

2021 Online KT Conference: Research Results for Policy Outcomes

Being Useful to Diverse Parents with Disabilities, their Children, and Families

Megan Kirshbaum

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JOANN STARKS: So that brings us to our first presentation today. It will be Dr. Megan Kirshbaum who has been working with infants, children, parents, and even grandparents with disabilities over a storied career. She founded Through the Looking Glass in 1982, and we look forward to hearing about the interaction of intervention, research including Nadler supported research, and knowledge dissemination to impact public policy.

MEGAN KIRSHBAUM: Thank you. I'm welcoming you here today. I'm Megan Kirshbaum. I'm a white woman in my 70s with curly, medium length graying hair. I'm wearing a purple and dark gray top and glasses.

The title of my talk is being useful to parents with diverse disabilities, their children and families. I'll be drawing from Through the Looking Glass's 39 years of response to the critical national lack of resources and barriers experienced by parents with disabilities and their families. And I'll be talking about the synergy between intervention, research, knowledge dissemination, and public policy action in our disability culture-based organization Through the Looking Glass.

I'll start with kind of context of this work. My husband and I founded Through the Looking Glass in 1982. We emerged from family therapy from the beginning of the disability civil rights independent living movement in Berkeley in 1973. Through the Looking Glass has always been based in the disability culture community. We've been committed to addressing obstacles faced by families with disability, nurturing the potential of all members of families with disabilities.

Our original vision was to bring a disability culture perspective to early preventive mental health and developmental intervention, and also to bring awareness about families and parenting to the independent living community throughout the country. So, from very early on in 1985, NIHR, which was what Nadler was called in those days, funded an innovation grant to Through the Looking Glass to demonstrate our core model, which has really remained our core model, professionals with personal or family disability experience, providing infant mental health,

family therapy, child development, and disability resources to families with disabilities and parent or child.

This is a photo of where Through the Looking Glass started. It is actually a cottage which is our renovated garage. When we received our very first-- when we were site visited for our very first National Center for Parents with Disabilities, the site reviewer said, well, this really is grassroots. So being in our backyard, yes.

And so, some about intervention Through the Looking Glass-- as I was saying, we've always been predominantly peer professionals, as well as being psychologists, social workers, developmental specialists, OTs, early educators, researchers who have personal or family disability experience and bring lived awareness of issues and social barriers. For a number of years half of our staff have been people of color; many, many different cultures and languages reflecting the diversity of Alameda County in the East Bay of San Francisco.

We've been really responding to the local needs with ongoing intervention because we have one of the most culturally diverse counties in the US, and with many low-income families. So, we are primarily have and are serving low-income families of color that have disability issues in the infant, or the child, or the youth, or the parent, or the parent and grandparent. And we're supporting secure attachment, parent, child, and family relationships through mental health services, and then supporting the development of the children through developmental services, supports through groups, disability adaptations that I'll be talking about a lot.

We have an Early Head Start center that specializes in families with disabilities and we do a lot of consultation in the community and nationally. In around 1990 we added ongoing internships and post-docs within TLG training psychologists and have quite a substantial program with that focus. We also train, have interns who are OTs and special educators.

So, we're dealing with what we think of now as the intersection of poverty, disability, racism, and often trauma. So, focusing on parents with disabilities and our intervention projects. For many years we've served around 175 families annually where the parents have all categories of disability or multiple disabilities, and then another around 150 families where children have developmental concerns or disabilities. And the families we serve have either weekly or twice weekly, or if they're in the Early Head Start center, daily services, plus groups, consultations and training that we do to the community.

And most of the activity I'll be talking about today were under the auspices of our Nadler National Centers for Parents with Disabilities from 1993 to 2017 where we had many research development, dissemination and public policy projects. I hope that our practical experience in dissemination and public policies, and many of them modalities we've used, will be interesting because we've always been a modestly funded disability community-based profit. So, we have not had the resources of universities, for instance.

So, regarding identification of issues, Through the Looking Glass evolved through discovering issues and gaps in services in the community out in national practice or research; and we're trying to respond with resources and development and training and services and research and public policy efforts addressing the gaps.

And a couple of examples of how that evolved were early on we discovered that parents with intellectual disabilities in our counties were not receiving any preventive services targeted to their parenting, and most of them were losing custody of their children. So that's how we started adding prevention services for that population since we already were surveying parents with physical or vision disabilities.

And more recently in response to the trauma issues, in our clientele we extended our infant mental health approaches to include child/parent psychotherapy as a more rigorously research-based approach to the trauma issues. And then in more recent years, we identified a need beginning in pregnancy and early parenting for youth and with disabilities that were in transition from foster care who become parents since it's very common for young people during that transition to become pregnant or to become parents.

