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TO: Task Force on the Assessment of Services and Supports for People with Intellectual and Developmental Disabilities

FROM: Dawn Adams, Executive Director, Indiana Disability Rights

RE: Public Comments

DATE: August 10, 2018

Task Force Members,

Indiana Disability Rights (IDR) serves as the State's Protection and Advocacy System, organized as an independent state agency under a federal mandate. The agency provides legal advocacy services to people with disabilities across Indiana and also conducts investigations into suspected cases of abuse and neglect. IDR supports the Task Force's deliberate inclusion and active participation of people with disabilities in discussions involving programs and services.

IDR offers the following comments regarding the Task Force's Assessment of Services and Supports for People with Intellectual and Developmental Disabilities (ID/DD). These comments are based on real issues that attorneys and advocates have researched due to client needs. These comments should not be considered exhaustive of all issues, as there is likely no end to the improvements that could be made to the current system in order for Indiana to maximize its ability to serve people with intellectual and developmental disabilities.

For these comments, IDR has chosen to focus broadly on key systemic issues that urgently need attention. Taking a look at the landscape of programs and service delivery in Indiana, serious concerns arise for individuals with ID/DD regarding the preservation of their rights, safety, and freedom for self-determination. Therefore, these comments will focus on four issues: lack of information about alternatives to guardianship, the segregated nature of sheltered work and subminimum wage, lack of quality education and supports for children in institutions, and abuse and neglect in residential service delivery.

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INDIANA SHOULD ENCOURAGE EFFORTS TO INCREASE THE USE OF SUPPORTED DECISION-MAKING AND OTHER ALTERNATIVES TO GUARDIANSHIP.

Historically, society has placed adults with ID/DD into one of two camps: completely able to manage their own affairs with little to no support; or unable to do so, and in need of a legal guardian to manage their affairs for them.¹ While the appointment of a guardian may be necessary for some individuals with ID/DD, the consequences of removing an individual's decision-making authority are significant and can sometimes be harmful.² Thankfully, the concept of Supported Decision-Making (SDM), whereby an individual can choose "supporters" to provide guidance and/or decision-making assistance in specified areas,³ has gained significant traction in recent years.⁴

The future of services and supports for individuals with ID/DD will help determine whether SDM is fully realized as a tool to empower Hoosiers with disabilities to direct their own lives. Despite the fact that decision-making has been proven to be a learnable skill, individuals with ID/DD are not often evaluated to determine their unique skills and abilities with respect to decision-making. Nor are they given the space to make their own decisions commensurate with their abilities. Individuals with ID/DD should be given opportunities to regularly practice and develop this important skill.⁵ Indeed, decision-making is often not a skill defined in service plans, transition plans, or employment goals. Reshaping this dynamic does not necessarily require major changes to the delivery of services and supports in Indiana. Instead, what needs to occur is an expanded emphasis on the dignity and personhood of all individuals with ID/DD, regardless of whether they currently have a guardian.

A perfect example of this concept is Jamie Beck, an IDR client represented in the first successful petition for termination of guardianship in favor of SDM in Indiana. While under guardianship, Jamie was regularly encouraged to exercise her independence to the greatest degree practicable, and decisions affecting her life were rarely made without her participation. The effect of her positive outlook and remarkable work ethic cannot be overstated, but it is

¹ It is estimated that between 1 and 3 million adults are under guardianship nation-wide. *See* BRENDA K. UEKERT & RICHARD VAN DUIZEND, NAT'L CTR. FOR STATE COURTS, ADULT GUARDIANSHIPS: A "BEST GUESS" NATIONAL ESTIMATE AND THE MOMENTUM FOR REFORM 107, 108-09 (2011), *available at* http://www.guardianship.org/reports/Uekert_Van_Duizend_Adult_Guardianships.pdf

² Several studies suggest that overbroad or undue guardianship can make people depressed, decrease their motivation and "set up expectancies of failure . . . that diminish subsequent performance." (Winick, B., 1995).

³ Either informally, or through a formalized Supported Decision-Making Agreement.

⁴ Since 2015, state laws recognizing or requiring consideration of SDM before appointing of a guardian have been passed in Texas, Delaware, and Wisconsin. Legislative efforts and/or pilot projects are underway in a number of additional states, including Indiana.

