HCBS
Updated Transition Plan
February 2016

Public Comments

Comments received during and after Public Hearings conducted
March 4th & 7th, 2016

Delaware Statewide Transition Plan
Public Comments

Good afternoon and thank you for allowing me this opportunity to advocate for my adult daughter. My name is Anne Vannucci and I am here today to be the voice for my daughter, [redacted]. I had hoped that [redacted] could join us this afternoon, however she is home sick.

Since [redacted] was not able to join us, I'd like to tell you a little bit about her. [redacted] is a beautiful 25 year old young woman who was born with a chromosome disorder, 1p36 deletion. [redacted] is deaf/blind, she has a seizure disorder, congestive heart failure and severe reflux. [redacted] is non-verbal and non-ambulatory and requires a feeding tube for her fluids.

While I believe every individual is unique and I respect their decisions and their points of view, I hope you will give me the same courtesy and respect my decision for MY daughter and my point of view.

[redacted] is cognitively impaired and physically challenged. However, our greatest concern is the fact that [redacted] is medically fragile. Because of her numerous health issues, [redacted] represents a very small percentage of adults in the disability community.

If the new guidelines in the Home & Community Based Waiver Program were to be mandated for all individuals in day programs, you would be forcing me to withdraw my daughter from her day program, CERTS, in order to protect her health.

Here are a few of my concerns: if [redacted] was forced to be out in the community vs staying at her day program

1) [redacted] suffers from frequent seizures, so she would need a nurse to be with her at all times when she is out in the community or on a bus.
2) [redacted] has a feeding tube that would need to be reinserted immediately if it came out while she was out in the community. If her tube was not reinserted immediately, [redacted] stoma would close up in just a matter of minutes and that would require a trip to the hospital.
3) Would there be changing stations at all these community outings? [redacted] suffers from Irritable Bowel Syndrome and it would not only be

degrading for her to have to sit for hours if she were to have a bout of irritable bowel, but since [redacted] was born without a spleen, it would be medically irresponsible to not be able to have changed immediately.

As I just mentioned, [redacted] was born without a spleen, so having her out in the community every day puts her at greater risk for infection. What could be a routine cold for you and I, is usually a serious infection for [redacted]. It is not uncommon for [redacted] to be bedridden for weeks when she catches the common cold and that is when we are lucky enough not to have that cold go into an upper respitory infection or pneumonia. Needless to say, we are very selective as to where we take [redacted] during cold and flu season.

I completely understand the good intentions behind the Home & Community based waiver program, but the ramifications it will have on my daughter's health are just too risky.

In closing I would like to say that when you are grouping individuals who are medically fragile in with individuals who are not, you are basically comparing apples with oranges. However, please remember that we are not really talking about apples and oranges, but rather people's lives and their welfare. No one knows what is best for my daughter better than her family, so please do not take that choice away from us.

Thank you in advance for the serious consideration I know you will give to this life altering decision.

March 5, 2016

Secretary Landgraf, Director Rogers and Director Groff,

I write to you today out of concern for my son, and what his choice for service programming may look like in Delaware in the near future. [redacted]is a 28 year old young many who likes a good joke and to listen to music. He is also a young man with a diagnosis of Autism and Moderate Intellectual Disabilities. But this diagnosis should not discount his right to choose where he wants to live and work.

I was recently made aware, once complete; Delaware's transition plan for the Home and Community Base waiver may no longer include the current options available to all of our profoundly disabled. [redacted] currently works in a facility based pre-vocational program which supports his needs and goals of eventually working in community. This is a necessary step for[redacted]because he is not yet ready for traditional employment. Will this type of programming no longer exist? Will [redacted] lose his right to choose because Delaware decides to no longer offer this option? What will [redacted] future look like? Do the decision makers in Delaware even care?

It is my understanding DDDS claims they do not have a choice in making these changes because Medicaid will no longer fund this type of programming. This is simply not accurate. Programming and settings must be based on the waiver recipient's quality of life, lived experience and opportunities for access to the community. All of this is documented within and individual's Person Centered Plan. Please do not disregard the dignity of our Delawarean's with I/DD and Autism who have the right to choose where they want to live and work in the community.

Due to [redacted] behavioral issues, my wife and I ([redacted] parents) needed to make an extremely difficult decision in awarding him to the State. We truly believe it would be detrimental to his well-being to make any drastic or even slight change to his extended Life Plan, to which he is adjusting and since he does not adapt well to change.

I urge you to make the right decisions for all and listen to the many voices who know their loved ones and know what supports they need now and in the future.

Respectfully,

Louis C. iccanti
C: Senator Gerald Hocker
Representative Ronald Gray

Remarks of Vivian J. Turner, MPA
Executive Director of C.E.R.T.S., Inc.
At the Public Hearing for the
Home & Community Based Services (HCBS) Waiver
March 4, 2016

C.E.R.T.S., Inc. has always tried to be a best practice agency, encouraging our participants to set high goals for themselves and supporting them to reach those goals. I am quite concerned about the consequences the Home and Community Based Services Waiver (HCBS) will have on the men and women in our program.

A high ranking staffer at DDDS recently told me that the HCBS standard will require all people in day programs to be out in the community for 15 hours per week, which translates to 3 hours per day. With due respect, there are many of our participants for whom that is impossible.

Please consider just a few of the challenges our participants face:

- At the Newark site, 60% of our clients are tube fed, which, according to Delaware regulations, must be done by a licensed nurse.
- Half of our participants cannot use a regular bathroom, or even an accessible one and must use an adult sized changing table for personal care. These simply are not available in the community. We have been told to just "let them sit in it" until they get back to the center. This doesn't seem like a "person centered" answer to me, to the individuals concerned or to their parents.
- 100% have a seizure disorder, half of whom require rescue meds, which must be delivered rectally, almost immediately after the seizure begins. This could be very difficult/upsetting in a public environment on an outing.
- 60% use very large wheelchairs that require a lift and won't fit into a standard passenger vehicle. This means we will need to rely on Paratransit to go out in the community with these participants, further taxing the Delaware Transit System.

C.E.R.T.S., Inc. does have a van at our Smyrna site and a Paratransit style bus at our Newark site. Participants go into the community 4 days a week. One or two participants go each day on a rotating basis. The trips last between 60 and 90 minutes. We have found that any longer fatigues the participants and is difficult to schedule around lunch time (with the tube feedings) in late morning or bus schedules at the end of the day. Even on this limited schedule, we have several parents who have specifically requested that their adult child not participate in the outings.

I humbly ask that the people in Delaware who are charged with deciding the parameters for the HCBS Waiver (especially the identification of the "most integrated settings appropriate" in person centered plans) to remember the outliers in our great State —those who are medically, physically and emotionally fragile and for whom a daily half the day in the community would be a hardship, not a help.

It might surprise you to note that CERTS has been running a pilot non-facility based program for a little over a year. The woman in the pilot is higher functioning than anyone else in our program. Her family came to us when the agency that was supporting their daughter in the community all day abruptly left the state with only 30 days' notice. Values into Action couldn't make a go of it financially left in a year, maybe less. Because we are aware that community services are the future of day services and this family really wanted us to do this, we decided to try. She is out in the community with a 1:1 CERTS employee who drives her where she wants to go — exercise class, the Y, the mall, shopping, wherever.

It would be great except every day she goes out into the community, CERTS loses money. By the time we pay our employee her salary and benefits, cover mileage and overhead, we lost $1000 last year, and are on track to lose $2000 this year. And this is without accounting for any portion of a supervisor's time. Long story short, based on our experience, community based programming is not financially sustainable at the current rates.

Greetings,

My name is Jessica Birkmire, program manager for Elwyn DE's Supported Employment program. I appreciate this opportunity to speak with you regarding Delaware's response to the State Transition Plan.

Elwyn DE provides Adult Day Service, a Sheltered Workshop and Supported Employment services.

Our Adult Day Program, a program serving over 50 aging Delawarean's, provides families and caregivers with a safe and comfortable place to care for their loved ones. Our robust program offers field trips into the community but is primarily facility-based. We run a "participant first" program that allows our members a choice of whether to participate in off- site trips or to stay at Elwyn and to be engaged in activities there. Whether in the community or facility, Elwyn's staff ensure that our participants are provided with a safe, professional environment where participants lead meaningful lives filled with friends, social outings and the ability to spend their days in an environment where they are nurtured, cared for and valued.

We ask the state to consider that we serve a diverse group of seniors; some mobile and some not. For some, moving them into an uncontrolled environment may cause unnecessary stress or trauma. Please protect Aging Delawareans' choice, safety and dignity.

For many individuals Elwyn's Work Center provides them with their first exposure to work. This includes many things such as following a schedule, working through the course of an entire day, correcting their own mistakes, accepting constructive criticism, and the list goes on. These are not skills that come naturally for many of the individuals that we serve. Our goal is to assist them in developing skills, building independence, and ultimately to get a job in the community when that is the choice they have made. Over the years we have placed numerous individuals into jobs of their choosing and they are successful and happy. Of course, as we all know, not every job works out, so we provide the option to return to the Work Center while they seek new employment. Having this option not only serves as an alternative to staying at home unemployed; for some it also serves as a safety net so they can have the courage to try working in the community.

Today we have individuals from age 21-70 all of whom can work given the proper supports and many of whom are looking toward obtaining a job in the community. But that is not the desire of all of our individuals. For those who are older or more significantly challenged the questions must be asked:

"What will happen to them in 2019?"

"What choices will they have?"

For some finding community employment is not appropriate because of their declining health both mentally and physically; some with early memory loss and even Alzheimer's/

Dementia. However, a senior adult day program may not be appropriate either because the individual does not look at themselves as "retirement" age. They want to make money and they want to be productive.

We ask the State to consider those individuals with more significant challenges who will need a much higher level of support than what is currently available to them through their ICAP funding. So again the questions must be asked:

"What will happen to them in 2019?"

"What choices will they have?"

Each state is charged with developing a plan that addresses the desires and needs of these individuals while satisfying the CMS Final Rule which states that the opportunity for employment must be available.

We serve many individuals in our Work Center that need more than one option for work. The State Transition Plan, as it stands today, will eliminate the option to have employment in a Sheltered Work Shop.

Supported Employment is a program that supports the IDD population with obtaining and maintaining employment. Individuals who receive this service have shown significant success with job retention due to the supports they receive from a Job Coach.

Drastic changes in the Supported Employment system occurred in 2010 when the state changed the reimbursement structure to fee-for-service. Since that time providers such as Elwyn DE have continued to serve individuals working in the community to retain their jobs and continue their success. However as we look to continue providing services to an ever increasing population of job-seekers with higher levels of need, we must recognize that the current rate of reimbursement for this service is insufficient. Consequently agencies and direct support professionals are faced with inadequate salaries and limited expertise. Additionally the economic climate for job seekers with significant challenges continues to limit job opportunities and the pool of jobs and employers open to accommodating significant needs or challenges.

When planning the final implementation of the State Transition Plan, we caution you that such a specific interpretation of the CMS Final Rule eliminates options for services. Removing options eliminates individual choice in person centered planning based on the individuals' assessed need for supports and services. This leaves our most vulnerable citizens without sufficient options to live a productive and fulfilling life. By understanding each individual's support needs and desires we can all recognize the necessity for a spectrum of services and settings that will provide service options and fully allow for person centered planning and individual choice.

[redacted]

TESTIMONY OF CYNTHIA M.
JENKINS, PARENT
HCBS PUBLIC HEARNING

MARCH 4, 2016

Thank you for providing me the opportunity to address you regarding the Home and Community Based Services Waiver.

I am the parent of a participant at C.E.R.T.S., Inc. My son, [redacted], is 29 years old. [redacted] had a cerebral hemorrhage prior to birth, and, as a result, has a complex combination of disabilities — epilepsy, cerebral palsy, mental retardation, legal blindness and inability to verbally express himself.

I am one of the parents who helped develop and shape C.E.R.T.S., and I served on the Board of Directors for several years. My husband is now serving on the Board. I tell you this to demonstrate the level of interest my family has in keeping [redacted] in a safe and nurturing environment where he is well known, his needs are met and our goals for him are pursued.

[redacted] disabilities cause him to become aggressive when in unfamiliar situations/environments. By aggressive, I mean he will swing at, pinch or bite someone near him if he feels threatened. Because of his low level of vision, [redacted] perceives a threat as being a person who has not introduced him/herself standing or sitting near him. Unfamiliar situations cause [redacted] much stress as do environments that are loud, which frequently leads to aggression.

[redacted] is not a good candidate to be out in the community on a daily basis. For his safety, and the safety of others, he should continue to attend the day program *he* has come to know and love. His family provides him with community outings that we know he enjoys and where we can manage the risks.

Mandating community outings, as the HCBS Waiver does, removes the element of person centered programming that C.E.R.T.S. practices. If [redacted] is forced to go into the community as the HCBS Waiver prescribes, we will have to strongly consider withdrawing him from the day program. This will negatively impact my and my husband's ability to work which would have financial consequences for our family and the amount of tax revenue we provide to the state.

I request that before enacting and funding the HCBS Waiver, exemptions be incorporated into the plan for those most significantly impacted by their disabilities, such as the participants of C.E.R.T.S.

Thank you for your time.

Cynthia M. Jenkins

[redacted]

Good Afternoon Everyone.