So, from the beginning of Through the Looking Glass in '82, we identified a pattern of pathologizing families with disabilities, and especially parents with disabilities in practice, and also in the research literature. And in response we began doing research from a disability cultural perspective.

So, the goal was to conduct research that was likely to contribute to the reduction of social obstacles including improvements in resources, practice and public policy; and also, we were investigating negative assumptions about child outcome, which were very common in the literature and also in practice; and on top of that, we were counteracting the invisibility of parents with disabilities in communities and systems and in data all throughout many levels of public practice.

For example, in the very beginning of Through the Looking Glass I interviewed parents with disabilities for a maternity nursing textbook that was published in 1985. And these parents were primarily very accomplished professionals and including leaders and the disability independent living community, including Ed Roberts actually, they described being very disrespected and questioned regarding their capability as parents.

This led to our groundbreaking research from 1985 to '88 that was funded by the National Easterseal Research Foundation where we videotaped 11 mothers with physical disabilities caring for their babies from birth to toddlerhood in all aspects of care without receiving any intervention. And we documented the inventiveness of the mothers and how they facilitated the babies adaptations to their disability needs.

We documented very, very early adaptations in infants, including a 30-day baby who in response to physical cues from his mom curled up like a little kitten and held very still during lifts, and then when he was done with his job of accommodating became the wiggly little 30-day-old baby that he naturally was.

So, this was very important work that influenced our practice throughout the years. I feel like it's very important to have enough presence, even immersion in diverse disability communities, not just with socioeconomically privileged people so that you can identify and respond to the issues of the most vulnerable families and the ones that have benefited the least from advances in the disability field, and because this immersion can really fuel awareness of the urgency for dissemination of research results and the importance of the impact on practice and public policy as it has for Through the Looking Glass.

I want to speak a little bit to the identification of issues through intervention and the role of intervention-derived knowledge. We've had a kind of unique experience because of 39 years of providing intervention to parents with disabilities and their children and their families.

We've had this core services model that's based on facilitation of child and parent and family relationships and child development and parenting adaptations that's been evaluated in numerous ways over time through funding systems and through research and demonstration projects. So, for more than 39 years we've provided varied services to many thousands of parents and caregivers with all categories of disabilities and cultural identities and at all different points in the family life cycle.

During pregnancy, throughout parenting, to grandparenting, many families have had very long-term services. Particularly parents with intellectual disabilities have lost custody of previous children. And we have had support systems which always must struggle with continuation of funding, just by the way, support systems that have been serving such families from their child's infancy to in a number of cases I'm going off to college.

Some parents with intellectual disabilities served by Through the Looking Glass have been in a support group together for 17 years. The necessity for out-of-home placement of children of these families despite many stressors has been very rare.

So, I want to talk a little bit about the dilemmas and opportunities of a commitment to responding to such urgent community needs for services. So, Through the Looking Glass tends to receive referrals of particularly stressed families, and the priority has been to meet their needs, sometimes presenting challenges for research. It's been challenging to continue critically needed availability of services to low-income families with a lack of public funding systems for parents with diverse disabilities and their children. And that continues to be a national public policy dilemma.

So, we, at Through the Looking Glass, have had to fund services through numerous different grounds, and fit parents into our funding coverage in a number of systems. For instance, we serve them through Medicaid, Medi-Cal in California, for mental health services to low-income children and their families. We serve them through Early Head Start through our specialized program that serves families, more families with disabilities than most Early Head Starts. And we serve them through Part C Early Intervention. We serve them through city grants.

Each funding system has its own varied requirements and evaluation modes. Though families benefit from the numerous Early Head Start services and the kind of wraparound services we do, it can be challenging to attribute outcomes to any one intervention, obviously.

So, to respond to critical services and resource needs, we've tended to do more development and demonstration projects. And some intervention has been workable for focused research, like our baby care adaptation research and our video intervention research with parents, with intellectual disabilities and their babies. However, intervention has always identified issues for research and training, and intervention knowledge has led to national technical assistance, our early national parent-to-parent network, and then especially research in our national centers for parents with disabilities.

So, all of this work has continued to reveal a daunting degree of need for improvements in national practice, training, and public policy for training of diverse professionals, and for public policy changes relevant to the lives of parents with disabilities. Parenting with a disability, all through the years, was uncovering many systemic issues, realms, systems, that had been minimally impacted by the ADA or other progress and disability awareness and access. For instance, legal and mental health, social systems, social work systems associated with child custody, pediatrician and OB-GYN practice, childcare access, and so many disability systems were focused on individuals, not families.

