

Mom2Mom Episode 12 – Keeping Special Needs Kids Active

Announcer: Welcome to Mom2Mom, a monthly chat about the challenges of raising active kids.... Mom2Mom is produced by Saskatchewan *in motion* in partnership with Saskatchewan Blue Cross. Now here's your host, blogger and mom of three, Tenille Lafontaine.

Tenille Lafontaine: Hello everyone and welcome to episode 12 of Mom2Mom. Today we're talking about kids with special needs and keeping them active. Joining me today are Marilyn, a mom of 3; Jessica, a mom of 2; and Vigya, a mom of one.

Thanks for joining me today ladies and welcome to the show. To start things off, why don't you tell me a little bit about your families?

Marilyn Westood: My daughter is 13 and she has cerebral palsy. She uses a wheelchair for mobility. And my boys are 20 and 22 and they're out of the house.

Jessica Tiefenbach: I have a four-year old girl and a two-year old boy. And my four-year old is deaf and so she uses hearing aids to be able to communicate with us as well as sign language.

Vigya Sharma: My daughter Kavya is three-years old. She's our only child. She's on [the] autism spectrum, so she's partially verbal and she has some social challenges, challenges with social interaction with other kids.

TL: Well, we know that all parents worry about making sure that our kids are active and it's not an easy job for any of us. So I'm wondering as the parent of a child with special needs, what sort of things do you have to consider that others might not even worry about?

MW: Well the first thing that I was considering was if you're trying to fit your child into a mainstream activity with typical kids, like... is it even possible? Will they enjoy it? Do they need a support person and who is that going to be? Like... is it going to be me or is it going to be someone the program provides or something like that?

TL: Hmm. Yeah that's something that a lot of people wouldn't even have to consider that you have to kind of play into, right? Jessica, what about you?

JT: With Emily, we have to be careful about the noise levels of the activity. Sometimes if it's too loud and if she has her hearing aids on, she gets very overwhelmed and she gets quite upset. As well as we have to be careful of water because she can't wear her hearing aids in the water.

TL: OK, that makes sense. Vigya what kinds of considerations do you have to do when you're looking at activities for your child?

VS: So Kavya finds it really hard to follow rules, to follow structured play, so a program has to be really flexible. It should not be very structured; it should have... very flexible rules. And that just takes off the pressure from her mind and makes it more fun for her. Also, it has to be something that she really, really enjoys doing, otherwise there's no motivation behind it. So we always focus on things like jumping, bouncing, hopping, chasing and we look for activities where we get a combination of these things. So I

just cannot pick a swimming class for her because she may not like it and then no matter how much I push her for it, she wouldn't do it. Yeah, so those are the things I always consider when I am picking her activities.

TL: OK. Well, I'm seeing a commonality with the three of you, but also with myself as well. I think it just really comes down to knowing your child and knowing what they are able to handle and are capable of and what things may then work against them and not help them be a part of the activities. So I like that that's a common ground between all moms too, as well.

VS: Absolutely.

TL: Now Vigya, your daughter is involved with Special Olympics. I'm wondering if you can tell us a little bit about that and your experience and the programs that they have to offer.

VS: So it's an absolutely fantastic place for Kavya. Special Olympics has various programs for kids of all ages. The program that Kavya has been attending from last two sessions is called an active start program and it's for kids aged 2-5. What I like about the program is that they include Kavya's interests. So there are about five to six different activities that the kids are engaged in in an hour and there are things like obstacle course, kicking a ball, throwing a ball, bowling, curling, a few games like Eye Spy and Chase the Leader. And my daughter just loves it because it caters to her needs.

So when she started the program last fall she was anxious of the people around her. She was new to it, so she wasn't sure what would be the expectation of her, so all she did was... she ran around in the gym for the first three classes. She did not do anything. And the coaches... with my help, they started pulling her into activities very gradually. So if she wanted to do, like two rounds of obstacles, she would do that and then she would get a break. If there's a game that she doesn't like to do at all, she can skip it and then she can wait for the next game to start. And I get... involved throughout the session because like you said I understand my child the most.

The coaches are mostly volunteers and they are fantastic. And Kavya gets to interact with other kids. She learns to share, to take turns, waiting – just so many skills that she has learned in these sessions. I've seen great progress in her and now when she enters the gym, she just knows what to do. She engages in every activity and she does it from start to finish.

We are also starting a swimming classes for her through Special Olympics and I'm really excited and looking forward to it.

TL: Getting her into those swimming classes!

VS: Yes. Yeah we are. I always try to give her a gentle and playful push, so I'm going to try that and see where that takes her.

TL: Wonderful. Well I've heard nothing but great things about Special Olympics and I think you make a very good ambassador for it. So that's maybe a new role to consider.

