



TIME FOR CHANGE

Discussion Guide for Families



Welcome to the Time for Change Discussion Guide for families of a person labelled with an intellectual disability. These are some questions to reflect upon after watching the *Time for Change*.

How this guide was created:

The following 5 questions have been developed with family members of persons labelled with an intellectual disability working alongside self-advocates at Respecting Rights. Respecting Rights thanks the family members for taking time to assist with this guide, and sharing their stories to help other families learn about the decision making rights of persons labelled with intellectual disabilities.

As you read the discussion questions below, remember, with some exceptions, all adults have the right to make their own decisions.

Respecting Rights is a project at ARCH Disability Law Centre, led by persons with disabilities who work together with ARCH lawyers and social workers to teach about legal rights and work on changing the laws for people with disabilities. The self-advocates in Time for Change want family members, staff in developmental services, government institutions, health care and other settings to take time to reflect on people's right to be treated equally.

How to use this guide:

This guide is not a formal training, but rather a set of questions self-advocates would like viewers to reflect on after watching the video. You can have group discussions to talk about ways to improve how family members with intellectual disabilities are supported to exercise their rights. It is important that people with disabilities have a voice. ARCH lawyers are available to do direct consultation with persons with disabilities if they need more information about what the law says.

For more information, contact Respecting Rights at ARCH Disability Law Centre. www.archdisabilitylawcentre.com/respectingrights



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Discussion Guide Questions



For Family Members of Persons with an Intellectual Disability



Question 1 - Supports

In *Time for Change*, Judy says: Making choices about what's important to me helps me be more independent and in charge of my life.

How Families Listen & Support Choices:

Vanessa is a young woman with an intellectual disability. Vanessa has the right to be involved in decisions about her life. She needs some support from the people who know her well to make those decisions. Vanessa is sensitive to certain loud sounds. However, she has communicated to her family that she loves music and certain artists make her very happy.

By knowing Vanessa's preferences, her family is able to support Vanessa to be involved in decisions that affect her life. For example, these decisions might relate to attendance at particular programs that won't have loud sounds that would be triggering for Vanessa. And – maybe her family will even play one of Vanessa's very favourite songs – “Thank you Baby” by Shania Twain.

Question for Families:

Share an example of a time that you supported your family member with a disability to make a choice about their life based on preferences you have learned from their style of communication.



Question 2 - Choices about Community Participation

In *Time for Change*, Victoria says: People with disabilities can accomplish anything they want to. All we need is your support.

How Families Listen & Support Choices:

Every person with a disability should be given the dignity to have their capabilities and strengths emphasized and acknowledged. Families are often told so many times what their loved one's deficits are – all through the school years. Regardless of the disability, when families focus on what their loved one's abilities are, then the possibilities open up.



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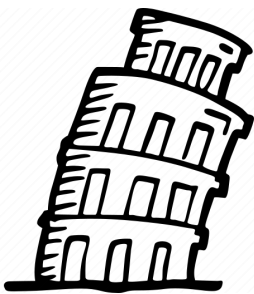
Question 2 - Choices about Community Participation

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One family shared with us that Jane loves coffee and socializing. When the family supported Jane to try out social programs, there was too much stimulation, and it didn't go so well. Then, at a quieter local coffee shop, Jane showed them how much she loved coffee and even began eating coffee beans! The coffee shop was open to Jane helping with packaging beans. Jane's interest grew until a booth at a local farmer's market was actively supporting Jane and about 20 of Jane's neurodiverse friends in selling coffee. The group has gone on to do catering. This is all based on the family's listening to Jane's wishes through her communication and their belief that Jane could accomplish what she wanted to in life.

Question for Families:

How have you listened to and supported your family member with a disability's choices to participate in the community the way they want?



Question 3 – Accessibility

In Time for Change, James says: We have the right to accessible information. This means communication in ways that we can understand.

How Families Listen & Support Choices:

Pedro's family shared with us that it was only when they realized that using clear images (rather than infantilizing ones) with choices, Pedro expressed his wishes and preferences clearly. Making sure that all the supports in Pedro's life are appropriate is important in upholding Pedro's right to be involved in decisions. It ensures that the choices made are Pedro's and Pedro's only, without pressure or influence of what others want for him.

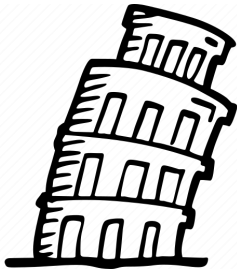
Pedro may need support, but under the law, adults generally have the right to make their own decisions, subject to some exceptions. Family members share how challenging this can be when we want to protect our loved ones from making bad choices.



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Question 3 – Accessibility

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Families have also shared that it is important to make sure that the person in your family with a disability has had access to all the information about a topic, in a communication style they can understand, before being asked to make a decision.

For instance, let's say someone is asked if they would prefer to go on vacation to Italy or Alaska. How are they going to be able to answer if they haven't been provided with information about these two places? Families and supports should give this information in a way that their loved ones can understand so they can make an informed choice.

Question for Families

Please give an example of a way that you have ensured that your family member has access to information in a way they can understand to make a decision. Regardless of how small the decision is, it is important, because what people want matters.



Question 4 – Keeping the Wishes of Persons with Disabilities Front and Centre

In Time for Change, Theresa says: It makes me feel good to make decisions about my life with a little bit of support.

How Families Listen & Support Choices:

Anika is a young woman with a disability who doesn't use words to communicate, who needed to purchase a scarf. Anika's mom shared how much she (not Anika) personally absolutely loves the colour pink. One day, she was supporting Anika out shopping to purchase a beautiful scarf. The scarf was very important to Anika, and her mom was very enthusiastic that it be the perfect scarf. It was an exciting moment.



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For Family Members of Persons with an Intellectual Disability



Question 4 – Keeping the Wishes of Persons with Disabilities Front and Centre

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When shopping, Anika’s mom kept showing pink scarves. She became aware that maybe she was imposing her own preferences. Ultimately, Anika made the choice herself. She chose a beautiful and elegant green scarf. Not a pink one!

Question for Families

Share an example of a way that you have ensured that your family member’s wishes and preferences are kept at the forefront, above your own potential preferences.

Question 5 – Advocating

In Time for Change, Sarah J says: I deserve to feel that my voice is being heard.

How Families Listen & Support Choices:

Many self-advocates and their family members have told us that sometimes at medical appointments, health care professionals will speak directly to the family member rather than speaking to the person with a disability directly about their health care. Regardless of the accommodations and supports someone may need to communicate, people always deserve to be consulted directly about matters regarding their lives. This includes health care.

Jayden’s family told us that they have had the experience of doctors speaking directly to them, while ignoring Jayden, who is right there in the same room.

Jayden’s father had to directly tell the health care provider that they can ask the question directly to Jayden, and they are simply there as a support. This is an example of an act of advocacy, ensuring Jayden is being addressed directly by the health care professional. Jayden’s father also ensured that information about Jayden’s health care was provided and discussed with them in a way that Jayden can understand. It may take a little more time, but is important that Jayden be involved in the conversation with his health care provider about his health care.





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Question 5 – Advocating

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Question for Families:

Share a time that you have had to advocate for someone in the community to listen to the voice of your family member with a disability, rather than your voice as a family member. This could be a health care professional, a social assistance worker or a staff at a developmental services agency.

Thank you to the family members who have assisted in developing this guide:

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**For more information, contact Respecting Rights at
ARCH Disability Law Centre.**

www.archdisabilitylawcentre.com/respectingrights