caregivers receive financial support, in the form of caregiver stipends, allowing them to make a full-time commitment to caregiving for as long as they are providing support to their loved ones.



- Easy-to-use technology that allows caregivers and care teams to easily communicate and collaborate on a daily basis – caregivers share information with their care teams regularly and as needed, enabling care teams to focus in real-time on changes in the consumer’s condition and developing circumstances in the home and to provide timely interventions that address medical and behavioral health issues and social determinants of health.

Structured Family Caregiving ensures that consumers needs are met in the community where they prefer to receive care, that qualified caregivers are supported to provide care to consumers with a broad range of complex medical and behavioral health needs, and that the State has a cost effective, predictable, fixed-price model that provides a real alternative to institutional care. FSSA should be proud of the success of the model to date as we are proud of our contributions to administering the model on your behalf. We believe the service has demonstrated value in supporting diversions from nursing facility admissions, extending the length of community tenure, and improving health outcomes for, and satisfaction of, consumers and caregivers. We also believe there is more that could be done to evolve the model to keep more care in the community.

As our State works to ensure the sustainability of our Medicaid program, we face additional challenges from the growing “caregiver gap” as the population of aging adults who will need long term care is increasing well beyond the supply of available caregivers. We also know there are specific populations in Indiana who are in need of more support including, for example, those living with Alzheimer’s and dementia and the families who struggle to support them. Now is the time to introduce additional innovations to address these concerns and extend our support to these Hoosiers.

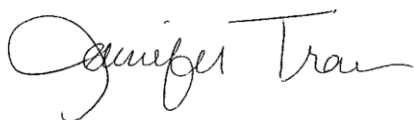
Such enhancements could include:

- **Creating a fourth level of Structured Family Caregiving for consumers with Alzheimer’s disease and dementia** - as noted above, we are serving an increasing number of individuals living with Alzheimer’s disease and dementia; these consumers have extensive and fluctuating behavioral health needs that require constant caregiver oversight and intervention, and their caregivers require more frequent coaching and professional support to continue managing those behaviors and the progression of the disease and related conditions. We are investing in the development of evidence-based programs, training protocols, and educational content specifically to support these consumers and caregivers and we need the State’s support in order to be able to deploy these resources broadly. (The results of some of our work to date have been published in the Geriatrics & Gerontology Education Journal.¹)
- **Introducing a meaningful respite benefit for caregivers in Structured Family Caregiving** – unlike other States, Indiana does not currently allow respite services to be provided to caregivers who are supporting consumers enrolled in Structured Family Caregiving. In our experience, the availability of respite is a significant factor in length of stay in Structured Family Caregiving and, accordingly, with the cost savings and other outcomes that can be achieved through the model. Our data demonstrates that consumers and caregivers who have access to respite benefits remain in the program, avoiding institutional admission, on average, three times longer than those who do not access such benefits.
- **Offering Family Caregiver Training to populations beyond those in Structured Family Caregiving** – the State could extend available expertise and tools to all caregivers who are providing support to Waiver-eligible consumers and/or to those caregivers who are providing support to those living with Alzheimer’s and dementia. We believe this would yield meaningful results in terms of caregiver capacity to support consumers to receive care at home, and develop confidence and competencies in caregivers as consumers needs progress and families begin to consider whether they can continue to provide sufficient support to keep care at home.

¹ See: <http://www.tandfonline.com/doi/full/10.1080/02701960.2016.1209419>

Thank you again for your commitment to engaging consumers, caregivers, and other stakeholders in the evaluation of Indiana's long-term services and supports system. We appreciate the opportunity to contribute our thoughts regarding HCBS and how the State can best extend the reach of community services and caregiver supports to keep more care at home. We look forward to engaging with you in the near future to further discuss these recommendations. Please feel free to contact us if you have any questions.

Sincerely,



Jennifer Trowbridge
Indiana State Director
Caregiver Homes
Phone: 219-263-9852
Email: jtrowbridge@caregiverhomes.com



Jennifer P. Crosbie
Director, Government Relations
Seniorlink
Phone: 617-955-6430
Email: jcrosbie@seniorlink.com