And through this narrow focus, still functioned as if assuming people with disabilities are not parents. That includes housing, that does not have accommodations for more than an individual, or perhaps a couple. Transportation, which we've done research on, which has numerous problems that impact parenting and getting children where they need to be, to doctors, to centers, et cetera.

Personal assistant services, which in most parts of the country, does not allow it to be used for any kind of parenting activities. It's only supposed to be supporting the disability needs of the individual person with a disability. Also, an assistive technology, and durable medical equipment, baby care adaptation, generally almost always are not covered, no matter how urgently they are needed by the parent with disability.

All of these problems have implications for custody by parents with disability, that is people can lose custody of their children solely because of transportation problems, or lack of baby care adaptations, or inappropriate housing, or not being able to use their PAS to assist with parenting. So, our work over the years has uncovered extreme lack of resources and deep and pervasive bias about parenting by people with disability in many realms.

That's why I've long said that parenting is the new frontier of disability rights. Since so many parents with disabilities and their children still have a critical lack of resources and face pervasive bias, discrimination in so many systems, I think it's really an ethical requirement to offer respectful reimbursement for their time when they participate in research projects, and whenever possible, include practical resources within those projects.

Through the Looking Glass has had a rule that all of our research projects include elements that are promptly useful to parents with disability because of this. So, examples are in having demonstration projects that include services to parents with disabilities that they cannot get elsewhere, the use of intervention therapy to support parents with ID and their babies, the actual

provision of baby care adaptation by our OTs, the National Technical Assistance we have done in custody cases, the college scholarships for young adults with parents with disabilities that we provided that was tied to research, a survey of more than 2,000 young adults with disability who had parents with disabilities. Young adults, a survey of more than 2,000 young adults who had parents with disabilities.

So, other elements that we have provided at the end of projects, like two idea books that were part of our research and demonstration projects about baby care adaptations, or a matrix of relevant parenting equipment on the market, on our website, or guides to support parents in custody situations. So, really, baby care adaptation and custody services provide the clearest example of our synergy between intervention, research, knowledge dissemination, and public policy action.

It started really in 1985 with the interview of the parents with disabilities for the nurses' textbook, because those interviews revealed problems and practice. And then that we followed up from 1985 to '88 with the groundbreaking video documentation study that was funded by Easter Seal Research Foundation that revealed beautiful reciprocal adaptation processes between mothers with physical disabilities and their baby as they adjusted to one another through time.

It also revealed overuse and repetitive stress problems in mothers who strained their bodies to avoid stressing their babies in any way when they did not have baby care adaptations. Though they invented adaptations themselves, they did not have anything provided to them. And you know, it also documented these ingenious adaptive solutions that were invented by the mothers.

Then we started getting custody cases. There was a very famous custody case. It was kind of a media firestorm, national case, called the Tiffany Callo case. Later there was a book written about it.

And that was when I was pulled into some of these early custody cases personally as a disability specialist. Tiffany was a mother with CP, that lost custody of two of her babies, and was never really provided with any kind of disability informed practice or adaptations until I got involved with her.

And then in Oakland, another case that made a big impact on me was a case of a very young Black mother in an Oakland project who had very high quadriplegia and had never been given any help with holding her baby, feeding her baby, playing with her baby, or anything. And was sent to numerous inaccessible sites to meet the requirements of her custody case.

These two cases, where I was struggling personally as a non-OT, as a psychologist, introducing adaptations as best I could with pillows, and front packs, and things, made me very aware of what the need was for some of the most stressed young parents in our community, and motivated our development of baby care adaptations by OTs. And it also led to me getting involved in other custody cases, which I have been involved with ever since as an expert.

And it led to the beginning of national media coverage, which had kind of engaged with as best we could. It led to a book. It led to a national network through the media coverage. And it contributed to our initial funding as a National Center for Parents with Disabilities in 1993.

So, then, it also led to our baby care adaptation work beginning in 1991, through a NIDILRR field-initiated research development grant on developing baby care adaptations. That were informed by the previous user sealed study that inventions of mothers and documenting the impact of offering those to parents with disabilities with pre-post videos, analyzing reciprocity between parent and child. Where we found an increased role of parents with disabilities and a positive impact on the parent child interaction when parents weren't so preoccupied with difficulty and pain, as one would expect.

And the resulting first idea book of our baby care adaptation was distributed online, system wide, by NIDILRR in those years. And the videos of both projects that used to sell and the NIDILRR project videos were channeled into intervention and custody cases for many years, into hundreds of training, including those associated with the development of legislation later in Idaho, and Kansas, and California.

