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Re: Proposed Service Definitions

The Ohio Association of Adult Services (OAAS) values the effort of DODD to include OAAS on the Funding Redesign Committee as a participant in the process of developing the proposed service definitions. The commitment of the group to shape a set of services that are realistic, logical and aligned with other systems is commendable.

As the service definitions unfold, OAAS holds the following positions:

- Fully supports community-based options to promote integration and inclusion
- Fully supports Person Centered Planning as the primary mechanism for directing services
- Does not support unrealistic ideal of wraparound/day supports being 100% community-based
- Does not support the lack of consideration for person-centered planning in terms of informed choice, day support options, and imposed, arbitrary timeframes
- Does not support the overstepping of DODD in business relations
- Significant concern regarding the lack of system infrastructure, knowledge base and experience of providers to serve all adults in the community

One of the unique and special attributes about the Ohio Developmental Disabilities services system when compared to many other programs in this country is that Ohio provides services for ALL individuals with developmental disabilities. Something for which many family members and leaders in the developmental disabilities field before us fought long and hard, and something we should all be very proud of today. We serve individuals who with minimal supports can be successful and achieve varying levels of independence and employment. However, we must not forget that Ohio also provides day services to hundreds of individuals who have very significant and complex disabilities. For many of these individuals, simply put employment is not a life priority. It is not to say that employment should not be considered, but recognition and respect should be given that the journey along the path to employment is going to be very long and secondary to other life needs such as medical, nursing, dietary, physical mobility, communication, and behavioral challenges.

Over the years Ohio has developed a service delivery model in which individuals with significant and complex needs have had the opportunity to safely leave their homes and residential settings and engage in a variety of activities in day service environments that provide the needed supports and specialized services to assist these individuals with achieving and/or maintaining his/her highest degree of independence as possible. The centers serve as hubs of supports in which staffing and personnel are scheduled and deployed to assist individuals with accessing the community based upon each participant's ability to tolerate and safely participate. During a recent state-wide webinar, the response from one of the subject matter experts consulting with Ohio was concerning when posed with the question about accessing adequate facilities to attend to an individual's health, safety and other support needs (such as changing facilities while spending the entire day in the community) suggested using churches for this purpose. Many of Ohio's programs began in church basements some fifty years ago. Thinking that churches would be adequate and even appropriate for this purpose today requires a much greater conversation and reflection. The four proposed service definitions do not provide an opportunity for ongoing services or represent the specialized service needs associated with individuals with severe and complex developmental disabilities.

Without a viable and financially sustainable service option for individuals with severe and complex needs, it is anticipated these individuals will not be served and promises made to maintain current levels of services will be broken which will jeopardize the integrity of the entire service delivery system.

Recommendation: Provide a fifth Service Option: *Specialized Day Habilitation Services* – such specialized day habilitation centers would provide a service option for individuals with severe and complex needs. Our current models could easily be re-designed, down-sized, enhanced and reconfigured such that any member of our community with similar needs could access the services offered and these centers could serve as a valued resource for our communities. Such services could include care-taker respite, nursing services, physical, occupational and speech services along with a variety of arranged social and recreational activities in both a stimulating center-based environment and community-based activities that provide the accompanying supports to assure health and safety. Reference: CMCS Informational Bulletin, Page 6 & 7: Day Habilitation. CMCS Language derived from CMS guidance on Day Habilitation:

Specialized day habilitation services would involve regularly scheduled activities in a non-residential setting, separate from the participant's private residence or other residential living arrangement, such as assistance with acquisition, retention, or improvement in self-help, socialization and adaptive skills that enhance social development and develop skills in performing activities of daily living and community-living. Activities and environments are designed to foster the acquisition of skills, building positive social behavior and interpersonal competence, greater independence and personal choice.

Specialized day habilitation services may be furnished to any individual who requires who chooses them through a person-centered planning process. Such services are not limited to persons with intellectual or developmental disabilities. For individuals with degenerative conditions, day habilitation may include training and supports designed to maintain skills and functioning and to prevent or slow regression, rather than acquiring new skills or improving existing skills. Specialized day habilitation services may also be used to provide supported retirement activities. This might involve altering schedules to allow for more rest time throughout the day, support to participate in hobbies, clubs and/or other senior related activities in their communities. Personal care/assistance may be a component part of specialized day habilitation services as necessary to meet the needs of the participant, but may not comprise the entirety of the service.

Specialized day habilitation services focus on enabling the participant to attain or maintain his or her maximum potential and shall be coordinated with any needed therapies in the individual's person-centered services and supports plan and place on the path to employment. Such services shall include but not be limited to nursing services, physical, occupational, or speech therapy and behavior supports.

Specialized day habilitation shall be furnished in any variety of settings in the community other than the person's private residence. Any such settings will optimize community access and is integrated in and supports full access of individuals receiving HCBS to the greater community, including opportunities to seek employment.

