

LifeCourse in Action

University of Massachusetts  
Boston - Institute for Community Inclusion  
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Hi

(Current Time: 11:00 a.m., CT).

Note: Captioner standing by in waiting room.

>> Beth Wike: We're on webinar mode today. We'll be muted. All participants will be muted both video yes and as mic. And in your chat, we do have a captioner -- someone looking to -- they might be helping us with captioning. It looks like it's under my name as Beth Wike.

>> Oh, okay.

(Standby.)

>> Beth Wike: Anyone in need of language support, both Spanish and Portuguese is available. You will find those links. As I mentioned. All participants is

muted both video and microphone. So we welcome you to use the chats feature for any comments or questions you might have throughout the session.

We will be closely monitoring the chat and we welcome your engagement. My last note before we begin, for every additional session from this point on, you will be receiving materials ahead of time. So that will include the presentations as well as the tools and resources that we'll be touching on in each of these sessions.

At this point, I want to hand over to Ellen Kilicarslan who will introduce our team and today's session

>> Ellen Kilicarslan: Thank you and welcome during our lunch hour. I'm Ellen Kilicarslan. I'm the support director at DD SAT Department of Disability Services.

(Hosts unassigned captioner. ).

(Reassigned.)

>> Ellen Kilicarslan: She will.

>> Ingrid Flory: Thank you all for joining us today. And today is going to be a little bit of a different format than it will be going forward. In future sessions for this, it will be much more interactive and you'll have opportunities to really practice what you're learning.

But we really wanted to kick off this series with an overview that gives you a sense of how this connects to things that are happening in our state and actually throughout the country. So there's a big movement to support families and engaging in this work and learning about trying the life course and helping us to do better, you are joining that movement.

So I'd like to -- I'll share a little bit about that with you today. So let me just take a moment here. Get my PowerPoint started.

So we are -- Massachusetts is a community of practice for supporting families. It's a mouthful. I will explain to you exactly what that means and give you a little bit of the history of how it came to be.

So, again, our purpose is to show this series how we're sponsoring and how it connects to the bigger picture. So I'll start by telling you how this supporting families movement was really kicked off, and then how this thing called the Charting the LifeCourse framework helps us to do the work and helps us to implement this vision.

And then I'm going to talk a little bit about what's happening in the work around the country and what's happen anything Massachusetts and then how you can get involved if you're so interested.

So in -- as often happens, and I know this quote gets used a lot, but it's so true... (reading.) Indeed, it's the only thing that ever has. It's from Margaret Mead. It's a group of national leaders in the disability field who came together in 2011, who came together to create an agenda to better support people with disabilities and their families throughout the country.

And because what we know is that that most people with disabilities live with families. And although, there's lots of family support programs, more so in Massachusetts, than in many other states, there's still a lot of needs to better support families and people who are living with families. So this group of professionals came together and came out with a national -- developed this national supporting initiative.

Their goal was to come up with best practices and better ways to support people and their families throughout their lives, and really ensuring that community integration

was the standard for all of it. So making sure that we're not only focusing on -- on service that is are developed just with people with disabilities, but looking at how our communities can better support people.

So the vision created in 2011 was the overarching goals to achieve self-determination, confident in doing so, to have them -- lead productive lives and integrate with our communities and be really included in all aspects of their community life. At the same time, we want families to be supported in ways that maximizes their capacity, that builds upon their strengths, and helps them to support all their family members so they can achieve their goals.

And the report that came out of this meeting of minds identified three big ways to help people in supporting someone with a disability. And those are these three columns at the bottom. So the first is discovery and navigation. People need to know what's out there and how to access different supports and services.

They need to connect and network with each other. Because we know that sometimes talking with someone with the same lived experience as you cannot be replaced by the most well intentioned professional. And the third category is looking at all of our goods and services. How do we provide those day-to-day supports to live the best lives they can and live productive lives as they define it.

The other -- another piece that came out of this national agenda for supporting families was a core belief, a mission statement, that all people and their families have the right to live, love, work, play, and pursue their life aspirations in their community. You'll notice this isn't even disability specific. This applies to everybody. And that's one of the beauties of this framework and tools that we're talking about is that, it really -- it applies to anybody.

Another key part of this vision for how to better support families, looks at the system that is we have created. So here you'll see three different versions of concentric circles. You have the person surrounded by their family and then their community to represent that we all live within our families and communities, right? These are really important pieces to our lives.

This middle circle represents a lot of our traditional services, and with this one, we still have the person at the center but we still have a band of services that's between that person and their family and their community. And that represents the fact that unintentionally oftentimes are traditional services create barriers to people and their families and communities.

