Transcription of Everyday Lives Webinar 2016

September 22, 2016

Nancy Thaler, Deputy Secretary of the Pennsylvania Department of Human Services’ Office of Developmental Programs (ODP):

Good afternoon everybody! There’s a great group of folks on the phone, a nice list of people. Thank you for giving up an hour of your afternoon to listen to this webinar.

We are coming off a great conference last week, the Everyday Lives Conference. We had over 1,600 people there. It was sort of like a big wedding and a family reunion, a lot of people networking and learning together.
That conference was built on this document, the *Everyday Lives document*, which we officially released about a week before the conference. We wanted to follow up the conference – both for people who were there and people who were not there -- with a little talk about this document, what it means, what the next steps are, and where we’re going with it.
Then and Now

So that’s what I’m going to do over the next hour. A good part of my presentation are pieces of that document. I think the notice you got gives you a link to download the document yourself. Lots of people have been asking for them. We won’t be able to distribute them through this webinar. We are developing a distribution system, likely to include the county administrative entities (AEs) as a place where you can get them as well as some organizations and support coordinator entities. Our Family Network has them. We will be following up with a communication about how to get a copy if you don’t have one already.

The (Everyday Lives) document has history in it. It has history because it provides the context to understand: how we got to where we are now, what are we carrying from the past with us that we have to understand, and how can that help us in the future?

The first Everyday Lives was published 25 years ago now. It was the work of a planning advisory group, much as the new one is, a planning advisory group made up of a lot of the associations in the state. Although there were fewer then than there are now.

At this retreat that produced Everyday Lives, it was in the very early stages of inviting people with disabilities themselves to the table to tell us what life is like and what they want. That’s really old hat now, but in 1991 it wasn’t so much. So when people came to the table and we broke out in small groups, they started to tell us what life was like. A lot of people had been in institutions who were involved in this.

The values that came out of that were really a surprise to everybody except folks with disabilities. What they wanted out of life were not a bunch of new services and programs, but what they wanted out of life were some basic experiences that everybody else in the world enjoys. Thus the title “Everyday Lives.” Things like having control over personal decisions in one’s life and choice in who you live with
and what you do and being treated as an individual and assuming citizenship. Those core values in that palette really have served and (have been) very much alive in our system all of these years. (They still are.)

The planning and advisory committee that we have now, which is the Information Sharing Advisory Committee (ISAC) felt a need to revitalize and restate what’s important to and for people and where we’re going.

So the new Everyday Lives was developed again by the ISAC. However, a lot of work had been done in preparation for this. There were 265 people involved in the futures planning workgroups. I’m sure there are people on the phone today who were in some of those futures planning workgroups, all of them working on a different topic, a different concept, developing ideas.

So last summer we asked all those futures planning groups to formulate some high level recommendations they would recommend to the ISAC so that when we sat down at a retreat, we had the benefit of that work, and it was very valuable work.
The ISAC began the discussion by discussing families, individuals with a disability and families. There was something different about this *Everyday Lives* in 2016. The difference is what’s happened in the 25 years. In 1991 when we did *Everyday Lives* we were at the height of the deinstitutionalization movement. We were to a great extent a group home system; although we did family supports and we had started an in-home waiver. But we were oriented to residential services and oriented to individuals as they came out of institutions. We didn’t talk much about families. Families were involved, but in the 1991 process, but (it was) more as part of other associations. The 1991 document is exclusively what’s important to people with disabilities and how should their lives be.

But by 2016, the profile of our community system is different.

We have few people in institutions, (approximately) 800 and dropping. We serve (approximately) 53,000 people, and most of the people we serve are living with their families. And 75 percent of them are living with their families. When you realize that there are in our state about 200,000 people (eligible for ODP services) and we only serve 53,000, all the rest are living with their families or perhaps on their own. So you get the picture here. Families are really the long term support systems. What the service system does is assist and help them partner.

There are two foundational beliefs here behind *Everyday Lives*. They are pretty common statements.

