

**Slide 1:** Thank for joining us, my name is Katy Kaplan, I'm an investigator with the Temple University Collaborative on Community Inclusion and I'm also the Assistant Director of Research and Evaluation for Community Behavioral Health in Philadelphia. So again, the focus of the talk today is on supporting parents with psychiatric disabilities with a particular emphasis on our online parenting education tool.

(The presenter was muted)

**Slide 2:** Sorry about that, for some reason my thing muted me, so I apologize. Anyway, for those of you who don't know, the Temple University Collaborative is funded by the National Institute on Disability, Independent Living, and Rehabilitation Research. We've actually been funded since 2003, so we're currently in our 3<sup>rd</sup> funding cycle right now. You can see what the goals of the Collaborative are:

- To target obstacles that prevent people with psychiatric disabilities from being full members of their communities
- To develop supports enhance integration
- And to expand the range of opportunities for people who have psychiatric disabilities to participate in their communities as active and equal members.

One of the things I like the most about our center is that we often address areas that don't always get a lot of attention, like intimate relationships, parenting, self-directed care, so I think that's one of the things that makes us more unique.

**Slide 3:** Just to give you a little sense of my background, I actually come at this issue from a personal perspective. I grew up with a dad who had bipolar disorder, and I wasn't aware of the high rates of child welfare involvement among parents until I began working with the collaborative and started to come up to speed on the research in this area. In terms of my dad's personal story there were three things that I think worked really well, that I think can work well for other families:

- One was a strong support network
- The other is that my dad sought appropriate treatment and services
- And the last one is my parents created an environment that promoted resiliency

So in terms of the support network that, unfortunately, is not the case for everyone. Not everyone has great natural supports, and that's where I think the public system needs to step in and help families living with parental mental health issues that needs supports that don't exist for them through family members and friends. This is a picture of me making my holy communion, cause church was a big part of our life and it was a big part of our support network. So my parents were very lucky to have lots of friends and close family members that helped us at times that my dad was really very sick, and couldn't get out of bed and couldn't work.

He did seek appropriate treatment and supports, but unfortunately they weren't very effective. So that was a struggle for him, he did everything he could to stay well.

And the last thing and this is something that resonates very well and very much with me is that they created an environment that promoted resiliency. So there was 4 of us, I was the youngest of 4 kids, I think like a typical youngest child you needed a lot of attention, was probably a pain, but my parents saw it as independence (nice way to think of that), but they also, my dad understood the power of positive communication. Of course this was at times when he was well but when he was well he made

sure to give us strong messages about what our capabilities were. So with me, he used to say that “with my determination I could go through brick walls”. So when I was like 5 or 6 years old I knew what the word determination meant, I knew I was determined, I knew I could accomplish things I set my mind to, and that message has no doubt stuck with me my entire life. And it’s helped me overcome obstacles or challenges that stand in my way.

My dad also promoted resiliency, or my parents, by being engaged or involved in our Parent Teacher Association, they got us involved in extracurricular activities, and they really taught us how to create our own support networks. So these are things, I think my personal story just tells us that there are things that we can do to help families that maybe don’t have these support networks. We can fill in the gaps where natural supports are missing, and we can also teach parents how to instill protective factors or promote resiliency in their children.

**Slide 4:** So just to give you a sense of the plan for the session, we are going to, I’m going to start with:

- Talking about just what do we know about parents with psychiatric disabilities?
- Some strategies for supporting parents
- I’m going to specifically talk about our Internet-based parenting intervention
- And then I’ll zero in on the online parenting education course, which is now available for free for folks to us and how this tool can be used to support families that you may work with or your own family.
- And then we’ll end with a Q&A session. When we get to that point of Q&A, you can use the Q&A feature, or the chat feature and the questions will get sent to Jared our moderator, who will work with me to, I’m going to spend at least 15 minutes or so at the end.

We had about 200 people register, I’m assuming that folks that registered for the webinar probably range in knowledge of this issue from maybe knowing very little, and they could be new to it, to people who are experts and my colleagues, I saw some names of some familiar folks I haven’t worked with in a while but are very knowledgeable and taught me a lot. This presentation will cover a broad range.

**Slide 5:** So the first thing is what do we know about parents with a psychiatric disability?

**Slide 6:** We know that having a mental illness does not mean you’re less likely to become a parent. In fact rates of parenting is very similar for individuals with psychiatric disability compared to the general population. We know that parents are more likely to be living in the community and raising their children as a result of things like deinstitutionalization, as a result of things like the Olmstead supreme court decision and the president’s New Freedom Commission that mandates that mental health recovery and community inclusion should be a priority of the mental health system, that it’s a right to live in the community, to be a parent, to raise your children. We also know that, unfortunately, parents with mental health issues are more likely to have child welfare involvement or lose custody, and I’ll talk about some specific data in a little bit. This last one is something that’s really important, we often know, though it’s not always recognized, that parenting can be a motivating factor in recovery, it can be a source of meaning, and connection and stability. And unfortunately this is sometimes missed. There are parents that have written articles that parenting could’ve been used in the recovery process, it was a missed opportunity that providers just didn’t see and so it wasn’t utilized.