Now Marilyn, I understand that your daughter is very busy. What sorts of activities is she involved in and what are you really gaining from them?

MW: Well, this year she's in an integrated choir, which is a choir of probably half kids with disabilities and half kids without. She does wheelchair dance and she does swimming and wheelchair basketball and she also goes to a youth group.

So, I guess when she was younger we tried to fit her into all kinds of activities to find out what she would like. Now that she's 13, we more stick towards the wheelchair sports, I guess, or the sports that are more specified for disabled kids.

TL: Great. Now I'm sure like every mom you've probably encountered some activities or some things that actually didn't work out as well as you had hoped or planned. So I'm wondering – again that commonality with moms – if you've kind of run into any activity that you thought “Oh, no, this is just not going to be good.” Marilyn has that ever happened to you?

MW: Well Taylor's tried a few sports. She tried sledge hockey and being in a wheelchair everybody figured she'd just love it. But she hated it because she was always cold.

TL: I get that.

MW: So ice hockey isn't for her. We tried musical theatre for her in a mainstream program and she really enjoyed it; it just... it conflicted with scheduling for her wheelchair dance, so she... had to pick. So she chose wheelchair dance.

TL: Got it.

MW: Scheduling is a problem and I think that's mostly it. Scheduling and sometimes they just don't like the activity.

TL: Sure. Jessica, what about you? Have you had any experiences that were an absolute no or just didn't pan out the way that you would hope?

JT: Oh yeah. There's been loads. One in particular was swimming lessons. It was really hard for us to do swimming lessons with her because she couldn't have her hearing aids in. And at the time she was about two and so we had to be in the water with her. So we had to hold her and try to sign to her to explain to her what they were doing and she didn't like that... She was not very happy about it, but she loves to swim, but swimming in swimming lessons without an interpreter there to explain it to her is just impossible.

TL: Got it. Got it. Vigya have you run into anything with your daughter and her experiences? You said that she... absolutely will let you know when she doesn't like something. So have you had an experience that you maybe wish you hadn't had with an activity?

VS: Yeah we tried gymnastics for her in the past because she's super active. She's a little gymnast, but a gymnastic class with like 10 other kids, one coach, is just way too much for her. She couldn't follow the fast instructions, the fast pace of moving from one obstacle to another, from one activity to another. So if she's on a trampoline, she would just like to be there for five minutes, but when you are in a structured group like that, you can't do that. You have to go along with the group and she isn't ready for that. So yeah, that didn't turn out well for us.

TL: I think as with all moms, it's a bit of a learning curve for us too, right?

VS: Oh, totally, yeah. All the time.

TL: Now I imagine it can be pretty overwhelming, especially at first for moms and all parents to figure out what's available and what will work for your child. So for those listening who either themselves may be starting to look or have a friend that may be in that position, I'm kind of wondering where you go for information and advice, and if there's specific places that you can kind of tell our listeners about.

MW: Well mostly, you just hear from other parents that have tried things or not tried things, I guess. There's a few really good programs in Saskatoon like the PAAL program, which they can start when they're about five, I think, at the university. And they have all kinds of activities. There's dance and gymnastics and soccer and swimming. It's a good program where you can get a taste of a lot of things and then can see what you like.

I found my best way was just talking to other parents that are there waiting for their kids, so that's the most important thing.

TL: Sure. Yeah, I mean parents are the best place for resources are they not?

MW: Right. So the City of Saskatoon puts out the leisure guide, which tells about all the public programs and swimming lessons is one of the things. So I was looking to put Taylor in swimming lessons, when she was young and she was too old to be in the parent program and I wanted her without me so she could learn, so I just noticed that they had a phone number on one of the bottoms of the one page that said if your child... or person needs additional help, give us a call. So I called them and talked to a recreation therapist and they put her in regular swimming lessons with an extra instructor. We did that for several years. I would just register her in regular swimming lessons and tell them she's coming and they'd provide... an additional instructor to be in the water with her because she... had to be one-on-one... She couldn't just be in a group with six kids, but then she could be with her peers, but still be safe and learning what she needed to learn. And it was no extra cost.

TL: That's important, for sure, right? And you know those resources are out there, but half the battle is, or course, finding them when you need them. That's great. Jessica... where... do you go... for your source of information or do you have any advice for parents that are looking for information here in the province?

JT: One of the places that we went to was the Saskatchewan Deaf and Hard of Hearing Services. They've really helped us to kind of ... think about some programs that might be more useful for Emily versus ones that aren't going to work. As well as just providing support for us to make decisions. It really does take a village to raise a child, especially when you have a child that's different. And so they've really helped. As well... there's an online group, too... of other parents with deaf or hard or hearing children and so it's good to work in there, to ask what's going on or what worked for your child. What kinds of activities are there out there? And so it's just a really good community.