One is that **we value (what is important to) people with disabilities and their families, who are striving for an everyday life.** We can’t take that for granted that we value people because we are coming out of a history – even a very recent history – where people are not valued. As people with disabilities know their place in society is always at risk. And so this expressively says we value people and their families AND we affirm in this document **the right for people to have an everyday life that is no different than any other citizen** in the United States, something that when you are disenfranchised and unempowered you can’t take for granted. So we have to affirm it and work on it.
There are a couple of pages of history displayed by the decade. It’s good to know history, for one thing to understand how much has been accomplished.

Back in the ‘60s when people were writing what then was the MHMR Act (of 1966), there was nothing. There were only state institutions or private institutions that people went to while they were waiting for the public institutions. In the midst of that dark time, when there were no options and no choices, people had the vision to write a law and pass a law that really changed Pennsylvania going forward forever. It established the community system.

Lots of laws have been passed, the ADA, the Education for All Handicapped Children Act. Many of these advances happened during times that weren’t that great, but people were still trucking along, forging ahead.
The history takes us all the way up to the current time. The next page shows us the 2000s and 2010s, all the way up to the Governor’s Executive Order on Employment and the ABLE Act, which was signed by the governor, and the fact that we’ve been able to change all of our regulations to change the language based on the term “intellectual disabilities.” So it’s a lot to be proud of, but mostly I like it because it says if we could do all that over those decades, there’s no limit to what we can do going forward.
As we go forward, as I said, this document is about people with disabilities and the families who support them.

The first values statement in the document is about and by people with intellectual disabilities who sat down and articulated a statement called “My life my way,” which are the things in life that are important to them in order to have an everyday life.

- The first two are control over all areas of my life and that people who support me honor that control and help me achieve that control. That I have choice about everything in my life and that my family and supporters and the community help me find out about opportunities from which to choose, and on it goes.
- Freedom, something we all like to take for granted, but something people can’t always take for granted.
- Stability. People want stability throughout their lives, not just a service or support today. Here is this statement “Nothing about me without me” because if I’m not engaged with people and not engaged in the life-changing decisions then they don’t feel they have it. Stability is not about there not being change. It’s about feeling like (I’m) in charge of the change.
- We have health and safety, being connected to other members in the community and on and on. I won’t read through all of them, but the desire for success, the opportunity for employment. All of these are the core values against which we design all of our services and measure our performance.
What is Important to Families?

The next slide is a statement, a reflection on families. There are a couple of things in this statement. It establishes that family is integral to an everyday life for each and every one of us.

We are all born into families. Sometimes we choose families that aren't our families, which of course complicates things in a service system. Somebody chooses somebody, and regards them as family, but they're not a guardian. They don't have legal standing. Do they come to the individual support meeting?

Here we're saying families come in all shapes and sizes and sometimes are chosen, and we must honor that. It says that if people are going to have an everyday life, remember most people live with their families, then the family's going to be a component of the everyday life and influence the quality of their life.

Families are at the table. They support their family member, but this says they need support. They cannot do it alone. They need information. They need advocacy skills. They need to be connected to other families. Three things we sometimes call the three buckets: Information, training and advocacy, and connections to other families.

I want to say here too that the discussion about these value statements was a difficult one because self-advocates do not view families as always helpful. We recognize that sometimes families are not helpful. Sometimes they're harmful. Basically, for all of us as adults, families don't necessarily know what our dreams and hopes are. We don't want to just presume that families can speak for people.

So the self-advocates and the families in the ISAC spent quite a bit of time and there are quite a few discussions sorting this out and coming to terms with recognizing that all are important.
Here are the family values:

- Families asking that their role be recognized, not that they be disregarded. Including if my son or daughter lives in a group home, I have a role as a family member and it’s an important role because I’m here for life.
- That the families are saying they need support and they need support throughout all the lifespan from when their son or daughter is a baby and little all the way through adulthood and through all those life changes.
- Here are families are asking for information, mentoring with other families.
- They are also asking for respect and trust.
- They are also asking for choice and control on behalf of their family member. This doesn’t say they want to make all the choices and be in control, but they’re seeking that on behalf of their family member. Again, creating a balance.
- They are looking for collaboration with everyone. Families want to be at the table. These are families now who have come through the education system, who have been at the IEP table who have had a tremendous amount of say in their child’s childhood, and expect to have a role going forward.