⁵ *See* Barbara L. Ludlow, *Life After Loss: Legal Ethical and Practical Issues*, in *AGING, RIGHTS AND QUALITY OF LIFE: PROSPECTS FOR OLDER PEOPLE WITH DEVELOPMENTAL DISABILITIES* 189, 197 (Stanley S. Herr & Germain Weber eds., 1999) (suggesting that decision-making is a skill that can be learned); ROBERT M. LEVY & LEONARD S. RUBENSTEIN, *THE RIGHTS OF PEOPLE WITH MENTAL DISABILITIES* 106 (1996) (noting that many persons with ID "are frequently not allowed to participate in decision making to the extent of their abilities").



unlikely Jamie would be where she is today were she not provided opportunities to practice decision-making that allowed her to take ownership over her future.

There are several strategies that could be utilized to create a more conducive environment for SDM and better the lives for individuals under guardianship. First, the goals and desires of individual consumers should be the primary driver in the delivery of supports and services; regardless of whether a guardianship is in place. IDR is encouraged by the state's push to advance person-centered planning as a philosophy within the service delivery system. However, this concept should be incorporated throughout other agencies that touch the lives of people with disabilities as well. Furthermore, the state should continue its efforts to expand this concept to service providers in a meaningful way. IDR has often seen petitions for guardianship initiated by a provider because of a lack of ability to determine the choices or wishes of a person under their care. Providers should be educated about ways to avoid unnecessary guardianship when one is sought as a convenience for service delivery.

Next, there needs to be universal procedures developed to permit providers to take action when a guardian is neglectful or is not making decisions that are in the best interests of the protected person. On limited occasions, IDR has been forced to intervene in order to seek the removal or resignation of guardians who were acting inappropriately. More often, IDR has received reports of protected persons who were denied fundamental rights and dignities for months, or even years, because providers could not obtain approvals from guardians. In most of those scenarios, providers eventually obtained the necessary approvals through Human Rights Committees after receiving citations or other reprimands from regulating state agencies. Citations from state agencies should not be necessary for providers to act in these situations.

In addition, the Task Force should work with the Division of Disability and Rehabilitation Services (DDRS) to assess the viability of a program or service that establishes best practices and guidance in assisting individuals with ID/DD to develop and maintain planning and decision-making skills. The Task Force should also work with the Indiana State Guardianship Association, disability advocacy groups such as IDR, and other stakeholders, in order to encourage the development of a curriculum for the training of family guardians to promote understanding of appropriate guardian roles and responsibilities, the rights of protected persons, and the use of SDM.

INDIANA SHOULD DETERMINE THAT SHELTERED WORK IS INSTITUTIONAL AND NOT A COMMUNITY-BASED SERVICE FOR PURPOSES OF MEDICAID FUNDING AND SHOULD SUPPORT COMPETITIVE, INTEGRATED EMPLOYMENT OPPORTUNITIES.

IDR believes that many working-age Hoosiers, regardless of disability, are capable of competitive, integrated employment. This is why the agency supported the 2017 passage of Senate Bill 390, which made Indiana an Employment First state. Unfortunately, despite both the Governor and General Assembly's strong commitment to develop employment opportunities within Indiana, legal and policy priorities have not significantly improved expectations and opportunities for working-age Hoosiers with disabilities.

First and foremost, it is important for policymakers to understand that sheltered work does not constitute employment. Individuals that work in these facilities are termed "workers"



but they are not entitled to any employment benefits under this model. Those benefits lacking include those that traditional employees generally take for granted, i.e. worker's compensation, unemployment benefits, earned paid time off, and insurance. When competitive, integrated employment is discussed, sheltered work should be removed completely from the table as an option. Any person with or without a disability should first have the opportunity for competitive, integrated employment. Sheltered work placements should be used sparingly and only as a tool to help build employment skills.

Unfortunately, sheltered work thrives in Indiana. According to the U.S. Department of Labor, 44 sheltered workshops are operating in Indiana as of April 1, 2018.⁶ Collectively, these workshops hire 5,282 individuals with disabilities at subminimum wages.⁷ In 2016, IDR conducted surveys of 36 sheltered workshops throughout the state. After interviewing more than 140 sheltered workers, it was determined that the average hourly pay rate was \$2.67 per hour. In addition to being compensated at subminimum wages, workers repeatedly expressed dissatisfaction with "downtime." Downtime are those periods when no work is available and facilities engage workers in mock work or day programming to avoid keeping them on the clock. Only three workshops surveyed attested that downtime never occurs; a third admitted occasional downtime. Indeed, the average workweek for a sheltered worker in Indiana is approximately 22 hours.⁸

Despite the local push for Employment First and federal efforts under the Workforce Innovation and Opportunity Act (WIOA), the IDR surveys indicate an average of 15 new workers per year were entering each sheltered workshop. This figure surpassed the average number of workers transitioning from sheltered workshops into competitive, integrated employment.⁹ Just under half of the sheltered workers interviewed reported having prior work experience in the community at competitive wages. Reasons for entering sheltered workshops included relocation, company closings, and frustration with workplace discrimination. These findings suggest that Indiana has not developed adequate policies and supports to enable individuals with disabilities to achieve and maintain competitive, integrated employment.

