

Parenting with Disabilities

Marjorie Aunos ([00:06](#)):

We all know that parenting is hard. So how do parents with disabilities do it? With creativity And because we know of the value of interdependence come here about ways experts say we can best empower these families and let's all learn about how parenting can be done differently. I'm your host Marjorie Aunos and today my guest is Marja Hodes. Marja is a psychologist from the Netherlands. She did her PhD research in the field of parents with intellectual disabilities as a way to demonstrate how effective support can impact positively the lives of these families. She has extensive knowledge and expertise as a clinical professional. Her research is solid due to the method she used and gives us tools that we can use confidently, enjoy. And don't forget, for more information about where to find the full recording and additional resources, check out the show notes.

Marjorie Aunos ([01:23](#)):

I am very excited today to be talking to Marja. A little fun fact about Marja and I is that we have an interesting connection through her son actually. This is really fun for me because as I was going to try an exoskeleton to be able to walk and sort of, try that Marja's son was actually designing one in the Netherlands and working on an exoskeleton. So we were back and forth sharing our experiences and it was quite an interesting sort of little thing that we had just the two of us. So Marja is a clinician but she's also a researcher and has been working in the field of parents and parenting with an intellectual disability for a long time now. And I'm really happy that you're here with us today Marja.

Marja Hodes ([02:23](#)):

Thank you.

Marjorie Aunos ([02:24](#)):

So the way that I start at the beginning is really to try to understand how you got into the field in the first place. So I will let you explain your journey in this field.

Marja Hodes ([02:39](#)):

Thank you. I'm very honored to be here in this podcast and I really want to share my experience because parents with intellectual disability, they are such a great group of parents. I still remember one of the families because we have a lot of migrant families in Rotterdam and we had a mother she was from a Turkish family and the problem was that this mother didn't take care of her child in a good way. And what the support workers and child welfare did is they took away the child. And at that moment the family came to our service organization and asked why are the child welfare doing this? Why are you not coming and talk with us? Then I went to the family and I think there were around 15 or 20 family members there, the grandmother, she was in fact also in the middle of our meeting and she explained to me how important it was that family could support.

([03:56](#)):

And for me it was so important to see what families can do for parents with intellectual disabilities. So we talked with the family, we could make very good appointments, we could convince the child protection services that the child should go back to the mother and that together with the family were going to take care. And at that time I was around 23, 24 and I felt so much that I could support for these families and for parents with ID because it takes a village to raise a child. Also for people without intellectual disabilities it's a hell of a job to do it with a lot of fun and with beautiful moments but also with moments of stress and then you need good advice and support from others. So that's the way it

started. And I was also very much in the early intervention field and what's very strange was that we had family support programs and parenting support programs, but parents had access to these programs when the problems with the child was already very, very high.

[\(05:11\)](#):

And I was convinced that we could support this family far much earlier with early interventions so that at the moment you know that there is something just go to the family and try out together with all the family members what you can do for this child. And inside that group there were a lot of parents with intellectual disabilities as well. And there was no, the way of thinking at that moment was when parents of intellectual disabilities will have problems with the child, it's because of the intellectual disabilities and not because something else is wrong, maybe something in the child or something because you are living in vulnerable circumstances. So that came all together and for me it was so clear that my future will be just supporting these families and supporting these parents.

Marjorie Aunos [\(06:04\)](#):

I love that everybody that I talk to, we all have sort of that one story and that's what I love about starting the interview with that question cuz we all have those little stories when we met the first mom or the first parents and how that impacted us and made us choose. Do you wanna tell us a little bit about your role and what you do on a day to day because you support parents with intellectual disabilities so it would be interesting to know what exactly you do and what's your role.