So, Through the Looking Glass, OTs have been doing baby care adaptations over 30 years now. More than 500 parents with disabilities have received those services. We've developed further baby care adaptation, curriculum for OTs, training of OTs under other NIDILRR projects in our national centers. And then we have just received an award working on manualization of our interventions to support replication, national networking, and training, and then training of another generation of OTs through more national programs and networks.

So, choices of research focused have always been related to issues that arise in custody cases of parents with disabilities. And then our roles as expert witness in many states led to access to family court and child welfare court records, as part of a process of analyzing disability appropriate practice.

And then this led to research analyzing parenting evaluation specifically, because I had been very shocked in serving as an expert witness in cases about the quality of those evaluations. Evaluations that were the primary thing resulting in loss of custody of parents with disabilities, children.

So, we focused in on evaluating those, and documenting poor practice, and developing guidelines for that. One of the factors in the parenting evaluation that was common was the prevalence of speculation about child burdening and long-term outcomes, that is, the evaluator might conclude that things are working fine now, or OK now, but in the long run, there's likely to be problems of that sort.

And we also saw speculation about child burdening and long-term outcomes, negative speculation about child burdening and long-term outcomes in the literature on parents with disabilities. And these led to Through the Looking Glass taking on conducting studies of older children. One of them was 273 teens and their parents with disabilities, where the findings were a comparable level of chores to teens whose parents were non-disabled. And then another study of 2,340 young adult children of parents with disabilities, the majority of whom reported positive or very positive experiences with their parents with disabilities.

Also, we started providing custody technical assistance nationally. And at the peak of our funding of our national centers, we were assisting in depth with 100 cases per year. This was the work of Ella Callow. Very fine work of Ella Callow, a family law attorney Through the Looking Glass. And this led to her study that found a disproportionate prevalence of parents with disabilities and large child welfare systems in three states.

So, we also were finding in custody cases, as well as an intervention with parents with disabilities, a lot of obstacles in transportation. I mentioned before that that was one of the, that not being able to use transportation, difficulties in transportation, were actually leading, in some cases, to loss of custody, not getting to visitations, and that kind of thing.

And so, we did a national study on paratransit [INAUDIBLE] that documented barriers and recommended improvements in practice with parents with disabilities and their children. That is, there were many, many problems in cost and in practice that interfered with parents with disabilities getting their children where they needed to go. Whether it was to center, early childhood centers, to doctors, to appointments, and that kind of things, that were undermining their functioning, and causing a lot of stress, particularly for low-income parents with disabilities who couldn't purchase their own vans or provide their own personal transportation through cars.

So, concerns about custody practice, in general, led to our involvement in assisting in the development of legislation that passed in Idaho, in Kansas, and in California. The example in Idaho is particularly important. The Idaho legislation regarding parents with disabilities has been considered seminal legislation. It was the first state to comprehensively alter its laws impacting parents with disabilities and their children. And it has significantly influenced subsequent legislation.

I do this work in particular with Kelly Buckland, who's the Director of the NCIL. And over five years, providing extensive consultation and training to the state system in Idaho that was working on the legislation. What I offered was particularly focused on our cross-disability intervention, our solutions, our parenting supports for parents with diverse disabilities, to the state legislative committee and the state system leadership. And then later, in two different waves, statewide system trainings, also including Judy Rogers at Through the Looking Glass. We did statewide system training as it was being developed to increase understanding of the legislation, the solutions that could be part a result of the legislation, and also later once it passed, to support practice statewide.

So, then after that, Kelly Buckland and I presented. And later, Ella Callow presented to MCD, urging focus on parents with disabilities under two administrations. And the Obama administration did become interested in that. And then that led to "Rocking the Cradle," which we were under contract to guide and introduce the issues. Ella and I, Ella was the second author and I was the third author, really.

So, we ended up writing quite a lot of the document too. It was really the culmination of Through the Looking Glass' public policy work from my point of view. There were around 100 references to Through the Looking Glass work. So, it was quite a dissemination project too, though it hadn't been envisioned as such.

"Rocking the Cradle" has been a catalyst for more interest in the issues in academia and a catalyst for significantly more legislation. There's really been a blooming of legislation since "Rocking the Cradle" was produced and disseminated. And then following a recommendation in "Rocking the Cradle," there was DOJ HHS guidance to national social services, CPS systems, following the ADN practice with parents with disabilities, that was distributed nationally by DOJ and HHS.

We did consult regarding implementation of this LNI, but it wasn't pursued in the previous administration, and it awaits impacting child welfare systems nationally. So, that's still a problem

and a big need. Because I don't feel that what I've continued to see from phone calls that continue to Through the Looking Glass regarding custody cases, I see continuing problems of parents with disabilities of many different kinds in child welfare systems around the US.