My name is Jack Jadach and I want thank you for this opportunity to provide my input on the proposed Delaware Transition Plan.

My background is that of an educator, administrator and advocate for individuals with disabilities.

My experiences include being a teacher of vocational agriculture to regular high school students, 15 years as a vocational teacher for student's with moderate to severe disabilities at the John G. Leach School, "a special school", and for 21 years assistant principal and principal at the same school.

Currently, I'm the volunteer Executive Director of EPIC, Endless Possibilities in the Community a 501(c)(3) non-profit organization. A DDDS Vendor

Endless Possibilities in the Community, Inc. (EPIC)-is a newly established 501(0(3) non-profit corporation providing adults with moderate to complex, multiple physical and intellectual disabilities the opportunity to engage in inclusive community programming in settings of their choice with the mission of improving the quality of their lives of its participant's and families.

EPIC Info:

EPIC is a microcosm of larger established organizations here today but able at this time, to make timely adjustments more seamlessly given our current number of 4 clients. We plan to expand to 30 over the next 18 months.

Currently, 4 EPIC client's self-determined health and wellness fitness activities take place at the Bear/Glasgow YMCA for 2 days/week (T/Thurs) for 2 hours/hrs./day for a total 4 hours per week each.

Upon my review of the Delaware Transition Plan, I would like to comment on the Day Habilitation Programs component, in which EPIC currently falls. I'll share some ways in which the goals from EPIC's perspective are being achieved with the right mindset, supports, and creativity.

Specific language includes:

Day Habilitation Services Services that are regularly scheduled activities provided 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 adapted skills that enhance social development and develop skills in performing activities of daily living and community living, physical development, basic communication, self-care skills, domestic skills, community skills, and community-inclusion activities.

Activities and environments are designed to foster the acquisition of skills, building positive social behavior, and interpersonal competence, greater independence and personal choice. Service are furnished consistent with the participant's person-centered plan and are integrated into the community as often as possible.

EPIC is in agreement with the research used by Delaware Department of Health and Social Services (DHSS), Division of Medicaid and Medical Assistance (DMMA), the Division of Developmental Disability Services (DDDS) and other's involved in the state division's leading to the development of this Transition Plan while being very cognizant of avoiding dysfunctional "Mental Models" that in the field of disabilities, have historically inhibited change.

Mental Models are deeply ingrained assumptions, generalizations, and images we may have to understand the world (Senge, 2006). They form the vision and culture of an organization and serve as the basis for leadership, values training, service delivery, outcomes evaluation, and Quality Improvement.

Chief among these dysfunctional "models" three citations:

1) Models of "dis-ablement" that focus on personal defects rather than focusing on human potential within a supporting inclusive, environment (Devlieger et al., 2003; Schalock, 2004);
2) An over-emphasis on quality of care that focuses on control, power, health, safety, and categorization as opposed to Quality of Life factors that focuses on social inclusion, self-determination, personal development, community inclusion, and the provision of individualized supports (de Walle et al., 2005);
3) Organizations as rigid entities rather than organizations as self-organizing systems that reinforce thinking and doing, creativity, coordination, priority setting, and communication patterns (Gardner & Carran, 2005).

As stated by Senge (2006, p. 100), "to change the behavior of a system requires that one identify and change the limiting factor(s) and-thereby-increase one's leverage".

It was important for EPIC, in it's planning, to bring these mental models to the surface in order to determine how these inhibiting factors could limit its efforts for change.

To accomplish the Day Habilitation inclusive community provision, EPIC's was proactive in its recognition and development of an array of community "Partnerships" to enhance each client's human potential within a supporting inclusive, environment

EPIC found through meetings with clients, parents, community businessmen, stakeholders, agencies etc., that there are many individuals and companies wanting to do good things. The problem is that they have never been asked. For example,

Site Selection:

When a parent asked the Bear/Glasgow YMCA why they did not have accessible programing for an individual with disabilities, the answer from the Bear Y administration was "why not", and lets see what can be done.

EPIC is now partnering with the Bear/Glasgow YMCA as a site for the "Y for All" program. The Y has established a positive tone and climate for our client's with their members and staff. EPIC introduced the YMCA to Enliten, an adapted equipment company, who has since purchased their harnessing system among other adapted equipment to support each client's active engagement.

Manpower:

EPIC is also partnering with the University of Delaware Behavioral and Heath Science department who are providing student interns to work individually with EPIC clients throughout self-determined exercise routines to improve their "physical development" while supervised by an EPIC staff member. EPIC is also finalizing on-site support in the areas of speech and assistive technology.
Currently, we're seeing sustained growth in the client's socialization skills with their use of basic communications while walking through the Y's hallways or when working out with non-disabled peers at the Bear YMCA.

How many of the Day Habilitation Services are addressed by this strategy?

Access Into The Community:

EPIC is a program "without walls". We meet our clients at the community venues of their choice to provide support. Current programs may consider initially meeting H a client at a community site upon their arrival in the morning, or when ending their day and then returning back to their program site or home upon completion of the activity through appropriate ,creative planning.

Again, this inclusive settings approach stands a greater chance for clients to generalize their learning by being within an authentic setting in their community rather than one manufactured in a more segregated one.

The last paragraph Day Habilitation Services focus is 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 such as physical, occupational or speech therapy.

EPIC is currently seeking contracted physical therapy services to provide support at community venues addressing specific client needs.

In closing, EPIC programming is off to a positive start, while recognizing that their will bumps along the way while embracing the language and direction contained within the Delaware Transition Plan.

Thank you.

Medicaid Transition Plan for Home and Community Based Services Testimony of Albert and Rea Lund, representing [redacted] Lund, March 4, 2016

We would like to introduce you to our son, [redacted] Lund, because he cannot speak for himself. [redacted] is 30 years old, is autistic, and has a significant intellectual disability. He has obsessive-compulsive behaviors, anxiety disorder, and seizures. Although [redacted] takes medication to improve his behavior and lessen his compulsions, he has good and bad days.

[redacted] is only partially verbal. He does not make conversation, and is very limited in his verbal ability to communicate his needs or wants to others. [redacted] has limited mental capacity. He does not comprehend even modestly complex tasks and is generally limited to following one or two-step directions. He is very sensitive to certain noises, such as children screaming or high-pitched sounds, and this disrupts his behavior until the stimulus is removed or stops. He does not like to stand to work, nor move around to do a job. He prefers sitting. Once [redacted] learns a task, it is very difficult for him to generalize to other similar tasks. He pretty much has to learn each specific step of each specific job, which requires one-on-one prompting and supervision. He enjoys repetition and can be annoyed by change.

Vocational training <u>and</u> opportunity should be based on Person Centered Plans: Wes attended the Delaware Autism Program where he received vocational, speech, and occupational therapy, and was exposed to a range of vocational options such as kitchen prep., dishwashing, and janitorial services. By graduation at age 22 he was not able to sufficiently master these skills to work independently, so he transitioned to Chimes pre-vocational center with an eye toward attaining community based employment when he was ready.

Chimes provided an opportunity to work "in the community" potting plants at the DuPont Stine/Haskell site. He worked with a job coach and two other disabled employees. He was able to complete tasks with one-on-one prompting and he worked for a two-hour shift, three days/week. Unfortunately after some months, [redacted] began having panic attacks that disrupted his work at DuPont, and he was not able to remain in that job. He returned full time to the Chimes Center, where the staff worked with him, and us, to provide work that met his particular needs. Over the years, [redacted] has let us know by his behavior what his preferences are, allowing us to fashion a Person Centered Plan based on his actual abilities and needs. Each morning we ask Wes "Do you want to go to Chimes today?" and his reply is "yes, please". We take that as proof that this is his "choice" based on his behavior and his affirmation.

For now, we assert that [redacted] is in the "most integrated setting appropriate". We are here to say that, for those who <u>can</u> work in a larger work environment, great. But one-size does not fit all. People like Wes do exist and there should be job-training sites appropriate for them. Do we need to monitor and improve these sites? Yes. But, please provide sites where they can have meaningful work in a safe environment.

We urge that the Statewide Transition Plan be revised to include a commitment from DDDS Director Jill Rogers and DHSS Secretary Rita Landgraf, that all programing will be based on Person Centered Plans to identify the "most integrated setting appropriate" for each individual supported. The needs identified in the Person Centered Plan should become the basis for the setting, which would be the most supportive for the individual. If DDDS believes a provider setting will not comply with federal regulation, then they should request a review of this setting based on the needs outlined for the individual in their Person Centered Plan.

Instead of eliminating options for individuals like [redacted], we feel the state should put more effort into making sure that Person Centered Plans are reviewed and adjusted as the individual's needs and abilities change. It is important that all options continue to be available, and that choice is based upon an individual's Person Centered Plan. When choices are *made,* the funding should follow the individual served to assist them in reaching their goals and to meet their support needs.

An urgent need for more supervised housing:

Lastly, we would like to address housing for individuals like [redacted]. Currently, [redacted] lives at home with us, his parents. However, both of us are 65 years old and [redacted] will need to transition to other housing before too long. There are approximately 3,000 adults with various levels of intellectual disabilities currently living with their parents in the state of Delaware. Addressing their future needs is of critical importance.

Again, one-size does not fit all. Where some individuals would prefer an apartment of their own and have the ability to live there with only occasional supervision, [redacted] would be very isolated in such a setting, unsafe, and unable to care for himself. [redacted] cannot adjust the shower temperature safely. He cannot safely use a stove to make a meal. He cannot manage his medications. He cannot attend to traffic to cross a street safely. He cannot ask for help to get home if left alone out in public, and is vulnerable to anyone who wishes him harm. But [redacted] also likes social interactions in small doses. He enjoys dances, eating out, going to movies, attending church, and singing in a choir, but cannot arrange for or initiate these activities on his own. Clearly a continuously supervised residential setting with people that know and care about him and are committed to implementing a Person Centered Plan is what [redacted] needs to be safe and happy. We would be happy for the state to provide a one-on-one companion for [redacted] 24/7, but if that is not fiscally feasible, then practical solutions are likely to require group homes or planned communities that leverage the high costs of staffing.

Restricting the range of housing solutions out of some misguided belief that one solution will work for everyone seems naïve and short sighted.

We ask that a new item be added to the State Transition Plan to convene working groups to discuss how DDDS plans to meet future service needs. Availability and affordability need to be addressed immediately, and creative choices for residential services need to be considered.

Albert & Rea Lund, [redacted]

My name is Terri Hancharick. My daughter [redacted] is 28. She spent all of her school years in a segregated setting. The school tried to tell me that [redacted] needed more and I fought them. I was wrong. She spent time with wonderful people who truly cared about her but she left 17 years later without real friendships. It's very difficult to start a social life at 21. I then sent [redacted] to a segregated day program. Again wonderful people who also truly cared about [redacted]. I thought it was what she needed at the time. Again I was wrong. She is now in the community trying to make friendships. It's not easy. But the more she is out there the better she gets. People at the Y know her when she works out. People who once had that look of what is she doing here now smile and say hello. Some even know her name and stop for a conversation.

[redacted] spends time in Dover and Washington. She does not speak. But if she were not there would they know that people like her exist and need their help? She is a self-advocate.

55 million Americans with disabilities fight every day to obtain the equality and respect in the workplace that non-disabled people take for granted. According to Congressman Gregg Harper when he introduced the TIME Act in 2015: Segregated, subminimum-wage work is just an expression of low expectations that instills a false sense of incapacity in individuals who could become competitively employed with the proper training and support. This is an issue of quality, respect and the civil and human rights of citizens with developmental disabilities.

People with disabilities deserve the right to live, work, receive their healthcare, and recreate in the same venues as people without disabilities. Until we recognize the gifts of each and every person and bring them out of the shadows they will be forever thought of as second class citizens, not worthy of the same rights that you and I have.

The Delaware Transition Plan is an opportunity. It's an opportunity to look to the future. To make sure everyone is included. To be seen in the community over and over until people know your name and look forward to seeing you again. And when you are not there, people notice that too and make sure you are ok.

Parents are being told that they are going to lose their services. The plan is not about losing services, it's about enhancing those services. We all know that people work or need a break from caregiving. Taking away the supports we have is not the answer. But transforming what the day looks like while they are there is. It's about making sure people are supported in their communities. It's about acceptance. The transition plan reinforces that residential settings should be smaller, within inclusive communities, and support control and decision-making by the people who live in those settings. It is clear that any residential settings supported with CMS funds must be inclusive and assure that those being supported have control and decision-making authority about such aspects of daily life. While challenges exist, the solution is not to begin building large congregate settings that segregate people with disabilities from their communities. Three decades of deinstitutionalization studies have found that people who move from institutions to smaller community settings are happier, healthier, have more control over their lives, and are better able to function independently after they move (Larson, Lakin & Hill, 2013). We need increased funding for long term services and supports and we need to incentivize providers for thinking progressively. We need to make sure that taking people one on one into the community is not a losing proposition for a provider. We shouldn't make it more profitable to have a large group of people in a segregated setting. If we could come together on this one issue we could transform our communities.

Easter Seals

Easter Seals Delaware & Maryland's Eastern Shore
Public Hearing Statewide Transition Plan
Kenan J. Sklenar, President/CEO
March 7, 2016

My name is Ken Sklenar and I am the President/CEO of Easter Seals Delaware & Maryland's Eastern Shore. Thank you for the opportunity to comment on the State Transition Plan.