**Slide 7:** We know that stigma and discrimination persist. When it comes to the topic of parenting you have to look at the recent history, because it really wasn't that long ago that the U.S. involuntarily sterilized thousands of people. So *Buck v Bell* Supreme court decision set the precedent that resulted in over 65,000 people being forcibly sterilized. I think this is worthy of reading, so in the ruling Justice Oliver Wendell Holmes said "It is better for all the world, if instead of waiting to execute degenerate offspring for crime, or to let them starve for their imbecility, society can prevent those who are manifestly unfit from continuing their kind. The principle that sustains compulsory vaccination is broad enough to cover cutting the Fallopian tubes...Three generations of imbeciles are enough." So it's this very negative and horrible history that may seem like a long time ago but really we're not that far removed and in fact not only has this case yet to be overturned but it's actually been used as recently as 2001 by a federal appeals court. So I think that's an important history to keep in mind.

Parenting is rarely addressed by mental health providers, though I have to say this is definitely changing for the better. There's a growing recognition of the need to recognize that the people in the mental health service system might be parents, they might need to be linked to additional services or supports. So I think we're making progress.

Discrimination and negative beliefs persist about mental illness, and like I said with the history of involuntary sterilization, and just in general how we treated people with disabilities in the U.S. not that long ago it's not surprising that we still limit rights. There are 35 states that list mental illness as a grounds. And under the "Adoption Safe Family Act" some states actually list a mental illness as grounds to not provide reasonable efforts to reunify a family and in fact list individuals with mental illnesses alongside those parents who've committed murder, torture, chronic abuse, and so on. So again, this is something that we need to continue to fight for civil rights of parents with mental health issues.

**Slide 8:** So I had mentioned earlier some research around custody lost, so this is a study that the Collaborative did back in 2006. We looked at 5,800 women on Medicaid, in Philadelphia, and we linked them to child welfare data and what we found is that mothers with a serious mental illness were about 3-4 times more likely to have child welfare involvement or actually lose custody of their children. And this is a conservative estimate and it still is extremely alarming. The findings from this study, this was conducted in our first funding cycle, we've used these findings to drive a lot of the work and resource development since this study has been conducted.

**Slide 9:** Right now we are in the midst of a national study Identifying Prevalence of Child Protective Service Involvement and Parental Resiliency Factors among Parents with Psychiatric Disabilities. Again we found the rates of parenting between those who self-reported having a serious mental illness and those who did not to be very similar, it was 67% of those with an SMI who reported being parents compared to 70% of those without an SMI. However rates of child protective service contact was dramatically different between the groups, with 23% of those with a SMI saying they had child welfare contact compared to only 5% of those without an SMI. And then the change of living arrangement can often times results in termination of parental rights was also very different. So 65% of those with an SMI reported a change in living arrangement compared to 23% without an SMI. So this is just the first phase of the study it's very much underway, and the other component is that we're going to be looking at, we're doing interviews with some of these families both who've had contact and who have not, and we're hoping to identify the resiliency factors. What does it look like for families that aren't coming in contact with child welfare, and how can we use this information to develop more supports for families.

**Slide 10:** So, now I've already outlined there's obviously issues around stigma and discrimination that exist. But there are barriers that parents may confront related to having a mental illness such as things that can stem from maybe the symptoms of the illness, so like in my dad's case for example, when he was depressed, he spent weeks and weeks in bed at a time. Without my mom it would've been hard on him to care for the 4 of us. He had horrible side effects from his medications, I'm not sure how much they interfered with his parenting, I just know they were personally pretty tough on him. So some of these things, a lack of support, whether it's from the mental health system or lacking natural supports, can certainly limit parental effectiveness and should be things we should think about in terms of how it impacts parent-child interaction, levels of parenting stress, those sorts of things.

**Slide 11:** So parenting is certainly a very subjective practice and it's influenced by a lot of factors like culture and religion and geographic region. Not all parents or experts will agree on a set of regimented parenting practices, but we know that there are agreements on factors that can produce positive outcomes in children. There are all sorts of risk factors, parental illness is just one of many risk factors, risk factors can bring about negative outcomes in children whether it's the child develops a mental health issue or they become isolated or they engage in risky behaviors. The important thing here is that parents can do things to buffer these sort of risk factors or the potential negative impact of the risk factors through learning coping strategies, reaching out for supports, and things we're going to discuss in more detail as the presentation continues. And then the goal would be to help their children form healthy relationships, have academic achievements, and avoid risky behaviors.

**Slide 12:** So now I'd like to switch and talk a little bit about some supports or strategies for supporting parents with psychiatric disabilities.