Another troubling practice that is not conducive to competitive, integrated employment includes the fact that Vocational Rehabilitation Services (VRS) routinely refers clients to a sheltered workshop for the consumer's benefits analysis, which includes a discussion of work incentives. IDR is concerned that this practice creates a conflict of interest. Workshops may not be forthcoming with the details of how to utilize work incentives to earn a competitive income

⁶ Wage and Hour Division, U.S. Department of Labor, *Community Rehabilitation Programs (CRPs) List*, Apr. 1, 2018 (available at: <https://www.dol.gov/whd/specialemployment/CRPlist.htm>). "Sheltered workshops" refer to entities holding 14(c) certificates under the Fair Labor Standards Act.

⁷ See Sheltered Workshop Presentation incorporated as an attachment for these comments.

⁸ Notably, the majority of workshops in Indiana denied workers more than 30 hours per week, even when work was available. Several workshops noted this 30-hour limit was enacted after passage of the Patient Protection and Affordable Care Act to avoid extending health insurance coverage to sheltered workers.

⁹ Multiple workshops reported that one or fewer sheltered workers transitioned to competitive, integrated employment in the prior year.



while retaining public benefits. This potential conflict could be easily resolved if VRS rules were amended to prohibit benefits analyses to be conducted by providers with 14(c) certificates.

Transportation issues are also a consistent theme with sheltered workers. An overwhelming number of sheltered workers stated that they are brought to and from the workshop by either workshop or residential staff – though sometimes these providers are the same. Were these individuals able to access public transportation or secure rides independently, many expressed they could have continued working in the community. Expanding public transit options, as well as creatively harnessing resources like Uber, Lyft, and privately-owned accessible vehicles, would likely permit more people with disabilities the opportunity to achieve and maintain competitive, integrated employment. Moreover, assisting workers to strategically utilize work incentives, such as Achieving a Better Life Experience (ABLE) accounts and Plans to Achieve-Support (PASS plans), would enable workers with disabilities to save money for a vehicle and, if needed, driver expenses.

Many sheltered workers interviewed expressed concern about losing critical public benefits – particularly Medicaid – if transitioned to competitive, integrated employment. This should not be a concern as Indiana has one of the most generous Medicaid buy-in programs in the nation.¹⁰ IDR believes that educating individuals with disabilities about programs like M.E.D. Works would encourage more to engage in competitive, integrated employment. Relatedly, multiple workers on the Family Supports Waiver shared that their guardians felt sheltered work was needed because it was the cheapest “bucket” in which Waiver dollars could be spent and the best way to stretch Waiver benefits. The State could preclude this phenomenon by changing the way prevocational services are reimbursed.

INDIANA MUST BETTER ADDRESS THE EDUCATIONAL NEEDS OF CHILDREN IN INSTITUTIONS.

The federal Department of Education states that in 2016, 688 students in Indiana were placed in residential facilities.¹¹ These students have the same right to a free appropriate public education (FAPE) in the least restrictive environment as students going to school in a traditional general education setting. However, preliminary investigations into this matter reveal that these students are not receiving the same education as their peers. The lack of education prevents these students from being set up to succeed when they re-enter society.

A residential placement is one of the most restrictive placements on the continuum of placement options. It should only be considered if no other less restrictive options are appropriate. If a student is placed in a residential setting, the student still has a right to FAPE. Before placing a student in a residential facility, the school must hold a case conference to

¹⁰ A Hoosier can participate in the program if, in addition to meeting other eligibility requirements, he or she earns less than 350% of the federal poverty level. *See* Ind. Code § 12-15-41-4(5). Importantly, after the deduction of certain expenses, including impairment related work expenses, half of the remaining earned income is excluded from being deemed countable income. *See* 20 C.F.R. § 416.1112. This methodology means that a working Hoosier with disabilities can potentially earn a salary of more than \$80,000 and maintain eligibility for his or her Medicaid benefits, simply by continuing to pay a monthly premium.