Marja Hodes [\(06:39\)](#):

Yes, I have a lot of different roles because I'm a clinical psychologist but I'm also head of the Department of Clinical Psychologists and we have a family service organization and we support the families inside their own homes and there are support workers coming inside of homes and the way they support them, they are supervised by the psychologists and I am the head of all these psychologists. I have a lot of talks with the psychologists, how we should help this families about the program what they need in all kind of things. And that can be just for the family support at home but that can be also in a clinical way when we have parents with personal problems we have also the possibility to do some treatment for that. What I do is talk, I do research, clinical research when we have very complex families, I do that together.

[\(07:43\)](#):

Sometimes I go, we invite families to come to my office but most of the time we just go to the families themselves and we try to do the investigation there. We have a lot of talks with child protection services and I think this is one this very red line inside my work because I see that very often parents are misunderstood when stress, when the stress level is rising. And most of the time of course safety first. I know that we need to be clear about safety for children but there are a lot of ways how we can support parents and families when stress or when problems are happening inside your family. And that's what we do a lot. We try to be next to the parents, next to the family and try to solve it and try to interpret what the Child Protection Service wants them to show how it can be safe inside a room and how we can support them for showing that they are parenting good enough And we are all the time integrating and the most important thing is that we try to listen to these parents and that there is respect for these parents and that we are also clear what's safe or not safe.

[\(09:14\)](#):

And I think the most important thing is building up that relationship with parents, family members and also with their children. So that's the reason why we often go to the families where we often go to

having discussions and meetings with child protection services but also with schools. In fact, when I start my day, I start my day quite early. We have nowadays in Corona time more teams meetings but I'm very often on the road to a meeting, to a family, to my department where we do some research and I give also a lot of training. So I'm also teaching a lot and I have the most beautiful job in the world. I'm very happy with it

Marjorie Aunos ([10:05](#)):

<laugh>. Awesome. You were talking about stress and support and I'll just switch to that because your PhD touched upon those two factors. So do you wanna talk to us about the two articles that you chose that are in relation to your PhD and talk about stress and support?

Marja Hodes ([10:27](#)):

Yeah, what we know already about parenting with ID is parenting is always a stressful job and when you look at parenting with ID, you have more stress than the average parents also because of all kind of choices you are not able to make about the way you are having access to all kind of information. And the most important thing, the judgment about being a parent with ID because there are still the idea that parenting with ID is not possible because you have an idea, you are not a good enough parenting and there are still really a lot of people who think that parenting with ID is similar to problems with safety. That that's normally it's connects very easily. So what I would like to do with my PhD first of all maybe it's important itself, I didn't want to do my PhD because I working as a clinician and I need to work practical in the field.

([11:32](#)):

But the only thing we can do and I was convinced on it to give our parents a voice and to get them grow and become stronger is to do proper research that prove what the facts are and the way we can support parents. And that was really my motivation to do my PhD. I did my PhD on a very late stage. I was 57 when I got my PhD so it's late career but we try to combine that to giving them a voice and I was convinced then we need to, should start early and early is with looking at the way the parent and the child are building up the relationship. It's about attachment, about sensitivity, about responsivity and there was always an idea that of course parents can learn a lot of tasks and a lot of skills, but the way how they needs to take the perspective of the child and how they can be responsive and sensitive there was to common idea that's not possible for parents with ID and for me I was not convinced about that at all because of my clinical experience, but I had to prove that with research.

([13:01](#)):

So my idea was to develop intervention, video feedback, intervention that was already proven to be helpful for parents, for first parents. And I want to change that program, that intervention and make it tailored for our group of parents and to prove that also these parents can be helped by this kind of interventions and this intervention. Also you make small video tapes at home and then with a step by step analyze together with the parents, you analyze what you see happening with the child. So then you can take the perspective for the child. And what I was sure of stress is happening when you are losing your overview, when you don't know what the information is telling you when someone else is putting pressure on you and you can't see properly what happened. So for me it was very much clear we have a lot of interventions for parents and then we say to them, if you do a little bit more of that then your child will behave.

