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**The Arc of Illinois Testimony
Senate Appropriations – Human Services
Subject Matter Hearing on SB 4099
March 10, 2022**

Dear Sub-Chair Feigenholtz, Sub-Vice-Chairs Fine and Johnson, and Committee Members,

Thank you for the opportunity to submit written testimony for your consideration as you determine budget priorities for the Department of Human Services. I write to you as the Executive Director of The Arc of Illinois, a statewide organization that advocates for the estimated nearly 215,000 people with intellectual and developmental disabilities (IDD), their families, and the community-based organizations that support them to ensure that people with IDD can live, work, learn, and play in communities across the state.

Like many of our colleagues, The Arc of Illinois is in support of the full implementation of the Guidehouse recommendations resulting from the study done and published in 2020.

The Arc is also requesting an allocation of funds and statutory provisions for an independent rate study of the Home Based Services Waiver program.

Background

- Participation in the [Home-Based Services \(HBS\) Waiver](#) enables the purchase of services necessary to support an individual with intellectual and developmental disabilities (IDD) to live successfully in their own home or with their family.
- The Home-Based Services Waiver:
 - is “self-directed” meaning individuals, guardians and families arrange and manage their own services and supports;
 - provides a monthly stipendⁱ to be used to purchase services and supports; and
 - enables family members to have the flexibility to work.
- 50% of the people with IDD in Illinois who are receiving waiver-funded IDD services are served through the Home Based Services Waiver.ⁱⁱⁱ

The Issue

- Individuals using HBS are responsible for recruiting, hiring, and managing their own Personal Support Workers (PSW), including setting the wage rate.
- A 2020 studyⁱⁱ resulted in recommendations which included much-needed rate increases for Direct Support Professionals (DSP), a role very similar to that of a PSW.
 - The study, however, did not include an exploration of the wages of PSWs providing supports to the 11,397ⁱⁱⁱ HBS Program participants.
- Because the HBS monthly allocation had not, until January 2022^{iv}, increased significantly since 2019, HBS participants’ ability to purchase needed services has been diminished.

- As a result of decreased buying power, families are competing with developmental disability provider agencies that have the ability to increase their DSP pay rate thanks to the implementation of the Guidehouse study.
- This has compounded by the COVID-19 pandemic which resulted in critical temporary rate increases to provider organizations which did not apply to HBS.

Therefore, an independent study of the HBS Program is necessary to examine the extent of the diminished purchasing power of HBS participants to access needed supports and live independently in the community.

We look forward to being a part of the discussion going forward with the Illinois Legislature to ensure that people of all ages with IDD can continue to receive the supports necessary to live, work, learn, and play in communities across the state. Please do not hesitate to contact Amie Lulinski at 779-243-7709 or amie@thearcofil.org for more information.

Respectfully submitted,

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ⁱ 200% SSI for children in school and 300% SSI for adults per [Section 2-6 of the Developmental Disability and Mental Disability Services Act, 405 ILCS 80/2-6](#)

ⁱⁱ Guidehouse, Inc. (2020). Developmental Disability Services Rate Study: Residential Services and Related Supports. Available: <https://3m4psa58y9z2v1hgrew7ram5-wpengine.netdna-ssl.com/wp-content/uploads/2020/12/Final-Guidehouse-Rates-Report-12.08.2020.pdf>

ⁱⁱⁱ Stark, A. (2022, January). Illinois Department of Human Services, Division of Developmental Disabilities, QIDP Conference presentation.

^{iv} <https://www.ssa.gov/cola/>