The State Transition Plan will redefine how Delaware cares for individuals with disabilities now and in the future. The question is - How is the state preparing for a dramatic shift in service delivery for people with disabilities? In essence, our system of care and the people we serve are perched on a cliff. Is Delaware preparing in such a way for them to have wings to take off and soar off the edge of that cliff? Or, is there danger of them falling without a safety net?

Easter Seals has two types of adult day programs which could be significantly impacted. We currently serve approximately 430 adults in programs under the Division of Developmental Disabilities Services (DDDS) and the Division of Services for Aging and Adults with Physical Disabilities to which the "integrated settings rule" would apply.

Easter Seals fully endorses each individual's right to choose what his or her services look like. Services should reflect the individual's strengths, needs, and capabilities consistent with his or her person-centered plan. As such, the array of choices available must encompass the complete range of supports needed by individuals, including those who require intensive staffing and personal care.

They are individuals like [redacted], who comes to our center in New Castle, and [redacted], [redacted], and [redacted], who come to Dover. Each of these Easter Seals clients require total assistance in personal care which necessitates the use of a mechanical lift to transfer them and specialized equipment in the bathroom that is not portable. [redacted], who has quadriplegia, must spend a minimum of one hour out of his wheelchair each day to prevent skin breakdown from sitting in one position. Each day, it requires 2 to 3 direct support staff to transfer him to a mat for alternative positioning.

[redacted] loves coming to our center each day in Georgetown. However, she will often run from staff if in the community and take things from anyone around her.

[redacted], who attends our Georgetown adult day program, requires nursing care full time due to her severe lung disease, continuous dependence on oxygen, and need for constant staff assistance with all personal activities because of a major stroke. Knowing [redacted] is well cared for, her son is able to work and maintain their household. Intense nursing needs, such as [redacted], are most effectively addressed in a setting with a full time nurse. This would be a very high cost to replicate in small, scattered day settings.

[redacted], also at Georgetown, has advanced dementia. He is closely monitored by all staff who know that in his confusion he will try to walk outside and near the street. His family is able to work because they are confident in the care and supervision [redacted] receives at Easter Seals.

It is common sense that supporting individuals with intense care needs in a more community based setting is going to require more staffing. It is going to require transportation. It is going to require more safeguards to assure the least amount of risk to the individual. All of those things will unquestionably require more funding. Is the State prepared to supply the funding and supports that will make it possible for [redacted] to be out in the community every day...to make certain [redacted] is safe when in the community?

What if individuals like [redacted] and [redacted] and their families determine that the day services setting at Easter Seals is the most integrated setting that is appropriate for them. The State Transition Plan must identify the "most integrated setting appropriate" in person-centered plans before any remediation plans are submitted to CMS. If there is a decision by DDDS or DSAAPD that any of the settings in the person-centered plans do not comply with the CMS rule, then the needs identified in the person-centered plan should become the basis for requesting heightened scrutiny.

We are concerned that the compliance date for the Transition Plan has been shortened by nine months. DDDS has said that the process of identifying "most integrated setting appropriate" in person-centered plans will take approximately one year so it's impractical to shorten the compliance time. We ask that the due date listed in the Statewide Transition Plan for complete compliance with Corrective Action Plans should be extended.

It is important that the State make clear its intention to fully fund the costs of the implementation of the State Transition Plan, and outline how that funding will occur as the service delivery model shifts. The shortfall in reimbursement rates for disabilities service providers just under DDDS has reached more than $39 million. This dollar amount does not account for the shortage in funding under DSAAPD.

A system that is already underfunded by $39 million cannot absorb dramatic changes in service delivery. There must be a major investment by the State to assure it remains a viable means of caring for Delawareans with disabilities. The Governor's budget this year contains an increase of $153,000 ($300,000 When matched by federal funds) which is to be shared by all DDDS providers.

There is a reference in the plan to "Review DDDS rates for adequacy to support the requirements of the Rule (especially related to smaller staffing ratios in the day programs). However, the deadline for that review is December 31, 2016. This is well after the Dept. of Health and Human Services Budget Hearings for the State's FY18 budget and less than a month before the new governor's budget is required to be introduced.

Let me conclude by saying that Easter Seals is committed to delivering community services of the highest quality in the most integrated setting appropriate, based on the individual's strengths, preferences and needs. We look forward to working with the State during this period of transition to assure that disability services meet the needs of all Delawareans with disabilities.

Thank you.

March 7, 2016
Members of DDDS

I am William Drake, father of [redacted] [redacted], who has Down syndrome and attends Chimes Vocational Center in Millsboro, in a Facility Based Program.

I do not object to Community based supported programs, in fact I support them if the individual is capable and willing to participate. My issue is Delaware's plan to eliminate Facility Based Programs.

Here in Delaware we talk about the empathy we have for people who are less capable than most of us. We talk about how we want to take care of everyone. We use a lot of "feel-good words". However, our ability to "walk the talk" sadly falls short.

Evidence from Michigan and other states were sheltered workshops have closed do not support the idea that people with DD who need and want employment will be able to find jobs when the only option is supported employment. In many cases after sheltered workshops have closed:

- Unemployment among people with DD has increased.
- The percentage of people using supported employment services decreased.

Washington state — among people with severe disorders only 17% have found work.

Maine — all sheltered workshops are closed.

- People previously employed in sheltered workshops had their hours worked per week decreased.
- Their income decreased.
- Number of people with IDD who were served in integrated employment declined.
- Average employment is 12 hours worked per week the lowest in the nation.
- Non-work placements increased dramatically from 550 people to 3178 people.
- That means people previously working in sheltered workshops are either at home, or in a daycare environment.
- Do you even remotely think, this has added to self-esteem of people who had pride in their work?

Vermont — was the first state to stop funding sheltered workshops.

- Vermont claims 80% of employees of the state's sheltered workshops h4.el fount paying jobs. That means 20% do not have jobs when tor-many they were in the sheltered workshop.

Many of the findings of Congress do, in fact, accurately reflect the state of the system of services and care for people with DD over the full range of disability:

Individuals whose disabilities occur during their developmental period frequently have severe disabilities that are likely to continue indefinitely;

Individuals with developmental disabilities:

- Often encounter discrimination in the provision of critical services.

- Are at greater risk than the general population of abuse, neglect, financial and sexual exploitation, and the violation of their legal and human rights.
- Do not have access to appropriate support and services, including access to assistive technology, from generic and specialized service systems, and remain unserved or underserved.
- Often require lifelong community services, individualized supports, and other forms of assistance, that are most effective when provided in a coordinated manner.
- in almost every State, individuals with developmental disabilities are waiting for appropriate services in their communities, in the areas of emphasis;

In conclusion: Lost in pursuit of the integration ideal is "concern for the individual". "Person centered planning", which is held up as the ideal by government, advocates, and nonprofit organizations alike, is shortchanged by system change advocacy "to eliminate specialized care options" for those who need it, which is exactly what the Olmstead court cautioned against.

Instead, Olmstead and the ADA reinforce the right of choice requiring a level of integration that meets the needs and wants of the individual. This right of choice is preserved only if we maintain a full range of options to meet the full range of needs for a diverse population.

These Goals can be accomplished by the following:

- The Statewide Transition Plan should be revised to include a commitment from DDDS Director Jill Rogers and DHSS Secretary Rita Landgraf, that all programming with be based on Person Centered Plans to identify the "most integrated setting appropriate" for each individual supported. The needs identified in the Person Centered Plans should become the basis for the setting which would be most supportive for the individual. If DDDS believes a provider setting will not comply with federal regulation, then they should request a review of this setting based on the needs outlined in the Person Centered Plan. Without this statement, facility based pre-vocational programming can and will no longer be an option.

> A new item should be added to the Statewide Transition Plan to convene working groups to discuss how DDDS plans to meet future service needs. Address the residential service needs of the more than 3,000 adults with I/DD currently living with their families is critically important. Creative choices for residential services are being developed in other states; Delaware should be following suit and focusing on an individual's experience and not only geographic location or number of individuals being served.

Finally, it's important that all options continue to be available and choice be based upon an individual's "Person Centered

Plan". When those choices are made the funding should follow the person to assist in reaching their goals and meeting their support needs.

William E Drake
[redacted]

KSI

Kent-Sussex Industries, Inc.

[redacted]

March 7, 2016

Good afternoon. My name is Craig Crouch, and I am the CEO of Kent-Sussex Industries (KSI). KSI has been providing services to Delawareans with disabilities and special needs since 1962. The services we provide are Pre-Vocational Training, Day Habilitation, Supported Employment, and Transportation. We serve approximately 270 individuals a year. Many of the individuals we serve have been with KSI for more than 20 years.

KSI provides services in several different settings. We operate a large Skill Development Center in Milford, and have been providing services in completely integrated community settings since 1974. Today we have four pre-vocational employment settings in the community. Proctor & Gamble and Kraft-Heinz in Dover, Merck Animal Health in Millsboro, and the Dover Air Force Base Postal Center. Collectively over 75 individuals are employed in these sites. All of KSI's supported employment placements occur are fully integrated community settings. KSI also serves and supports a number of volunteer sites in the community Some examples are: Meals on Wheels, the Abbott's Mill Nature Center, God's Way Thrift Store, and the Food Bank of Delaware.

As you can see, KSI is very supportive of providing service delivery in a community integrated setting. We have been doing it for more than 40 years, and we are good at it.

With regard to the State of Delaware's Statewide Transition Plan, I have the following concerns:

KSI does not believe that one size fits all. Not everyone is capable of being supported in a community setting for various reasons. With unlimited resources, perhaps everyone could be supported in the community That may not be every individual's choice, however. Some of the individuals we serve prefer KSI's facility-based programs. That is their choice and we respect it. In addition there are some people it would be unsafe and dangerous, not only for the person but for the larger community, to serve in the community.

KSI also believes that the setting in which one receives services must do two things: The service must be supportive of the person's Individual Support Plan and most importantly, the person being served should be able to CHOOSE the setting where they receive services.

KSI also knows that the current funding levels will not allow us to support all of the people we serve exclusively in the community. The ratio of participants to Direct Support Professionals is smaller and more expensive in community placements. In our geographical area of lower Delaware, transportation can also be a barrier to those we serve accessing the community. KSI has a very good understanding of transportation costs, because we operate one of the largest private fleets, if not the largest in the State.

Moving services to the community and closing facilities has been done in other states. Everywhere this has occurred, employment went down, wages went down, the extent of services provided went down, and the number of people served went down. These are not good outcomes for people with disabilities and their families.

Again, KSI has been providing services in the community for over 52 years for those people that it was appropriate for and was their CHOICE. We continue to provide more and more services in the community, but we also believe that the needs and wants of many of those we serve are sometimes better provided in a facility-based program.
KSI wants to see MORE choices for those we serve, not less.

I would also like to consider a couple of thoughts. There is all this discussion of how the State and Federal governments can decide how their money will be spent. The State and Federal Governments do not have any money. The money that was given to them was given by us the citizens of our the great country and State. I believe we should have a say in how our dollars are spent or invested.

Thank you for your time and attention and the opportunity to testify.

Respectfully Submitted,

B. Craig Crouch

B. Craig Crouch
Chief Executive Officer

DATE: March 1, 2016 D.D.D.S,
TO: DDDS, Director Jill Rogers

DHSS, Secretary Rita Landgraf

Re: Proposed Home and Community Based transition for Medicaid

As the parent of an individual who has been receiving services for 15+ years I am very concerned to hear about possible changes to current services. The services that have been provided to my son have been vital in assisting him and our family as well as so many others. Without these services, so many individuals would not have the ability to achieve a quality of life; build on their social, living and vocational skills; and function as part of the community.

Staff at vocational centers have the skills and abilities to assist these individual gain more independence and lead fuller lives — many gaining skills to become gainfully employed. For others it is a way to stay connected with the community. Staff at residential homes also have ability and training to assist with independent living skills and provide a safe living environment that many families would be hard pressed to supply on an individual basis.

Losing funding would have a profound impact on the lives of these individuals and their families. We need your help and support to ensure funding is not cut or that new funding can be found to assist these individuals in having a sustained quality of life. In these hard economic times, it would be a crime to not fund these vital programs and services.

The following specific items should be noted and addressed — these are the concerns of all families and should be the concerns of all Delawareans:

- The Statewide Transition Plan should be revised to include a commitment from ODDS Director Jill Rogers and DHSS Secretary Rita Landgraf, that all programming with be based on Person Centered Plans to identify the "most integrated setting appropriate" for each individual supported. The needs identified in the Person Centered Plans should become the basis for the setting which would be most supportive for the individual. If DDDS believes a provider setting will not comply with federal regulation than they should request a review of this setting based on the needs outlined in the Person Centered Plan. Without this statement, facility based pre-vocational programming can and will be no longer be an option.
- A new item should be added to the Statewide Transition Plan to convene working groups to discuss how DDDS plans to meet future service needs. Address the residential service needs of the more than 3,000 adults with I/DD currently living with their families is critically important. Creative choices for residential services are being developed in other states; Delaware should be following suit and focusing on an individual's experience and not only geographic location or number of individuals being served.