([14:17](#)):

Or if you do a little bit less of that then you will see it has a proper effect. But for our parents and even I think also for a lot of other parents, our parents, they really don't know where to look at what are the signals of my child, how can I interpret it? So our very first step is just support and help our parents to look at the child, to observe the child, to be inside the head of your child and help them to discover the intentions of the child and what is the child's feeling, hearing meaning why is she walking, all that kind of things. That's the very first step before we give an advice. And I knew already from my clinical work that if you understand better then your stress will lower down. And for me, stress and parenting, when there are stress factors, it's very difficult to parent good enough.

[\(15:20\)](#):

So that was the reason I really want to do that. So we tailored this video feedback intervention that was already evidence based for the average population of parents and I was very happy because that intervention was developed here in Liden where I live and we were allowed to tailor it for our group. And in a random randomized control trial we test these intervention for our group of parents and it was amazing to do that. Also the process to work together with the parents randomized controlled trial is always a hell of a job. It takes you years to get your group and really to be a randomized trial. So we had a group, we offered them, did some questionnaires and when there was a kind of stress level for parents then we offered them the intervention. But we had two groups. We randomized a group by just finding out first to start with the intervention or we had a waiting group list and we start with it later so that we could just compare the group.

[\(16:41\)](#):

And what's very nice that all the parents were on the waiting list, we offered later on the intervention and every family choose to get the intervention later on. So that was really, really very great. And when we look at the results of this intervention, well first I was a little bit disappointed because I thought we had that the stress level would be very much down and lowered and that the way we did intervention would be help parents to improve the skills. What we find out is that on parenting stress level, that's stress related to child problems that really lowered. So we are very happy about that. What we also saw is that the intervention we did, so to become more sensitive for the way we you explain things of your child they didn't decrease so much. But when we look better at the group of parents, then we saw that a subgroup really profits of it and that was the subgroup of parents with an IQ between 50 and 85 because that's was the group we were working with and with low social adaption skills.

[\(18:10\)](#):

And that was really amazing for us because what we know before already that parents can improve parenting skills no matter the level of IQ. So we proved that. I was happy about that. But the second thing, what happened is that a group of parents with low social adaptive skills, no matter the IQ between 50 or 85, they profit the most from the intervention. And that's the group of parents inside the Netherlands but I think also internationally who are always the one when they are in court case the judge is saying, well now we are not going to offering anymore because they are such a low level so they have no access to these interventions. And my research proved that this group profits most. So that was really, really amazing to discover. And for me then I was very happy that I did this research because that will bring these families in another position.

Marjorie Aunos [\(19:27\)](#):

I could hear it in your voice one, it's a huge job that you took in doing that research and randomized controlled trials or like you mentioned, very difficult to do. But I think the results of paid off in terms of really illustrating what you saw in practice <affirmative> and that's very strong and that's something that

we could always use you or we also collaborated together and wrote a chapter on the choice of becoming a parent when you have an intellectual disability. Do you wanna talk about that chapter?

Marja Hodes ([20:08](#)):

Yes, it was really I was so happy to do that together with such beautiful and yes colleagues you are one of them. I was so proud of you also the way we collaborated on that and I think the most important statement, we all know that for parents with intellectual disability and becoming a parent with intellectual disability, although we know it's a fundamental right because of the convention of the United Nations, still people with intellectual disabilities has no free choice at all. Cause there are so many barriers about how to access to proper information. They are more living in for number circumstances. There's a lot of stigma around being a parent with intellectual disabilities. So for me it was so important to write a chapter in an international handbook book that in an early stage students can also read about the position of parents or future parents with intellectual disabilities. And I think we did a very great job. I advise everyone to read a chapter,

Marjorie Aunos ([21:31](#)):

Its a chapter that we collaborated on with so many people and a lot of these people are actually on the podcast. So I'm talking about Gwyneth Llewellyn and Margaret Spencer, Beth Tarleton. So it was incredible to be working together on this chapter. There's another article that you're suggesting and this one is in Deutch, right? Yeah. Do you wanna talk about this one and why you wanted to share it with us?