That draws providers and support coordinators and people in the service system into what is sometimes pretty mucky territory. We are supporting people who live with their families. We have to be part of the dialogue when the son or the daughter wants to date or get married and the family is nervous and doesn’t want it to happen. Or somebody wants to get a job and the family is afraid of losing the benefits. Or people simply want to go out with friends.
We know all of us have grown up in families. We know the tensions between children and their parents and adult children and their parents. We don’t see eye to eye. Our job will be to facilitate mutual understanding, problem resolution, conflict resolution as we support families and the individuals they serve. The point of supporting families is first and foremost is that people with intellectual disabilities and autism can master their own lives.
So with those values down, I’m going to do just two slides that have metrics in them.

The Information Sharing Advisory Committee (the ISAC) looked at the IM4Q ([Independent Monitoring for Quality](https://www.im4q.org)) data. So we have in this state and in every county, people (maybe you’re on the phone) who go out and interview people every year, a random sample of individuals with a structured interview. They are trained to do this, to collect information and get people’s points of view, to get their view of how their life is going and how supports are working for them.

We are one of I think now 43 states to do this. We can compare our data from year and year to ourselves. We also compare ourselves to other states.

Here are the results for a couple of areas that are important in the *Everyday Lives* document and in real everyday life:

- Let’s take employment. This colorful pie chart says that of everybody interviewed who was a working-age adult (not children and not people who would be retired), 14 percent of the folks interviewed had a job. It’s pretty much like this every year, around 14 percent. That’s really great. We’re about the national average.

  But other people that don’t have a job -- of that 86 percent that don’t have a job -- 38 percent of them say they want a job. Of that 38 percent that say they want a job, only 23 percent of them even have it in their service plan as a goal. So there’s a mismatch there. And there’s a lot of room for improvement here.

  So definitely over the next couple of years when the IM4Q teams go out and interview and we look at the results, what we want to see is: more people actually working at paid, competitive
jobs; more people who want a job; and that everybody who says they want a job has it in their goal, in their plan. So this is our opportunity for improvement.

- The other one on the right is about communication. This question is for people who do not communicate effectively through speech. That’s who was queried here. And of those people who don’t use speech, 67 percent do not have a formal communication system. They have no (well planned) system to substitute for speech. Of those who have a system, it doesn’t work always. So here’s an opportunity for us to improve as well. That is, get everybody a communication system, whether it’s sign language or cards or a Dynavox or an iPad. Whatever it is, that we enable everyone to express themselves and make sure they have the support, the assistive technology they need to do it.
So the next slide is about choice. This says that where you live really predicts how much choice you’re going to have. As you can see, people who live in their own homes have the highest score in choice making and it altered depending on the living arrangements.

This also hints to us what we ought to do to improve things. First of all we ought to help people live in the arrangements that give them maximum choice. And for those people who live in all these arrangements, all their scores could be 78. We want to see everybody -- no matter where they live -- with lots of choice and control over their lives.

The last one is about relationships: In my mind maybe the most important value in this whole document. Relationships are what keeps us healthy and safe, what makes us feel good and gives us purpose. What the IM4Q data tells us is that 78 percent of the people in Pennsylvania who were interviewed said they have friends who are not family or staff. That is really terrific.

You can see the comparison to the national data. We are at close to the national norm, a little above the national norm, which doesn’t mean there isn’t room for improvement. Somehow we are making it possible or at least we aren’t interfering with people having friends in their community.
VALUES IN ACTION: RECOMMENDATIONS

ISAC recommendations for *Values in Action* are built on the values, goals, expectations, and aspirations of people with disabilities and their families. The recommendations are a guide for ODP to develop policy and design programs for people with disabilities, families, providers of service, and advocates who support people to have an everyday life.

1. **Assure Effective Communication**
   Every person has an effective way to communicate in order to express choice and ensure their health and safety. All forms of communication should consider and include the individual’s language preferences and use of current technology.

2. **Promote Self-Direction, Choice, & Control**
   Personal choice and control over all aspects of life must be supported for every person. Choice about where to live, whom to live with, what to do for a living, and how to have fin all are key choices in life, as are seemingly small choices, such as what to eat, what to wear, when to wake up in the morning, and when to go to bed. It is important to be able to trust the people who provide assistance, to feel confident that they respect you and your right to manage your life, and to enjoy each other’s company.