Thank you for hearing my concerns and those of so many families and clients who will be impacted by lack of service if these changes are not addressed.

Sincerely,

Heather Taylor, parent/guardian
[redacted]

From: David Machledt [[redacted]
Sent: Monday, March 07, 2016 4:09 PM
To: dhss_HCBSTransition
Subject: Date comment period doses for STP comments

Dear sir/madam,

I am writing because I cannot find on the DE website what the deadline is for comments on the DE State HCBS settings transition plan. I found public hearing dates for March 4 and 7, but no deadline for written comments. I would appreciate if you can send me that information.

Thank you,
David

David Machledt, Ph.D.
Policy Analyst
[redacted]

Bryan W. Pepper
[redacted]

DHHS

March 3, 2016

Dear Sirs,

I am writing as a concerned Delawarean about the proposed transitioning of our citizens with special needs from facility based programs to community based programs.

In theory this sounds good, but when you really think about it, some citizens that are in need of assistance are not equipped to independently function in a public workplace on a daily basis. This may cause unnecessary stress on many due to being in a fast paced public setting. Some will unfortunately be subjected to harassment and ridicule as we live in a very vicious world today. We should be trying to do the best we can for our citizens at the least cost to the taxpayers. Public introduction programs require more supervision than a group setting. This will add to the cost of this type of program.

I would urge you to reevaluate your proposal. It would appear that this will not result in anything positive. It will only cause grief for our special needs citizens and their families. These people and their families already have day to day issues to deal with that most of us do not even consider or realize. There is no need to disrupt a pleasant, dependable, fulfilling work environment just to put them in a possibly hostile environment at extra costs to the taxpayers.

Thank you for your consideration.

Bryan W. Pepper

1St 170
CLASI

DISABILITIES LAW PROGRAM
COMMUNITY LEGAL AID SOCIETY, INC.
[redacted]

MEMORANDUM

To: DMMA Planning, Policy & Quality Unit

From: Brian J. Hartman, Project Director, Disabilities Law Program

Re: Comments on HCBS Transition Plan, 19 DE Reg. 782 (February 1,

2016) Date: March 14, 2016

I am submitting the following comments on the Delaware Statewide Transition Plan in response to the DMMA solicitation appearing at 19 DE Reg. 782 (February 1, 2016). Given time constraints, the comments should be considered preliminary and non-exhaustive.

General:, Each page in the State Transition Plan ("STP") has been dated "February 1, 2016". However, many pages have not been updated and refer to plans and expectations from 2015. This is confusing. Perhaps each page should have a "revision" date so it would be clear that same original pages reflect planning as of March, 2015 and some pages contain updated information as of a later date.

1:1, 1: In the "Introduction" section, DHSS could consider embellishing the "core values" discussion by including some explicit references and/or quotes from the DD Bill of Rights (16 Del.C. Ch. 55) and the Employment First Act (19 Del.C. §§(740-747) confirming State public policy. Proponents of the "status quo" and interest groups espousing a "low expectations" approach could easily overlook the consistency in values contained in State law and the CMS "Community Rule".

Consider the following examples:

> §5502. Persons diagnosed with intellectual disabilities or other specific developmental disabilities have the right to proper medical care and physical restoration and to such education, training, habilitation, and guidance as will enable them to develop their abilities and potentials to the fullest possible extent, no matter how severe their disability may be.

> §5503. Persons diagnosed with intellectual disabilities or other specific developmental disabilities have a right to strive for productive work in meaningful occupations, economic security and a decent standard of living.
>
> §741. All persons, including persons with disabilities, have a right to the opportunity for competitive employment. In order to achieve meaningful and competitive employment for persons with disabilities, employment opportunities in fully-integrated work settings shall be the first and priority option explored in the service planning for working-age persons with disabilities.
>
> §743. It is hereby declared to be the policy of this State that competitive employment in an integrated setting shall be considered its first and priority option when offering or providing services to persons with disabilities who are of working age. All state agencies that provide services and support to persons with disabilities shall follow this policy and ensure that it is effectively implemented in their programs and services.

Moreover, the Plan contains many references to a goal of promoting employment paying at least the "minimum wage" (pp. 4, 5, and 6). As an update, a reference to current State legislation to raise the minimum wage could be mentioned. S.B. No. 39 passed the Senate in January, 2016 and represents an initiative which would benefit many individuals enrolled in HCBS waivers.

p. 3: It would be informative to update the 2014 figures on enrollment in the DDDS waiver and DSHP and DSHP+ programs (by footnote or otherwise). It would also be informative to provide recent statistics demonstrating DHSS success in transforming its service delivery system to one which is predominantly community-based. See Secretary's FY17 JFC presentation, p. 5 (http://www.dhss.delaware.gov/dhss/fiscalyearjfchearingsecretary.pdf).

p. 11: In two documents, CMS requested DHSS to provide information concerning plans and strategies to assure ongoing compliance after March, 2019:

> Please provide a step-by-step approach (supported with precise timeframes) for both provider remediation and compliance activities (based on a provider's approved CAP), and ongoing compliance after the March 2019 deadline.

September 24, 2015 CMS letter to DMMA, p. 2. [emphasis supplied]

> Please amend the STP to provide a step-by-step approach (supported by precise timeframes) for both provider remediation and compliance activities (based on the provider's approved CAP), and ongoing compliance after the March 2019 deadline. In the approach, please describe how often monitoring will occur, whether it will be integrated into existing licensing processes, and what specific tools and processes the state will use to ensure compliance of settings.

STP, Attachment 5, p. 2. [emphasis supplied]

I infer that CMS would prefer to deter "backsliding", i.e., achieving compliance by March 17, 2019 but discontinuing efforts to promote continuing compliance after that date. In contrast, the Plan contains an "end date" of March 17, 2019 throughout the document. See, e.g., pp. 11 and 18. Page 70 would also benefit from clarification that activities would extend beyond March 17, 2019.

p. 11: There is some "tension" between identification of a March, 17, 2019 end date to "implement remediation strategies" on p. 11 with a different targeted "end date" of July 31, 2018 for implementation of provider CAPs on other pages. Compare pp. 37, 56, 62, 68 and Attachment 5, p. 3.

pp. 13-14: The list of State laws, regulations, and policies on pp. 13-14 could be updated based on the content of the STP, Attachment 6, including a reference to the IBSER regulations. [Attachment 6, p. 26] See also p. 39.

p. 15: The IBSER-regulated program should be added to the bulleted list of settings subject to review.

pp. 15-17: There are several references to planned development of an appeal process for providers to dispute findings. Since reports with findings are due by March 31, 2016 (p. 26), the appeal process should have been developed by now and should be described. The time line for development is omitted from the matrix on p. 26.

p. 17: The following statement is contained on this page: "Any Corrective Action Plans and other strategies identified in Phase 4 must be fully implemented by March 17, 2019 so that the entire waiver service delivery system will be compliant with the Community Rule." This date does not conform to the July 31, 2018 target adopted in other sections. See comments on p. 11 above.

p. 23: The review of DDDS and DLTCRP regulations by these divisions is "underinclusive". The DDDS waiver covers children between the ages of 12-17 (p. 3). Such children served in an entity (AdvoServ) covered by the adult IBSER regulations are covered by DSCY&F regulations. See 16 DE Admin Code 3320.2.0 and 9 DE Admin Code 105. The DSCY&F regulations have not been identified for review.

p. 23:The following recital appears on this page: "Advisory Council to DDDS will review and must approve any DDDS strategies for remediation." The Advisory Council should not be accorded the authority to "trump" or "overrule" DDDS decisions. Under its enabling law (29 Del.C. §7910), it an advisory body to DDDS.

p. 24:CMS questioned the "distant" target of January 13, 2017 to complete legislative revisions. [Attachment 5, p. 3]. The State is now extending that "distant" date for legislative changes to March 17, 2019 (p. 24). The State completed its review of the landlord-tenant code by April 30, 2015 (p. 22) and contemplates completion of its review of other laws by March 31, 2016. It should not take three (3) years to effect legislative revisions. The STP would also benefit from some interim targets rather than a single global target (March 17, 2019) for all legislative changes.

p. 24: The "end date". for DDDS to revise the monitoring tool used by the DDDS Office of Quality Improvement to include the HCBS settings requirements is July 1, 2016 (pp. 24 and 28). There is some "tension" between that Office conducting "look behind" reviews of providers by May 31, 2016 (p. 26) and development of the monitoring tool by July 1, 2016 (p. 39). Ideally, it would be preferable for the Office to have finalized and been trained in using its assessment tool to assist with the "look behind" assessments to be completed by May 31, 2016.

p. 26:The May 31, 2016 date to complete "look behind" reviews (p. 24) is different than the date to complete "look behind" reviews (March, 2016) identified on p. 34.

p. 27:The status of the new home being built with an expected December 31, 2016 move-in date is not provided. See also pp. 38 and 56 and Attachment 5, p. 4. It would be useful to know the status of construction.

p. 29: Activities to "begin" correction of regulations and policies will not occur until October, 2016. This is ostensibly too long to begin work. It is also inconsistent with the January 1, 2016 date to start changing regulations and policies listed on p. 24. See also November, 2016 date on p. 58.

p. 32: It would be interesting to assess any patterns between surveys completed by guardians versus those completed by waiver participants themselves.

p. 32: The setting (AdvoServ) regulated by the IBSER regulation is omitted from the bulleted list of provider settings to be reviewed. Compare Attachment 6, p. 26.

pp. 34-35: It would be appropriate to add the DDDS Human Rights Committees as a source of consultation on provider compliance with the CMS "settings" regulation, client rights, and restrictions of rights in behavioral plans. The HRCs review an aggregate of hundreds of plans annually as well as rights complaints. See HRC policy published at http ://www. dhs s. del aware. gov/dhs s/ddds/p o cy_administrative.html .

p. 35: The STP recites that a Behavior Support Plan may authorize deviation from the HCBS Final Rule, including authorizing restrictions of rights, only if there is "informed consent of the individual or legal representative (see 42 CFR §441.301(c)(2)(xiii)(G))." In practice this is not accurate since many DDDS waiver participants lack capacity to consent and lack a guardian or other substitute decision-maker.

p. 35: The behavior plans of DDDS clients covered by the IBSER regulations often deviate from the bulleted plan requirements, including adoption of generalized "levels" systems to earn access to preferred food and privileges. Cf. Attachment 6, p. 32 (setting standards not compliant). DDDS review which exceeds the minimum sample standard would be appropriate.

p. 36: The bulleted section could be improved by requiring some interim milestones towards achieving compliance . This would be consistent with the "quarterly on-site visits" contemplated on p. 37. As written, a CAP could simply have a single date (e.g. July 31, 2018) which undermines meaningful progress assessments. For example, an interim benchmark might be compliance by 25% of the provider's settings within 3 months, compliance by 50% of the provider's settings within 6 months, etc.

p. 38:The STP (p. 54) contemplates identification of out-of-state sites in which Delaware waiver participants may live by September 30, 2015. There is some "tension" between that date and following recital (p. 38):

> Several DDDS waiver members are supported in residences in other states that were determined to best meet their specialized needs. ...DDDS has begun the process of communicating with (those) states for this purpose.

If would be preferable to provide the current status and identify an "end date" for this process.

p. 39:The STP recites that DLTCRP regulations "largely involve attributes of the physical plant in which the services are delivered, as opposed to addressing the experiences of the individuals who are receiving the services." This is inaccurate. Compare, e.g., 16 DE Admin Code 3320, §§5.0 and 9.0-26.0.

p. 40:The references to "Plan of Improvement", "plan of correction", and "Plan of Correction" should be converted to "Corrective Action Plan" for consistency with the rest of the STP. Compare pp. 18, 27, and 45. The word "division" should also be capitalized.

p. 42: Per comments on p. 23 above, DSCY&F regulations should be added to the list of standards to be reviewed.

p. 42: The STP recites that "(a)dditional materials will be added to the review as they are identified." The current list include the "Landlord-Tenant Code". See also p. 50. Legislation (S.B. No. 179) to amend Delaware's Fair Housing and Landlord-Tenant Codes has been introduced to ban discrimination based on "source of income". Under current law, a landlord can refuse to rent to a tenant based on SSI or SSDI being their source of income. Delaware has 27,404 SSDI ("disabled workers") beneficiaries and 16,687 SSI beneficiaries. Almost all DDDS HCBS waiver participants and a high proportion of DSHP+ participants are SSI beneficiaries. The legislation would obviously facilitate implementation of the HCBS Community Rule for individuals with leases. The legislation has been supported by several State agencies, the DLP, AARP, League of Women Voters, and a host of other organizations. It passed the Senate in January, 2016. In contrast, the Delaware Department of Health & Social Services has declined to support the bill, adopting a "neutral" position. S.B. No. 179 should be added to the list of initiatives for review and DHSS should reconsider its lack of support for the legislation.

p. 43: The State recites as follows: "DMMA will develop an acceptable response rate for the provider self-assessment." This is somewhat vague. It would be preferable to include a specific percentage figure. The actual response rate was high. See p. 65. See also Attachment 5, p. 1.

p. 43: The State indicates that the Governor's Commission on the CBAID will assist in conducting look-behind reviews "as determined appropriate". Since the end date for this activity is February and March of 2016 (p. 55), the State should be able to provide greater specificity in describing the Commission's role

p. 45: The State identifies a March 17, 2019 target date for completion of Corrective Action Plans. This is inconsistent with the July 31, 2018 date identified in other sections of the STP. See comments on pp. 11 and 17 above.

p. 45: Grammar should be corrected as follows: "The State...to continuously monitoring participant health...."

p. 45: Identifying an "end date" of March 17, 2019 and no activities after March 17, 2019 is inconsistent with CMS directives to include activities after March 17, 2019. See comments on p. 11 above.

p.p. 52-53: The Plan envisions an end date of July 31, 2016 to develop remediation strategies for laws which are not fully compliant. It then adopts a March 17, 2019 end date for legislative changes. This is almost three years. If the strategies are completed by July 31, 2016, it should not be difficult to prepare legislation over the next six months for introduction by February 1, 2017. Instead, the Plan identifies no work on remediation activities between August-October, 2016, i.e., "implementaion of all remediation activities will begin no later than November 2016" (p. 58).

