#### **DISABILITY ADVOCACY ALLIANCE**

Protecting the Rights of Ohio's Most Vulnerable Citizens
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January 29, 2015

The Honorable John Kasich Governor, State of Ohio 77 South High Street, 30th Floor Columbus, OH 43215

John McCarthy, Director Ohio Department of Medicaid 50 West Town Street, 4th Floor Columbus, OH 43215

CC: Ohio House of Representatives
Ohio Senate

Governor's Office of Health Transformation 77 South High Street, 30th Floor Columbus, OH 43215

Greg Moody, Director

John L. Martin, Director Ohio Department of Developmental Disabilities 30 E. Broad Street, 12th Floor Columbus, OH 43215-3414

Dear Governor Kasich and Directors Moody, Martin and McCarthy,

"When you die and go to heaven, I don't know that St. Peter is going to ask, did you balance the budget? He is probably going to ask what you did for the least of those [around you]." (Governor Kasich as quoted in The Economist, November 2014)

Disability Advocacy Alliance (DAA) appreciates this opportunity to provide comments in response to the Strategic Planning Leadership Group's (SPLG) Final Report (December 2014)<sup>1</sup> as we advocate for Ohio's most vulnerable citizens.

DAA is comprised of volunteer advocates whose family members receive and/or are waiting for high quality residential, employment and day services in a variety of settings, including Intermediate Care Facilities Homes for Individuals with Intellectual Disabilities (ICFs/IID), community based care, sheltered workshops, and day programs. As recognized by the U.S. Supreme Court in its *Heller v. Doe* decision, "close relatives and guardians, both of whom likely have intimate knowledge of a mentally retarded person's abilities and experiences, have valuable insights which should be considered" in placement and care decisions [509 U.S. 312 (1993)].

According to the Ohio Department of Developmental Disabilities (DODD) -

"The SPLG is developing a set of recommendations that will be presented to Director Martin, who will review the group's input to see what items can be implemented. *It's important to remember that these are just recommendations, and may or may not be implemented; decisions about whether or not items can be implemented will be based on many factors.*" ["Our Future: A Brighter Future for All Ohioans," DODD (*emphasis added*)].

<sup>&</sup>lt;sup>1</sup> See, <a href="http://dodd.ohio.gov/OurFuture/Documents/SPLG%20Final%20Report.pdf">http://dodd.ohio.gov/OurFuture/Documents/SPLG%20Final%20Report.pdf</a>

We are grateful for this opportunity. We have grave concerns about the following SPLG recommendations:

- "The total number of ICF beds is reduced by 50 percent, to 2800 beds."
- "1500 people will leave ICF facilities of 16 beds or larger and move to community homes. The average setting size of these community homes is four beds or fewer."
- "The number of people employed is 50 percent of the adults served."

As explained in more detail below, the proposed SPLG recommendations will eliminate the right of individuals with intellectual and developmental disabilities (I/DD) to receive person-centered services and supports in the settings of their choice, contrary to the Supreme Court's *Olmstead* decision. In addition, these recommendations narrow rather than expand service options, which will unfairly nullify any effort to assist the more than 42,200 individuals waiting for necessary services.<sup>2</sup>

## **Detailed Comments**

## I. Citizens Who Receive ICF/IID Care And Support Have A Right To Person-Centered Care And Choice

As its first and second benchmarks, the SPLG recognizes the right of people with disabilities and their families to receive information about all service options and individuals have a right "to "experience person-centered services and supports and achieve outcomes that matter."

Likewise, the U.S. Supreme Court's landmark *Olmstead* decision requires the provision of individualized supports and individual choice as prerequisites to community placement.<sup>3</sup>

DAA wholeheartedly agrees with these principles but asserts that SPLG recommendations to force thousands of individuals from their ICF/IID homes, to the neglect of those waiting for services, are inconsistent with its first two benchmarks and directly contrary to the *Olmstead* decision. Indeed, Justice Ruth Bader Ginsberg, writing for the majority, cautioned against such a scenario:

"We emphasize that nothing in the [Americans with Disabilities Act] or its implementing regulations condones termination of institutional settings for persons unable to handle or benefit from community settings...Nor is there any federal requirement that community-based treatment be imposed on patients who do not desire it." 119 S. Ct. at 2187.

<sup>&</sup>lt;sup>2</sup> Ohio Developmental Disabilities Council and the Ohio Colleges of Medicine, Government Resource Center, June 30, 2014 at <a href="http://grc.osu.edu/ddisabilities/waitinglist/">http://grc.osu.edu/ddisabilities/waitinglist/</a>.