And more recently in fact, in 2019, I conducted an analysis of New York City practice with parents with cognitive disabilities for a legal action, a class action. And then we've continued through many years, we've trained county and state child welfare systems in different county and state levels regarding parents with disabilities. So, that training effort has been very important.

I mean, we really have developed one of the-- before I said that the issue of parents with disabilities uncovers a lot of problems and realms that haven't been enlightened by the disability civil rights movement, or the ADA. And that it also uncovers tremendous training needs across many disciplines that have not had to deal with sensitivity to people with disabilities and a lot of doubts.

I feel like while there's been progress, great progress in education and in employment, there's still really deep bias and lack of familiarity with how parents with disabilities take care of their children and love their children. And a lot of times, when we have done training that's very focused on parents with disabilities, even showing images of parents with disabilities, inexplicably people interpret it as we're talking about children with disabilities, as if parenting by people, by adults with disabilities, is inconceivable. So, there's very deep bias and a huge need for training.

And because of our awareness of the urgent need for diverse professionals to address the lack of appropriate practice in many different fields that affect parents with disabilities and the children, we have always emphasized training in many disciplines. So, we've trained nurses, physicians, attorneys, advocates, early intervention, OTs, early educators, mental health professionals. We trained hundreds of thousands of diverse professionals in person through national and international conferences at the UN, more than 55 countries, but especially more in depth in Japan, Korea, and Sweden, particularly Japan.

And Paul Preston, who retired from Through the Looking Glass, also had a very extensive training role regarding practice in custody situation of deaf parents in Canada. And through contact to the Ed Roberts Campus, I think I showed you the little cottage we started in, but for many years, we've been in the Ed Robert Campus where there's many different disability civil rights movements and resources for parents, for people with disabilities.

So, as prior to COVID, received many visitors where we've been doing many trainings of visitors from countries that are working on developing their own ADA programs. And we always advise them to include parenting in their ADA, because the gap, the non-inclusion of parenting in our ADA has created so many legal difficulties for parents with disabilities.

I'm going to, in conclusion, I want to say that all along, tenaciousness, flexibility, adaptability to evolving needs and opportunities has been absolutely crucial. Engaging, because we were so central, we were privileged to have many media come directly to us. So, we didn't really have to reach out, in the past, local, national, and international media over the years.

But recently, also, the flexibility and adaptability to evolving needs brings up how we've had to pivot so quickly to remote services during COVID. And deal with the extra issues of parents with disabilities in our communities where they couldn't get to food distribution sites because of the transportation obstacles. So, we had to begin a home delivery program of food, and diapers, and many different items, masks and everything, educational materials.

So, the pivoting to evolving community needs is absolutely important. And I want to say that social media on websites and remote training have opened up tremendous avenues of communication and identification of issues. But for many of the most stressed low-income parents with disabilities, these modalities have not been working so well. Though we pivoted really promptly into remote services, families still struggle, our families, our low-income family, our families who are predominantly low-income, struggle with technology, with Wi-Fi, with literacy, with English, and with concrete needs for adaptations, parenting equipment in their homes.

So, there remains a really critical need for local services with expertise regarding parents with disabilities and their children. Legislation is crucial, but not sufficient. My experience as an expert witness in many custody cases led me to conclude that the legislation wasn't meeting all the needs, because in the cases when courts would be convinced that their practice wasn't adequate but justified termination of parental rights on the basis of the lack of appropriate local services. That's why in our recently funded FIP NIDILRR project, we're so focused on national training and networking of OTs and replication of our baby care adaptation work. So, those services are more available to parents with disabilities and communities throughout the country.

Just some recommendations. That training to intervention systems should be provided by those with expertise in preventive supports and intervention, like funding of demonstration projects in different regions that increase provision of supports for parents with disabilities would be one

step. More linkage between researchers and intervention programs would be helpful. And there's an urgent need for legal representation in family court and dependency cases for low-income parents with custody problems. And then associated need for more attorneys to be trained and committed to the intersection of disability rights and family law.

And really, we would encourage the Disability Rights Protection Advocacy Network to be expanded to cover custody by parents with disabilities. That's a huge need. And of course, we recommend implementation of the recommendations of "Rocking the Cradle," including mandating training for custody evaluators on parents with disabilities and their children and expanding the definition of medical equipment to include adoptive parenting equipment, expansion of the definition of ADLs to include parenting in order for personal assistant services to include parenting assistance.