D. 56: The timetable envisions providers being given "findings" by April 30, 2016 in anticipation of providers submitting a Corrective Action Plan immediately or within a few days (e.g. between April 30 - May 6). This is ostensibly unrealistic.

MI 70-71: It would be preferable to clarify that described activities would extend beyond March, 2019. See comments on p. 11.

Given the 82-page length of Attachment 6, the following observations are based on an abbreviated review of content.

Attachment 6. pp. 2-9. The section omits any reference and consideration of "Adult Day Care" regulations, 16 DE Admin Code 4402. I understand some DDDS clients are served in this setting. The section also omits any consideration of the standard DDDS provider contract. The standard FY16 DDDS "contract" with appendices for day programs is published on the Web. See http://dhss.delaware.gov/dhssiddds/providercontractiltml. Appendix A (Divisional Requirements: Day & Residential Program Services) contains many standards.

6

Attachment 6. p. 7: The matrix omits the PROBIS and HRC policies. The PROBIS and HRC committees are key DDDS entities protecting waiver participants from unjustified rights restrictions and chemical, mechanical, and physical restraints. See http ://www. dhss . del aware. gov/dhss/ddds/p o cy administrative.html .

Attachment 6, p. 7: The "day hab" section of the matrix has a"freedom from coercion and restraint" section. It omits the IBSER regulations which cover the day program of the covered entity. See 16 DE Admin Code 3320.3.0 (definition of "resident'). The IBSER regulations address restraint in detail. See 16 DE Admin Code 3320.20. The Plan focuses on the IBSER regulations only in the context of residential settings (pp. 26 and 29).

Attachment 6. pp. 10-18: If there is a standard DDDS contract with appendices for providers of prevocational services, it should be included in the matrix and assessed for compliance with the CMS Community Rule. See comments on Attachment 6, pp. 2-9.

Attachment 6. pp. [9-43): If there is a standard DDDS contract with appendices for providers of residential services, it should be included in the matrix and assessed for compliance with the CMS Community Rule. See comments on Attachment 6, pp. 2-9.

Attachment 6. pp. 19-43: Although the IBSER regulations are mentioned, an accurate assessment of domains can only be completed through a review of other documents. For example, in the "food domain" (p. 39) the program regulated by the IBSER regulation has "levels" systems in which preferred foods may have to be "earned". Similarly, in the "choice" domain (p. 32), phone access at preferred hours may have to be "earned".

Attachment 6, p. 22: The State assesses itself as compliant with the following domain: "The individual receives services in the community with the same degree of access as individuals not receiving Medicaid HCBS." It solely cites the following regulation as documentation of compliance: "4.2.1.5_ The individual has access to all areas of his/her environment." I do not understand how this regulation can serve as the sole basis for the State's conclusion that it meets the domain.

Attachment 6. p. 35: A corollary to the "choice of roommates" standard is whether an individual could opt to have no roommates (e.g. live alone). This is partially addressed on p. 24 but is not very clear. In practice, my impression is that few waiver participants are offered the option of their own unit.

cc: Kyle Hodges
Pat Maichle
Wendy Strauss

E:leg/hcbscomments3 1 6
F:leg/20 16P &L/hcbsc onunents 3 1 6
E:leg/hcb sc onunent s3 16

Good morning,
Another KSI-related comment for the record.

From: Melody Booker-Wilkins [redacted]
Sent: Tuesday, March 15, 2016 2:17 PM
To: dhss_HCBSTransition
Subject: HCBS Statewide Transition Plan Comments

Good afternoon. My name is Melody Booker-Wilkins and I am a Kent-Sussex Industries Board Member. I am writing out of concern because I have been a proud supporter of KSI for over twenty years and this potential ruling would be detrimental to the organization and to the hundreds happily and appropriately served. I know one size does not fill all and the same setting is simply not appropriate for all individuals. I believe the ISA or ISP should help determine the appropriate setting for service delivery and that the individual being served should have a choice in the setting in which they receive services.

Can you help me understand what problem we are trying to fix with the Final Rule? It is my understanding that there was not one person who testified in support of the Final Rule on Settings in all of the public hearings. This tells the story of the needs of our community.

Please make the right decision. If you have questions or need additional information, do not hesitate to contact me directly.

Very sincerely yours,
Melody Booker-Wilkins

Melody Booker-Wilkins, MPA
[redacted]

From: Fred Dawson <[redacted]
Sent: Thursday, March 17, 2016 4:50 PM
To: DMMA_PublicHearing
Cc: Vivian Turner ([redacted]'
Subject: Home & Community Based Services (HCBS) Transition Plan.

Importance: High

Dear Sirs/Madam;

I have recently been made aware of a Federal Plan that mandates getting disabled people out of facilities and into the community. The people cared for at C.E.R.T.S. have such severe disabilities that it is absurd to think this could work. Their bodies are fragile and their needs are many and quite demanding. Their limitations are so extraordinary that this will not possibly work and may endanger their lives and well-being. It will certainly not enhance their standard of living and at the same time be cost prohibitive.

I strongly recommend further study of this situation before such mandates are put into place.

Please feel free to contact me, or please contact Vivian Turner, Executive Director at [redacted]

Sincerely,

Frederick J. Dawson
Financial Advisor to C.E.R.T.S.

Frederick J. Dawson, ChFC, CLU
[redacted]

[redacted]

ASSETT, DAWSON & FOY, INC.
WEALTH SOLUTIONS

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From: Alex Eldreth [redacted]
Sent: Friday, March 18, 2016 9:42 AM
To: dhss_HCBSTransition
Subject: HCBS plan updates

I received an e-mail with the following headline: MARCH 22 IS DEADLINE FOR PUBLIC COMMENT ON HOME AND COMMUNITY-BASED SERVICES STATEWIDE TRANSITION PLAN UPDATE.

NEW CASTLE (March 10, 2016) - March 22 is the deadline for public comment on the state's proposed updates to the Statewide Transition Plan for compliance with the federal Home and Community-Based Services (HCBS) final rule.

Can you please tell me what the specific updates are that you are looking for comment on? We have previously gone to public comment meetings about the plan, but am wondering how much, or what areas, have been updated since the last round of public meetings. Thank you.

Alex Eldreth
Policy & Community Outreach Director
Autism Delaware
[redacted]

March 17, 2016

Attn: HCBS Transition Plan Updates
Delaware Division of Medicaid and Medical Assistance

To whom it may concern:

Mandating that people with disabilities must be in the community for a specified amount of time is not a good idea.

Our nineteen year old son has severe disabilities. He has cerebral palsy and is wheelchair dependent. He has a seizure disorder, having small seizures throughout the day. He is about 18 months developmentally and is tube fed. Although he can go to the bathroom on his own special toilet after being lifted onto it, when we are in the community, I have to lay him down on a bathroom floor to change him.

Currently our son is in the Meadowood Transition Program until age 21. He regularly goes into the community for various activities: adaptive physical education with typical peers at the University of Delaware, swimming at the Y, shopping at the grocery store for supplies for Meadowood's Sugar Rush Bakery. He loves the activity. Getting him into the community, however, requires a lot of planning and coordination of staff. Our son's special diet requires that he be tube-fed at a certain time. Since a nurse must feed him, the nurse's schedule must be taken into account. Since our son cannot take care of any of his daily living activities and cannot reliably bear his own weight, at least two staff people have to help him dress after swimming. Even in a store one staff person must push our son's wheelchair. If he has a seizure, someone has to monitor that. If the seizure is severe enough, he has to be given a suppository to stop the seizure or 911 must be called.

One of our son's options for the future is to attend a program like C.E.R.T.S., Inc. C.E.R.T.S. provides enough community activity to engage him, but it also provides opportunities for mobility at the C.E.R.T.S. facility, movement that he does not get if he is sitting in a wheelchair all day.
I do not think that being forced to be in the community more will be helpful to our son. In addition, it will require more staff and planning to make it possible. The idea of getting people like our son more into the community may sound good, but the financial, staffing and planning costs are prohibitive, and he will miss out on activities that can be better provided within the C.E.R.T.S. facility. Please look at each case individually instead of making the system-wide mandate that everyone transition from a facility into the community.

Sincerely,

Susan M. New
[redacted]

From: Dbt557 [redacted]
Sent: Saturday, March 19, 2016 4:06 PM
To: Mahoney, Kathleen (DHSS)
Subject: Community based services statewide transition plan

My daughter currently lives with three other ladies in a group home staffed by Bancroft. She has lived there for approximately 12 years and has been very happy there. She does come to my home on many weekends and is very happy with the living arrangements.

Since I am 74 years old and live alone I am very pleased and comforted with the knowledge that she is in a good place and has like friends who are like her sisters were something to happen to me. Since I am her legal guardian I have spent a considerable amount of time ad research in providing a safe, positive and happy environment for her and would like to see this continue.

Thank you.

Diane Thomas
[redacted]

Sent from my iPad

From: Patricia Secrest [redacted]
Sent: Sunday, March 20, 2016 3:21 PM
To: DMMA_PublicHearing
Subject: RE: H.C.B.S.

As the parent of a mentally disabled daughter of 57 years old. I must submit that I am sure the intentions of those in charge of the rule are well intentioned, but of limited understanding. As parents we have lived with and gone through all the obstacles it takes to obtain the services that are meeting the needs of this very specific person.

One size does not fit all in this community of very talented yet limited population.

Our daughter is of the mental age of 5 yrs. Our concerns for her are many

1. In an open , yet loosely supervised setting she would be open to abuse, neglect, dangers beyond description in this type of setting.

In her current setting at KSI She is allowed

1. room to grow as far as her unique gifts allow.
2. to learn new skills
3. be part of a caring setting. Those who work at KSI treat each client as in individual not a number. She has received training
   That has allowed her to overcome negative behavior and learned the rewards of positive behavior.
4. Received training to develop independence as far as her abilities allow.
5. At KSI she receives a level of acceptance, that is unique to this facility. A staff that is trained to care about each individual .

Please do not take these advantages from her and the many others who need this environment of protection, training and care by withholding funds from KSI.

Respectfully submitted,

Ronald and Patricia Secrest
[redacted]

March 20 2016
Public Comment Re: Statewide Transition Plan

First of all, I would like you to know that my daughter [redacted] is an amazing women, she's resilient, she's strong, she has a great memory, she loves unconditionally' I couldn't be more proud of her She is both a residential and vocational client with Chimes DE

She had been living for many years at Cavalier Apartments (see pictures attached) It was suggested at her ELP meeting in 2014 that we begin to look for another housing arrangement for [redacted] as her Cavalier apartment and the complex itself, had been steadily going downhill Each time Chimes would ask to move her into one of their renovated apartments, the request was denied So the search began for a new living arrangement [redacted]. On December 2, 2015,[redacted]moved into *her* new apartment in Bear She is thrilled and each time she is asked about the apartment, she says 'it's amazing'. For you see she now has a clean bathtub, a spacious kitchen with a washer and dryer behind bi-fold doors a functional HVAC system and a security system which puts a mother's mine at ease_ You might be asking why it took so long for[redacted]to get moved into a new apartment.
Part of the reason is because she has a mother who also loves her back unconditionally one who would never let her move into just any apartment. Additionally because I am aging, I wanted [redacted]to be in a comfortable, safe place where she can hopefully remain for several years

I spent a lot of time looking at apartments. it was suggested by [redacted] state case manager. mat 1 look at St Andrew s also in Bear I did go there and was happy with what I *saw,* but would later team the complex was ¯over saturated with clients who have a disability At the point when [redacted] case manager was unable to assist me, I started working with the Director of Professional Services_ each time she gave me the name of an apartment complex. I went to look. After looking at each suggested complex. I sought input from the New Castle County Police Department relative to crime in the area and potential sexual predators. To get to one of the complexes suggested, you had to drive through another where there had been a homicide and multiple arrests of individuals for buying drugs including heroin Certainly not a safe situation for a client with a disability

I believe that DODS staff genuinely had [redacted] best interests in mind when suggesting apartment complexes however, I also believe that their hands were tied, based on the FMR (Fair Market Rent) for New Castle County, FMR is basically low income housing. If families allow agencies to move their loved ones into FMR based housing. we will begin to see the development of disability ghettos. Our love ones deserve better than that
Public Comment: Statewide