TL: Absolutely, I love online groups, parenting groups, so, so much. Vigya, I'm curious with you and having a child on the autism spectrum, where do you look for help in the province or what have you found in terms of groups or assistance that's been really helpful?

VS: Like Marilyn and Jessica said... parents know the most, so I found out about Special Olympics through a parent support group on Facebook. And when I contacted the program co-ordinator... I asked her a lot of questions. What activities are the kids engaged in? How structured it is. How many coaches? What do they do? And I even asked them if I can come and just check out a class. And when I got all the positive responses for my questions, that's how we got started with Special Olympics. I'll just say that talk to other parents. They have been on the spot before and they know [more] than anyone else can tell you. So just talk and explore.

What I typically do is I maintain a page in my notebook where I have the list of all the programs that Kavya is not eligible for right now... because she's too young for those. But I have their details in my notebook so I don't lose track of them and I don't have to go back and search for them again. So once I hear about anything, I just make a point of writing it down so that when she is of that age, I can go ahead and enrol her. And then Google is my best place to go; I do a lot of research. So just talk to more parents and do more research, I'd say.

TL: Vigya, you are a mom with a plan. I like that. Well you all live in major centres and that, of course, gives you a lot more options to utilize for information and activities. Now we know that we live in a very vast province here in Saskatchewan, so do you have any advice for families who do live in so many of these smaller centres in our province?

MW: One of our things with the wheelchair sports is that they go around to a lot of smaller centres and do "have a go" days, where they'll bring... equipment for several different sports and people can come and try it out. So then if you're in a smaller centre, my advice would be find a sport that your child might like... and maybe go try it out in Saskatoon or at one of the "have a go" days. And then, unfortunately or fortunately, you're going to have to be the champion for that sport in your small centre. You can get lots of resources from Wheelchair Sports and organization like that, but they're going to need a contact person that's going to book the gyms and co-ordinate things and just be a contact person. So I think if you can find a sport that your child might like, you can be the champion for it in your area.

TL: Sure. That makes sense. Jessica or Vigya, do you have anything to add to that?

VS: Pretty much the same. I'll just say just get out and get active with your kids. Get involved with them and talk to other parents. Go to [the] library, who knows if there is already a small circle of parents just like you who are running a program and you can join it or you can start your own circle.

TL: Mhm. I think that makes sense. Jessica, do you have anything to add?

JT: Yeah, I would say the web. There's lots of good ideas on the web that you can kind of implement within your home, in your back yard. I love Pinterest. I found so many good things on there and that's kind of my resource to turn to to look for those gross motor activities, those fine motor activities that are going to get her moving, get her busy. That don't necessarily break the bank and that you don't have to travel very far.

TL: We're so lucky that we live in the time that we do right now with all that – the online resources for support and activities and ideas. So, definitely I think that's a really great point.

Now Vigya, you mentioned, of course, being a champion for your child and doing things with them. And I think that too, whether you're in a big city or in a smaller centre. But maybe you can tell us a little bit more about how you integrate activity with your daughter just as a family.

VS: As a family, I make it a point to go parks every now and then, like at least maybe, in the summer, at least four times a week. Her dad and I, all three of us will go out. Some days we will just bike and some days we'll just go on the swing, depending on what Kavya wants to do. And it's a great place to meet other parents and other kids, and I have seen that Kavya would like to interact with other kids when she's in the park. She has to take turns on the swing or something, so she really enjoys doing it. And sometimes it just could be a walk like... [to] a close by lake or somewhere. It could just be a walk but we try to [get] the maximum use of the summer time that we get or the sunshine that we get. And sometimes it's just being in the backyard. We just love the outdoors, so sometimes we are just hanging out there in the backyard with her.

TL: Mhm. I love it! And you said "every once in a while" you go the park and then said "four days a week". You are beating me!

VS: Yeah we just love outdoors.

TL: That's wonderful. Well let me take a minute right now to thank our partner, Saskatchewan Blue Cross. Like us, they know that kids need to move at least an hour a day. Their Push2Play resources offer over 100 game ideas, for simple unstructured play. Visit push2play.ca for fun games and a link to the app... then start playing today!

TL: Now we've come to the portion of our podcast where we like to kind of take a look at some of the recent headlines and some online stories that we found. So the first story is an [article by Jennifer Pinarski](#) over at ActiveforLife.com. And we've talked a lot about, of course, physical literacy on this podcast and this article offers tips for helping special needs children become confident movers. Now, the article quotes adapted physical activity consultant Amanda Ebert, who says the key to success – and proving assumptions wrong – is removing the words "I can't" from a family's vocabulary.