And also, we recommend including parents with disabilities to be included in data systems on the local, state, and national level, because that supports the identification of needs and therefore funding to meet the needs. It's really important that there be respectful collaborative relationships between researchers in academia and disability community organizations. In the case of parents with disabilities, there's so much crucial and urgent public policy work that needs to be done that can be expedited and improved by building upon one another's work.

And this is contact information for Through the Looking Glass. And that's the end.

JOANN STARKS: Thank you so much. That was really quiet the journey that you took us through of 39 years of your work. And I can only imagine when you were starting there and just beginning to find out what some of the issues were, and then realizing that there was absolutely no attention to those issues. It's really mind boggling to think about parents losing their children and there's no services out there to help them, and there should be.

It's like saying, well, you have a problem, and we're not going to help you solve it. So, we're going to solve it by taking your child away. That's just seems so cruel, and just almost unbelievable. But I can see you've really covered so many-- you've probably uncovered so many new ideas and issues over the years of your work. It's really quite impressive. Thank you so much for bringing all this to us.

I know everyone has been very interested in some of the things you've done and some of the dissemination activities you've had over the time. So, thank you again, Megan. And we'll now go ahead and move on to our discussion session. And Kathleen Murphy is going to head up that. So,

we ask the reactors if they would turn on their cameras. And Kathleen if you're ready to take it away?

KATHLEEN MURPHY: Sure. Hello, everyone. That was really fantastic, Megan. Thanks for sharing that. We're very fortunate to have you with us and our other panelists this afternoon, who really have been able to make real changes in the world as a result of what you're doing. So, congratulations again on making a contribution in the world better.

We're joined today by some people who have had a chance to look at your slides ahead of time, and think about it a little bit, and have been working in the field, or have lived experience with some of these issues as well. One of them is Piper Hansen from the University of Illinois, Chicago. We also have Marsha Ellison from the University of Massachusetts Medical School. And Dahlia Shaewitz, from the Institute for Educational Leadership.

My name is Kathleen Murphy. I'm Director of the Center on KTDRR. I have blond hair and wearing glasses today and a dark green scoop neck dress with a brown collar jacket and some brown beads on. I am going to ask our reactors to describe themselves. And if there's something else that you'd like to share with the audience about yourself, this is your opportunity to do that as well. And then I'll go back around and ask you for any thoughts you may have had prior to or since hearing Megan's presentation.

So, I'd like to start with Marsha Ellison. Marsha, do you want to say, hello, to everyone?

MARSHA ELLISON: Sure thing. It's a pleasure to be here. My name is Marsha Ellison. I'm a woman in her 60s, wearing glasses, and shortish brown hair.

KATHLEEN MURPHY: Piper.

PIPER HANSEN: Hi, everyone. I am Piper. I use she/her pronouns. I am a white woman in my 30s, and I have kind of darker blonde hair that straightens. I have on a blue shirt, and I'm sitting in front of a brick wall.

KATHLEEN MURPHY: Thank you, Piper. And Dahlia.

DAHLIA SHAEWITZ: Hi, everyone. I'm Dahlia Shaewitz. I use she/her/they pronouns. I'm a white female, middle-aged, with brown hair, kind of long, and glasses. I'm wearing a green sweater and a scarf.

KATHLEEN MURPHY: OK. So, now as I said, I'm going to go back around. So, back to you, Marsha. Did you have any thoughts, or feedback, or just insights about what we're talking about today here?

MARSHA ELLISON: Well, I have to say that after listening, I understand why you were introduced as having a storied career. It's really tremendously impressive the work that you've done and accomplished. So, I have a thought, which is kind of a question. I have been on the outskirts of research of the parenting of individuals with mental health conditions who are parents, and who are in terrific custody battles all the time, as you mentioned.

So, I think that the pervasive stigma about mental illness is really plays into those challenges. And so, what I was thinking about was, what direction does it go in, or is it just sort of bidirectional, does policy influence public perception and public stigma, or does sort of the training that you were advocating for and the sort of grassroots advocacy changes public perception, and that impacts policy? I was just sort of thinking through that a little.

MEGAN KIRSHBAUM: So, you're talking to me?

MARSHA ELLISON: I am talking to you. I hope that's OK.

MEGAN KIRSHBAUM: OK. Yes, OK. Well, I think, first of all, many parents with other disabilities have mental health issues as well from trauma, for instance, and that may not be identified. It's very often not identified, postpartum depression or depression in women with other disabilities is often not identified, and it's very important to be identified, because of the long-term possible impact on children and on their functioning.

And so, many parents have multiple disabilities. And it may be, in the case of particularly parents with intellectual disabilities, depression is often interpreted as part of their intellectual disability. The impact of depression is often misunderstood as part of their intellectual disability. So, I just wanted to bring up that point.