**Slide 13:** So there's two things to think about, there's helping parents overcome barriers to getting supports, and then there's actually targeting those factors that I just discussed. So overcoming barriers, we know that for parents with mental health issues there's a lack of services, so somebody may be engaged in mental health services but that doesn't mean they necessarily are getting supports as their role as a parent. There are some great programs, there are some wonderful stuff happening with employment options up at Massachusetts, mental health association of NY state has done great stuff, mental health association of Passaic county. There are particular areas in the country where there's a lot of awareness, a lot of effort that goes into creating programs and services for families. But they don't exist everywhere, and other issues like maybe the meeting time doesn't work for the parent because it's during the day, maybe somebody doesn't feel comfortable going because of the stigma that the feel of having a mental health issue. Child care is always a huge deal once you become a parent who's going to watch your kids, can you bring them with you. Transportation and fatigue are also huge issues. So we want to think about how we can overcome these barriers, and then what are we trying to target, what are the supports? Do we have strategies to reduce the parental stress?

**Slide 14:** One of the mechanisms for trying to accomplish some of these things could be the internet. It certainly is a vehicle to overcoming participation barriers, and of course I recognize there is still a digital divide, I think it continues to decrease but not everybody has access. This parenting study is actually our third internet based study, we have had participants with serious mental illness that have engaged through the library, through a group home, or a facility. So there are ways of accessing the internet even for folks who don't have it. For a lot of people who do have access it could help overcome the barriers, like I don't do anything until 8:30 at night because that's when my kids are in bed and I finally get time

to myself. So for some parents, having that flexibility of being able to login when you need to a website at 10 o'clock at night when they're awake and they have time could work. There's all different facilitation options that you can use, or platforms that you can create so people can be anonymous, there's also literature to show that internet interventions can be effective.

**Slide 15:** So this is just a little bit of the information around effectiveness of internet interventions so there's evidence that therapies with a support component are more effective. We know that some of these interventions have empowered individuals who have taken active roles in their treatment. I know we did a study on women with breast cancer and some of the communications were "This is something I used in my treatment, you should go talk to your doctor about it" and so they were empowering their peers on the listserv, to go back to their provider and ask more questions, raise issues that are concerning, and get more actively involved in their own treatment. We know that anonymity can be preferred among individuals that may have health conditions that often can be stigmatizing so there's other health issues beyond mental health issues where the internet has been popular as well. And we also know that sometimes that participation might continue on beyond the scope of a study, so for example our breast cancer study again was a pretty small group of women but they were so concerned about what would happen when the study ended, how would they continue to communicate with one another because they formed these sort of lasting relationships.

**Slide 16:** So now I'd like to specifically talk about our intervention. So let me go back, the study was an internet-based parenting intervention for mothers with psychiatric disabilities, and it was a randomized controlled trial.

**Slide 17:** So this was the model for the study, on the left side you'll see the factors that limit parental effectiveness that I introduced earlier. It might be low parenting self-efficacy, lacking confidence in your own abilities as a parent. We know that actually sometimes parents with mental health issues might actually be harder on their own parenting, they might be more critical of their parenting behaviors and contributing some of their struggles to their mental health issues rather than just a common struggle. And I've seen this among my friends that have mental health issues and are parents, they're so self-critical and really some of the things they're struggling with are things people without mental health issues are struggling with because being a parent is hard. It's very rewarding but it's exhausting, takes a lot of energy, and it's just not always easy. Helping parents build up their own sense of confidence and confidence in their abilities, and access to knowledge and skills, supports around parent-child interactions, improving coping, ideally increasing levels of supports, and helping parents how to manage their levels of parenting stress.

So on the far right were the outcomes we were hoping to achieve with this study. So basically taking all those factors and flipping them, attempting to increase supports and so on. So in the middle the study basically consisted of two components. We had two conditions and experimental condition and control condition, because we wanted to make sure that the findings of our study were attributable to the actual intervention and not something else. So our control condition was actually given just an online healthy fact sheet series, it looked very similar to the experimental conditions course, and it just gave them basic information about living a healthy lifestyle, but was less focused on parenting. The experimental condition parents were asked, it was actually mothers and I'll talk about that in a little bit, were asked to participate in an online parental education course that had 4 section areas about child development, stress reduction, the intersection of mental illness and parenting, and positive parenting.

Then they were also added to a parenting support group, it was an email listserv that was co-moderated by a provider, we worked with the folks at Mental Health Association of Passaic County, they have a consumer-parent support network. So the woman that runs that program, Rebekah Leon, and one of the parent advocates, Dennise Babin, who is a mom with a mental health issue and has worked as a parent advocate for years, co-moderated the list.

**Slide 18:** So we had a total of 131 moms that enrolled in the study they were randomly assigned to one of the two conditions, so we had 66 moms in the experimental condition and 65 who were assigned to the control condition. The assessments took place at baseline when they first enrolled in the study, at three months later, twelve months, and eighteen months.