<sup>&</sup>lt;sup>3</sup> Olmstead v. L.C., 527 U.S. 581, 587 (1999)(The Supreme Court held that community placement is only required and appropriate (i.e., institutionalization is unjustified), when "[a] the State's treatment professionals have determined that community placement is appropriate, [b] the transfer from institutional care to a less restrictive setting is not opposed by the affected individual, and [c] the placement can be reasonably accommodated, taking into account the resources available to the State and the needs of others with mental disabilities" (emphasis added).

### A plurality of Justices added:

"[N]o placement outside the institution may ever be appropriate . . . 'Some individuals, whether mentally retarded or mentally ill, are not prepared at particular times - perhaps in the short run, perhaps in the long run - for the risks and exposure of the less protective environment of community settings' for these persons, 'institutional settings are needed and must remain available'" (quoting *Amicus Curiae* Brief for the American Psychiatric Association, et al). 521 U.S. at 604-604; 119 S. Ct. at 2189.

"As already observed [by the majority], the ADA is not reasonably read to impel States to phase out institutions, placing patients in need of close care at risk... 'Each disabled person is entitled to treatment in the most integrated setting possible for that person — recognizing on a case-by-case basis, that setting may be an institution' [quoting VOR's *Amici Curiae* brief]." Id.

Yet the SPLG recommends the displacement of approximately 3,754 individuals from ICF/IID homes: 954 individuals<sup>4</sup> from state-operated ICFs/IID and 2,800 individuals from private ICFs/IID. (Another transfer of 1,500 individuals from ICF homes with 16 or more residents is indicated, but it is unclear if this number will draw from both state and private ICF homes or only private ICF homes.)

Quotas such as these are completely inconsistent with the letter of and spirit of the *Olmstead* decision as they are not based on individual choice, but political decisions of state officials. Quotas are antithetical to, and prevent, individual choice and person-centered planning. As cited above, the *Olmstead* court expressly cautioned against forcing individuals out of individually appropriate placements against their will and best interests, placing them at great risk. SPLG could not know the individual, person-centered needs of the 3,754 individuals impacted by SPLG's recommendation to remove them from their homes.

DAA urges the Governor, Governor's Office of Health Transformation (OHT), Ohio Department of Medicaid (ODM), and DODD to expressly reject SPLG quotas and support a range of residential services to accommodate person-centered care and individual choice.

## II. Citizens Who Work in Sheltered Workshops or Receive Day Program Supports Have A Right To Person-Centered Care And Choice

SPLG recommends that the "number of people employed is 50 percent of the adults served." The principle associated with this benchmark refers to "employment" as something as little as one hour per week and an aggregate of 20 hours per week, with individuals "choosing activities for the remainder of the day with as much community involvement as possible."

<sup>&</sup>lt;sup>4</sup> "Strategic Planning and the 2016-2017 Biennium Budget," John L. Martin, Director, DODD, June 26, 2014

This recommendation is completely disconnected from individual choice and need. Currently, over 31,300 individuals with disabilities are enjoying productive days in specialized workshop settings or in day programs that connect people with activities. Without these opportunities, individuals unable to find and handle competitive employment could be left with long, isolating days in front of a television. The New Jersey Legislature recognized this when voting in support of maintaining sheltered workshops:

"Many said a competitive workplace, even with support, was not a realistic goal, noting that those who can move into those workplaces do so." (Burlington County Times, July 29, 2013)

Even in robust economic times, unemployment rates for individuals with disabilities remain very high. Historically, employers have not had the time or funds to train, supervise and support someone with a disability. Setting a goal while simultaneously eliminating sheltered workshop and day program choices will not necessarily translate into employers' ability or willingness to hire these displaced individuals at competitive wages. Many constituents **will** find themselves without a place to productively spend their days. Sheltered employment and day programs offer alternative choices for workers with I/DD, but if such options are discontinued, the few opportunities for people with more profound disabilities will disappear along with their sense of self and accomplishment.

At the DODD CMS Transition Forum in Cincinnati, Ohio, a participant asked if the State of Ohio's Employment First initiative would be more costly to the taxpayer than facility based settings. Kristen Helling of DODD responded that Employment First would actually be cheaper for the state since Ohio would be relying on private-sector and non-profit resources for employment opportunities. In his concurring opinion in *Olmstead*, Justice Kennedy warned states against this "compliance on the cheap," "driving" individuals "into settings with too little care and supervision" out of "fear of litigation." <sup>5</sup>

DAA asserts that the quality of day programming should take priority over the shifting of financial responsibility for these services away from the state. We believe that individuals with I/DD deserve a setting appropriate to their unique challenges and abilities, not what is "cheaper" for the state.