   Self-determination works when individuals have clear and understandable information, opportunities to exercise choice, and assistance with making decisions when needed. Self-direction is only possible when family, friends, and people who provide support respect the individual’s preferences and their right to make mistakes and facilitate the implementation of the individual’s decisions.

The big part of this document is what the ISAC recommended. The ISAC came up with 13 recommendations. Six or seven come right out of the futures planning work groups. And then they added a few.

These are simply stated recommendations and why they are important. The ISAC has worked on a second document that people will see in the next couple of months, which are specific strategies and performance measures for each of the recommendations.

The ISAC is made up of all the associations, providers, families, advocates, self-advocates, support coordinators, and the counties.

This is jointly owned. It’s not ODP’s call to action. This is the call to action for everyone.

Let me walk through these rather quickly:

1. **Assure Effective Communication**
   It is intentionally number one. This references individuals’ language preferences, not only speech difficulties or impediments or a disability in communications, but also language preference.

2. **Promote Self-Direction, Choice, & Control**
   There are really two dimensions to this. One is making our self-direction model easier to use, the fiscal intermediary, the idea of hiring and firing your own staff and managing your own resources is to try to make that more user friendly. But the other dimension of self-determination has nothing to do with hiring and firing or managing a budget. It has to do with people having control over the most simple and intimate aspects of their lives, like when they get up and what they wear and what they eat, some of
those really daily things that we take absolutely for granted that often for people with disabilities are restricted.

That lack of choice is a stress in people’s lives and enough stress causes illness and depression. When any one of us does not have control over as much of our lives as we can, we typically get frustrated, anxious, depressed, unhappy, and not pleasant to be around. So this is a really core principal here, that people need to have as much say about their own destiny as they can.
3. Increase Employment
This is a no brainer. This is so much of what we’re all about.

I think we’re coming from decades when we didn’t think about employment to thinking people probably can’t work, to discovering that 14 percent of them already do, and we have no idea how many more people can. So we don’t know what the ultimate is, but we do know from other states that the numbers can go up. There are lots of reasons for this.

You know how important a job is to people when they introduce themselves to you as a worker someplace and they only work four hours a week. No matter how little the job or even volunteer work, people identify with this contribution they make to the community. You meet friends. You make money. You get out of poverty. You have a little money on the side. There is tremendous dignity and meaning. Talk about everyday lives and being part of your community.

4. Support Families Throughout the Lifespan
This is a declaration that we have to focus on families, supporting them so that they can support their family member to have everyday lives, and that we need our behavior to be supportive.

If you’ve been to any of the Employment Connection sessions around the state, they open it up with a little vignette, a little theater. They have a young woman who has disabilities going from office to office because she wants a job. She goes to school. She goes to OVR. Over and over she is referred to somewhere else. No one ever picks up the phone and says, “Let’s call together.” So it’s the behavior of supporting families, not the services for families. I’m going to talk about that a little later when I talk about next steps.
5. **Promote Health, Wellness, and Safety**

If we use the IM4Q data, it would tell us that 2/3 of the people that we support – 2/3 of the 53,000 -- are overweight or obese, and that they exercise very little. I think they walk twice a week. So we have lots of data that repeats itself year after year that says that we are serving 53,000 people, we’re spending $3 billion, and they’re generally overweight and get no exercise, which also is obviously not good health and wellness (or) for mental health. So we want to promote health and wellness and we don’t need money to do this. Every hour of community habilitation or companionship or every hour of residential habilitation can focus on health and wellness: being active, eating well, having good habits, and building good mental health. It is a focus that we need not services that we need. One of our plans here is through our HCQUs (Health Care Quality Units) to do this promotional kind of work, but also to measure people’s health and wellness.

6. **Support People with Complex Needs**

You all are very aware that we’ve got folks with either complex medical needs or complex behavioral needs. By complex we mean that it takes more than the average effort to support them and more than the average know how.

We have lots of providers in the state who do a great job supporting people and supporting families who have people with complex needs. But we need more and we need them to do more. We need to reach everybody, even folks who are at the most extreme ends of behavioral health issues. We have a bunch of strategies to build capacity in our state to do that.
7. Develop and Support Qualified Staff

We all know direct support staff are the core of the system. They need training, recognition, also some control over their lives, some say in their work environment, and adequate pay, a living wage.