Other tips include:

- enroll in a group program, which can work for some kids, not so much for others, of course
- create an active environment at home – something we advise all parents to do, of course
- get outside, again great advice for every parent
- have a positive attitude
- celebrate those milestones together

So what do you think about Amanda's advice? Is there anything that you would add to the list? Vigya, I'm going to go to you first on this one.

VS: I totally agree. I say just be active yourself and your kids will follow you. Also keep lots of patience. Like, learning any skill or mastering a new sport activity is such a slow process, but it will come. And just keep giving them a gentle push or playful push and don't stop.

TL: Don't stop. Love it! Jessica, what about you?

JT: Um, I agree with Vigya that if parents are involved in activities then your child is likely to be involved too. Right? I mean we want them to play at the park, maybe they need us to help play with them, right? Versus sitting on the bench or sitting down and watching them play. Children always learn best when they have a role model to look up to...

VS: Absolutely.

JT: Somebody that's going to... um, be engaged in their milestones and celebrate those things with them. And I think sometimes we think that, "oh if I take them to the park, I get a chance to relax as a mom." But really we should be playing with our children together."

VS: Totally agree. Yeah. Yep.

TL: Great point. Marilyn what about you? Do you have anything to add to those tips in the article or elaborate on any of them?

MW: Well, I just... um for us, something that we do together is bike ride. So, now that Taylor's 13, she doesn't want to play at the park. There's little kids and stuff there, but uh, she will go for bike rides with us, so we do that quite regularly in the summer time.

TL: Everything that I read in that article and that you've mentioned, again are great tips for all parents regardless of what their children happen to be dealing with. All that patience and doing things together. And taking away "I can't" from vocabulary, I think that's... that's important for all parents. And maybe for us moms to remember once in a while too.

So to story number two. This one is [Eight Important Tips for Working With a Special Needs Child](#). Now this is a blog post by Karen Wang from FriendshipCircle.org. Now, Karen points out that many program and activity leaders, whether they're volunteers or highly trained staff have little or no knowledge of disabilities. In the post, she shares her tips for those working with special needs kids and the post has a ton of tips and information in there, but a few things that stood out to me were:

- to be flexible, so make changes to accommodate different abilities
- bringing in parents or others to help if needed
- have a plan, but a back up plan – that, of course, goes back to that being flexible

But I think those are great tips for anybody that is working with special needs kids, so I'm curious how does this article resonate with you? If you had that opportunity – and I'm giving it to you right now – for those listening, what would you really want to highlight to people that are working with your children and with all special needs kids? Marilyn, I'll go to you first.

MW: Well, I think, um, if there's any specific things that you... you need someone working with your child to know about your child, uh, it's essential to get that brought up before... before you start anything so you don't get off on the wrong track right from the very beginning. And so that you can have a... it can be a positive experience right from the beginning by making it the best it can be.

TL: I like that. Jessica, what would you give as, you know one or two points for anybody that's working with special needs kids.

JT: Um... one of the ones from the article was “observe” and I think it’s important that when we’re working with special needs kids to understand when enough is enough. Some days they’re going to be really into an activity and they’re going to give it their all and some days they’re going to be so tired that they’re just... they don’t want anything to do with it. And I think it’s important that we respect their... their boundaries at where they’re at. There’s some days that Emily is just so busy all the time and then there’s some days that she’s so tired from... from using sign language, cause she uses her body to speak, or she’s so tired from working on her listening skills when she has her hearing aid in, that she just doesn’t want to be bothered to do anything else. And so I think it’s important to recognize when... when they’re just too tired to keep doing it.

TL: That’s a really great point, Jessica, about the sign language and how taxing that could be on a child’s body. And it’s something that I didn’t even realize, so you did teach me something today.

JT: Mm-hmm. She tires pretty easy some days.

TL: Vigya, I’ll go to you next. If you had the power to instill certain points to anybody working with special needs children, what would you want them to remember first?

VS: Interacting with a child one-on-one and developing a relationship with them is so important. Uh... you have to have that rapport with them in order for them to work for you. So interact with them, be flexible, go with the flow and involve parents as much as it is required because we know our child the best. And just include everyone’s interests. Cater to everyone’s needs and that will make everyone happy.

TL: I love it. Great advice from all three of you... Well, can you believe it? That’s a wrap on this episode of Mom2Mom. Thanks to Vigya, Jessica and Marilyn for sharing their stories with us today. And thanks to all of you for listening. If you’d like to continue the conversation about getting our kids moving, visit saskatchewaninmotion.ca/mom2mom. Feel free to leave us a comment. And we’re **always** looking for guests to join us on the podcast. If you know someone you’d like to recommend – maybe that’s you – you can email podcast@saskinmotion.ca.

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