**Slide 19:** So to be enrolled in the study we had moms that were over the age of 18 with a serious mental illness. So we confirmed with a provider whether or not they had major depression, bipolar disorder, or a schizophrenia spectrum disorder. One of the reasons we actually did this confirmation process was if we were going to enroll a group of women to an online support group we were going to make sure they were really moms with mental health issues and not just some creepy person on the internet, so ethically we felt, it was a national study the only way to confirm that these were legitimate people were to do that. And also to get a better sense of the population that we were studying. They had to have primary or shared custody and be serving as caretaker for at least one child under the age of 18. One of the reasons we did this is because we want to make sure moms had an opportunity to practice some of the new skills or strategies with their children. At the end I'll talk about non-custodial parents and because I recognize that parents that are caught up in child welfare that may have limited visitation to their children have huge needs for supports and resources on how to improve things so they can reunify. But for the purposes of this study it was folks who had custody. You had to have access to the internet but it could be from wherever, the library, pretty sure we had moms participate using smart phones. The continental U.S. and you had to be fluent in English because the support group was in English.

**Slide 20:** So what we were hoping was that mothers in the experimental condition were going to have gains in parenting efficacy, so that sense of confidence in their own parenting abilities, that they would have gains or improvements on their parenting skills, their coping skills, and feel an increase in social support largely through the listserv. And that they'd also experience lower levels of parenting related stress and this was all in comparison to the moms in the control condition.

**Slide 21:** So the intervention was designed using techniques that were adapted from cognitive behavioral therapy. So cognitive therapy, behavioral therapy, came about as an intervention initially for depression/anxiety, but more recently has had modifications and has been used to treat people living with bipolar disorder or schizophrenia. Here I'm using CBT techniques similarly to how they've been effectively used in some of the internet studies that I mentioned earlier.

So the first one is stress inoculation where you're trying to teach effective coping strategies and it would also be included as our effort to increase parental knowledge. Skill acquisition was one of the core functions of the treatment, or this intervention, and should include a rationale that's motivating, clear instructions, relevant examples and client practice. So this kind of went into how we structured the lessons, what kind of examples we tried to provide, and then also a link to the support group, which I'll mention in a minute. Homework was a big part of it, we did ask, at the end of each lesson, we asked moms to complete a quiz to kind of give them immediate feedback on the content that was covered,

maybe areas that they'd want to go back and visit, but also asking them to do things. If we suggested a new strategy for effective communication with your child, the homework might say "5 strategies for effective communication try 1 strategy out over the next week or so, and see if you can incorporate it into your parenting." The interactive model of education was this notion where we had the support group, the moderators of the group were apart of developing the curriculum, they worked with families living with parental mental health issues for many years since about 2001. So their goal was to, since mothers were completing the curriculum in isolation, you know this was self-directed, they were doing it at home or at work or wherever, but they weren't really it wasn't part of a larger group intervention, so the support group, the email listserv, was an opportunity where they could share experiences about some of the content that was being discussed or some of the issues they were facing with the day to day with their kids. And trying to make the intervention personal and just more interactive.

## **Slide: 22**

So this is the overview of the Education Sessions that are on the online Parenting course. To just give you a little background about how we developed it, I think this is really important. So when we were when we were first looking to begin this project to create an online resource. The folks Rebecca Leon from her shop said when they started there program which was The Invisible Children's project of the Mental Health Association, she said "We didn't want to make assumptions about what we thought parents needed and wanted. We asked parents what do you need, what would be helpful, what's of interest to you, and we used that to create our program."

So we did a similar thing we put out a survey, that had about 220 respondents from all around the country, and we asked them very specific questions about what kind of information if we were going to create an education course, what ages they would want, what topic areas they would want us to cover. Unfortunately, only 20 of the respondents were Dad's. I clearly have a personal connection to fathers, since that my connection to having a Dad with a mental health issue. But given the fact that we had an online support component and say all 20 dad's enrolled, maybe only 10 of those would be assigned to the support condition. So we were worried that it might be a weird dynamic to have a handful of fathers amongst almost all mothers. So for the purposes of this study, we just enrolled mothers, but fathers are a group that I would continue to like to address in future work.

50% of the parents who responded to our survey wanted a curriculum for teenagers, which to totally be honest just from a selfish standpoint, I was like oh my god we have to create a curriculum for teens that is going to take forever. You know there are so many issues from becoming a teen you know, from sexuality and drinking, and getting a job and smoking, you know all those sorts of issues that confront parents with teenagers. You know but if we were going to be true to what we say and create a curriculum that parents said they wanted they we should extend the age to 18, so that's what we did and it did take longer. And then we asked how long the course should be, what kind of platform you would like to see for support, should it be moderated or not moderated.