You know, I have long really advocated for them than newer knowledge in the infant mental health field, the infant mental health specialty, to be a resource for parents with psych disabilities, so that very early prevention work can be done to facilitate the relationships and the parenting, and the parenting interaction between parents with psych disabilities and their children. And a lot of times, we're dealing with impact of trauma too in situations of parents with psych disabilities.

There is a big problem I've seen in custody cases around the country that even a history of perhaps brief postpartum depression and hospitalization can be used against a parent and resulting in termination of their parental rights at the outset of parenting without even giving them a chance to demonstrate that they can be effective parents with their children. So, those are some of my thoughts.

MARSHA ELLISON: Thank you. Appreciate that.

KATHLEEN MURPHY: Thanks, Marsha. A really good point, obviously. Piper, did you want to comment?

PIPER HANSEN: All right. Thank you so much for your presentation, Megan, and also, for the impact it's had on my career as an occupational therapist. So, one of the things that really stood out to me was this kind of push and significant need for training, training of medical health professionals, of other occupational therapists. In my training, there was nothing that I remember that was related to parenting within the education, and specifically related to assistive technology and creating adaptations. That's an area that I specifically work in. And I've very much used the resources from Through the Looking Glass over the years to educate myself and to share that with my own colleagues.

So, you know, I'm very excited to hear that you're working on kind of standardizing the training, and the education, the manual that's going to be available. As someone who has also transitioned recently to academics and training future occupational therapists, and other Allied health professionals, what are a couple of the key things that seem to be most impactful in terms of training to professionals that we should be highlighting specifically before we even implement kind of the full standardized training?

MEGAN KIRSHBAUM: Well, I think that there is deep unconscious bias about parenting by people with disabilities in general, and my guess is it influences OTs perhaps less, understanding the perspective of OTs, but it is there in many disciplines, whether it's talked about or not. So, it's I think that normally in training, when we do, I didn't do it today, but normally in training, I think it's very important to use images of solutions enacted by parents with disabilities and their children.

A multitude of images to counteract the deep bias, to kind of replace that with perspectives about solutions, positive solutions, and fun and joy, and between parents with disabilities and their children. So, that's really how we have approached it and needed to approach it. If we didn't have

these many images, it doesn't touch on the deep attitudinal bias. You know, it's something that really needs transforming. And that know we carry societal biases of many kinds, of course. And this is one of the ones that isn't talked about much, very seldom talked about.

PIPER HANSEN: Yes, thank you. I think especially when we think about adaptations that OTs can do. We sometimes talk about it, here's the thing you can create, and it's coming very much from a medical model perspective. And I think particularly in the area of parenting, it's so important to have that disability culture perspective that's influencing those decisions and approaches. So, the--

MEGAN KIRSHBAUM: Right. And the partnership with the parent and developing the equipment is very integral to our approach too. Because as I talked about in the beginning, all of our equipment development grew out of the natural solutions that were invented by parents with disabilities.

PIPER HANSEN: Yes, thank you so much, Megan.

KATHLEEN MURPHY: Thanks, Piper. So, Megan, a lot of people in the audience, before we turn to Dahlia, just very quickly. You've talked about videos, and there's a lot of interest in those videos. And some people have gone over and looked at your website like trying to find them. So, just kind of quickly, where would people find the videos, or are they available to the public, or should people contact you?

MEGAN KIRSHBAUM: Well, I think we're working on a new generation of videos in getting more up to date. Videos in our new project that just began funded by NIDILRR beginning September 1st, we'll be developing new more up to date videos. We do use, when we do training, direct training through Zoom or in-person training, we've always used video material. But we're wanting to develop a whole new body of video knowledge to disseminate at this point.

KATHLEEN MURPHY: OK, so, I guess people can continue to monitor your website. And I know--

MEGAN KIRSHBAUM: Or can contact us. I mean, in terms of providing training, they can contact us.

KATHLEEN MURPHY: OK. And I'm sure when you have those videos, you'll share them with the National Rehabilitation Information Center and ARC.com, which has a weekly news and notes. And we'll get the word out. So, anyone on this can subscribe to NARIC's newsletter to

find out all that NIDILRR is up to. OK, so, without further ado, we're going to turn to Dahlia, because I know she has really interesting things to share here.

DAHLIA SHAEWITZ: Great. Thanks. Megan, I think there's 100% consensus and this is a fantastic presentation, because you touched on something that we really don't hear a lot about in the disability community. And I was telling Kathleen in a separate text message. So, this is very personal for me. My parents have disabilities. I was raised in a deaf family. I've deaf cousins. I have relatives with all kinds of disabilities.

