

FROM THE MARGINS:

# VOICES OF YOUTHS

WITH DISABILITIES ON FRIENDSHIP, INCLUSION,  
AND QUALITY OF LIFE.



**BELONGING MATTERS!**  
**WHAT THE YOUTH TOLD US:**  
**A FINAL REPORT**

## TABLE OF CONTENTS

<b>THE VOICES OF YOUTHS RESEARCH PROJECT .....</b>	<b>3</b>
<b>WHY DO RESEARCH WITH YOUTH? ..</b>	<b>6</b>
<b>LISTENING TO YOUTH.....</b>	<b>9</b>
<b>WHAT DID THE YOUTH TELL US? ....</b>	<b>11</b>
<b>BELONGING MATTERS: A FRAMEWORK.....</b>	<b>12</b>
<b>HOW CAN YOU HELP US GROW? .....</b>	<b>18</b>
<b>MORE INFORMATION .....</b>	<b>24</b>

## THE VOICES OF YOUTHS RESEARCH PROJECT

The *Voices of Youths (VOY)* project was done by researchers and their students at the University of Toronto and McMaster University, along with members from community organizations and young adults with intellectual and developmental disabilities (IDD). This research was paid for by the Social Sciences and Humanities Research Council (SSHRC). SSHRC is an organization connected to the Canadian government that gives money to help people do research.



## WHAT WAS THE PROJECT ABOUT?

The VOY team wanted to learn more about youth (13 to 24 years) with IDD from their point of view. We wanted to know about their own experiences and thoughts about the important parts of their lives to help people who provide services to youth with IDD to do that better.



## WHO WAS ON THE RESEARCH TEAM?

### UNIVERSITY RESEARCHERS

---

REBECCA RENWICK (UNIVERSITY OF TORONTO)

ANN FUDGE SCHORMANS (MCMASTER UNIVERSITY)

DEBRA CAMERON (UNIVERSITY OF TORONTO)

### COMMUNITY PARTNERS

---

LISA SCHUMPH (LAWSON MINISTRIES – SALVATION ARMY)

MELISSA NGO (HAND OVER HAND COMMUNITY ORGANIZATION)

KEVIN STODDART (THE REDPATH CENTRE)

### PROJECT CONSULTANTS

---

DAVID CONFORTI

ZOE STANLEY

PETER LAURETANI

### PROJECT COORDINATORS

---

DENISE DUBOIS

SHAUNA EISEN (PAST)

### STUDENTS

---

NATALIE ROSE

JASMINE COWEN

## WHY DO RESEARCH WITH YOUTH?

When the VOY project began, the goal was clear: to ask teens and young adults with IDD about their views on friendship and participation in community life. Until now, most of what is known about teens and young adults with IDD had been found from talking to parents or professionals, instead of youth.

## WHAT IS RESEARCH?

Research can help us understand the lives and experiences of people with disabilities. By looking for and collecting information, researchers can find out what might make programs and services better for youth with IDD. There are many different ways to collect information. For example, a researcher might use interviews (talking with people), surveys (asking people questions on a computer or piece of paper), or by taking photographs or videos of people.