8. Simplify the System

There are lots of components to this and the big one starts with simplifying the individual support plan. You all can imagine others: simplifying how we document claims, simplifying eligibility. Lots of parts of our program are overly complex, but it does start with the individual service plan.

9. Improve Quality

The ISAC after they published the recommendations are turning into a quality council for our system. For all of these recommendations they are developing metrics, the performance measurement. As a community that cares about people with disabilities and wants them to have an everyday life, we are going to hold ourselves accountable to each other by having the courage to measure whether we are making a difference or not and to plan changes if we are not making a difference. We will be releasing a quality management bulletin to strengthen, reactivate, and encourage the local quality councils that have gone on over the years to use data to measure whether we are making a difference and to change if we’re not. We can’t improve everything at once. We can’t do everything at once. But these groups can pick one, two, or three areas that they want to do better on as a community and focus on them for a couple of years.
10. Expand Options for Community Living
This is a recommendation to broaden how and where people live. Right now you live in a group home or you life with your family. Or if you live on your own you've got to do it with some community habilitation hours.

Two outcomes of this are to:

- Open up Lifesharing: to fund it better, to have better rates, to open it up to immediate families who can enroll in Lifesharing as a way of paying family caregivers, but in a better structured and supportive way. In Lifesharing, the Lifesharing provider that is the family or the person whose home it is gets support and training and guidance and respite care and behavioral support and so we want families to have those same benefits as well.
- Start a supported living service. Those of you who’ve been around a long time remember something called maybe minimal supervision or transitional living. It’s an option where people have their own apartment. They might live with somebody else. They don’t need somebody in their apartment all the time, only sometimes, maybe sometimes to stop in. But they do need an agency to watch out for them and make sure all parts of life are addressed from medical appointments to getting places on time to having people in their lives.

11. Increase Community Participation
I already talked about this a little bit. That is creating more service options, alternatives to the adult day and vocational training centers. You've already seen a hint of this. The new service definition in the amendment to our waiver that came out for community habilitation has a long laundry list of what community habilitation is. It’s not about teaching a skill. It can be that, but community habilitation is to help and assist people to participate in their community. That definition is wide ranging from meal planning and maintaining health and going to medical appointments to volunteering in the community to assisting with personal care to developing relationships. So (with) these services the delivery of community habilitation itself can increase community participation.
12. PROVIDE COMMUNITY SERVICES TO EVERYONE

Some people with disabilities — whether living on their own, with families, or in institutions — are waiting for community services. The goal is to build a system that has the capacity to provide services in a timely fashion for all people who need support.

13. EVALUATE FUTURE INNOVATIONS BASED ON EVERYDAY LIVES PRINCIPLES

Future considerations of service models and reimbursement strategies must be based on the principles of person-centered planning, individual choice, control over who provides services and where, and full engagement in community life. Innovative approaches should be evaluated based on the recommendations of Everyday Lives, including: employment, recognizing and supporting the role of families, and meeting the diverse needs of all individuals. Stakeholders should be fully engaged in designing, implementing, and monitoring the outcomes and effectiveness of innovative service models and service delivery systems.

12. Provide Community Services to Everyone

This of course includes people on the waiting list and people who are on the waiting list because they are in institutions or other kinds of facilities.

13. Evaluate Future Innovations Based on *Everyday Lives Principles*

What that means is if in the future Department of Human Services or state government decides it wants to go down some path like pay for performance or managed care or affordable care organizations or health homes or any of those modalities -- like our autism ACAP is a different payment model -- that no matter what that is, it should be based in these values, on these principles, and with these goals
The next thing is all the great pictures in the *Everyday Lives* publication. There are great stories about artists and workers and children, and Austin, who hired his sister, Tiffany. These are all stories that represent a vision and what’s possible. So I hope you read them and enjoy them.
This is the list of all the associations and the executive directors, the staff, and the people in these agencies and associations that have all joined together and are always there, all the time. Attendance is very high. They are very present, very engaged, and taking what we agreed to in the ISAC and in *Everyday Lives* back to their organizations and communicating it. So hats off and thank you to all of these people.
The Next Steps

