
Summary of Key Messages

from the ICAV Webinar on 23 Nov 2022

Navigating Disability and Rare Medical Conditions as Intercountry Adoptees



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Key Messages

Video Timecode 00:15:19

The changing definition of disability - Farnad Darnell

It is important to remove the stigma of disability by looking at what it historically meant in the medical and social senses and focusing on what I am able to do.

Video Timecode 00:17:58

Reframing how adoptees with disability can be viewed - Mallika Macleod

We are not charity nor should we be pitied. We are disabled by the world around us. See my disability and see how the environment is designed to exclude people like me. We are an asset to our family, friends and community. We bring new ways of thinking.

Video Timecode 00:20:39

Processing the shame and brokenness often associated with being adopted and living with disability - Wes Liu

Shame and brokenness is an everyday experience. It's an isolating, lonely feeling. Adoptive parents please consider how impactful these feelings can be. You can't force the conversations but be mindful that we can lack the ability to articulate how we are feeling.

Video Timecode 00:23:34

Dealing with people's reactions and expectations - Maddy Ullman

Physical disability cannot be hidden and this can be really hard. We don't overcome our disability. We learn to work through it. Trying to find the middle ground and learning we are okay the way we are is our lifelong journey. We have to fight so hard to advocate for ourselves and be seen. Having a good sense of humour is necessary.

Video Timecode 00:28:44

How my sense of belonging has been impacted - Emma Pham

I felt no sense of belonging where ever I went. Some families made it clear I was not wanted. The sense of isolation and not being included in many activities made things difficult knowing I'd never be a part of those families.

Video Timecode 00:30:14

Navigating the health care system - Daniel N Price

It's important to find someone you trust who understands the complexities of the health care system, including insurance and legal rights. It can be very difficult getting some medicines covered by insurance in the USA so you can survive.

Video Timecode 00:31:58

What helped me come to terms with living with disability - Mallika Macleod

Most important was a family and friend support network. Super important was knowing there is a system that supports me fully as a person with disability. In Australia we have the National Disability Insurance Scheme (NDIS). <https://www.ndis.gov.au/>

Video Timecode 00:35:58

Does disability add some extra complexities in reunion - Maddy Ullman

I'm glad I waited until being older to search. I learned things in my search that I wouldn't have been ready for when I was younger. The language barrier is immense and I don't know how my biological family will regard my disability.

Video Timecode 00:39:44

The dynamics between adoptive parents and what would be ideal - Wes Liu

Equal emotional support from both parents, empathy and an attempt to understand my daily challenges would have been awesome and would have helped me feel loved.

Video Timecode 00:42:48

Preventing the risk of suicide amongst adoptees with disability and rare disease - Daniel N Price

Checking in with your loved ones daily, listening to them, understanding and being there for them, supporting them in a way that's meaningful to them. You don't know what's going on in their head. When one of the members of my rare disease community ended their life, it shocked me that it could easily have been me. We are at such a higher risk of suicide.

Video Timecode 00:44:26

Children being sent overseas via intercountry adoption because of their disability - Farnad Darnell

Consider how the home country defines disability. Their cultural understanding of disability impacts whether they want the child and allow it to fit in with what is culturally perceived as “normal”. Being accepted by our birth country and culture would shift or limit the need for intercountry adoption because it revalues the child and family preservation.

Video Timecode 00:47:09

What people need to consider when starting off adopting a child with disability with “good intentions” - Emma Pham

Do your research to find information on how to help the child remain in their country and be fully supported. When all avenues are explored and they must come abroad, find out what services are available to support the disability for life. Don't hurry the process and ensure emotional reasons are not the priority. Once here, keep the child connected to language, country and culture. Enable the child to explore their identity and beginnings. Enable access to therapeutic and trauma informed counselling.

Video Timecode 00:50:13

How the experience of feeling isolated changes over time - Wes Liu

I couldn't hide my adoption but I could hide my medical condition. I suffered in silence through most of my childhood. It's exhausting emotionally and physically to deal with every day life. Being able to connect with other adoptees was really monumental. There's still the extra layer of medical issues that most adoptees can't relate to but my personal relationships with other adoptees is just as valuable. Meeting other adoptees with disabilities has been very comforting, a breath of relief and empowering. It has helped me accelerate my sense of belonging.

Video Timecode 00:53:25

The role of genetics in my condition - Maddy Ullman

Finding out I was diabetic and that it was genetic because my birth mother and brother also had it was illuminating.

Video Timecode 00:56:35

What worked for me when facing employment challenges - Mallika Macleod

Be powerful. We are so employable. Approach jobs with a mentality of, “This is what I have to offer and the disability is an additional asset”. Finding workplaces where you

feel safe with leaders who give you opportunities to thrive. Talk about disability as an asset that you bring to the place of employment.

Video Timecode 00:59:11

How I became self sufficient and independent - Emma Pham

Important to find job training, accommodation, practical help to get around. I had the help of good friends and support services. It took time to learn all this. It was important to cater for my emotional needs, trying to maintain the balance between when should I call a friend vs when should I try on my own. Trust is a huge issue when we have been hurt multiple times.

Video Timecode 01:02:42

Suggestions for adoptive parents - Daniel N Price

Open up to understand the adoptee. Think about what they are going through. Educate them and yourself for the long journey ahead. Be more involved in helping them explore their racial heritage and origins.

Video Timecode 01:03:48

Suggestions for adoption professionals to better prepare adoptive parents - Farnad Darnell

Check for the medical history. Find out the most current research on that medical condition. Inform the adoptive family and help them find the supports and strategies they'll need to rely on long term. Reach out to the community to help support the adoptee's and your needs.

Video Timecode 01:06:20

How adoptive families can best discuss with their adoptee whether disability was the reason for relinquishment - Farnad Darnell

Be honest and upfront. Be truthful in talking about the larger cultural issues where people with differences are not as valued and the cultural expectation is for you to take care of their parents when they age.