



“[M]undane enactments of ableist prejudice and privilege ... reflects broader sociocultural relations of power, while also being a profoundly personal, relational, and embodied experience” (p. 135).

1. WHAT IS THE RESEARCH ABOUT?

This research shifts the focus from disability and difference to an exploration of the nature and effects of **everyday ableism** on youth living with disabilities. The authors acknowledge that western culture privileges vision over other senses; this orientation is *ocularcentric*. Based on an ableist understanding of what disability *looks like*, bodies are classified using the binary of ‘abnormal’/disabled or ‘normal’/able-bodied.

Everyday experiences of ableism are often more difficult to identify or challenge than “deliberate and overt forms of identity-based discrimination and exclusion” (p. 135); the perpetrators may deny or be unaware of the problematic nature of the interactions, and their intentions may be unclear. Regardless, **the psychosocial burden of these experiences** is carried by the youth.

2. WHERE DID THE RESEARCH TAKE PLACE?

This research took place in Auckland, New Zealand.

3. WHO IS THIS RESEARCH ABOUT?

This research is about **youth living with disabilities and their family members**, all of whom have **navigated ableist interactions** in everyday life.

The **35 young people** included in this study are Deaf or blind or have vision, hearing or mobility impairments; some use visible technology or supports (i.e. service animals, wheelchairs, hearing aids or cochlear implants,

sunglasses, canes) and some do not, many have “perceptible differences in body shape and comportment, and some had a degree of visible facial difference and/or a noticeable difference in communication style” (p. 138).

4. HOW WAS THE RESEARCH DONE?

Researchers recruited participants using a *snowball sampling* approach (existing participants recruit additional participants through their networks), as well as websites, blogs, and online newsletters. In order to be eligible, participants had to qualify for the Ongoing Resource Scheme, an initiative of the New Zealand Ministry of Education that provides funding to students who have the highest ongoing levels of need for specialist supports at school.

Researchers met with participants on at least three – and on up to 12 – occasions, from mid-2016 to early 2018. They collected a range of **data**: *qualitative* (describing qualities, characteristics, processes), *quantitative* (counted or compared as numbers), *experiential* (relating to participant experiences), and *observational* (relating to observations of participants). Researchers conducted **in-depth interviews, surveys, trip diaries, ‘go-along’ interviews** with participants in the community, and **interviews** with parents/caregivers. Meetings took place in person or sometimes by phone (and with support from New Zealand Sign Language interpreters and Alternative and Augmentative Communication devices as necessary). Whenever possible, the same researcher would meet with each participant to ensure **continuity** and **accountability**, preventing the overlapping or repetitive questioning of participants, which many described as being a frustration in communication with teachers, healthcare professionals, and civil servants.

All interviews were **recorded** and *transcribed* (written out word for word), and the transcripts were edited by the research team to remove any identifying details. Researchers *created codes* to organize data and to **develop and refine themes and subthemes**. A **reference group** of participants and disability

advocacy workers provided advice on the analysis, and **post-data collection workshop sessions** were held with participants and disability community representatives to invite comment and direction.

5. WHAT ARE THE KEY FINDINGS?

Researchers found that everyday ableism between able-bodied strangers and youth living with disabilities plays out in **two ways**: strangers use a *diagnostic stare* to determine that a young person is ‘abnormal’/ disabled and offer unsolicited opinions or advice, or young people are required to prove the existence of their disabilities in order to overcome the *skepticism* of strangers. In both types of interactions, able-bodied strangers feel entitled to ask questions about the bodies of young people living with disabilities.

a) Diagnostic Stare: Ableist stereotypes about disabilities enable able-bodied strangers to assume that they can **‘diagnose’ and classify the disabled body simply by looking or staring**. This is experienced by youth as invasive, interrogative, dehumanizing, and relentless. For youth with visibly perceptible disabilities, this type of staring takes on a ‘diagnostic’ function because the able-bodied stranger assumes a position of authority and becomes focused on **deciphering difference** (and consequently not recognizing the full humanity of the young person).

In these interactions, the stranger **directs questions and comments** at the young person (i.e. ‘What’s wrong with you?’), which are followed by even more questions about their physical capabilities and personal history. The young person bears the burden of having to **explain their body** – which is seen as ‘abnormal’ and, therefore, ‘wrong’. The stranger feels entitled to offer ‘help’ by providing their opinions and giving advice, whether medical or religious, as an attempt to ‘fix’ or ‘cure’ the disability.

b) Disability Skepticism: Youth living with disabilities who *appear able-bodied* are spared from staring and invasive questioning, suggesting that “disabilities must be seen to be believed” (p. 146) and revealing the limits of *looking* as a way to ‘diagnose’ disability.

These youth must then navigate whether, when, and how to *disclose their disabilities*. When disclosure occurs, able-bodied strangers may assume that the young person is mistaken or lying, which can result in interrogation and even “overt hostility” (p. 147).

The young person is still required to **explain their body** to the stranger, and must decide whether to try and *prove their disability*, subjecting themselves to further scrutiny.

Young people shared that these everyday interactions are not dissimilar to those with healthcare professionals, educators, and decision-makers, demonstrating how the “clinical gaze extends far beyond the formalized domains of clinic, the courtroom or the classroom” (p. 151), spaces in which youth must continually **explain and prove their disabilities** to access accommodations and supports.

6. WHY DOES THIS RESEARCH MATTER FOR YOUTH WORK?

Youth workers need to **continually challenge ableist understandings of disability**; they must be **aware of the microaggressions** that youth with visibly perceptible disabilities experience regularly, as well as the **difficulty around disclosure** that youth who pass as able-bodied may need to navigate.

The responsibility must be on the youth worker or program to **ensure accessibility** that invites the participation of *all* youth, and be prepared to **provide accommodations to support young people’s full inclusion**. **Create safe spaces** for youth and seek to understand the needs of young people living with disabilities from a place of **curiosity, empathy, trust, and nonjudgement**. Youth workers must always **recognize the full personhood** of youth living with disabilities and strive to celebrate their strengths, successes, interests, and goals.



Calder-Dawe, O., Witten, K., & Carroll, P. (2020). Being the body in question: Young people’s accounts of everyday ableism, visibility and disability. *Disability & Society*, 35(1), 132-155.