- **Implement ISAC Recommendations**
- **Renewing Our Waivers** *
  - Incentivize employment
  - Promote full inclusion in the community
  - Greater supports for families
  - More independent living options

- **New Service Rates** *

- **Implement New Federal HCBS Rule**
  - Employment; inclusion and rights

- **Training**
- **New 6100 Regulations** *
  - Promote full inclusion
  - Reflect the HCBS Rule

- **Rollout Supporting Families Community of Practice**
- **ISAC serve as Quality Council and measure progress on Everyday Lives**

* Will be issued for public comment

Two more slides. This one is next steps. The next one is going to be a timeline. These are some next steps, not all the next steps. We are taking these recommendations very seriously. They are the foundations for the next bullet, which is how we are

- Renewing our waivers. Our waiver renewals will incentivize employment, and strongly promote inclusion in the community. There will be greater supports for the families and more independent living options.

  If you see a little asterisk – there are three items here that have asterisks -- that means they are all going to be issued for public comment in the future, and I’ll let you know when that is.

- New service rates are really part of renewing the waivers. When you renew waivers you have to refresh all of rates. We are doing that for every service, with an eye to not only what it costs, what staff salaries should be, and benefits, but what we want to see happen out there, what we want to incentivize.

- Implement the new federal rule. As I said, that’s not why we are doing anything, but we have to have an eye to it. Our transition plan to the federal (government) has been approved and our transition plan is that we will rewrite our waivers, create new service definitions to requirements and measure our performance against those waivers.

  Training, there will have to be lots and lots of training in all components of these waivers as we roll them out.

- We are going to publish in October sometime the 6100 regulation.

  The waivers and the regulations are going to be out there at the same time for comment. That’s a good thing. It’s going to be hard on all of you because it’s a lot to read and you might want to
split it up amongst yourselves, in your organizations. These must dovetail. What we change in one we have to change in another.

- Rolling out Supporting Families. As you recall, one of the recommendations was supporting families throughout the lifespan. We've initiated a collaborative. We sent invitations to all the counties, inviting them to participate in statewide collaboratives. Many, most, have responded positively. There's not a lot of money. There's virtually no money in this, but a lot of guidance and technical assistance and opportunities to talk to other people across the state and people across the nation. There are about 11 states involved in this Community of Practice. It's about making this system -- at the local level and the state level -- a system that families would walk away from saying, “Gee, I feel supported. I could find out what I needed to find out. I got training in the things I need training in. I got to talk to other families, and I got services not just from ODP, but from the community.” And so we are looking forward to launching that.

- Lastly, the ISAC is going to serve as a quality council, as I said, measuring our progress of *Everyday Lives.*
The very last slide is the timeline slide that shows these things rolling out.

The timeline starts back in 2015. The fiscal workgroup started in June (2015), but we just began this timeline starting in October (2015), when we went out in the field and had webinars and public forums asking people “What do you want in the waivers?” We used some of that in the more recent amendments, by the way. We had the fiscal work groups. We have Everyday Lives coming out. You can see as you progress across the timeline what will happen.

Our ultimate goal in March is to submit the waivers to CMS (Centers for Medicare & Medicaid Services) because they expire on June 30 (2017). We want CMS to have enough time to approve these waivers. They will be effective July 1 (2017).

In the green you see comments (that) we will be issuing notices of webinars. We are going to host a range of webinars when we release the waiver applications so that we can talk people through them. They can be complicated documents. We want people to know what’s in them and have an opportunity for back and forth before submitting comments.

We will be releasing the waivers in two sections, Appendix A-H, which are all the sections that relate to: eligibility, person-centered plans, all the services, self-direction, and protections. We will release that for comment. While people are commenting and sending comments in, we are going to be finalizing rates. Then Appendix I-J, which are the fiscal appendices, we will release for comments.

We will put in all those comments, publish the comments. We have to publish what we did with the comments as we submit the application to CMS. You can see we expect the waivers and the new rates to go into effect July 1, except for the residential rates, which will go into effect January of 2018. That’s so you can know what to expect. Actually, January 2018 is when the next Everyday Lives Conference is.