



# “My Independence Is by Myself”: a co-research study about supporting independence for adults with Down syndrome

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## The DS-TO-THE-MAX Co-Research Team



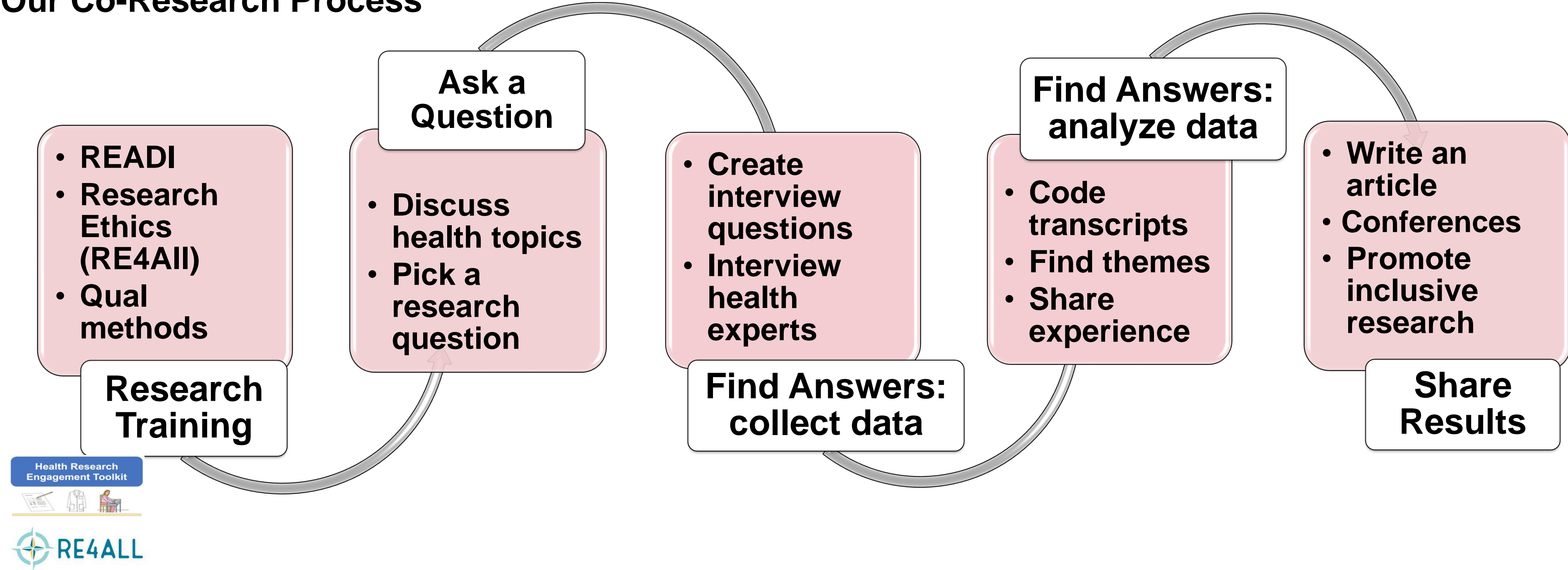
In June 2022, 7 adults with Down syndrome with experience as self-advocates joined our research team. **Our goal** is to do research together that helps the Down syndrome community.

## How We Work Together

### What is Co-Research?

Co-research means doing research with people being studied. It is an inclusive method to conduct research by and with people with Down syndrome as equal partners in all stages of the research process. Co-researchers choose research topics and work with researchers on the design, data collection, analysis, and to share results.