So our goal and the vision for the supporting families movement is to change that way of thinking, and to create services of supports that are sprinkled throughout someone's life so that they are there when and where they need them, so not only relying upon disability services, but relying on all different kinds of support that is everybody relies upon. Whether it's relationships, or different community activities, or technology.

There's so many different way that is we rely upon the world to support us and people with disabilities are no different. And we want to make sure that they have access to all different kinds of support because that's what's going to decrease those unintentional barriers and what's going to create better lives, that are more integrated into people's communities.

So this raises the question of how to do that. So what we really need to do is we have to change our system. And it can't just be a transitional change. A retooling of the system. We can't keep just like changing names and adding things on. We really have to think differently. And that requires more of a transformational change, right? Changing how we're thinking. Making sure our actions are in alignment with our values.

And that we're partnering with the people and families that we're supporting so that they can be telling us how to do our best work and make sure that the changes we're making, again, are in alignment with our values and with what people want.

That kind of transformational change isn't easy. So now, the question is, how do we do that? And this is where you hear about this thing called Charting the LifeCourse framework and tools. Because this -- this framework and tools was developed to help us to achieve that transformational change, to help us to change conversations, to help us problem solve in our lives, and to keep our actions in alignment with our values.

So the same group of people from different states and national organizations who came together to create this agenda for families, back in 2011 they developed what is new called Charting the LifeCourse framework and tools.

This idea of a framework, it's very conceptual. Really what we're talking about is a way of thinking that's based on values and beliefs. Right? So it's just -- it's a lens for which we can approach our work, it's a lens to help us to apply this in our own lives as well. And one of the things that's great about Charting the LifeCourse, is it also comes with tools and resources that help us to put it into action. So it's one thing to have lots of good theories and ideas.

But to also have concrete things that we can use to help put those beliefs into action. This is something that is different. And that's one of the reasons why this thing called Charting the LifeCourse has really taken fire throughout the country and increasingly in Massachusetts as well. I'll be speaking to that more a little bit later.

So I also want to mention that this framework and tools was developed by families, for families. The original founders of it, it was lead as a coalition effort by the University of Missouri, Kansas City who in partnership with the National Association of Developmental Disability directors and they continue to be leaders in the supporting families movement. And what is now called the community of practice for supporting families.

One of the things I appreciate is it builds upon a lot of community centered practices. And this is a ( ) person-centered theories and that had been used in the past. And Charting the LifeCourse builds upon all of these things, like social capital, person-centered practices, anticipatory guidance, definitely determination. These are all different concepts and Charting the LifeCourse builds upon that and builds it together into something that is easier to access.

Because it has those concrete tools to help you to implement. So that's some of the background and the theory. I'm going to give you -- I'm not going to teach you all of the Charting the LifeCourse framework and tools today, but I'm going to give you a flavor of the way people are using it and show you samples of some of the tools so you can get a sense of what it's like. And then in the future sessions for this life course and action series, what will be happening is we'll have different people presenting on how they're using.

Using these tools in useful ways. In their lives and in their work, and you'll have opportunities to practice them yourself. So this is an example of one of the tools and the principles, the values, where we want to make sure that everybody has an opportunity to attain a good life, however, they define it. And sometimes, that's as simple as asking people and their families what they want and what they don't want, what they want to avoid.

And having that be the starting point for any conversation, and any planning that we do with them, to help them to attain their goals.

These tools also help us to help people plan for different parts of their life. To be thinking beyond just health and safety which our system focuses on a lot. And to be, you know, helping us professionals to remember, to be asking people about what's important to you in your spiritual practices? What do you want for employment? Or what makes a meaningful day for you? What relationships are most important for you? And how can we support you in making sure that those relationships are established.

Established and maintained? So it helps to break down into category that is we all have so we can brainstorm around it and help us define that vision. Because sometimes -- it can be overwhelming when someone says, what do you want in your life? We all need a little bit more structure to that question Charting the LifeCourse also helps us to anticipate and prepare for different stages in life. DDS, the Department of developmental services, helps throughout their lives. So a lot of the work we do is helping people get ready for what's next. And this is something that -- obviously that even if you aren't supported by DDS, we all needed to do. And these are tools we need to do that.

And lastly, the Charting the LifeCourse framework and tools really helps people to identify and use different kinds of supports. So, I know within the Department of developmental services, we have to go right to -- what services can we offer? And those are wonderful services. How far they don't make for a rich life. We don't want people to -- we don't want people's lives to be defined by the services that they are eligible for.