So we used the survey with combination with the latest research and all these sorts of issues, and we also developed a partnership with Persons in Recovery who were also parents, researchers, and providers. Most lessons of the curriculum were drafted by my colleague Lauren Kundra who wears many hats, she's a social worker, she's a certified peer specialist, and she's a mom. So she kind of came about

with these issues from a personal perspective as well as knowing the literature and the research. And like I said I peer support specialist co-moderate it with a social worker and a parent advocate.

So I will zero in on one this when we talk about this with the tool. So some of the educational sessions are general parenting. But in reality I think a lot of the mom's in the study didn't need, you know they could access general child development information from other sources. And in fact it was a really hard thing to include, how do you condense, you know child development can be its own thing all by itself. So our goal was to provide everything best as possible, but I think the areas that resonated best, and I will talk a little about it more later, is the specific intersection of mental health and parenting.

So we had a stress reduction section that got at what are the parenting techniques that you can do to reduce your stress. And then how taking care of your own emotional and physical health is part of being a good parent, and how it is really important even if you it's difficult to make time for yourself or to figure out how to do that.

The Mental Illness and parenting sections focuses on how do you talk to your child about your mental illness, what if you have to get hospitalized? How do you talk to your supporters about what you need? How do you take care of your own mental health, to know your warning signs and things like that.

And the last one is positive parenting, again for me it's where I personally connect to because my parents did very good, and I have no doubt that it made the difference in the lives of my siblings and I. You know parent and child communication, the importance of communicating with your kid, and communicating positive messages. The important of creating structure and boundaries, and the importance of being engaged and helping them create their own networks.

### **Next Slide: 23**

So our findings from the study, is that we did find that the intervention decreased levels of parenting stress, we had moderate schemes in parenting efficacy but they were not statistically significant so you know we have more work to do to figure out how to better improve parenting skills, coping, parenting efficacy, and support.

We also know that the satisfaction and participation in the online support group were very mixed. Some of them were lack of effect may also be attributed to how the support component was utilized and in fact 20% of the moms that were assigned in the support group never participated. They didn't read any of the emails, they didn't send any emails. We did have a couple of people who has technical issues but usually we were able to troubleshoot those and help people learn how to use it. A lot of people are familiar with email, so most folks didn't have a hard time getting on. You know I think one of the things is we need to create a variety of support options out there, a variety of tools, and people will find what fits them the best. And I think for some people this might not have been a personal fit, it was interesting 45 of the 52 mothers who responded to our questions say they would recommend support groups like this be recommended to parents with mental health issues. So almost all of them were saying that they think a group like this should be available, so I think again that they realized it wasn't a fit for them but they recognized other mothers who were benefiting.

### **Next Slide: Study Findings: 23**

So we had a tool called parenting knowledge, and this was to give input on the content of the lessons. So we asked mom's to report on how much each of the topics that were given during the course

enhanced their parenting knowledge. And the biggest gains of enhanced knowledge were primarily the sections that covered the intersection of parenting and mental health. And it makes sense right? This is the sections that are filling the gap, you know parents might be able to go online or a book store and get information about child development, but it's not easy to find information about, well how do you help your child cope with the symptoms of your mental illness or if you get hospitalized.

How do you talk to them about your mental health issue? That was a definitely an issue in my own family, it was the 80's, people didn't openly talk about mental health issues as much, I don't think my parents knew how to talk to us about my dad's mental health issues. And I think for my older siblings there were times that they thought were hard, like do they need to do something differently. So that knowing how to talk to a child, because it's not an easy conversation is an important tool.

These are the things that resonated and the parenting techniques to reduce stress was very highly rated, I think it was 68% of mom's said that enhanced their knowledge. So we saw large gains on the reduction of parental stress. Also about how their mental illness impacts their child and their family, important messages they should convey to your child when talking about their mental illness, how you can help your child cope with his/hers feelings about the parent's mental health issue. When it's appropriate to seek counseling a child or family therapy, you know when is it something bigger and you want to reach out for more supports. And then how to promote resiliency in your child. So these were the content areas, so if you're thinking about using this tool, these would be some of the areas that you might want to check out first, or the person that you're working with might be interested in.

**Next Slide: 24**

So in terms of the study implications this tool was able to overcome some of the barriers to accessing services and supports because it was available nationally, and people were able to access it from home, at work, or at the library. Like I said there are not a lot of programs that exist and a lot of the ones that exist are locally based, it expands the reach of service for parents, and it can be utilized across a variety of systems. So you know families that are affected by parental mental health issues come into contact with numerous systems beyond mental health, some they may come in contact with child welfare, the courts, the education system, so you know our goal is to further connect with these systems and make them aware of how they can support parents.

This intervention is also a proactive approach to supporting parents so than rather waiting for parents to struggle or to have issues, or to get caught up in child welfare, we should be reaching out and developing supports to help them parent well, and without incident. Lastly, it is low provider burden I know a lot of service providers may have larger caseloads or they may feel overwhelmed, and the last thing they want to deal with is someone's kid. They may be focused on employment issues or housing, so this is the chance to give folks the resource that doesn't require much of them because it is self-directed.