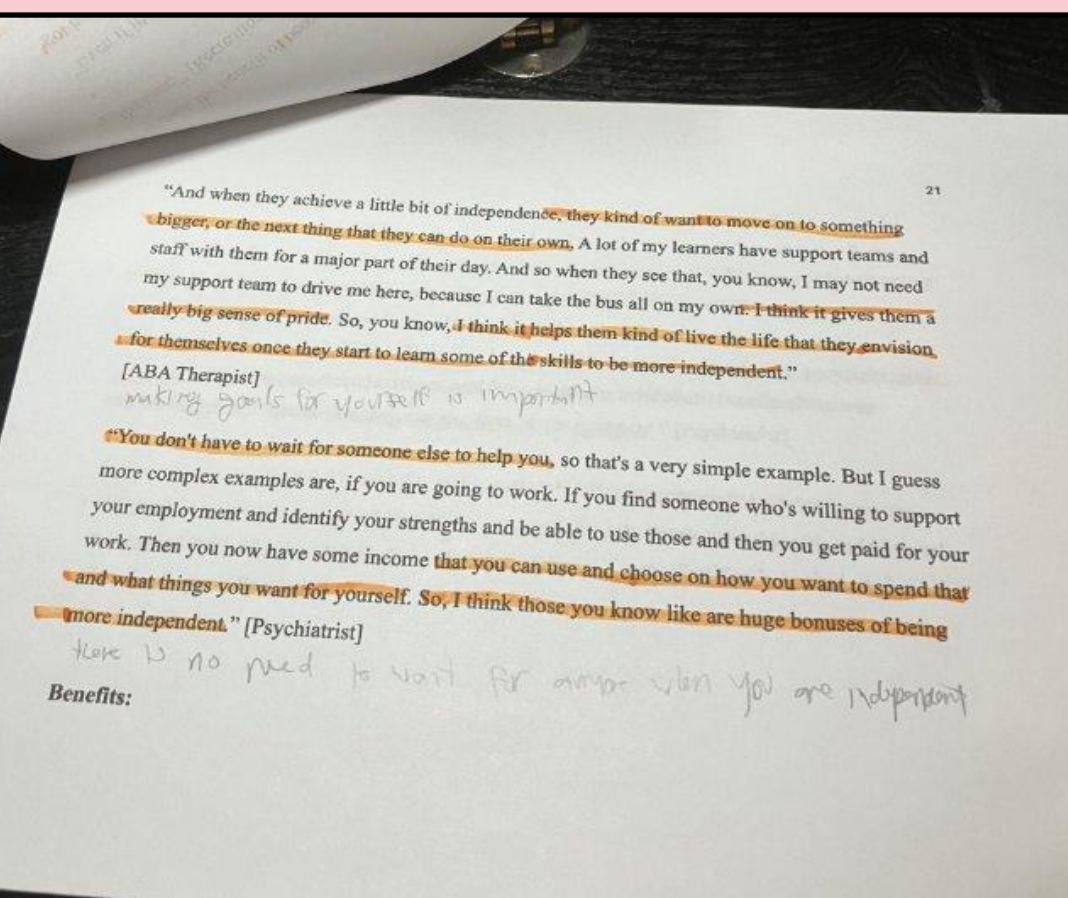
### Our Co-Research Process



## Why Independence Is Important

- Independence means taking care of yourself and having autonomy to make choices. It can look different for each person.
- Age, health, level of intellectual disability, support, and unfair treatment can make independence easier or harder.
- People with Down syndrome live longer and want more self-determination.
- **Project Goal:** understand how health professionals support independence for adults with Down syndrome

## What We Did



- Co-researchers interviewed 8 health professionals and with Down syndrome between May and Sept 2024
- We asked about independence with communication, daily skills, education, employment, health, and independent living
- We made a list of codes, co-coded transcripts, conducted analysis, and generated themes

- Research Teams** 2 adults
- 1 **Interview Team** (6 CR\* + 2 staff)
  - 2 **Analysis Team** (3 CR + 3 staff) thematic
  - 3 **Writing Team** (3 CR + 3 staff)
- \*CR = co-researcher

## What We Found

### Demographics – who was in the study

We interviewed 8 health professionals who work in health, mental health, and support services. We also talked to 2 independent adults who live independently and receive support services.

### Themes – what were the main ideas

1. **Professional Support:** health experts often support foundational skills and personal priorities
2. **Challenges:** others’ fears and assumptions hold back independence growth
3. **Benefits:** professionals perceived improved self-esteem, skills, health
4. **Support Network:** it’s important to understand and use your support network
5. **Skills:** Communication skills are building blocks for independence growth.

### Table 1: Main Theme Examples & Co-Researchers’ Perspective

Themes	Quotes	Team Perspective
Professional Support	"We were starting to work on just simple daily living skills. And again, the things that were important to him, the things that he wanted to learn how to do more of" (Recreational Therapist)	"Health professionals help me eat healthy and stay healthy [because] I have a special diet" - Alexis
Challenges	"[Parents] are worried about their loved one being abused or exploited and may be overly cautious.. [others] don't fully understand or appreciate what strengths their loved one has" (Psychiatrist)	"It's easy to copy the environment you are in" - Eden
Benefits	"Being able to communicate your needs to other people...not only being able to identify and articulate, but also feeling confident and safe that you can" (Doctor)	"My support system helps me every day. They are important to me" - Alexis
Support Network	"It's important to just understand your network....understanding who to go to for what" (Program Director)	"I am able to be as healthy as I can be and have friends and family who support me." - Gus
Skills	"Being able to communicate your needs to other people...not only being able to identify and articulate, but also feeling confident and safe that you can" (Psychologist)	"I was able to find out how important advocacy and self-empowerment were from a lot of ... what the health experts have said" - Kaethe

## What We Learned & How It Can Help

- We found that health professionals focused on 3 main areas to support independence growth for people with Down syndrome: health, communication, and life skills
- Independence centers on having a choice and support available for those choices
- A person’s ability to make choices (self-determination) and the help they get from others (support systems) work together to help build independence or make it harder

### How Lived Experience Helped Our Project

#### Brining real life resources to teach the team

"I started [working on] independence when I was 5 years old. [For our project], I shared the resources that has helped me with this team so that they can think outside of the box more"

- Eden, co-researcher

#### Interpretation by sharing a lifetime of skill building

"It has been helpful since I was a little kid. It started with my mom asking me for help to do laundry and I also helped with organizing things, helped to cook. Practicing skills has helped me be independent even when I moved to different houses. It was helpful to know about independence before the project".

- Benjamin, co-researcher

#### Guiding how we make choices and find answers

"[I've] learned a lot of important things ... about my health, self-care, how I manage to do things on my own, and having a healthy mindset. This experience helps me to figure out what kinds of questions are good for interviews, analyzing data, and sharing the results".

-Kaethe, co-researcher

## Conclusion

- Supporting independence for people with Down syndrome means understanding their abilities, helping them make choices, and using supports that work for them.
- Programs and policies should focus on both giving people choices and providing support for those choices in everyday activities and big life events.
- Clinicians and professionals can strengthen independence by supporting decision-making and communication and recognizing that independence is both personal and relational.

#### Website QR



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