DAA urges the Governor, OHT, ODM, and DODD to expressly reject SPLG quotas and support of a range of employment and day habilitation services to accommodate personcentered care and individual choice.

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<sup>&</sup>lt;sup>5</sup> Omstead v. L.C., 527 U.S. at 610 (Kennedy, J., concurring)

## III. SPLG Recommendations Are Cost Prohibitive and Would Cause the Loss of <u>at</u> <u>Least \$111 Million</u> in Federal Funding Which Benefits All Programs in the DODD Service System

From a cost perspective, SPLG's recommendations are simply not viable.

Caring for individuals with complex needs in a disjointed community setting without the efficiencies and expertise of ICF/IID homes will astronomically increase the cost of care to taxpayers. It is not unheard of for the State of Ohio to provide community services for individuals with severe I/DD at a cost of as high as \$500,000 per year for a single individual.

If this level of care is pursued for the thousands of individuals noted in SPLG's benchmarks, funds will ultimately be so lacking that individuals displaced from ICFs/IID homes will be put at great risk due to the lack of the ability to pay for their life-sustaining, highly specialized care and support in scattered community housing. Given the rapid increase in the cost of health care, the expense of caring for highly involved individuals in community placements will spiral out of control, depleting resources for less disabled individuals, including those individuals already receiving waiver services. Furthermore, individuals with disabilities now on the waiting list will continue to wait and the waiting list will continue to grow as the displaced, highly vulnerable ICF/IID home residents assume their places at the front of the line ahead of those deserving citizens who have already waited far too long.

According to SPLG recommendations, the following populations with disabilities will be competing for already insufficient community resources, even with the projection of new Level One, Self-Empowered Life Funding (SELF) and Individual Options (IO) waivers each year:

Residential Program	Number of Individuals Impacted	Number of Four- Person Community Homes Needed	Number of Four- Person Homes Needed Per Year Over 10 Year Implementation	Number Earmarked by SPLG Per Year	Projected Cost
State Operated ICFs/IID Closures	954	239 homes	24 homes	Not specified	Not specified
Private ICFs/IID	2,800	700 homes	70 homes	Not specified	Not specified
Waiting List - All Services	42,205	Not specified	Not specified	1,200/ year (500 Level One; 600 SELF, and 100 IO waivers).	Not specified
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	45,959 individuals	Unknown	Unknown	1,200/year earmarked for waiting list	Not specified

The SPLG benchmarks are not grounded in reality as there are no cost projections included in the report.

With current complex community placements costing taxpayers as much as \$500,000 per year for a single placement, how can the DODD consider SPLG's sweeping policy proposals without first performing cost projections? Such a cavalier approach to policymaking risks the financial viability of Ohio's entire DODD service system, putting **all** individuals being served by DODD at risk of losing vital services.

The SPLG recommends earmarking 1,200 new HCBS waivers each year for eligible individuals now on the waiting list for services. Yet, SPLG also recommends displacing approximately 3,754 individuals from their ICFs/IID homes to be served in alternate four-person community homes. The SPLG fails to specify the number of individuals on the waiting list who require residential placement.

The SPLG benchmarks for new waiver services cannot be taken seriously when the housing needs of those currently on the waiting list have not been identified. In the absence of this information and any cost projections, the immediate housing needs of the displaced ICF/IID home residents will assume priority over those individuals needing residential placement on the waiting list, and quite likely over all unmet waiting list needs. With 3,754 displaced ICF/IID home individuals to house, it could take at least three years before a single person on the HCBS waiting list receives residential placement or other vital services, assuming there is not an influx of new emergency placements and the ICF/IID transfers are cost neutral. We know the latter will not be the case.

Current residents are happy and well-cared for in their ICF/IID homes and the law requires that their choices be honored. From a cost perspective, there is a growing acceptance among all interested parties that closing specialized settings serving people with I/DD will not save money and will cost more. In addition, Ohio will lose important revenues from the ICF/IID system (i.e. the provider bed tax and federal funding for ICF/IID room and board and nursing services) which help fund and reduce financial pressure on Ohio's HCBS waiver system.