We want those services to support a person's life at what they want it to be. And so, that requires much more holistic thinking about what's out there. So we're finding regularly new ways of using technology to help people use their goals and dreams. We want people to have relationships and friendships to help them keep them safe and happy. We want people to access what's in their community.

Whether it's faith-based organization or their parks and rec to make sure they can get around with transportation. So again, Charting the LifeCourse is helping us to problem solve in our lives, so that we can be using all these different types of supports that are available to us.

So I just through a lot at you, let me help connect the dots here. So we started with in 2011, a national agenda for supporting families was created, and that defined a vision. I should add that vision was revisited in 2022 and has been updated. That vision helped to create the charting life course framework and tools. It helped us to apply and implement that vision. And then there are a lot of professionals and families and people who said, okay, this is great, how do we do it and, how do we help each other do it. And that's.

And that's where they create add national life course of supporting families where states work together to work towards that vision and teach each other. So that's what I'm going to talk about now and I'll talk about what's happen anything Massachusetts.

So, what is this thing called? A community of practice. Communities of practice are groups of people who share a passion for something that they know how to do, and they interact regularly to learn how to do it better. So in this substance we all care ability supporting families. And the community is everyone. Right?

It's self-advocates, it's families, it's state departments, it's state departments on disabilities. It's other organizations that support people with disabilities, and we all get-together regularly so that we can learn from each other.

So again, what we care about is supporting families and transforming our service system so that people have support and services when and how they need them and always thinking about that person and family in this center. Who cares about it?

There are 22 states that are currently participating in supporting families. You'll notice that a few of them are colored lighter purple that's a different level of participation. But Massachusetts has been a full member state since 2019. So we are -- we've learned a lot and from all these other states, some of whom have been participating since 2011 or 12 or something like that, when it was first created.

And now what we do together, so, we have these two leaders. The University of Missouri Kansas City, and they're disability department, and then the national association of state developmental disabilities directors. That's a mouthful.

And they -- those are the two national department that is do these works. So they pull these together and facilitate to help us to learn from each other and improve our system. So this image pulls it together. So it's three concentric circles. In the center is that value statement that all people have the right to live, love, work, play, and pursue their life aspirations in this community.

That's the center for all this work. The second concentric circle has a lot -- has the principles, the values, from the Charting the LifeCourse framework. So people are using those to help them to -- achieve that goal, right? And then the third concentric circle is the -- is policy, culture and, practice. So that's a little bit more of the other end of things. Where we use those tools and that vision to improve policies and create new policies.

To change our organizational cultures and to change our practices, which is how we do our work. How we approach our work. Both with individuals and families.

So as I mentioned, we've been a member of the national community of practice since 2019. I'm going to share with you some of the work we've been doing.

So first of all, we -- one of the reasons we joined this community of practice is because that core belief of the supporting families community of practice of all people and their families have the right to live, love, work, play, and pursue their life aspirations in their community is in alignment with the Department of developmental disabilities mission statement. Which is to create in partnership with others, innovative...

Genuine opportunities for individuals with intellectual and developmental disabilities to participating fully in their communities and engage as members. So in departments, we're seeing -- this aligns with our mission, and now we have access to all these other states who are pursuing the same mission and, who are using this guiding framework and tools it help us to do it.

So the vision for Massachusetts community of practice is to create innovation and transformation that enhances support to individuals in the context of their family and community. We do this by using the Charting the LifeCourse framework and principles to support existing priorities for system change, to influence policy, practice, and procedure. So how we do our work and how it's defined.

And to empower families and their professional supporters to think differently and have different conversations that begin with the person and their family at the center. And make sure we aren't drifting from that, and lastly, to embed charting life course principles, those values, into existing planning processes to create a common language and person-centered thinking across agencies.

So the community of practice in Massachusetts is not only DDS, but the Department of developmental services. It also includes partners from lots of other organizations. And so it goes beyond just DDS. It goes beyond our family support programs, because we're not talking only about family support, we're talking about supporting families and changing our mindset and our approach to our work.

Some of the activities that have been having in Massachusetts include -- well, we're you're at right now, this life course in action series. We're looking to empower all people with information. Information about Charting the LifeCourse, information about supports that are available and the department realizes, we have some work to do in terms of getting out information ability our services in plain languages so it's better understood by the general public.

So we are in the process of creating plain language one pagers on services which will benefit everybody. We are partnering with other family organizations to adapt during the Charting the LifeCourse tools so that they are even more user-friendly for people better served and for advocates and for families who might have limited English.