Marja Hodes ([21:59](#)):

Well I think that's when you're doing research and when you're working with parents intellectual disabilities, you also have a political task. And if you want to improve rights for parents with intellectual disabilities, then it's important to bring up all the results of your research in the right places. So in the past I did some guest lectures for judges, for child judges and we are talking a lot that time about how they get proper information to make good decisions for parents and especially when parents need to go to court about the safety of their child. So then I was invited to write an article. So to summarize my research, my PhD research inside an article connected to the UN convention and to give advices from my research in combination with UN and convention to judges. And that was really amazing. It's in a Dutch paper, it's a law paper.

([23:12](#)):

And what I did, I tried to reach all the judges with all the decisions they need to make based on information they get delivered from psychologists and most of the childs of child protection services. So what I'm proud of that article is that the judges were reading it quite well. They understand that when child protection services saying well it's not safe enough that first you need to do is what are the facts about not safe enough? What are the circumstances families are living in and not safe enough has that to do with parenting skills and when it have to do with parenting skills how did you support his families and help them to get access to proper support? So what this article did is give judges more tools and more questions to go back to child protection services and just ask them how did you do that?

([24:21](#)):

And if they can give a right answer because we have unsafety situations for children then but they can also send the child protection services back with doing their homework just to first do your homework. And for me it's so important to give parents with intellectual disabilities the equal chance like other parents without intellectual disabilities when they are in court just to explain why they are in that

situation and how much support they got. And beside of this article now and then I advocate for families especially when they are only in courts because the parenting skills are question because they have an intellectual disability. And why I'm so proud about this article is now and then I'm looking at all court case and law and now and then I see that judges use this article for the explanation for when they are sending child protection services back and do their homework. So they really refer to that article, they're really using it and that's really, that's very, very nice. I think it's important that researchers understand that when you have results of your research, just that it will be accessible at all the fields where it's needed to improve position of parents.

Marjorie Aunos ([26:02](#)):

And I think in what you're showing with your work is that it really it's about educating and it's about informing people that the context has a great impact on some circumstances that parents with intellectual disabilities are in and that it's not linked to intellectual disability. So it's something that could be changed, modified, worked on and that the desire of these parents to stay as a family is definitely sort of there and their desire to work and to make sure to provide for their children in the best way is also there. And I think that that's what we're talking about when we share that message. There is also something that was pretty amazing cuz I have to say that it's one of the few things that are available in the world specifically for parents with intellectual disabilities and that is a toolkit and I would like you to introduce us to the toolkit and what it is and to tell us also if it's available for anyone to use.

Marja Hodes ([27:17](#)):

Well together with my colleagues, we developed toolkits talking about children and that's because we discovered that people with intellectual disabilities when they are thinking about forming a family support workers really don't know how to talk about these subjects. And it's so strange that when you take a very important decision in your life, we have families, we have close friends, we have a lot of people we can talk about and support. Workers are very often close to to people with intellectual disabilities. But when I talk to younger people with intellectual disabilities and we are talking about do you want to be a mom or a dad? And they say yes, I really want it. To whom are you talking about it? No, when I talk my support worker, they are telling me that it's not a good idea to do that and I'm afraid that we will quarrel about it and they will say, well don't do it.

([28:22](#)):

And it's even so I'm living here now in a group home when I become pregnant they sent me away. So all that kind of things are happening. So we are thinking about, it's so important that we support youngsters and future mom and dads about talking about being a mom or dad and that that's not my decision, but that's decision. You need to just discuss with every close people to you but also to become aware what the consequences are when you become a mom or dad. And for instance, everything is changing the way you can spend your money, your housing, the things you can do for leisure maybe you're working circumstances. So what we did is we create all kind of tools. One of these tools is just finding out what is changing in your life. Everything is changing and then we have questions and also assignments for people and they first discuss it and find out without children and then for the same situation we are going to figure it out when there is a child.