At the Arc of Ohio's Fall 2014 Conference, John Martin, Director of DODD, in response to a question from a participant, acknowledged that the State of Ohio can provide care for individuals in ICF/IID homes more cost effectively than it can serve these same individuals in community settings.

In "The Past and Future of Deinstitutionalization Litigation," author Samuel Bagenstos, a Professor of Law at the University of Michigan, former Principal Deputy Assistant Attorney General in the United States Department of Justice Civil Rights Division (2009-2011), and a well-known proponent of deinstitutionalization, also acknowledges the reality of runaway costs associated with community placements:

". . . advocates have increasingly focused on the creation of high-quality, ever-more integrated services in the community, [and thus] fiscal concerns have become more of an obstacle to their efforts." (Bagenstos, p. 39). (Emphasis added.)

Director Martin's statement and Attorney Bagenstos' admission are consistent with peer-reviewed research:

"Findings do not support the unqualified position that community settings are less expensive than are institutions and suggest that staffing issues play a major role in any cost differences that are identified." ("Cost Comparisons of Community and Institutional Residential Settings: Historical Review of Selected Research," *Mental Retardation*, Vol. 41, No. 2: 103-122 (April 2003); *see also*, Bagenstos at p. 43, identifying cost shifting, differences in staffing costs, and adequacy of services as cost factors which will cause the cost gap between institutions and community services to "narrow further or even in some cases reverse.")

These views and findings also follow common sense. A hospital would not treat its intensive care patients – the most costly and vulnerable – in the patients' living rooms. Such a model would be dangerous and cost prohibitive. Likewise, Ohio's ICFs/IID homes are serving its most disabled citizens. To be eligible for ICF/IID placement, an individual must qualify for Medicaid assistance financially and require "active treatment." ICF/IID home residents have multiple disabilities and limited functional abilities, in addition to intellectual and behavioral disabilities. As the ICUs of Ohio's I/DD service delivery system, ICF/IID homes serve a vital function as compassionate, cost effective safety nets.

As recognized publicly by Director Martin, ICF/IID homes are inherently cost effective. In addition, the State of Ohio receives approximately \$40 million<sup>6</sup> per year in revenue from the provider bed tax which is used to help pay for Ohio's HCBS waiver services. The State of Ohio also receives \$25 million<sup>7</sup> per year in federal dollars to pay for the room and board of ICF/IID home residents. This revenue/funding which totals \$65 million per year would be lost to the state if ICF/IID home residents are moved into the waiver system, directly increasing the financial pressure on individuals with I/DD currently receiving and waiting for services.

On May 17, 2005, Gary Brown, CPA, with Nipps, Andreas, Brown & Leppert, Inc., testified to the Senate Finance and Financial Institutions Committee regarding a State proposal to eliminate the ICF/IID program. Mr. Brown had worked for the DODD, was the director's appointee to the ICF/IID Long-Term Care Committee at the time, and was involved with the original submission of the Individual Options and Residential Facility waivers. Mr. Brown testified that the elimination of Ohio's ICF/IID program would mean lost revenue from the provider bed tax, lost federal funding for ICF/IID room and board and nursing care, and added transportation and infrastructure costs connected to caring for ICF/IID level residents in community settings. In total, he stated that the cost to the State of Ohio would be a minimum of \$111 million per year in the form of lost federal participation. This was in 2005. Imagine this cost now, in 2015, and beyond.

<sup>&</sup>lt;sup>6</sup> Gary Brown, CPA, Director, Brady Ware & Co. (See attached testimony.)

<sup>&</sup>lt;sup>7</sup> Id.

#### Mr. Brown told the Committee.

"This proposal is projected to cost the [State of] Ohio a minimum of \$111 million in lost Federal Participation, which will ultimately reduce services below minimum health and welfare federal standards." (Emphasis added.) (Gary Brown, Testimony before the Senate Finance and Financial Institutions Committee, May 2005)

How can the Ohio DODD service system withstand such a blow? Every Ohioan with I/DD currently being served and waiting for services would be adversely affected.

# IV. To Achieve "Outcomes that Matter," the State of Ohio, SPLG, DODD, and DRO Must Heed Lessons Learned and Listen to Individuals and Their Families

Attempting to provide high quality care in a community setting will cost significantly more than the state is now paying for ICF/IID home supports, and doing so, place the DODD system at considerable financial risk. It is crucial to acknowledge, that high quality care in a community setting cannot begin to be accomplished before addressing the commonly accepted crisis-level condition of Ohio's home care system. Moving fragile citizens into a "community" model devoid of continuity of care, adequately compensated, well-trained nurses and caregivers, on-site managerial supervision, and the safety that peer-to-peer supervision provides has led to well-documented tragedies in other states and in Ohio.9

But, SPLG's recommendations appear to have been made in a vacuum as they totally disregard the realities of Ohio's home health care crisis as reported by the *Columbus Dispatch* in December 2014 and *ABC News Channel 5 Cleveland* in November 2013.