So we want to make these accessible to everybody. We are -- the department is also increasing direct communication between DDS and families. We have a

s letter that has started. We are working to rely less on the provider agency that we fund and communicate more directly with families. And we've been working to train self-advocates and families from all different cultural backgrounds and lived experiences in Charting the LifeCourse.

So that they can be bringing that information to other people in their communities.

>> Beth Wike: Ingrid there's a question in the Q and A about how to get this information to teacher prep programs and to seasoned teachers already in the field.

>> Ingrid Flory: Hmm that's a good question. So I will be sharing some resources at the end. There is a lot of information available online that -- and there's a lot of -- I know teachers who are using this. So the Charting the LifeCourse framework and tools. And I can -- let me speak to that a little more when we talk about the resources.

So another focus of our work for the Massachusetts communities of practice and for families is looking for ways we can use Charting the LifeCourse framework and tools as a common language. Among different state agencies, among schools, among families. Because the great thing is, it's a way for people to communicate their vision and their priorities in their life and their support needs in a way that's very user friendly.

And they can bring that to whatever meeting they're going to. If it's an EEP meeting or IEP meeting. Whatever group of meeting their meeting with, people and their families can be using these. As a parent myself going to a lot of different planning meetings, that's also excite together me.

We have been embedding a lot of the Charting the LifeCourse in trainings and conferences and strategic planning. Just to make sure that our actions are aligning with our values and we are sharing information without this with people that might be interested. To find ways it might be helpful in their lives and their work. So and doing a lot of training with service coordinators and families. Just trying to get the word out to empower people with this information.

So, and in terms of influencing system change, we've been integrating these values and principles into a lot of our new initiatives. So our employment and day work are supportive technologies, new planning processes, and embedding it into some of our operations plans, and creating -- and then we've created an interagency statewide network for supporting families that have lots of different -- that is meant to create synergy and connect people.

Connecting people in terms of what's Charting the LifeCourse so we can support people and collaborating.

So I don't know if I have any Hamilton people out there, this is not a moment it's the movement. So if you're interested, you can be involved in this in different ways. You can learn how to use charting life course in your life and work in helpful ways.

So you can come to future sessions of this life course in action and we'll -- it will -- again, it will be more interactive, we have family members, we have professionals, we have advocates, we have great people coming and talking about how they're using this framework and tools in helpful ways, in their lives and in their work. And you'll have opportunity to help us using the tools. There's a lot of information on [lifecoursetools.COM](http://lifecoursetools.COM).



That is the hub for Charting the LifeCourse. You can view the Web site in different languages, and there's different topics. So if you're working with transition age youth, there's a section on that it's broken up by life stage or you can -- there's lots of instructional videos. It's all free. Available for download. They offer a lot of training, but you don't have to take any of it. You can just practice and kind of learn it on your own.

There's a Web site for the national community practice for supporting families. Called supporttofamilies.org. And Massachusetts has a page on that as well as every other state. You can learn a bit more of the history. You can read some of the reports that came out if you get into that, you know, that defines this national agenda that I spoke about at the beginning.

And then we have a state wide Web site that the arc of Massachusetts host it is a Web page that has some short videos that we had made that are -- that are just good examples of why's that people are using Charting the LifeCourse. It has a message from commissioner Jane Ryder and information coming out from Massachusetts.

And soon we will have more information on ICI's Web site, that's kind of undergoing some reorganization right now, correct, Beth?

>> Beth Wike: Yes, yep. We'll be sending out all of the recordings and have more information on where everything will be housed.

>> Ingrid Flory: Great. So if you want to share your knowledge with other people, if you want to get involved, or if you're interested in sharing information at one of these sessions, or sharing information with people you know informally. This is -- this is a bit of a grass roots movement. People are getting turned onto Charting the LifeCourse, I to the share this with other people. I've done it myself of sitting -- visiting with a friend and talking about life struggles. You know, what? Let me draw this out for us and I draw out a little trajectory which is one of the tools and it's helpful. In terms of defining, you know, problem-solving and defining our priorities in life. And just finding ways to practice and, you know.

Or using it in your work or other people. So if you're interested in getting involved more formally like in our statewide network or other kind of coalition events, please contact me and we can talk about what you're interested in and what might be a good fit.

Thank you for listening.

(Laughter.)

>> Ingrid Flory: I know I through a lot at you. So I'm going to -- I'm going to stop sharing my screen. And I'm going to rely on my friends to tell me what's in the chat and answer some questions. So if you have additional questions, please put them in the chat.