**Next slide: 25**

First step we all have certain ideas about how we can improve the tool, I think one thing I would love to have happen is to create a screening tool, so that as parents go to use they can answer a very brief questionnaire that says these are the sections that you should check out first or are of greatest interest for you based on your needs. Online support, it would be great to have it as an optional, online support

would be optional for we know that it doesn't work for everybody. We also would like to see it expanded to include other populations, I mentioned fathers as one population, and I mentioned individuals that are not non-custodial parents and are working towards rectification, individuals that have co-occurring substance abuse issues. There is additional information which we have already pulled together, that I would love to add on to this course so it can meet more needs for parents that are out there. And of course we need to do more research I mean this is the first study so I think it has given us a lot of information about how to move forward.

**Next slide: 26**

So now I want to shift to the actual tool, so this is the home page, and if you haven't done so already it is free to sign up. Just go to [tucollaborative.org/parenting-online-education/](http://tucollaborative.org/parenting-online-education/) so if you go to that website, and you can just go to our website [tucollaborative.org](http://tucollaborative.org) and you can find it. You go there and click the link to the registration page, it just asks a couple questions including, name, email, address, how you identify yourself, and why you're interested in accessing this resource, and then you can use it whenever you want.

On the homepage you can see we have across the very top gives you information about the team who developed it, how to get technical support, the main navigation bar, there is a video section. I didn't mention this earlier, but so for the first three months of the study we ask Mom's to complete weekly lessons that you can access by age group, ages 0-3, ages 4-9, 10-13, and 14-18 on the right side. So there was weekly lessons for twelve weeks but it was self-directed so parents could navigate at their own pace. And after they completed the lessons we had series of interviews, which we interviewed experts in a lot of the areas that were covered by the course, and reinforced the content that was covered through the lessons.

I used to be a teacher and I recognize that people learn differently, some people may love to read stuff, while another may like to watch an interview, so just to tap into different strategies on how folks learn and take in information. The LISTSERV is obviously not functional right now because the support group is not going. But the resources has all sorts of website, books, and other resources that can be helpful for parents with mental health issues.

**Next slide: 27**

So this is a screenshot of the section for mothers who have children 10-13. So you can see if you look down you can see all the courses and the lessons, you can also see there is a little speaker icon, and this where you can download a MP3 final. So we wanted to make this accessible for mom's who may have learning disabilities or dyslexia and reading is a struggle they could listen. People that just prefer to listen or mothers with visual impairments. And each lessons has a quiz so you would click on the quiz to complete the quiz at every lesson. You see there is a weekly progress tool bar to help folks see how they are progressing through. Moms were asked to complete lessons if they had more than one kid, with the child who they most needed the information for, but they of course where given access to all the information that was needed for their life.

**Next Slide: 28**

So these are just some screenshots from some of the sections. Like I said childhood development was a really difficult one to create because of the vast amount of information and I think it was the one that parents needed the least, because mothers could access this information from other resources. So we tried to cover the key issues of key development.

**Next Slide: 29**

Stress reduction again was about three focus areas: what are the parenting techniques you can employ that will make life predictable for your children and overtime reduce your stress. So the bedtime routine is a big one, in my own personal life it is huge, it was kind of a pain to get in practice. But as my son knows it's time to go potty, to wash our hands and brush our teeth, and we read stories and we go to bed. And we do the same thing every night and it's predictable, and I don't have to fight with him once I get him over the hump of getting him upstairs. So things like that, what are the strategies that you can employ that will make your day to day much more bearable.

And how do you take care of your own emotional health, how do you take care of your physical health. Parents always have a hard time making time for these things. But these are crucial to being a good parent, and to being physically and emotionally there for your child.

**Next slide: 30**

The Mental Health and Parenting section is much more focused on lessons on how to educate your supporters about your mental health issues and your needs for support, also how to educate them on your parenting styles. If I had my sister stepping in to help as the role of a parent, I'd want her to know what my rules are and respect my authority as their parent. So I think that's important.

I think understanding the impact it can have on your children, and how to talk to them. Like what are you going to do when you have to get hospitalized or someone else has to step in to provide more support, you know how do you help them cope. So again parents rated these lessons as the ones that had the most enhanced knowledge.

**Next slide: 31**

The last one is positive parenting, and again this is the area where we cover parent/child communication, discipline, boundaries, and responsibilities and the important of educational involvement and extracurricular activities. These are the lessons that are focused on how do you put the factors in place to potentially buffer any negative effects that your mental health issue or other issues can impact your children, and these are concrete tools these are things that we can teach parents. These are things that I try to use in my parenting, with my children. So there's a lot that parents can do ensure positive outcomes for their kids.

**Next slide: 32**

So how can you use this intervention to support families? I mean the first thing is actually helping folks and making sure they know about it and creating a free account, and that an email address is required. That they can create email account if they don't have one. It might also be parents can work

independently, but they also may want to work with the support of a staff person, they might want help reviewing what they're going to work.