Community preparation, flexibility for providers to create and maintain opportunities for day services/wraparound supports and employment, and provider knowledge base/training are imperative for the success of this transformation. If infrastructure is not adequately addressed, and the individuals are placed at risk or experience negative impact on their lives, who will be held accountable for this? The providers of the services, who do not have the knowledge base or experience to support individuals 100% in the community? If CMS accepts the ten year proposal, will it be enough time to change a culture? A system change of this magnitude will demand a shift in culture. Many entities make up the culture. If the change isn't workable/understandable/palatable, for one or more of the entities, the change is not going to be successful. It is noble to aspire to help the people we serve have a better life, and to create rules of a system for providers to follow, however, if the others are negatively affected because no consideration was given to the effect on them, providers(public/private) cannot be held accountable for a flawed system that was created without considering the whole person and the entities that play a part in their quality of life.

We must be very cautious in regulating our activities and preparing our communities to witness the needs and, frankly, behavioral challenges of the people we serve. Community businesses and programs will find it overwhelming which very well could cause the opposite effect of our goal. History tells us this will happen. How many times can we visit a business, use their facilities, but not offer anything in return before we are not welcomed, but simply tolerated ("here they come again"), and then not welcomed, and then kicked out?

Recommendation: Comprehensively review the rules as a system, and consider how each party will be affected, such as Individuals, families, businesses, communities, county boards, providers, and taxpayers.

DODD's interpretation of CMS regulation/aspirations, and expansion of services and definitions is overreaching and extreme, creating a system that is administratively cumbersome. County Boards, state administrators and providers will be spending more time "crossing t's and dotting i's" in keeping track of timeframes, securing approvals, consents, prior authorizations, and agreements for this and that; and documentation requirements haven't even been addressed.

Recommendation: Outline proposed requirements to ensure alignment and simplicity across the system of services. Make certain the focus is on the person, not the paper.

Regarding the Informed Choice process, we feel that "no means no". If the individual/guardian doesn't think employment is a priority at this time, the process of a work experience should not be forced upon them. It seems that the blame for the issue of under/lack of employment has been placed on providers for not putting in enough effort; however, it is also the responsibility of the individual to participate in that choice through the person centered planning process. If this is done properly, the outcome will be the choice of pursuing employment opportunities or not. It should not be the provider's responsibility to force employment upon the individual, just as the issue that, fortunately, brought this entire change to light is a system that forced people into the sheltered environment. To think every adult served in the state of Ohio will be required to participate in a community-based work experience is not realistic. Person Centered Planning is the premise of the CMS guidance and should be employed to determine whether employment is an option or not. (CMCS Informational Bulletin, Page 2: Emphasizes the critical role of person centered planning in achieving employment outcomes; Page 3: Because it is so essential to people's economic self-sufficiency, as well as self-esteem and well-being, people with disabilities and older adults with chronic conditions who want to work should be provided the opportunity and support to work competitively within the general workforce in their pursuit of health, wealth and happiness. All individuals, regardless of disability and age, can work – and work optimally with opportunity, training, and support that build on each person's strengths and interests. Individually tailored and preference based job development, training, and support should recognize each person's employability and potential contributions to the labor market.)

Recommendation: In accordance with the Person Centered Planning process, when employment is identified as a priority, the provider will be responsible to work with the individual to find appropriate employment.

As the service definitions develop, Adult Services Directors and CEO's of privatized agencies are appalled at the notion that day services or wraparound supports should be provided in a community-based setting with no consideration of a location/facility. Many personal care services cannot be performed safely and discreetly, in a community setting, and we are not seeing any consideration or acknowledgement of this in the current service definition. It is irresponsible to believe the individuals who require these services will be served in the community without a facility in which they can be provided necessary and safe care.

The several variables of care identified in our previous comments, and they are listed again here:

- Delegated Nursing – current rules do not allow for insulin injections in the existing day service environment
- Personal services such as the use of a lift, changing adult briefs, oral hygiene after meals, frequency and duration of restroom time
- Food modification preparation – ground, textured, chopped, etc.
- Safety zones for people who have behavioral challenges
- Routine-oriented people – it seems community-based services could easily lack the structure desired/ needed by some people
- Inclement weather – impact on people who are delicate and/or use wheelchairs

CMS calls for the same degree of access to the community as those who do not have developmental disabilities. Is there anyone who, if they are not working, leaves their home in the morning and spends six hours out and about five days a week? This sounds exhausting, regardless of the personal care that may be required. It shouldn't be forgotten that the service should depend on the person and the outcome of the person-centered planning process.

One of the big over riding issues here continues to be the issue of income and poverty. Removing the option of income from a workcenter simply perpetuates the unfortunate situation of people with disabilities living in poverty if they become unemployed or under employed in community employment. depend on the income made from employment in a workcenter. Further, individuals will have less money if they cannot work hands-on. They are already poor, will become more poor, and the typical poor person cannot afford to run around 30 hours a week. They cannot afford a \$25 art class in the community for two hours one time a month, they cannot afford to become a member of a rec center.