¹¹ *See* <https://www2.ed.gov/programs/osepidea/618-data/state-level-data-files/index.html#bee>



develop the student's Individualized Education Program (IEP) for this placement.¹² Personnel from the residential facility must attend the case conference.¹³ After the student is placed in a residential facility, the public school must still attend case conferences to ensure the student is receiving FAPE.¹⁴ IDR has ample anecdotal evidence that this process is not being uniformly followed, resulting in children in institutions without an appropriate IEP and not receiving the services and supports they need to continue their education.

IDR is in the process of reviewing records from students with disabilities placed in residential settings. While the review is still in the preliminary stages, there exist concerns regarding whether a new IEP is fully developed prior to entering a facility. For example, one student still had "going to the resource room" as an accommodation on his IEP even though there was no resource room at the facility. IDR also has concerns regarding whether some facilities provide all of the required educational and related services for students receiving special education. For example, students in institutions may not have access to general education classes, or services like physical, occupational, or speech therapy. IDR encourages the agencies involved in this Task Force who interact with students in institutions to consider this concern and study the matter in-depth.

INDIANA SHOULD ADDRESS SYSTEMIC PROBLEMS IN RESIDENTIAL SERVICE DELIVERY THAT INCREASES THE LIKELIHOOD OF ABUSE, NEGLECT, OR EXPLOITATION.

IDR investigators have observed several concerning trends among providers serving clients with DD on community integration and habilitation (CIH) waivers or in supervised group living homes (SGL) that have led to abuse or neglectful care. The three broad categories that IDR has encountered are a lack of adequate training for direct care staff, lack of supervision within the homes, and a delay in calling 911 in emergency situations.

There appears to be a lack of consistent, quality training for new direct care staff and a lack of adequate opportunities for on-going training for current direct care staff. While most providers have a training program for new employees, typically lasting a full week, the training does not appear to be sufficient. Each client in a CIH or SGL setting will typically have an individualized support and/or behavioral plan and may also have one or more risk plans in place to protect the client's health and safety. We are concerned that providers are not providing consistent client-specific training for each plan and that on-duty staff are responsible for training new or relief staff on client-specific information. IDR investigations have revealed that staff have little to no discussion on client-specific needs between shifts and that changes in a clients' behavior or health are not often properly recognized, documented, or tracked. This can lead to serious health concerns being overlooked and a subsequent delay in treatment. Specifically, IDR investigations have substantiated cases of abuse and neglect by direct care staff that could have been prevented with quality training and appropriate supervision.

¹² See 511 Ind. Admin. Code § 7-42-13(a).

¹³ See 511 Ind. Admin. Code § 7-42-13(b).

¹⁴ See 511 Ind. Admin. Code § 7-42-13(c).



Direct care staff are not subject to consistent oversight or supervision. Direct supervision is usually the responsibility of a team leader or equivalent position. This supervisory role does not always require additional training or qualifications beyond those of direct care staff and there may not be a team leader on all shifts. Supervision of waiver sites is especially problematic as managers may be responsible for multiple homes,¹⁵ making it difficult to visit each site on a weekly or even monthly basis which leaves sites unsupervised for extended periods of time. We have observed in investigations that during periods of limited oversight, direct care staff are more likely to offer minimal care to clients. Additionally, program managers have admitted that, due to time constraints, they prioritize supervising homes with the most significant issues and leave the other homes without regular monthly visits. Conversely, other program managers have regular scheduled visits, allowing staff to know when the supervisor will be present. Investigations have shown that lack of supervision has created more opportunities for residents to be subjected to physical abuse and neglectful care.

Due to the aforementioned lack of training, direct care staff often overlook or are unable to recognize changes in behavior or medical conditions¹⁶ that are indicative of a serious condition that requires medical attention. Additionally, staff reported that they do not feel they are allowed to call 911 in the case of a life threatening emergency because the provider's policy requires a supervisor's approval before calling 911. In 2017, IDR received at least 15 notifications of death in which a delay in contacting 911 may have contributed to the cause of death. IDR encourages this group to address safe harbor options to allow workers to feel empowered to seek immediate medical attention in an emergency without fear of losing their job.

IDR is grateful to the Task Force for the time and consideration taken to consider these important issues facing individuals with intellectual and developmental disabilities in Indiana. IDR stands ready to provide support to the Task Force as it begins to develop strategies to address the systemic issues that impact Hoosiers.

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¹⁵ Managers have reported being responsible for waiver sites spread out over multiple counties.

¹⁶ Medical conditions that have been over looked include, but are not limited to, elevated temperature, rash, and change in skin color or condition.