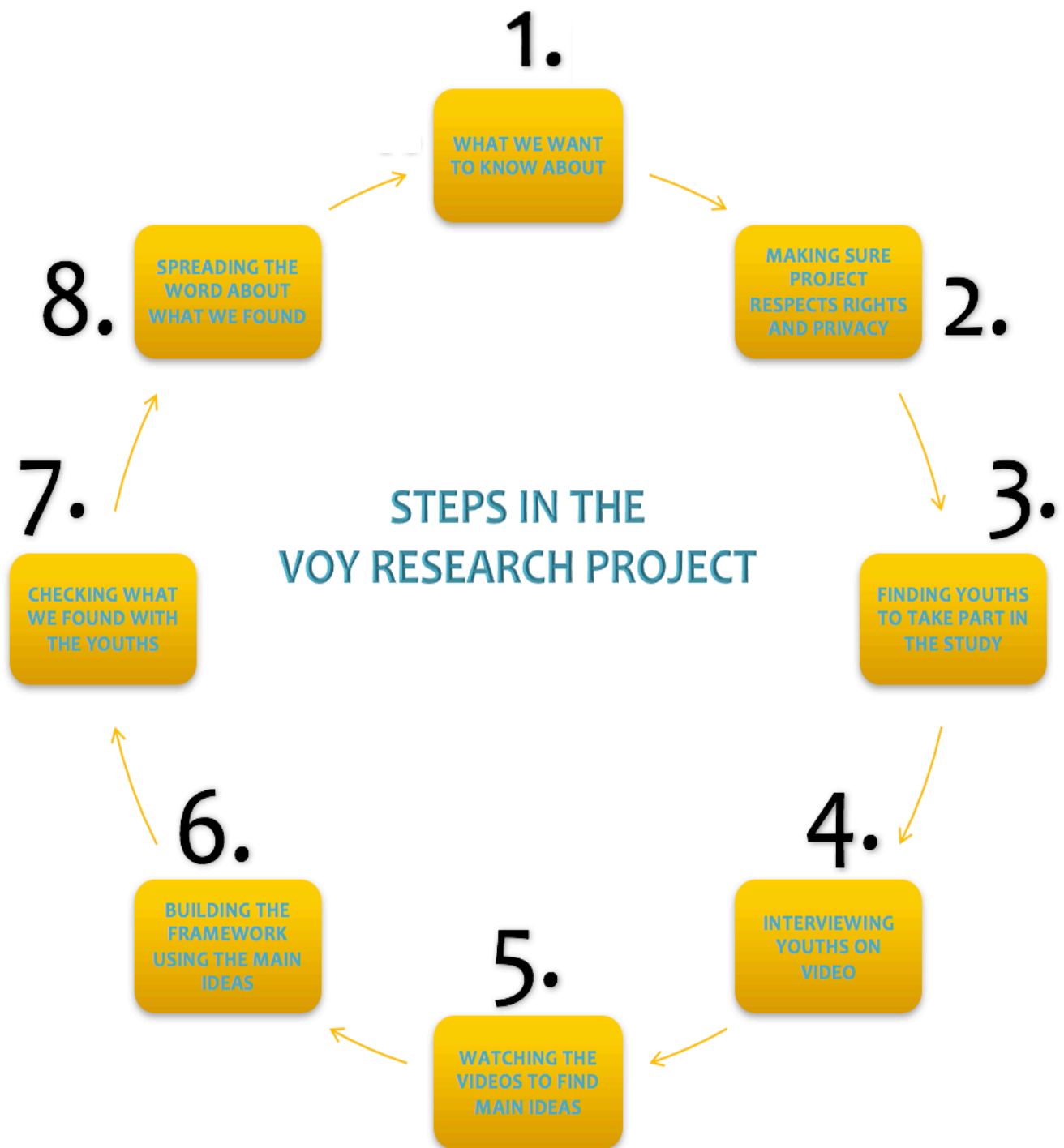
## WHAT IS INCLUSIVE RESEARCH?

Inclusive research happens when researchers partner with people with IDD to work together and make decisions together about the research project. Doing inclusive research makes sure that the way a research team collects information respects people's abilities and the way they like to communicate.

The VOY team included:

- Three researchers and their students
- Three project consultants who were young adults with IDD
- Three community partners from organizations that serve youth with IDD

As active members of the research team, the project consultants and community partners participated in every stage of research. For example, they worked together to choose research questions and to make an informational video for potential participants. They were also involved in looking at what the youth said and deciding what it meant, and in making a film about the study.





## LISTENING TO YOUTH

### COLLECTING INFORMATION



We interviewed 24 teens and young adults with IDD on video in their own homes and communities. The VOY team filmed more than 70 hours of interviews that were looked at and discussed by researchers and their students.

Each youth was interviewed one-on-one, at least two times. Most of the youth were interviewed on their own because sometimes it can be hard for youth to say how they feel with others in the room.

Twelve of the teens and young adults also took part in a third interview. The youth were asked to interview one of their friends on film. The youth and their friend also did an activity together that they usually do in their home or community. Some activities included going out to eat, playing video games, going to a community dance, or going to the library.

## WHY FILM THE INTERVIEWS?

Filming the interviews helped the researchers record more than just what the youth said. It also showed the activities and places where the teens and young adults in our study engaged in community life, and how they felt about these experiences. Some youth with IDD communicate in different ways. This can make answering questions or writing down answers hard. Filming was also a way to let youth use more than just words to show us what was important to them. The VOY team also could watch the videos over and over.

We took all the videos from all the participants and put them together. We watched the videos again and again and did **research analysis**. We developed the Belonging Matters Framework to describe the results of our analysis.