>> Kerry Mahoney: It's just so excite together see how many people jumped on today's webinar and the interest in charting families and Charting the LifeCourse. I think that's where it all starts, just getting that information and getting excited about -- you know, there's a possibility of some changes. So, thanks for all coming today.

>> Ingrid Flory: Thank you, Kerry. I'm seeing one how do you get buy in? I think -- everyone's going to have different approaches and it's going to depend on the person. I think demonstrating how this works is sometimes a really solid approach. So whether you're kind of integrating into your work and modeling that in different ways,

that can be really effective, people say, oh, this is really interesting. How did you come to that?

And certainly, bringing -- sharing the information may be encourage them to learn a little bit about Charting the LifeCourse. If there's specific information that you would like we can certainly share it. I think some of our approach in Massachusetts in terms of kind of nurturing this grass roots movement has been to offer opportunities for training for people who are interested.

And for people who become champions to elevate those voices, and then it starts getting contagious and other people get inspired and interested. So that's one approach. Do any of my colleagues have anything to add? It's a big question?

>> Ellen Kilicarlan: No I think you addressed it nicely. We want to make it available and offer it and have people learn about it.

>> Ingrid Flory: Right. We have -- yes. One of the things we don't want is for people to see this as a mandated form to fill out. Because that takes the whole spirit out of it. The idea is this is a way of approaching our lives and works in helpful ways. And that -- that is being used across the country and is increasingly to be -- proven to be really effective.

>> Beth Wike: We have a question in the Q and A what would you recommend as the next step after this training?

>> Ingrid Flory: I would recommend, if you're new to this. I would recommend going to [lifecoursetools.COM](http://lifecoursetools.COM). And taking a look at some of the -- and looking at -- watching one of the introductory videos. And looking at some of the tools that they have. And seeing what resonates with you. And pick one. And try it out on yourself.

So in one of the videos, it's on the arc of Mass Web site. It's the first time I used a charting the life course tool. I found out the bus was arriving 15 minutes before my babysitter and never been alone before and need to problem solve for that. Okay. I'll tried integrated support star. Let me see if I can figure this out, and it worked. So it helped me solve a problem in my life.

So I'd recommend trying on yourself with some problem that you're having, or something that you want to plan for. People will often -- you know, use some of the visioning tools to help you for requirement or healthy living goals. Anything that resonates with you right now, and once you did it on yourself, you can show other people how to use it

>> Kerry Mahoney: And I also think that it's great because it's not a once and done because people think okay, person-centered planning, you have a big meeting and get ( ) in the room and this sort of thing, this is really a strategy that can be used over time. And, you know, things come up over our lives. So using some of these tools in resources to figure things out.

>> Ingrid Flory: Any other questions in the chat or Q and A?

>> Beth Wike: No questions just some clapping hands, acknowledgement, I think the power of the tools, and the power of this approach. We did have -- I wanted to say. So Lisa Morgan shared doing the initial start at the family and brought the poster of his stars with photos. It's great to hear that we have people -- some never used any of the tools and learning for the first time and we have firsthand experience.

And yeah, it's not a one and done. It's continual learning. And so I'm grateful for everyone here today. Maybe one more. So this is a good closing question. What can we expect in the upcoming webinars?

>> Ingrid Flory: Do you have the list in front of you to talk about the next one?

>> Ellen Kilicarslan: We have -- the next session next month will be with Roger Kelly who is from Mass Stanley and some of her work with self-advocates and how she really modified some of the tools here folks with developmental disabilities.

Closer to the holidays, we'll have Sonja Stewart -- that's not her -- she's married -- I can't remember -- but she'll be talking to us about planning for the holidays.

Now after each of these presentation it is and, again as Beth mentioned earlier, you'll get information earlier prior to the session with a blank tool. Because we're going to actually practice using the tools during the next sessions.

We will have later somebody doing a session on the trajectory and life stages. And I think we have somebody that will be talking about mapping relationships and using a tool that really looks at and relationships in a person's life and different roles in people's lives and how to look at that so it's helping the person achieve his or her goals to be living in their community and being included.

And we -- I think that's who we have lined up so far. But we'll be doing this monthly. And again, you'll have the opportunity to practice using the tools. So I guess we'll see you all next month, hopefully.

(Laughter.)

>> Ellen Kilicarslan: And thank you. Thank you all for being here. And I hope you have a delicious lunch.

(Laughter.)

>> Ingrid Flory: Thank you for your time.

(Captioning ended at 11:55 a.m., Central Standard Time.)

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