Parents also beyond this might need connections to other local resources. They might have identify areas in the curriculum where they would like more information, or maybe they want help or encouragement supporting them in executing a new parenting strategy or technique. Parents need encouragement and recognition everybody needs that, that's always something that we can do that doesn't require a lot of effort I think. And it might be that their child needs to be connected to resources and services. That other thing to think about is if you're doing it locally say you're a peer specialist getting something going at your agency, is there a support group that you want to start to help parents connect with other parents. So thinking creatively about all the ways that this can be used as a tool to support your efforts with family living with parental mental health issues.

### **Next slide: 33**

So I just want to say before I open it up for questions and answers is that this is one tool and one resource that we're very excited about, I mean it's got a huge reach, it uses a bunch of different learning strategies, it has content that was formed by parents who have mental health issues, and developed by parents with mental health issues. But we have so much more to do in this area, there are some great folks who have been doing work and have been creating resources for families. This last slide just has some organizations that you might want to check out of course our stuff is listed but Parenting Well Resources and Child and Family Connections has national support group that folks can call into from all over the country, and Through the Looking Glass is another organization that has advocated for families living with disabilities.

### **Last slide: 34**

And this last slide is all the people that made this possible, mainly the moms who were willing to participate in our study for a long time, for a year and a half, and give their honest feedback and opinions so that we can make pages and improvements to our team that created it. So I am going to turn it over to Jared and we will do some questions and answers.

### **Questions/Comments (52:24)**

#### **Question One**

**Jared:** The first one is from Rhonda, her question is; Suggestions on parenting with a mental illness when your child also has a mental illness. Her child is 22 now but she spent 20 years being her case manager due to system failures. It feels like a situation of take care of me or take care of her...not much of a balance in between.

#### **Katy:**

Ok so, I just want to make sure that I understand the question. So the struggle to, this was definitely one of the topics that came up in the support group. The parents were struggling with their child's mental health issues and finding that balance is tricky. I mean unfortunately if the system is failing you, I think the one strategy would be to look to the internet for types of support that you can get virtually that you can't get in your local community. Organizations like the Mental Health organization or NAMI because they tend to be much more family focused and family oriented.

Another strategy that may be helpful is that if your child is an adult or 22 I think you're always going to be a parent for the rest of your life, and I think it's tough because their needs always seem to come first. It's part of being a parent, so finding that balance is not easy. So my thought is that I would connect with organizations like that I don't know if you already have, and encouraging your adult child to look for their own resources and helping them find a fit. And maybe it's a traditional treatment, or an online support group or face to face group. I know locally in Philadelphia the Mental Health Association in Southeastern PA runs a family group so if you have a sibling with a mental health issue, or you are a parent of a child with a mental health issue. I don't know if where you live those types of groups exist, but it may be helpful in getting you some support in your role as a parent while you're dealing with your own issues and your child's. I hope that was helpful. Ok Jared what do we have next.

### **Question Two:**

**Jared:** Ok so the next question is from Donna and this is a question about one of the slides that you showed. She was asking where the sterilization took place, when they were sterilizing people who had psychiatric disabilities.

### **Katy:**

Sure so sterilization happened all across the country in Virginia, California were some of the worst offenders. I think in Virginia there was actually a model sterilization law that was in place, so it happened everywhere. I don't know whether it happened in every state, but again if it did it happened in almost every state. If you want to email us I can get you more information.

The National Council of Disability Folks will be interested in this, where there is more information in there, put out a report called "Rocking the Cradle" ensuring the rights of parents with disabilities and their children. This was something I was thrilled to be involved with, because it causes attention on a national level of the needs and barriers that parents with disabilities, and it wasn't just mental health issues, face in terms of being able to adopt children, being able to maintain custody, be able to get fertility treatments, you name it. And in Rocking the Cradle which you can access on the National Council of Disability's website it has a lot of history about the sterilization.

There is actually journal articles published in Kennedy and Leo Kannur I think that was his last name, where they debated euthanasia of people with disabilities and who was unfit, and the benefit of things like eugenics. So it was a bad time, and like I said we're not that far removed from like I said Bucksville hasn't been overturned and was used as recently as 2001. So now you know it's not really socially acceptable to forcibly sterilize people, but I make the argument that you list statues of a person with a mental illness alongside someone who has committed a murder, that's a different way to limit parental rights, and it violates civil rights. Ok next question.

### **Question Three:**

**Jared:** Next question you have is from Nadia Grey, she asks if there was any information offered to the participants about providing support for children with their own mental health troubles for learning disabilities like Autism?

