May 11, 2023

Thanks to a series of listening sessions hosted by the Division of Developmental Disabilities and a dedicated inbox to receive feedback, Illinois families have been heard! The Arc of Illinois is pleased that the Illinois Department of Healthcare and Family Services has announced implementation of a live-in caregiver exemption for Electronic Visit Verification (EVV). For additional information, please see our previous statement on EVV.

We know that family caregivers are the backbone of IDD supports in the United States. Nationally, 72% of people with IDD live with a family caregiver, though only 10% of total spending was dedicated to family support. In Illinois it is also 72%, yet only 3% of spending was dedicated to family support in FY19. Despite the funding disparity, participants in Home Based Services Waiver, Illinois’s self-directed support waiver, surpassed the number of participants receiving Community Integrated Living Arrangement (CILA) services in 2021.

The Arc of Illinois and its membership strongly advocated for a live-in caregiver exemption to alleviate the unnecessary burden of family members repeatedly clocking in and out at their own home when they are providing PSW services for an individual who also lives in their home. By electing to use a live-in caregiver exemption, Illinois is engaging in respectful practice and thereby providing hope to thousands who receive supports through this waiver.

--- Amie Lulinski, PhD, Executive Director

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IDHS: Adults with DD by Living Arrangement - FY10 to FY22 (state.il.us)