Transition Plan Page 2

In the late spring / early summer of 2015, !found an apartment complex where I thought [redacted] would be quite comfortable. But the cost of a single bedroom apartment there was above the FMR So began the quest of trying to get additional money for [redacted] to move into this complex around the same time PM-62 (Policy Memorandum) was issued which stated 'if the actual cost of rent is higher than the HUD FMR then the provider may be able to apply for an adjustment that will allow the final rental cost to be up to 30% above the HUD FMR The maximum additional add-on percentage will be determined based on certain factors: accessibility improvement to the property, programmatic or geographical'

Once I became aware of PM-62. I started working with Chimes personnel who completed the 'Programmatic Features Assessment' of [redacted] Her state case manager also had to complete the same assessment Once the two were reviewed it was found that Chimes personnel scored [redacted] at 33 while her case manager scored her at 2' How could this oe possible Continued discussion between Chimes and the State. finally got [redacted] scores to 11 and 9 respectively, A score of 11 got [redacted] to 10% above the FMR and the Director of DODS Jane Gallivan) allowed a 20% increase above the FMR in [redacted] case But this still did not allow her to move into the apartment which I thought was most appropriate for her

So, I appealed the ODDS decision and found myself meeting with Secretary Landgraf and several members of her staff, including the Director of Constituent Services and the Director Division of Management Services. Chimes personnel accompanied me to that meeting, interestingly enough. I found out the morning of that meeting, that some of the points values assigned to each individual item if the assessment had been changed as continued assessments exchanged hands between the State and Chimes personnel When I met with the Secretary and her staff, we discussed the evolvement of the PM-62. the changing point values and the assessments interrator reliability After much discussion, the Director of the Division of Management Services grantee [redacted] a 30% increase over Me FMR A $29 deficit remained between the 30% FMR and the actual cost of the apartment. [redacted] stepfather and I are paying this monthly deficit. This has allowed [redacted] to move into a single bedroom apartment the complex most suitable to her needs

As noted by Jane Gailivan former Director of DDDS. I have heard that she has made great strides living on her own" She has and am very proud of her i suggest to people that they shouldn't ever be afraid to advocate for loved ones' Each one is an individual with very different needs including housing What works for my daughter may not work for your loved one' Advocate for what you believe is right and fair I did and [redacted] is the winner'

From: [redacted]
Sent: Friday, March 18, 2016 6:30 PM
To: dhss_HCBSTransition
Subject: Settings Ruling - Public Comment

To Whom it May Concern,

As a member of the Board of Directors of Kent-Sussex Industries, Inc., I am writing to submit a public comment relative to "settings'.

I feel strongly that individuals with disabilities and their families should have a choice in the setting in which they receive services.

The same setting is not appropriate for all and does not best serve individual needs.

The ISA or ISP should be a participant in determining the appropriate setting for service delivery to each individual.

Please consider these important points when deliberating on the final ruling relative to "settings" for the State of Delaware.

Thank you in advance for your consideration,

Dr. Donna L. Smith-Moore

March 21, 2016

Dear DMMA Director Stephen Groff,

I attended the second round of HCBS State Transition Plan hearings in NCC and Kent counties. I testified representing Families Speaking Up in Dover. Now I write as a family member and friend of adults with intellectual and developmental disabilities.

What struck me at both events was the number of parents who testified, some accompanied by their adult child with a significant intellectual/ developmental disabilities. All passionately advocated for their loved-one's CIVIL RIGHT to the CHOICE of day program or employment program *appropriate* for their particular needs and desires. The parents explained in detail why the sheltered work setting or day habilitation program was the right PLACE (with the RIGHT *PEOPLE)* providing the MOST POSITIVE & MEANINGFUL EXPERIENCE for their loved one. In each case, the adult child clearly lacked capacity to conduct their own affairs. The parent or guardian IS the VOICE for their adult child. Many of us who care deeply about and understand the issues affecting the profoundly intellectually disabled are concerned that the HCBS regulations are being so rigidly interpreted by the state of Delaware that these voices are not being heard or heeded. One parent challenged the state officials present to spend 24 hours with his or any of the other families present, and then decide if the HCBS regulations make sense.

I urge the state of Delaware to speak up for its most vulnerable citizens, and let the federal government know that certain of the HCBS regulations *may* very well work for physically disabled or "high-functioning" I/DD people. However, there are thousands of intellectually and developmentally disabled people for whom HCBS State Transition Plans could have dire consequences, many unintended but none the less terribly impactful. Extreme ideology and/or the desire to save money should not drive how our most vulnerable citizens are treated.

My brother, Eric, who recently passed away, lived through significant changes in public policy and societal attitudes toward those with intellectual and developmental disabilities. Born in 1947, he was fortunate to have parents who were determined to raise him themselves, not place him in a large institution. Other parents followed the advice given by many experts in the field then, that this was the best option for families and society at large. Certainly no one would want to return to anything like the worst of institutional care for those with I/DD. However, the current extreme swing toward "everyone in the community" is also troubling. During the greater part of the 20th century, it was "everyone into the institution". It appears to me that parents are again being told by the experts, "we know best" without regard to reality on the ground.

Eric had what is now called a "dual diagnosis" - which actually sounds too simple. His mental and physical challenges were many and complex. Not unusual for adults with I/DD, he was an uneven mix of almost-adult and an overly trusting, impulsive, and difficult young child. He was unable read or write, aside from his name. He had little comprehension of number or how to handle money. He tried mightily to do menial "mainstream" jobs but was overwhelmed by the stress of trying to "keep up", even with a job coach. Once he began to work at Elwyn of Delaware, he thrived. He could won(at nis own pace in a setting wnere people were '<Ina ana supportive. He was extremely proud of his work and his paycheck.

In January, when Eric was hospitalized after a serious accident, worried about when he would be able to return to "work". Although retired and attending a Service Source day program for seniors, he still spoke of going to "work". He enjoyed socializing, riding the exercise bike, drawing , listening to music, and just relaxing. "I'm retired now!" Eric would say, but he had *always* been a hard worker. This was an important value within our family that he took to heart. Referring to his senior program, he would also say: "I help the staff. I don't know what they would do without me!" Eric was active in the broader community as well, with supports from Mosaic, his service provider. He was an enthusiastic volunteer and talented artist. A host of skilled and compassionate people made his full and meaningful life possible. He also knew I was there when he needed me, serving as his advocate and legal guardian. We were brother and sister but also life-long friends. He was loved by so many.

During Eric's last hours on earth, he wanted me to know how vital his work was to him. As I think of his peers working in workshops today, I am reminded how deeply interwoven their work is into the fabric of their lives.

Regarding facility-based day habilitation programs for those who cannot work: At the hearings, I heard providers and parents express their dismay that physically and mentally vulnerable individuals might be required to spend the majority of time each day "in the broader community". They described quite graphically how stressful and upsetting it was for these individuals to leave settings where they felt safe & secure. Transitions of any kind are very difficult for them, and because of the severity of their disability, they cannot be "trained or "educated" in the "normal" sense, no matter how we might wish it. Also voiced were worries about the extra transporting in vans each day - the added costs and the added risks.

Facility-based programs that are vibrant and well-run, where participants are flourishing and *choose* to be there, should not be closed. These providers should not be required to ferry participants around in vans in order to satisfy a current public policy "fad"!

If these public hearings are to have any real meaning, those speaking for the voiceless in Delaware need to be listened to.

To quote playwright Arthur Miller: "Attention must be paid!"

Sincerely,
Lisa J. Elias

From: Vivian J, Turner, MPA
Sent: Tuesday, March 22, 2016 11:45 AM
To: William Holland
Subject Re: HCBS Transition Team Updates

Thank you very much for taking the time to respond to the HCBS Transition Plan on behalf of your son and others attending C.E.R.T.S., Inc.

It is very much appreciated!
Warmly,

Vivian 7. Turner, MPA
Executive Director

[redacted]

On Mar 22, 2016, at 11:27 AM, William Holland [redacted]> wrote:

We have a son attending the CERTS program ([redacted]) and we would like to respond to the Delaware Mandate.
We don't have comprehensive knowledge of the actual specifics of the mandate as it pertains to the type and extent of community exposure. However, we are aware of the limitations that are present with a majority of CERTS participants in which extended (possibily 2 hours or more) would be extremely difficult for their medical and emotional needs. While we believe we understand what the intent of the mandate is we do believe there are a number of individuals who would not benefit from the objective. We believe there should be specifically described afflictions or medication needs for those who should be exempt from the mandate.

As information, we have observed the care, treatment and environment provided by the CERTS Smyrna Del facility and it is brightly lit, well appointed and staffed, with cheerful, caring staff members.

We hope our continents are helpful.

Sincerely,

William and Rosemary Holland
[redacted]

From: Naomi Schwartz <[redacted]
Sent: Tuesday, March 22, 2016 12:05 AM
To: DMMA_PublicHearing
Subject: Suggestions for [redacted]

Hi,

Hopefully this is the best way to reach you.

I found your website while looking for tips for teaching kids sustainability and wanted to say that I found your page here: [redacted] - to be a very helpful source of information. Thanks for putting it together!

I see myself as a serious advocate of sustainability and I want to teach my kids, [redacted] and [redacted], about being aware of their impact on the environment as they grow up.

By the way, I found a couple of useful resources while reading up online and I think they can be good additions to that page as well:

Guide to Sustainability & Recycling for Kids [redacted]

Ollie Recycle's
[redacted]

Thought I'd return the favour by recommending those links to you for the benefit of your visitors. Let me know if you like them?

Many Thanks!
Naomi

From: Cherry Kathie <[redacted]
Sent: Tuesday, March 22, 2016 9:30 AM
To: DMMA_PublicHearing
Cc: Robert Overmiller [redacted]Strauss, Wendy (K12); Brian Hartman ([redacted]
Subject: Draft Home and Community-Based Services (HCBS) Settings Transition Plan Updates
Attachments: GACEC Letter Endorsing DLP Letter on 19DE Reg782 HCBS Transition Plan Updates 3-21-16.doc; BJH Comments on HCBS settings plan 3-14-16.pdf

Importance: High

On behalf of Robert Overmiller, chairperson
Governor's Advisory Council for Exceptional Citizens (GACEC)

Please accept the attached letter of endorsement from the GACEC on the commentary provided by Brian Hartman, Esq. of the Disabilities Law Program. A copy of Brian's commentary is also attached for your reference. A hard copy of the letter will be sent via U.S. Mail. Thank you for this opportunity to share our input.

Kathie/P. Cherry
Governor's Advisory Council for Exceptional Citizens (GACEC)
[redacted]

It's Here l - the DelAWARE DisABILITY HUB website

[redacted]

Governor's Advisory Council for Exceptional Citizens (GACEC)
[redacted]

MEMORANDUM

DATE: March 21, 2016

TO: HCBS Transition Plan Updates
Division of Medicaid and Medical Assistance
Planning, Policy and Quality Unit

FROM: Robert D. Overmiller, Chairperson
GACEC

RE: Draft Home and Community-Based Services (HCBS) Settings Transition Plan Updates, 19 DE Reg. 782 (February 1, 2016)

The Governor's Advisory Council for Exceptional Citizens (GACEC) has reviewed and would like to endorse the March 14, 2016 commentary provided by Brian J. Hartman of the Disabilities Law Program on the HCBS Transition Plan Updates, published as 19 DE Reg. 782 in the February 2016 Register of Regulations. The GACEC agrees with the observations provided by Mr. Hartman and thank him for his analysis. A copy of the memorandum from Mr. Hartman is attached for your reference.

Members and staff of the GACEC worked with the Division of Developmental Disabilities Service (DDDS) on the Transition Plan and resulting provider surveys and will continue to be involved with the process of monitoring and providing advice on behalf of citizens with disabilities. We thank DDDS and DMMA for the opportunity to share our input.

Thank you for your time and consideration of our observations. Please feel free to contact me or Wendy Strauss should you have any questions.

Attachments

CLASI
DISABILITIES LAW PROGRAM
COMMUNITY LEGAL AID SOCIETY, INC.
[redacted]

MEMORANDUM

To: DMMA Planning, Policy 8c Quality Unit

From: Brian J. Hartman, Project Director, Disabilities Law Program

Re: Comments on HCBS Transition Plan, 19 DE Reg. 782 (February 1, 2016)

Date: March 14, 2016

I am submitting the following comments on the Delaware Statewide Transition Plan in response to the DMMA solicitation appearing at 19 DE Reg. 782 (February 1, 2016). Given time constraints, the comments should be considered preliminary and non-exhaustive.

General! Each page in the State Transition Plan ("STP") has been dated "February 1, 2016". However, many pages have not been updated and refer to plans and expectations from 2015. This is confusing. Perhaps each page should have a "revision" date so it would be clear that some original pages reflect planning as of March, 2015 and some pages contain updated information as of a later date.

13. 1: In the "Introduction" section, DHSS could consider embellishing the "core values" discussion by including some explicit references and/or quotes from the DD Bill of Rights (16 Del.C. Ch. 55) and the Employment First Act (19 Del.C. §§(740-747) confirming State public policy. Proponents of the "status quo" and interest groups espousing a "low expectations" approach could easily overlook the consistency in values contained in State law and the CMS "Community Rule".