The *Columbus Dispatch*<sup>10</sup> found widespread fraud, low-paid, poorly trained workers, caregivers not showing up for work, and a lack of information for families to properly vet services. *News Channel 5 Cleveland* <sup>9</sup> found sexual and physical abuse, neglect, the failure of health care providers to follow state health and safety regulations, and the failure of DODD officials to act on and prosecute well-documented cases of criminality against citizens who cannot defend or speak for themselves.

<sup>&</sup>lt;sup>8</sup> "Widespread Abuse, Neglect and Death in Small Settings Serving People with Intellectual Disabilities," (VOR, revised July 2014).

<sup>&</sup>lt;sup>9</sup> "Ohio Department of Developmental Disabilities often fails to act, leaving disabled at risk," (NewsCenter 5 Cleveland, November 7, 2013)

<sup>&</sup>quot;Hundreds of Ohio service providers for disabled repeatedly ignore health, safety regulations" (NewsCenter 5 Cleveland, November 8, 2013)

<sup>&</sup>quot;Sexual abuse, neglect trigger increased scrutiny of service providers for Ohio's disabled," (NewsCenter 5 Cleveland, November 8, 2013)

 <sup>&</sup>quot;Home-care crisis: Fraud costs taxpayers, vulnerable Ohioans," Columbus Dispatch, December 14, 2014
 "Home-care for vulnerable Ohioans leans hard on poorly paid workers." Columbus Dispatch, December 15, 2014
 "Families on their own in trying to find reliable home health care," Columbus Dispatch, December 16, 2014

In fact, Michael Kirkman of Disability Rights Ohio (DRO) is quoted in *News Channel 5's* report in regard to their investigation as follows,

"I think what you're uncovering is that it's actually not working." (Michael Kirkman, DRO, *News Channel 5 Cleveland*, November 7, 2013)

SPLG's recommendations in face of the generally accepted crisis-level condition of Ohio's home health care system reek of placing political and ideological goals ahead of the very health and welfare of the individuals the DODD system was established to serve. This coupled with the lack of any realistic fiscal considerations applied to SPLG's benchmarks calls into question the legitimacy of SPLG's Final Report and recommendations.

"Community integration" is said to be the goal of SPLG's proposals, but DAA asks how that goal will be accomplished on the \$614<sup>11</sup> per year at 0.43<sup>10</sup> cents per mile that the average individual on the IO waiver receives in community access transportation? Given that many ICF home residents require wheelchair accessible vehicles, the cost of transportation increases to at least \$1.50<sup>10</sup> per mile leaving a wheelchair-bound individual with 1.12 miles per day in community access transportation. The reality of "community integration": Individuals with I/DD will face isolation in the "community" based settings SPLG envisions.

The SPLG cites "movement away from the institutional services delivery model" as one of the drivers of SPLG's recommendations. Yet, as noted, the Supreme Court spoke loudly and clearly in *Olmstead* expressly stating that institutions must remain available to those who require and desire them, as has the U.S. Congress. **And please listen to individuals with I/DD and their families:** there were **NO** families demanding that their loved ones be removed from ICF/IID homes and day habilitation programs at recent public meetings and opportunities for testimony hosted by DODD and DRO to announce their proposals. **But there was a strong representation of parents and family members at all meetings who spoke out eloquently for the preservation of their family member's ICF/IID homes, sheltered workshops, and day programs.** 

The SPLG cites "federal budget problems and entitlement cost control" as another driver of SPLG recommendations. Yet Ohio's voluntary implementation of ACA Medicaid expansion has resulted in the addition of 471,452<sup>12</sup> people to Ohio's Medicaid rolls since January 2014. The State of Ohio has chosen to expand Medicaid to able-bodied adults even when 42,200 disabled individuals wait for Medicaid services on Ohio's HCBS waiting list. Is it proper for the State of Ohio to continue to expand Medicaid when already eligible, disabled citizens cannot receive the Medicaid services for which they have been waiting for years? Regardless, this decision should not come at the expense of Ohio's most fragile citizens.