([29:44](#)):

So that's very important tool. Another tool was based on the support interview guide of Gynnyth Llewellyn and Dave McConnell is which people are around you in your social network that can support you and not only support for companionship but also support for when was a child who's going to

support you in real. So that's also very nice tool to do. And with the store we invite of course the future mom and dad, but also all the friends and parents or family members they are who are maybe going to support or not so that we can have to talk together. It's really very nice tool with also tools for support workers but also for managements in organizations because I believe that the mindset of the support workers, psychologists, or someone else is so important. First you need to know how you feel yourself while when you are talking about parenthood by parents with intellectual disabilities and if you are doing your practical work to support, but inside your head is all the time the idea, okay, I'm supporting them but I'm doing that maybe for the future child because, well I don't believe that this person with intellectual disability can become a good parent.

[\(31:14\)](#):

Then it's all the time inside your head and we know for sure that that influence the way you are supporting, the way you are working, the way you are talking, the way you can build up relationship with these parents. So we think that the mindset is also part of the toolkit is very much important and should be discussed before in the past we feel ashamed about talking about sexuality for people with intellectual disability and we don't know how to talk about and we feel in fact now the same parallel with talking about parenthood for people with intellectual disabilities. So what we'll we'll do with this tool kit, everyone can download it for free because we first designed it and we had a very nice physical one, bright colors, but we had about 350 and within a few months it was sought out. And then it was very nice, we get a national award for this toolkit and we decided to build a website with free downloadable tools for everyone who wants to work with it. And we always ask, please let us know because we want still want to improve and to add new tools that everyone can download it. And for instance, in Sweden with two of our colleagues there, they do research on this toolkit as well. And I think it's a wonderful toolkit to use everywhere. And I think very often we'll learn that people without intellectual disability said, Well I wish that I had this toolkit before I chose for children myself as well.

Marjorie Aunos [\(33:05\)](#):

So definitely a great resource and of course I'll have all of that information in the show notes for everybody to be able to get that. We'll go into the sort of third part of the interview and that's really about the future. So where do you think the future should look like or in clinical practice and in research, what should we do to improve the lives of families that are headed by parents with intellectual disabilities?

Marja Hodes [\(33:37\)](#):

I think that there are several things. One of the things I learned a lot, we are also basically a very nice article based on the keynote we did for the IASSID conference and one of our moms, she's telling her about stress and Rushlina, she's one of our moms. I work a lot with her. I I've a lot of respect for her and I learned an extra lesson when I interviewed her and that's about how support workers are causing stress. And she explains that of course we need support and I know I need support, but when you're first, when I'm stressed and you're coming here and you are just accusing me from everything I didn't do and I really don't know what to do, but then I explode and then I'm stressed and my stress is here and then I explode and everyone is amazed I explode.

[\(34:42\)](#):

And then you sit down and you said, how can I help you? Is it not possible to support me in a proper way to help me before the explosion so that you are not causing stress but that you are helping me first and then stress is not necessary. I think that's one of the most important thing that we are looking at what is

causing stress and that we are supporting the parents and listen to them. What cause stress. We have a lot of parents worth talking about that they have a lot of depths and just they are quite poor and these depths give them so much stress they are not able to listen anymore what they need to do in the parenting part at that moment. So we have an other duty at that moment. We should help them just to reduce the stress to help them with the depths.

[\(35:44\)](#):

So I think that's very often the focus is on the parenting skills of the parents. And I think the folks need to become more about all these items that are around parents. It's much more important and then we can make connections, we can build up relationships, we can listen before the stress and we can first listen respect without judgment. That's the other part. Our parents very often feel a lot of judgments and they are unable to protect themselves to that judgment because they have the intellectual disability. And if the outside world all the time saying you're doing this because you have intellectual disability, then they never can be there as a proper mom, proper dad. I think that's the very first thing to have to respect, to listen, to have to respect, to see all the items around all the subjects. We also need to do together, help them through build up the relationship and it's really takes a village to raise child for everybody. And I think that's the most important thing we should do.