## WHAT DID THE YOUTH TELL US?

Now we are going to talk about the findings of our study. The findings are what the youth told us. We have put quotes from the youth in our study in **blue**. These quotes help give some examples of what the youth told us. The names of the teens and young adults have been changed to protect their privacy (so that people don't know who they are).

So what did the youth tell us?

### ***BELONGING MATTERS!***

The main thing youth said again and again was that they wanted to feel like they belonged. Sometimes they did, and sometimes they didn't but, most often, it was some of both. What is important though is that belonging can always be added to and made stronger in many different ways. Neil (fake name), one of the youth, said that places and people in the community help him feel like he belongs.

*I just think it's very important to have friends because when you have friends you actually belong somewhere and with people and... so that's why I think it's important.*

**–Neil**



## BELONGING MATTERS: A FRAMEWORK

The Belonging Matters Framework includes four main ways (or branches) that build belonging from the perspective of youth with IDD.

### WHAT IS A FRAMEWORK?

A framework is a way to take a lot of big ideas and explain them with a picture or a model. The different parts of the framework describe, or talk about the main ideas the youth shared. Frameworks you may have seen before could be the Canada Food Guide, the Three 'Rs' of Recycling (reduce, reuse, recycle), or the Circles program.

## THE BELONGING MATTERS FRAMEWORK

The VOY team took all the information collected in the interviews (big ideas) and broke it down into four main ways that youth talked about belonging, which we call the Belonging Matters Framework.



- We pictured belonging as a tree. The branches are the four main ways that build belonging (or not).
- Like a tree, belonging is something that can grow and change, as long as it receives attention and care.
- The Belonging Tree is a place where many different types of birds come together – the tree and birds both benefit from this back and forth (reciprocal) relationship.
- We pictured the birds in the tree to show that all kinds of birds can gather in the same tree. Just like people, the birds are all different, but want to belong in similar ways.

## EXPLORING THE BRANCHES

### INTERACTING WITH PEOPLE SIMILAR TO ME



The first way to build belonging happens through *interacting with people who are similar*.

People can be similar when they like some of the same things, do things together,

or have similar challenges. Hannah tells us that spending time with her friend who also has a disability makes it easier to just be herself.

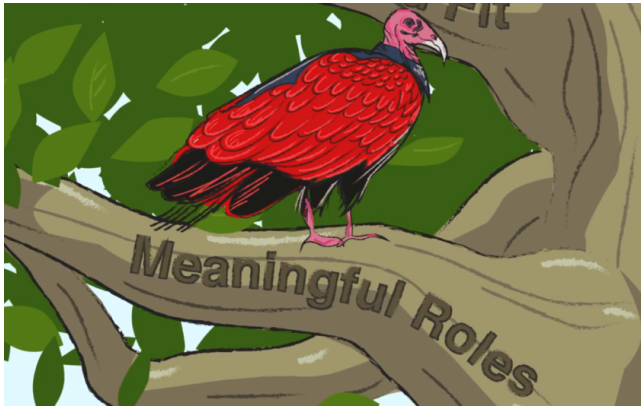
*“She has the same problem as me because of... because with people, communicating, and feeling like you’re not a normal person... She makes me feel like... not like normal... but like I do not have a disability.”*

*–Hannah*



---

## NEGOTIATING MEANINGFUL ROLES



The next way to build belonging happens through *negotiating meaningful roles in the community.*

These roles happen through activities like volunteering or work, participation in teams or groups, or experiences like going to the library.

***"I'm trying to be an advocate for people with disabilities since I know someone in politics. I've already gotten a head start by getting push buttons for two schools now"***

***–Xena***

For Xena participating in a political campaign made her feel like she was making a difference in her community. She is proud of her contributions, such as getting automatic door openers for two schools.

## HAVING SOCIAL RELATIONSHIPS

The third way to build belonging happens through having social relationships.

Social relationships happen through spending time talking or doing activities with friends, family, or other people in the home or community.



*“My sister [makes my life good by] calling me a lot, comes visits me, takes me out places or I go over to her house. [...] We go out to restaurants together. Or we go out to stores and she'll buy me something. We watch TV, we listen to music, we play card games with each other. It's nice.”*

*–Callum*

For Callum spending time with his sister doing lots of different kinds of activities makes him feel good. They like to do activities together at home, but also out in the neighbourhood. These outings help Callum connect to his community through family relationships.



## FINDING A GOOD FIT

The final way youth talked about building belonging was through navigating norms and expectations – finding a good fit.