<sup>&</sup>lt;sup>11</sup> Gary Brown, CPA, Director, Brady Ware & Co.

<sup>12 &</sup>quot;ODM Eligible Clients Report," Ohio Department of Medicaid, December 2014

### V. CONCLUSION

DAA is encouraged that SPLG's recommendations are not a "fait accompli" as the health and welfare of Ohio's most vulnerable citizens is detrimentally impacted and their right to the pursuit of happiness is trampled upon by these proposals.

We strongly urge the State of Ohio to support residential and employment choice for individuals with I/DD and reject SPLG's draconian recommendations that will displace thousands of citizens with intellectual and developmental disabilities from their chosen homes, sheltered workshops, and day programs without regard to their individualized choices, person-centered needs, or their constitutional rights.

In the *Olmstead* decision, Justice Kennedy noted in his concurring opinion:

"It would be unreasonable, it would be a tragic event, then, were the Americans with Disabilities Act of 1990 (ADA) to be interpreted so that states had some incentive, for fear of litigation to drive those in need of medical care and treatment out of appropriate care and into settings with too little assistance and supervision." 119 S. Ct. at 2191. (Emphasis added.)

We recognize that the State of Ohio is under a great deal of pressure from the Disability Rights Ohio, the Department of Justice, Centers for Medicare & Medicaid Services (CMS) and other parties to close specialized ICF/IID residential care, sheltered work, and day options for citizens with disabilities. The express threat of litigation hangs heavy in the air and we must guard against the "compliance on the cheap" that Kennedy thoughtfully warned against in Olmstead,

"In light of these concerns, if the principle of liability announced by the Court is not applied with caution and circumspection, States may be pressured into attempting **compliance on the cheap,** placing marginal patients into integrated settings devoid of the services and attention necessary for their condition." 527 U.S. at 610 (Kennedy, J., concurring) (Emphasis added.)

Yet, the law is on the side of person-centered planning and individual choice, as recognized by the U.S. Congress this past December:

"Deinstitutionalization.-There is a nationwide trend towards deinstitutionalization of patients with intellectual or developmental disabilities in favor of community-based settings. The Department [of Justice] is strongly urged to continue to factor the needs and desires of patients, their families, caregivers, and other stakeholders, as well as the need to provide proper settings for care, into its enforcement of the Americans with Disabilities Act." [Conference Report to accompany H.R. 83, Consolidated and Further Continuing Appropriations Act, 2015 (Division B, Commerce, Justice, Science and Related Agencies) (Pub.L. 113-235, December 16, 2014)

SPLG and other groups calling for the elimination of ICFs/IID homes, sheltered work options, and day habilitation programs do not speak for individuals with I/DD, who are happy, safe and exceptionally well-cared for in ICF/IID home and day programs of their choice. As legal guardians and family members, we have a moral and legal obligation, and unmatched insight into our loved one's needs, to know and do what's best for them. Contrary to SPLG's condescending assertion that parents and guardians need to "engage in education" to better understand the alleged virtues of "community" settings, DAA members are well-informed and critically concerned about the needs of our family members and where they are best served.

As we all strive for "outcomes that matter," let us remember those to whom the outcomes matter the most - not the State of Ohio, not the DODD - but the individuals with I/DD and their family who have been dealt, quite arguably, life's toughest hand. DODD must remember that it profoundly affects the health, welfare, and happiness of individuals with I/DD when the DODD considers (based on SPLG recommendations or DRO threats) to move vulnerable individuals out of their chosen and successful homes to a "community" model that has not been tested to the degree the SPLG proposes. Given the fragile nature of the individuals affected, it is not an overstatement to say that lives are at stake. *That is ultimately the "outcome that matters."* 

DAA asks that you respect the residential and day service choices made by individuals with intellectual and developmental disabilities with the loving aid and wisdom of their parents and family members. No state authority can possibly match a parent's insight into their child's needs, nor can the state match the motivation a parent has to do what's best for their child. Whether applied to children who are disabled or children who are not, this is a time-honored truth that no set of government regulations will ever overcome.

We look forward to receiving your written response to our comments in writing.

Sincerely,

Caroline A. Lahrmann

Caroline Dholumana

Founding Member Disability Advocacy Alliance, Parent Advocate

**VOR State Coordinator** 

CC:

Jane Mills Atwood, Founding Member DAA, Parent Advocate Harris Capps, Founding Member DAA, Parent Advocate Dan Jones, Founding Member DAA, Parent Advocate Sherry Rinck, Founding Member DAA, Family Advocate