Consider the following examples:

> §5502. Persons diagnosed with intellectual disabilities or other specific developmental disabilities have the right to proper medical care and physical restoration and to such education, training, habilitation, and guidance as will enable them to develop their abilities and potentials to the fullest possible extent, no matter how severe their disability may be.

KENT COUNTY [redacted] [redacted]
SUSSEX COUNTY [redacted] [redacted]
DELAWARE'S PROTECTION AND ADVOCACY SYSTEM FOR PERSONS WITH DISABILITIES

> §5503. Persons diagnosed with intellectual disabilities or other specific developmental disabilities have a right to strive for productive work in meaningful occupations, economic security and a decent standard of living.
>
> §741. All persons, including persons with disabilities, have a right to the opportunity for competitive employment. In order to achieve meaningful and competitive employment for persons with disabilities, employment opportunities in fully-integrated work settings shall be the first and priority option explored in the service planning for working-age persons with disabilities.
>
> §743. It is hereby declared to be the policy of this State that competitive employment in an integrated setting shall be considered its first and priority option when offering or providing services to persons with disabilities who are of working age. All state agencies that provide services and support to persons with disabilities shall follow this policy and ensure that it is effectively implemented in their programs and services.

Moreover, the Plan contains many references to a goal of promoting employment paying at least the "minimum wage" (pp. 4, 5, and 6). As an update, a reference to current State legislation to raise the minimum wage could be mentioned. S.B. No. 39 passed the Senate in January, 2016 and represents an initiative which would benefit many individuals enrolled in HCBS waivers.

It would be informative to update the 2014 figures on enrollment in the DDDS waiver and DSHP and DSHP+ programs (by footnote or otherwise). It would also be informative to provide recent statistics demonstrating DHSS success in transforming its service delivery system to one which is predominantly community-based. See Secretary's FY17 JFC presentation, p. 5 (littp://www.dliss.delaware.gov/dhss/fiscalyearjfchearingsecretary.pdf).

p. 11: In two documents, CMS requested DHSS to provide information concerning plans and strategies to assure ongoing compliance after March, 2019:

> Please provide a step-by-step approach (supported with precise timeframes) for both provider remediation and compliance activities (based on a provider's approved CAP), and ongoing compliance after the March 2019 deadline.

September 24, 2015 CMS letter to DMMA, p. 2. [emphasis supplied]

> Please amend the STP to provide a step-by-step approach (supported by precise timeframes) for both provider remediation and compliance activities (based on the provider's approved CAP), and ongoing compliance after the March 2019 deadline. In the approach, please describe how often monitoring will occur, whether it will be integrated into existing licensing processes, and what specific tools and processes the state will use to ensure compliance of settings.

STP, Attachment 5, p. 2. [emphasis supplied]

I infer that CMS would prefer to deter "backsliding", i.e., achieving compliance by March 17, 2019 but discontinuing efforts to promote continuing compliance after that date. In contrast, the Plan contains an "end date" of March 17, 2019 throughout the document. See. e.g., pp. 11 and 18. Page 70 would also benefit from clarification that activities would extend beyond March 17, 2019.

p. 11: There is some "tension" between identification of a March, 17, 2019 end date to "implement remediation strategies" on p. 11 with a different targeted "end date" of July 31, 2018 for implementation of provider CAPs on other pages. Compare pp. 37, 56, 62, 68 and Attachment 5, p. 3.

pp. 13-14: The list of State laws, regulations, and policies on pp. 13-14 could be updated based on the content of the STP, Attachment 6, including a reference to the IBSER regulations. [Attachment 6, p. 26] See also p. 39.

p. 15: The IBSER-regulated program should be added to the buffeted list of settings subject to review.

pp. 15-17: There are several references to planned development of an appeal process for providers to dispute findings. Since reports with findings are due by March 31, 2016 (p. 26), the appeal process should have been developed by now and should be described. The time line for development is omitted from the matrix on p. 26.

D. 17: The following statement is contained on this page: "Any Corrective Action Plans and other strategies identified in Phase 4 must be fully implemented by March 17, 2019 so that the entire waiver service delivery system will be compliant with the Community Rule." This date does not conform to the July 31, 2018 target adopted in other sections. See comments on p. 11 above.

p. 23: The review of DDDS and DLTCRP regulations by these divisions is "underinclusive". The DDDS waiver covers children between the ages of 12-17 (p. 3). Such children served in an entity (AdvoServ) covered by the adult IBSER regulations are covered by DSCY&F regulations. See 16 DE Admin Code 3320.2.0 and 9 DE Admin Code 105. The DSCY&F regulations have not been identified for review.

p. 23:The following recital appears on this page: "Advisory Council to DDDS will review and must approve any DDDS strategies for remediation." The Advisory Council should not be accorded the authority to "trump" or "overrule" DDDS decisions. Under its enabling law (29 Del.C. §7910), it an advisory body to DDDS.

p. 24:CMS questioned the "distant" target of January 13, 2017 to complete legislative revisions. [Attachment 5, p. 3]. The State is now extending that "distant" date for legislative changes to March 17, 2019 (p. 24). The State completed its review of the landlord-tenant code by April 30, 2015 (p. 22) and contemplates completion of its review of other laws by March 31, 2016. It should not take three (3) years to effect legislative revisions. The STP would also benefit from some interim targets rather than a single global target (March 17, 2019) for all legislative changes.

o. 24: The "end date". for DDDS to revise the monitoring tool used by the DDDS Office of Quality Improvement to include the HCBS settings requirements is July 1, 2016 (pp. 24 and 28). There is some "tension" between that Office conducting "look behind" reviews of providers by May 31, 2016 (p. 26) and development of the monitoring tool by July 1, 2016 (p. 39). Ideally, it would be preferable for the Office to have finalized and been trained in using its assessment tool to assist with the "look behind" assessments to be completed by May 31, 2016.

p. 26: The May 31, 2016 date to complete "look behind" reviews (p. 24) is different than the date to complete "look behind" reviews (March, 2016) identified on p. 34.

p. 27: The status of the new home being built with an expected December 31, 2016 move-in date is not provided. See also pp. 38 and 56 and Attachment 5, p. 4. It would be useful to know the status of construction.

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Attachment 6, p. 7: The "day hab" section of the matrix has a"freedom from coercion and restraint" section. It omits the IBSER regulations which cover the day program of the covered entity. See 16 DE Admin Code 3320.3.0 (definition of "resident). The IBSER regulations address restraint in detail. See 16 DE Admin Code 3320.20. The Plan focuses on the IBSER regulations only in the context of residential settings (pp. 26 and 29).

Attachment 6, pp. 10-18: If there is a standard DDDS contract with appendices for providers of prevocational services, it should be included in the matrix and assessed for compliance with the CMS Community Rule. See comments on Attachment 6, pp. 2-9.

Attachment 6, pp. 19-43): If there is a standard DDDS contract with appendices for providers of residential services, it should be included in the matrix and assessed for compliance with the CMS Community Rule. See comments on Attachment 6, pp. 2-9.

Attachment 6, pp. 19-43: Although the IBSER regulations are mentioned, an accurate assessment of domains can only be completed through a review of other documents. For example, in the "food domain" (p. 39) the program regulated by the IBSER regulation has "levels" systems in which preferred foods may have to be "earned". Similarly, in the "choice" domain (p. 32), phone access at preferred hours may have to be "earned".

Attachment 6, p. 22: The State assesses itself as compliant with the following domain: "The individual receives services in the community with the same degree of access as individuals not receiving Medicaid HCBS." It solely cites the following regulation as documentation of compliance: "4.2.1.5. The individual has access to all areas of his/her environment." I do not understand how this regulation can serve as the sole basis for the State's conclusion that it meets the domain.

Attachment 6, p. 35: A corollary to the "choice of roommates" standard is whether an individual could opt to have no roommates (e.g. live alone). This is partially addressed on p. 24 but is not very clear. In practice, my impression is that few waiver participants are offered the option of their own unit.

cc: Kyle Hodges
Pat Maichle
Wendy Strauss

E:leg/hcbscomnients3 16
F:leg/201 6P&L/hcbscomments3 1 6 E:leg/hcbscomments316

From: William Holland <[redacted]
Sent: Tuesday, March 22, 2016 11:28 AM
To: DMMA_PublicHearing
Cc: [redacted]
Subject: HCBS Transition Team Updates

We have a son attending the CERTS program ([redacted] and we would like to respond to the Delaware Mandate.
We don't have comprehensive knowledge of the actual specifics of the mandate as it pertains to the type and extent of community exposure. However, we are aware of the limitations that are present with a majority of CERTS participants in which extended (possibily 2 hours or more) would be extremely difficult for their medical and emotional needs. While we believe we understand what the intent of the mandate is we do believe there are a number of individuals who would not benefit from the objective. We believe there should be specifically described afflictions or medication needs for those who should be exempt from the mandate.

As information, we have observed the care, treatment and environment provided by the CERTS Smyma Del facility and it is brightly lit, well appointed and staffed, with cheerful, caring staff members.

We hope our comments are helpful.

Sincerely,

William and Rosemary Holland
[redacted]

From: Shronda Bynum [redacted]
Sent: Tuesday, March 22, 2016 1:48 PM
To: DMMA_PublicHearing
Subject: my concerns DELAWARE

March 22, 2016

Greetings to All,

I want to take the time out and address my concern for the Community Based Setting ruling. First I would like you to know that my heart goes out to the many parents and loved ones that shared their sincere stories with us back on March 7, 2016 at the DMV building. I could only imagine having to think about this final ruling day and night stressing about the deathly change. Knowing that their loved one is currently in a great location, being social and having trips that they like and someone wants to disrupt their lifestyle and bring stress to the families.

I come to you as a taxpaying citizen and a person that has a genuine connection to many genres of people. One of my concerns is for my friends, who also are taxpaying citizens and are able to work because of great places like Kent Sussex Industries and Easter Seals (just to name a few). If you take away a safe, social setting for their daughter and force her home, well I can tell you now the family will suffer. My friends daughter needs to eat and her wheelchair it is not accessible throughout some of the home especially in the kitchen. So would their daughter be able to get food for alone? NO would she have access to the refrigerator? NO! So do you think that the mother or father can afford to quit their job? NO! I really do not know what they would do if their daughter does not have a trusted, comfortable and safe day program.

How can people who need income afford to have someone come to their house each day, while they are working? Who is going to pay for that private service? Wouldn't a private service cost more than a day program, which is designed for several people rather than one? What would the private service do in engage that person into social groups? How could that private service provide the transportation, the fuel and the necessary equipment to transport? If a person needs medicine at a certain time of the day, who is going to administer that? A private RN? Who is paying for that service on top of all the other private services?

What happens to a person when you force them to do something they do not want to do? Some regress, become behavioral, and stop participating in the main functions of daily living, such as eating or drinking.

What is going to happen to all these 18-21 that are getting diplomas or attendance certificates? Where are they to go? Some need to work on some skill before getting that integrated community job and some others have no desire, so do you force them to become alone in a house with no one to assist them (especially in DE we have working families). Families care too much for their loved ones and want them to have a happy prosperous lifestyle doing the things they are fully capable of doing and obtaining some things to make them better. So why invest in their educational process in being a viable part of the community if they won't have the opportunity to make choices of how they want to love their life.
Please consider that Delaware is not ready for this mandated change and it would affect more families in harm than in good. Our country always says "God Bless These United States" and I'm going to say especially DE!

Shronda Bynum
Dover Resident

MEMORANDUM

DATE: March 22, 2016

TO: HCBS Transition Plan
DMMA Planning, Policy & Quality Unit

FROM: Daniese McMullin-Powell, Chairperson
State Council for Persons with Disabilities

RE: 19 DE Reg. 782 (HCBS Transition Plan)

The State Council for Persons with Disabilities (SCPD) has reviewed the Department of Health and Social Services/Division of Medicaid and Medical Assistance's (DMMAs) revised Statewide Transition Plan (Plan) for Compliance with Home and Community-Based Services (HCBS) Setting Rule. The "Notice of Public Comment Period" was published as 19 DE Reg. 782 in the February 1, 2016 issue of the Register of Regulations. The Plan is required to comply with the Centers for Medicare and Medicaid Services (CMS) final rule related to Home and Community Based Services (HCBS) for Medicaid-funded long term services and supports provided in residential and non-residential home and community-based settings.

SCPD endorses the enclosed March 14th letter regarding the Plan submitted by the Disabilities Law Program. In addition, as Delaware moves forward in its efforts to comply with the CMS rule, SCPD encourages the State to strictly follow the Olmstead guidance on integrated v. segregated settings and the CMS guidance on settings that have the effect of isolating individuals receiving HCBS from the broader community.

Thank you for your consideration and please contact SCPD if you have any questions or comments regarding our observations on this most important issue.

cc: Ms. Rita Landgraf
Mr. Stephen Groff
Ms. Jill Rogers
Mr. Glyne Williams
Mr. Brian Hartman, Esq.
Governor's Advisory Council for Exceptional Citizens
Developmental Disabilities Council

19reg782 dmma-hcbs transition plan 3-22-16

STATE OF DELAWARE
STATE COUNCIL FOR PERSONS WITH DISABILITIES
MARGARET M. O'NEILL BUILDING
[redacted]
[redacted]
[redacted]

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19reg782 drama-hcbs Transition plan 3-22-16

CLASI

DISABILITIES LAW PROGRAM
COMMUNITY LEGAL AID
SOCIETY, INC.