Marjorie Aunos [\(37:06\)](#):

It's funny because in the service where I worked we also had the realization how we need to take into consideration and work on the context and everything that's happening in their lives often first before even working on the parenting skills. And because we had realized that that's why we worked as a team and in the team there was a psychologist who was me but also as social worker. And the role of the social worker was very pivotal and crucial because she was there to really look at issues with poverty, with having enough money to buy diapers or milk or just looking in terms of intimate partner violence. And so looking at all those extra factors that are in the social network and environment of these parents to be able to really reduce that stress to then liberate space for them to be able to learn the skills that they would need and if they needed the parenting skills because sometimes the parenting is doing, they're doing quite okay in that sphere. Yeah. But if everything else that's having an issue, finding a housing for example.

Marja Hodes [\(38:32\)](#):

And the other thing what's important that we are going to the narratives of these moms and dads and families. I think narratives are so powerful and when you listen to the narratives of parents that you can also learn about our needs but also about their strengths. And what I see that when we put our parents in a position they can be proud of that they are hurt and seen and that as a person and as a parent, they are important. And like Rushlina, the mom we're working with, she was very happy that she could contribute to other parents. And now and then she's helping us in our organization when we go to a family and a mother hesitating to accept support and when Rushlina is there she can easily convince the mother why it's important to accept it. I'm not able to do that. But Rushlina is heard and seen as a specialist, as a parent, as a specialist, she's the only one we can do that. And I think it's so important that we are putting parents in other ways that they are worthwhile, that they are seen, that they are heard and that they have a special experience we don't have.

Marjorie Aunos [\(40:06\)](#):

Yes, listening to people's story I think is very powerful. We will end on one question. If there was one thing that you could tell child welfare services, what would it be?

Marja Hodes ([40:21](#)):

Sit down, listen to this parent and first listen before judge, this parent has to tell you very important message and story and this parents are doing that by the heart and all parents want to do the best for the child. So first sit down, listen. And after that just discuss with the parent. We have one important thing because there's a lot of stress on child protections workers and I can understand because it's also very difficult job. Please take your time for it. Even if there is no time and an out of home placement of a child is very often not the solution. Just try to find your ways incorporating with the support workers, with agency where I really want to support families at home. At the moment there's a call in the Netherlands, political wise there are too much out-of-home placements so they really want to reduce it and I hope I can contribute to that.

Marjorie Aunos ([41:36](#)):

I think it brings a lot of different sort issues and I think the rate of out of home placement is high in all of our countries and it's definitely something that we need to look at in terms of how do we empower families before we decide that children needs to be removed. And I think that's what we're all trying to do really is to empower families.

Marja Hodes ([42:00](#)):

And I think empowering families is also not we have a lot of migrant families and we have one family and her mother is in <inaudible> and she's very much important. So we'll make a connection with this mother. We can do that by video, by teams. And the last summer it was important that her mother should come over so we could do some crowd funding for the ticket for the mother. And the mother came to the Netherlands and it was amazing how this mother of ideal, she grows so much and it was really a pleasure for everyone. And before this grandmother came, the child protection service want to take out of the child and after the grandmother paid her visit, it was not in charge anymore. So I was so very happy. So I think we also need to think more out of the box and we just need to dare thinking out of the box.

Marjorie Aunos ([43:00](#)):

I will. And on that note, I think because that's a pretty powerful note to end by saying we need to sometimes think outside the box to make the best decisions. So thank you so much for your time and congratulations for all the good work that you're doing.

Marja Hodes ([43:18](#)):

My pleasure. Thank you so much.

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This podcast was supported in part by a grant from the Minnesota Department of Human Services, Children and Family Services Division.