OAAS cannot support setting arbitrary time limits for Integrated Prevocational Services and Supported Employment – Small Group Supported Employment. We do not support 2-year or cumulative 24-month limitations for these services. CMS guidance is silent on specific time limits. CMCS Informational Bulletin, Page 2: Explains that pre-vocational services are not an end point, but a time limited (although no specific limit is given) service for the purpose of helping someone obtain competitive employment.

Recommendation: Where CMS Guidance is silent on specific time limit(s), let the default be the Person Centered Planning process to serve as the determining factor when the service is no longer needed. When developing the rate, units should be utilized in addition to a day rate so those who have less stamina and ability (only tolerate a few hours of work a week for example) can maximize their opportunity to grow and prepare for community employment, and live a full life for many years, again, aligned with the Person Centered Planning outcome. CMCS Informational Bulletin, Page 7: Prevocational Services - Services that provide learning and work experiences, including volunteer work, where the individual can develop general, non-job-specific strengths and skills that contribute to employability in paid employment in integrated community settings. Services are expected to occur over a defined period of time and with specific outcomes to be achieved, as determined by the individual and his/her service and supports planning team through an ongoing person-centered planning process.

It is understood that there will be a transition process, however, if understood correctly, the transition to the new services could occur as soon as the new services are in place for those entering the system and anyone who has been receiving “legacy” services makes a change in provider. Again, it is not that we cannot let go of the “legacy” programs, it is a question of the capacity and readiness of the community and providers, and whether it creates the best life for the person receiving the services as identified in the person centered planning process.

PREVOC Pre-voc: The definition offers too much classroom time without little opportunity to apply what they learn hands-on. there will be fewer, by far, opportunities for internships and work experiences as compared to now. This goes back to the example of someone with an MBA who has not had a job in their life. Further, businesses do not want different people working all the time. The reality is the businesses is concerned with quality assurance. We will lose opportunities

OAAS cannot support the group size limitation in Supported Employment - Small Group Supported Employment stating "businesses and providers having negotiations and develop a formal written plan to reduce the size of the group to 4 or fewer people". This is not business friendly, unrealistic, and intimidating to businesses. If a larger group is capable of quality work with one job coach, the management personnel of the business should have input into whether an additional person should be on their site of business. Providers know best when and how far to push each individual business, when to back off and try again later. This will put an end to opportunities and business relationships. People in business talk to each other so any relationship that is destroyed with one, damages three more. Providers should have as much flexibility as possible to work with the business community to nurture relationships, keep commitments and develop future opportunities. DODD is overstepping their function by dictating to businesses who to hire and what they can do; and monitoring the activities/relationships provider has with businesses.

Recommendation: Apply CMS allowed group size per CMCS Informational Bulletin, Page 11: Supported Employment - Small Group Employment Support, Core Service Definition, Supported Employment Small Group employment support are services and training activities provided in regular business, industry and community settings for groups of two (2) to eight (8) workers with disabilities. We have already provided extensive comment regarding the fact that services must be business-friendly if employment is going to work. Further, continuing effort on this service with the limited group size without further work on funding is premature and a costly use of time.

Small group - clarify cleaning crew in agencies like ICF. CMS p 12 - facility based work settings specialized that CMS states: (small group employment) does not include vocational services provided in facility based work settings or other similar types of vocational services furnished in specialized facilities that are not a part of general community workplaces. Cannot clean after hours? Real jobs that is real work that someone is going to do - typical employment situation - up to person centered planning.

OAAS generally supports Supported Employment – Individual Employment Support. We request clarification on “retention” payment based on outcome for job coaching. Is there a scenario where the provider does not receive payment for the supports they have delivered?

OAAS fully supports and promotes community-based options for all individuals with developmental disabilities. On a philosophical level, OAAS agrees and supports much of the content in the proposed service definitions. However; it seems that little or no consideration has been given to person-centered principles, reasonable time-frames to implement these new services or the infrastructure and resources needed to support these efforts. The OAAS board feels it would be entirely irresponsible to move forward with any formal adoption of these service definitions into Rule without serious discussion, consideration and a financial commitment given to support such a dramatic shift in the service delivery model in Ohio. We are very concerned that such an abrupt and uncoordinated approach could very well have unintended consequences and jeopardize the health, safety and human dignity of the very individuals we serve.

With all due respect to the members of the work group and the subject matter experts commissioned to assist Ohio in these efforts, we have been encouraged to share and submit comments and feedback on these service definitions. To date, the only follow-up received has been that our comments have been passed along to the consultants. This gives the impression that little if no consideration is being considered to stakeholder input in this process and the path to the future is being predetermined by a few.

We would ask that our input be formally acknowledged as stakeholder input. We would also request that any reference to CMS guidance be further defined to cite the particular CMS regulation or language in the guidance that set parameters for services such as specific time limits for services, group size, informed choice process and other content included in the proposed service definition. It would be helpful to understand what items might be aspirational in nature and which items are regulatory per CMS.

This is an exciting time in our field. We truly wish to be part of the system redesign. Our association represents members who provide daily services to thousands of individuals whose lives will be greatly impacted by any change. We look forward to hearing back from you on how we as an Association and the individuals we provide services and their families can become more involved in the process.

Best Regards,

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