[redacted]

MEMORANDUM

To: DMMA Planning, Policy & Quality Unit

From: Brian I. Hartman, Project Director, Disabilities Law Program

Re: Comments on HCBS Transition Plan, 19 DE Reg. 782 (February 1, 2016) Date:

March 14, 2016

I am submitting the following comments on the Delaware Statewide Transition Plan in response to the DMMA solicitation appearing at 19 DE Reg. 782 (February 1, 2016). Given time constraints, the comments should be considered preliminary and non-exhaustive,

General: Each page in the State Transition Plan ("STP") has been dated "February 1, 2016". However, many pages have not been updated and refer to plans and expectations from 2015. This is confusing. Perhaps each page should have a "revision" date so it would be clear that some original pages reflect planning as of March, 2015 and some pages contain updated information as of a later date.

In the "Introduction" section, DHSS could consider embellishing the "core values" discussion by including some explicit references and/or quotes from the DD Bill of Rights (16 Del.C. Ch. 55) and the Employment First Act (19 Del.C, §§(740-747) confirming State public policy. Proponents of the "status quo" and interest groups espousing a "low expectations" approach could easily overlook the consistency in values contained in State law and the CMS "Community Rule".

Consider the following examples:
§5502. Persons diagnosed with intellectual disabilities or other specific developmental disabilities have the right to proper medical care and physical restoration and to such education, training, habilitation, and guidance as will enable them to develop their abilities and potentials to the fullest possible extent, no matter how severe their disability may be.

KENT COUNTY
SUSSEX COUNTY [redacted]

DELAWARE'S PROTECTION AND ADVOCACY SYSTEM FOR PERSONS WITH DISABILITIES

> §5503. Persons diagnosed with intellectual disabilities or other specific developmental disabilities have a right to strive for productive work in meaningful occupations, economic security and a decent standard of living.
>
> §741. All persons, including persons with disabilities, have a. right to the opportunity for competitive employment. In order to achieve meaningful and competitive employment for persons with disabilities, employment opportunities in fully-integrated work settings shall be the first and priority option explored in the service planning for working-age persons with disabilities.
>
> §743. It is hereby declared to be the policy of this State that competitive employment in an integrated setting shall be considered its first and priority option when offering or providing services to persons with disabilities who are of working age. All state agencies that provide services and support to persons with disabilities shall follow this policy and ensure that it is effectively implemented in their programs and services.

Moreover, the Plan contains many references to a goal of promoting employment paying at least the "minimum wage" (pp. 4, 5, and 6). As an update, a reference to current State legislation to raise the minimum wage could be mentioned. S.B. No. 39 passed the Senate in January, 2016 and represents an initiative which would benefit many individuals enrolled in HCBS waivers.

0. 3: It would be informative to update the 2014 figures on enrollment in the DDDS waiver and DSHP and DSHP+ programs (by footnote or otherwise). It would also be informative to provide recent statistics demonstrating DHSS success in transforming its service delivery system to one which is predominantly community-based. See Secretary's FY17 JFC presentation, p. 5 (http://www.dhss.delaware.gov/dhss/fiscalyearjfchearingsecretary.pdf).

p. 11: In two documents, CMS requested DHSS to provide information concerning plans and strategies to assure ongoing compliance after March, 2019:

> Please provide a step-by-step approach (supported with precise timeframes) for both provider remediation and compliance activities (based on a provider's approved CAP), and ongoing compliance after the March 2019 deadline.

September 24, 2015 CMS letter to DMMA, p. 2. [emphasis supplied]

> Please amend the STP to provide a step-by-step approach (supported by precise timeframes) for both provider remediation and compliance activities (based on the provider's approved CAP), and ongoing compliance after the March 2019 deadline. In the approach, please describe how often monitoring will occur, whether it will be integrated into existing licensing processes, and what specific tools and processes the state will use to ensure compliance of settings.

STP, Attachment 5, p. 2. [emphasis supplied]

I infer that CMS would prefer to deter "backsliding", i.e., achieving compliance by March 17, 2019 but discontinuing efforts to promote continuing compliance after that date. In contrast, the Plan contains an "end date" of March 17, 2019 throughout the document. See. e.g., pp. 11 and 18. Page 70 would also benefit from clarification that activities would extend beyond March 17, 2019.

p. 11: There is some "tension" between identification of a March, 17, 2019 end date to "implement remediation strategies" on p. 11 with a different targeted "end date" of July 31, 2018 for implementation of provider CAPs on other pages. Compare pp. 37, 56, 62, 68 and Attachment 5, p. 3.

pp. 13-14: The list of State laws, regulations, and policies on pp. 13-14 could be updated based on the content of the STP, Attachment 6, including a reference to the IBSER regulations. [Attachment 6, p. 26] See also p. 39.

p. 15: The IBSER-regulated program should be added to the bulleted list of settings subject to review.

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p. 17: The following statement is contained on this page: "Any Corrective Action Plans and other strategies identified in Phase 4 must be fully implemented by March 17, 2019 so that the entire waiver service delivery system will be compliant with the Community Rule." This date does not conform to the July 31, 2018 target adopted in other sections. wee comments on p. 11 above.

p. 23: The review of DDDS and DLTCRP regulations by these divisions is "underinclusive". The DDDS waiver covers children between the ages of 12-17 (p. 3). Such children served in an entity (AdvoServ) covered by the adult IBSER regulations are covered by DSCY&F regulations. See 16 DE Admin Code 3320.2.0 and 9 DE Admin Code 105. The DSCY&F regulations have not been identified for review.

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p. 24: CMS questioned the "distant" target of January 13, 2017 to complete legislative revisions. [Attachment 5, p. 3]. The State is now extending that "distant" date for legislative changes to March 17, 2019 (p. 24). The State completed its review of the landlord-tenant code by April 30, 2015 (p. 22) and contemplates completion of its review of other laws by March 31, 2016. It should not take three (3) years to effect legislative revisions. The STP would also benefit from some interim targets rather than a single global target (March 17, 2019) for all legislative changes.

p. 24: The "end date". for DDDS to revise the monitoring tool used by the DDDS Office of Quality Improvement to include the HCBS settings requirements is July 1, 2016 (pp. 24 and 28). There is some "tension" between that Office conducting "look behind" reviews of providers by May 31, 2016 (p. 26) and development of the monitoring tool by July 1, 2016 (p. 39). Ideally, it would be preferable for the Office to have finalized and been trained in using its assessment tool to assist with the "look behind" assessments to be completed by May 31, 2016.

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Attachment 6. pp. 2-9. The section omits any reference and consideration of "Adult Day Care" regulations, 16 DE Admin Code 4402. I understand some DDDS clients are served in this setting. The section also omits any consideration of the standard DDDS provider contract. The standard FY16 DDDS "contract" with appendices for day programs is published on the Web. hssiddds/providercontract.htm Appendix A (Divisional Requirements: Day & Residential Program Services) contains many standards.

Attachment 4, p. 7: The matrix omits the PROBIS and HRC policies. The PROBIS and HRC committees are key DDDS entities protecting waiver participants from unjustified rights restrictions and chemical, mechanical, and physical restraints. *See* http ://www.dhss.delaware.gov/dhss/ddds/policy_administrative.html .

Attachment 6, p. 7: The "day hab" section of the matrix has a "freedom from coercion and restraint" section. It omits the IBSER regulations which cover the day program of the covered entity. See 16 DE Admin Code 3320.3.0 (definition of "resident'). The IBSER regulations address restraint in detail. See 16 DE Admin Code 3320.20. The Plan focuses on the IBSER regulations only in the context of residential settings (pp. 26 and 29).

Attachment 6. pp. 10-18: If there is a standard DDDS contract with appendices for providers of prevocational services, it should be included in the matrix and assessed for compliance with the CMS Community Rule. See comments on Attachment 6, pp. 2-9.

Attachment 6, pp. 19-43): If there is a standard DDDS contract with appendices for providers of residential services, it should be included in the matrix and assessed for compliance with the CMS Community Rule. See comments on Attachment 6, pp. 2-9.

Attachment 6, pp. 19-43: Although the IBSER regulations are mentioned, an accurate assessment of domains can only be completed through a review of other documents. For example, in the "food domain" (p. 39) the program regulated by the IBSER regulation has "levels" systems *in* which preferred foods may have to be "earned". Similarly, in the "choice" domain (p. 32), phone access at preferred hours may have to be "earned".

Attachment 6, p. 22: The State assesses itself as compliant with the following domain: "The individual receives services in the community with the same degree of access as individuals not receiving Medicaid HCBS." It solely cites the following regulation as documentation of compliance: "4.2.1.5. The individual has access to all areas of his/her environment." I do not understand how this regulation can serve as the sole basis for the State's conclusion that it meets the domain.

Attachment 6, p. 35: A corollary to the "choice of roommates" standard is whether an individual could opt to have no roommates (e.g. live alone). This is partially addressed on p. 24 but is not very clear. In practice, my impression is that few waiver participants are offered the option of their own unit.

cc: Kyle Hodges
Pat Maichle
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From: Lotus Cheng Brown <[redacted]
Sent: Wednesday, March 23, 2016 8:51 AM
To: DMMA_PublicHearing
Subject: HCBS Transition Plan Updates-resubmitted due to FAX failure

To whom it may concern:
My son [redacted]age 26, is quadriplegic, cannot talk, is fed by feeding tube, uses diapers, and is mentally impaired - in other words, he requires total assistance in order to live, and his condition will never improve. Despite the fact that I had a full-term pregnancy at age 29 with no complications, and saw my obstetrician regularly, [redacted]l suffered 20 minutes anoxia at birth. We later brought a case of negligence which was settled out of court by the doctor's malpractice insurance.

[redacted] attends CERTS and has thrived there. He receives therapies, participates in appropriate activities, and socializes with the other participants. They are equipped to tube-feed him and change him when his diapers are soiled, re-position him in different seating arrangements when he is uncomfortable, and monitor him in case of seizure activity or
choking. He participates in the MOVE program which encourages him to bear weight, stand and use the gait trainer. The staff treat him with respect and interact enthusiastically with him.

From a practical standpoint it is unfeasible for [redacted] to spend daily time in the community. Our community is not readily handicap accessible. There are no facilities that are available for changing diapers - try to find an adult sized changing table in a public restroom! When I take [redacted] to appointments, even medical offices barely have elevators large enough or doors wide enough for wheelchairs to enter, let alone turn around, or doors that will stay open for us to get in with the wheelchair. Even the doors to the Dover office where the public hearing last summer took place did not accommodate wheelchairs due to a metal bar between the doors. What about all the extra vehicles that would need to be available to transport everyone in wheelchairs and additional equipment - Hoyer lift, feeding supplies and equipment, emergency medical supplies? How about the increased number of nurses that would have to accompany all of these medically needy people?

It is not medically safe for[redacted]to be in the community more. He is at risk for respiratory infections. If he is exposed to flu, he is at risk for pneumonia which results in hospitalization of at least a week. More transport increases risks of injury [redacted] worst injury was a severely broken arm due to travel in ambulance transport where the driver did not notice he was positioned incorrectly. Besides the risk of car accidents, moving in and out of vehicles increases the risk of physical injury.

For a person who does not eat on his own, cannot use his arms and legs and who will never be able to live independently, spending several hours DAILY outside of CERTS is a poor use of time. Why take a person who cannot eat on his own to places where there are restaurants, a person who cannot move to bowling alleys, skating rinks or mini-golf, or to shopping centers where he cannot buy things that he would use.

Finally, why would [redacted] need to spend more time in the "community"? Currently CERTS does take the participants out on excursions in the community, recreational time in parks and field trips. It takes a good 30 minutes just to get [redacted] in and out of his wheelchair - usually with 2 people. It takes just as long to change a diaper. A tube feed can be an hour. By the time everyone is loaded and ready to go outside, hours are used and for what? Just the preparation time for a trip takes up time that could be used for other therapeutic activities - working with switches, gait trainer, and physical therapy. Due to his condition, [redacted]s life span will most likely be shortened. Why risk shortening it more by exposing him to infections, or waste it exposing him to our commercialized society in exchange for therapies that will make his life more comfortable?

Thank you for this opportunity to speak.
Lotus Cheng Brown

3/7/2016

[redacted]

1,172

Fastenal pcs.

This is an example of [redacted] output for one day (at KSI
She treasured these notes from her supervisor, and keeps them on her dresser for weeks, because she knows they represent earnings and a pay check.

RK

[redacted]

Notice:

Our 56-year-old daughter [redacted] has been mentally challenged since birth.

She has been in sheltered workshops for most of her life in five (5) different states. She is currently a client at KSI Milford.

She loves her situation there. Most of all she looks forward to the bi-weekly pay check.

Tho she does not read (only recognizes brand names by colors and shapes) nor write (only prints her name and copies what others print) nor cipher (recognizes coins but not bills), she knows the pay check (whether large or small, she does not know) means she has the power to buy things.

If she loses KSI (has to do only volunteer work or ends up in a day care facility) she will be profoundly affected and suffer a serious setback.

If the alternative was <u>supervised</u> employment, this might be possible if the work was simple assembly, repetitive, and within her cognition.

Our concern is that any change does not result in a negative situation for [redacted].

Ron and Pat Secrest