A good fit happens when there is a match between what the youth wants for themselves and what



others, like parents or staff, expect of or want for the youth.

*“I had a really good night at church and I tried talking to my mom about it... she laughed at me... she’s not really supportive.”*

*–Farah*

Farah wants her parents to go to church with her, but they are not religious and don’t support her decision to go. This makes Farah feel sad because she sees other families at church together. Farah’s family does help her in other ways – like with her finances. But for Farah, the way they support her is not a good fit with what she wants from them.

## HOW CAN YOU HELP US GROW?

Because the findings of this research project are shared with community agencies, organizations, policy makers, and youth with IDD and their families, they may help others to do things differently. So what can you do to help this project grow? First, you can spread the word that belonging matters. We have been sharing these findings with communication agencies that serve youth with IDD, people in government, youth with IDD and their families. We hope that by sharing these findings we can help make programs in schools and communities that put belonging at the centre.

So what can YOU do to help us grow and create belonging?

## WATCH AND SHARE THE FILM

We made a film about our research project and the results of our study. It explains a lot of what you read in this report.



Film is a good way to share our findings because, it:

- uses a mix of words, pictures, actions, emotions, and sounds.
- is easy to share with lots of people.

The VOY's community partners and project consultants with IDD, who appear in the film, were involved in every stage of production and approved the finalized version for a wider audience. We hope you will watch the film on our website and share it with those in your network and through social media (using #belongingmatters and #VoicesofYouth).

## USE THE FRAMEWORK

The VOY project showcased the Belonging Matters film at a big meeting attended by community stakeholders including youth with IDD and their families, government officials, researchers, and disability advocates. At the forum, stakeholders discussed some of the ways you can use the film (and the Belonging Matters framework) to influence policy and practice.

For example, you could use the film as:

- a way to talk about belonging for youth with IDD in the classroom or with staff.
- a way to show how youth with IDD can have a voice in research and about the programs and policies for and about them.
- an example of how to make self-advocacy groups or teams that include people with IDD work better.

This report, the film, and other articles that our team is working on, can also be used to apply the Belonging Matters Framework to evaluate current programs or to develop future programs.

## SUPPORT MORE RESEARCH

The VOY team hopes to continue this line of research by looking at pathways to belonging from multiple perspectives, including youth with IDD, their families, and the professionals that support them. This framework can then be applied in policy, research, and be used to develop and evaluate programs focused on belonging as both a process and outcome.

# QUESTIONS?

For more information,  
please contact:

DENISE DUBOIS  
Project Coordinator  
Voices of Youths Research  
[Voices.ofyouth@utoronto.ca](mailto:Voices.ofyouth@utoronto.ca)

Or, feel free to visit the project's  
website at:

[www.voicesofyouthresearch.com](http://www.voicesofyouthresearch.com)



## **ACKNOWLEDGEMENTS**

**THANK YOU TO ALL THOSE  
WHO MADE RESEARCH  
PROJECT POSSIBLE!**

**OUR STUDY PARTICIPANTS**

**OUR RESEARCH TEAM**

**OUR RESEARCH FUNDER**

A special thank you to Lawson Ministries for supplying the photos for this report. None of the people in the photos were interviewed as part of this study.

© 2018 REBECCA RENWICK

**SSHRC  CRSH**

Social Sciences and Humanities Research Council of Canada  
Conseil de recherches en sciences humaines du Canada

## MORE INFORMATION

### WEBSITES

Voices of Youths Film <https://youtu.be/brAsG2CidwA>

Voices of Youths Website <https://voicesofyouthresearch.com/>

Hand over Hand Website <https://handoverhand.ca>

Lawson Ministries <http://www.lawsonministries.org>

The Red Path Centre <https://theredpathcentre.ca>

### READINGS

Frankena TK, Naaldenberg J, Cardol M, Linehan C, van Schrojenstein Lantman-de Valk H. Active involvement of people with intellectual disabilities in health research - A structured literature review. *Research in Developmental Disabilities*. 2015.

Haigh A, Lee D, Shaw C, Hawthorne M, Chamberlain S, Newman DW, Clarke Z, Beail N. What Things Make People with a Learning Disability Happy and Satisfied with Their Lives: An Inclusive Research Project. *Journal of Applied Research in Intellectual Disabilities*. 2013; 26: 26-33.

Milton D, Sims T. How is a sense of well-being and belonging constructed in the accounts of autistic adults? *Disability & Society*. 2016; 31(4): 520-534.