And your presentation really reflected the history that I also experienced. And as society and culture has changed, even though we've become a little more accepting of people with disabilities, it's some disabilities, and not all disabilities. And what remains a challenge in my view is really that basic awareness and understanding of what is a disability. How does disability intersect with individuals and families? And I noted a few things that you said that I thought were really salient.

And one of them is providing information and resources to parents with disabilities, for sure, but also having more conversations and telling the stories of those parents with disabilities, so that the general public as well as policymakers understand that people with disabilities are not just fully competent as parents, but they're successful even when those experiences are complex. A person with a disability does not have to be a perfect parent, because most parents are not perfect, right? So, just sort of bringing a little more normalization to that.

I love that you're working on self-advocacy training for parents as well. And my perspective is really from a knowledge translation perspective, right? Creating research that is reflective of parents with disabilities. Making sure that they're comfortable in their roles of knowing what to ask for and how to promote their own interests. And I'm just wondering, what do you see as the next stage in your work to, again, promote these parents with disabilities to be the decision makers in how they raise their families?

MEGAN KIRSHBAUM: Well, I mean, we are working on, I mean, particularly, we don't have the funding for the National Center anymore. You know, so, we're not in the position to do as much as we were. We do have this development project from NIDILRR at this point. And there will be many voices of parents with disabilities included in that project, telling their stories and documenting through video, and also narrative, their experiences to contribute to the manualization of our approach to developing baby care adaptations. And we have many people,

parents with disabilities, on staff that are involved in training too. So, those are two of the things that come to mind right at the moment.

DAHLIA SHAEWITZ: Great. Thank you.

KATHLEEN MURPHY: OK. So, sorry. I was trying to look up your new project, Megan. And I'll drop it in the chat later. So, we do have some questions, of course, from the chat, in addition to the one that we've already addressed about the videos. Jessica Lukefahr is quite asking, what kind of help did you have to provide parents when they were going through the loss of a child custody case?

MEGAN KIRSHBAUM: Well, we still are getting calls, though we don't have funding, to support that work at this point, because that was part of the National Center's. And we still are getting contacts from all over the country from parents with disabilities and custody cases. And what we've done, without having funding for an attorney to be on staff, really what I have been doing is, as in the past, is analyzing practice in the particular case regarding disability appropriateness and analyzing evaluations of parenting that have been done, because that's my particular thing.

Whether they've been done, because many of those, as I mentioned, evaluations of parenting capability reveal a lot of stigma, and often are poor quality. You know, so, I mean, and we're also able to talk to the attorneys. But we don't have the full program that we had before dealing with a hundred cases a year. That is something that needs to be funded by other programs and taken up by programs with much more capacity at this point, such as I mentioned, the disability rights protection and advocacy systems.

I recommended that they have expanded funding to take on custody issues. You know, this is a big problem that there are also very few attorneys trained in the intersection of disability rights and family law. So, that's something that needs to be encouraged and supported at universities that are training attorneys. There are very large changes beyond the ability of one medium-sized program, like ours, to make.

KATHLEEN MURPHY: Well, that makes sense. The other, this is kind of combining a few questions, and we just do have a couple of minutes. But some of the people were noting in the chat that there seem to be analogies to caregiving for older adults. And that grandparents are often raising children, and they themselves, even if they didn't have a disability during the course

of their lives, maybe acquiring disabilities as they grow older. So, do you have any experience with this issue, with disabled grandparents who are parenting?

MEGAN KIRSHBAUM: Yes. In one study, around 40% of parenting grandparents have disabilities. They may not identify as being disabled, but they have disabilities. And we've worked with many. We do work with many parenting grandparents with disabilities and their children. And often their solutions are comfortable. The baby care adaptation work can be very helpful with pain, or also with energy problems, you know, fatigue.

And so, many of the same baby care adaptations can be developed, and workstations and simplification, easing of the difficulty of the baby care, supporting the relationships between parent and child, if there are mental health issues, and there may be inter-generational mental health difficulties, stresses in the families, that we pull in supports for. Most of these families also are low-income.

So, again, lacking in the resources that more upper-class parent with a disability may have, such as vans that are accessible, and that kind of thing, to avoid the dilemmas with transportation. I think this area, this issue, really needs to be addressed more by organizations that work with older people all over the country. Because I don't think that they are really that informed, generally, about disability solutions.

KATHLEEN MURPHY: For sure. So, thanks, everybody. Megan, for presenting, and for our reactors for joining us. We are going to turn to our next presentation now to keep on schedule, which is Michael Morris.