### **Katy:**

That's a great question, I'm going to be honest I can't remember how much that was touched on in the curriculum. I think not about specific learning issues in children, but it may have been touched on. I know it came up in the course on Communications, because we did have mom's involved that either had children with disabilities, whether it be learning disabilities. We definitely had mom's involved that had autism and other issues. So I think it might have just come up on the support group and if it was in the curriculum it was less of a key aspect of the curriculum because our focus population was on the parent piece, but I certainly recognize that a lot of the mom's that we had in the study were also dealing with children who had their own issues and things like Autism were the prevalence's and off the charts with 1 in 68 kids being diagnosed with Autism. There is going to be a high need of parents getting resources for support. So I think we touched on it, but I certainly think it is something that as we move forward thinking about the populations you know you raise a good point that might be adding a section more focused on, like I said I would have to go back to our positive parenting section, and see how much we touched on that. Because that's a huge stressor, being a parent of a child with a disability it can be exhausting trying to advocate. Philadelphia where we live our school system is really struggling on a lot of levels, and I just spent the last couple of years working for city council and we would deal with constitutes all the time that were fighting in meetings to make sure that their child was getting what they needed. You know it can be a full time job. So it certainly a place where we would like to think about adding information for more parents, so I'm glad that you brought that up. Ok next question.

#### **Question Four:**

**Jared:** We have another one from Diana again, she asks what did your dad have? In her case she had to calm down her mom down. And that was her job, from a very young age, so it felt like to her she was the parent.

#### **Katy:**

So my dad had bipolar disorder, so again my Dad died when I was nine so I the impact it had on me was different than my siblings who were 14, 15, and 17 when he passed away so they were older. But he suffered very debilitating depression, like couldn't get out of bed. I remember seeing him in his bathrobe a lot which as a little kid I didn't really totally understand it, and when I got older I was like "oh I guess the bathrobe was when he was depressed." You know he often couldn't work he tried to get disability, and you know it was a completely humiliating process to get approved for disability. He took medications but they weren't very effective, I remember sitting down at the table for lunch, and he bite down on a sandwich and his tooth fell out, so the side effects were brutal. I think we were lucky in terms of the notion that when children are put in the position of taking the caregiver role, you know it happens.

I think we were lucky because my mother was able to care for my Dad and raise us, and like I said we certainly had supports such as my Dad's sister and my uncle were very supportive of our family. And we were lucky not every family has that, and the curriculum does cover some information about being aware that your child is not taking on too much. I think honestly my older sister took on some responsibilities at a young age, she was also extremely close to my dad they had a really great relationship. So I don't think she would have done things differently but you know not expecting too much, because that can have really detrimental effects on children. And a lot of the international researchers like the folks in Australia, Canada, and the UK look very much at the carer role, these children that take on these carer roles, and how we can help parents avoid doing that or help children not have to take on that role.

**Question Five:**

**Jared:** This is from Mike from London, Ontario. He asked, is there any attempt to do something similar with immigrants or refugee parents? If yes, please provide references, if not, he would like to be involved in some way or updated on eventual trials or projects.

**Katy:** That's a good question. It's not an area that I know very well. I know that Through the Looking Glass, Ella Callow, who is their legal director, is very interested (she's actually partially of Native American descent) in Native Americans, 'cause in the US we have different laws around Native Americans and Child Welfare. I know actually in Canada I went to a presentation where rates of removal from child welfare can be very high, so that might be a good person to reach out to, to see what they're doing. I don't know that area that well so I don't know the literature, but you raise a big issue. Refugee families, which we'll be seeing more of, and immigrants, I mean they're dealing with so many other issues, especially in the US where our healthcare system still has yet to be very inclusive even with the Affordable Care Act. So my recommendation would really be to check out Through the Looking Glass and maybe try to connect with Ella Callow because I think she's someone who has more expertise with marginalized populations and might be interested in discussing this further.

**Question Six:**

**Jared:** We have a question from Robert, he says that the Texas model seems to view child mental health as a negative outcome of parental mental health, but was wondering about a more bi-directional relationship, such as child mental health also impacting parental mental health, and wondering how this program may handle that.

**Katy:** I don't know if our program handles it. I mean, I agree. Children can have mental health issues regardless of whether or not the parent has mental health issues. Kids can certainly be at risk if there's a genetic factor. And like I said, in my recent position working in counsel, I often got with families that had children with disabilities, and the strain that it put on the parents, you know, worrying about your child, advocating, making sure that they're getting the right services and supports, and that you have the money to pay for the services and supports – since, you know, again, health care in the US is sometimes a little daunting. I feel like, the tool as it stands now is more focused on the adult sides, we probably delve into some of the children's issues a little less. It's something we can think about moving forward, but I don't think it's something that we touch on too much in the curriculum.

**Conclusion:**

**Katy:** I want to thank everyone for joining. If you haven't accessed the tool, please sign up, it's free! Tell people about it; I hate when there are projects that are federally funded and then the stuff doesn't get out there to people. The whole point of creating resources like this is that the people that need them get access to them, so I appreciate you taking the time to hear about the tool and learn how to support parents with mental health issues. Thank you!

