The CDDHV years

A focus on health, mental health and behaviour

February 2025

CDDHV – Monash University

Living Well research

- Small proportion of participants took part in:
  - Cholesterol screening
  - Blood sugar screening
  - Blood pressure checks
  - Cancer screening
  - Hearing and vision tests

Living Well research

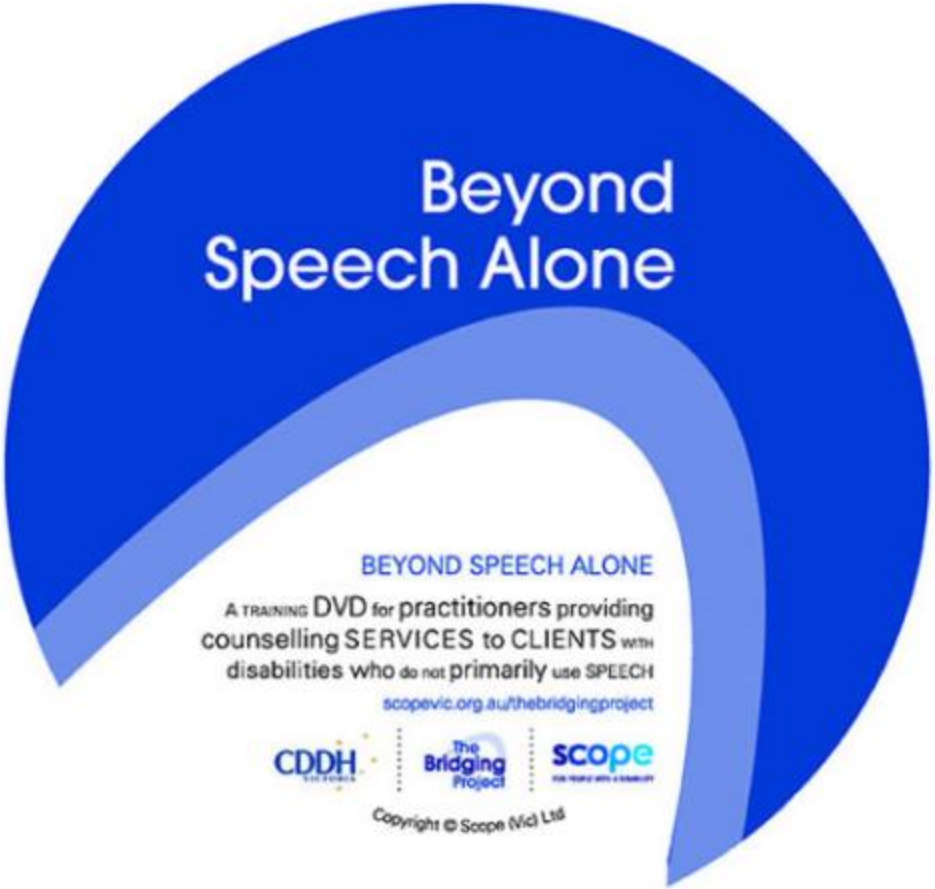
- Secondary conditions:
    - Physical fitness and conditioning
    - Weight
    - Dental and oral hygiene
    - Communication difficulties

Behaviours of concern and mental health

- Individual level - Use of restrictive practices was related to **only** disability worker attitudes
- Restrictive practices related to support needs
- Half of the disability workers had been exposed to behaviour that resulted in injury to them; more than half exposed to behaviour resulting in injury to others
- Poor psychological wellbeing
- Strategies to manage behaviour were limited

Scope

- The Bridging Project
- The Triple C Checklist
- Beyond speech guide



Beyond
Speech Alone

BEYOND SPEECH ALONE

A TRAINING DVD for practitioners providing counselling SERVICES to CLIENTS WITH disabilities who do not primarily use SPEECH

scopevic.org.au/thebridgingproject

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Special issue: Human rights

The human rights context for ethical requirements for involving people with intellectual disability in medical research

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OPINIONS & PERSPECTIVES

Ethical challenges and complexities of including people with intellectual disability as participants in research

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Keywords: *Research ethics, informed consent, intellectual disability*

Introduction

Knowingly or not, every researcher submitting a proposal to a research ethics committee does so in the shadow of the Willowbrook study and other similarly infamous experiments conducted with individuals who were vulnerable because of their limited cognitive capacity and/or being in a powerless position (e.g., prisoners of war) (Beecher, 1966). Willowbrook is of particular relevance to the focus of this article because children with intellectual disability were infected with viral hepatitis without their knowledge, and the nature of the informed consent obtained from their parents was questionable (Beecher, 1966). Revelations of similar horrors that had occurred with prisoners of war were the catalysts for the development of the Nuremburg Code of 1949 and the World Medical Association Declaration of Helsinki in 1964 (World Medical Association, 2004). This declaration continues today to form the basis for ethical guidelines proposed by various government bodies, such as the National Health and Medical Research Council (NHMRC) in Australia, the National Institutes of Health in the United States, and the National Health Service in the United Kingdom. The aim of this article is to consider the implications for research involving people with intellectual disability – a vulnerable group – of ethics committees' attempts to apply these guidelines. The issue explored is whether committees are becoming increasingly conservative in their decisions and approaches, with the potential to exclude at least some people with intellectual disability from research.

Protectionism or discrimination?

A central tenet of ethical considerations about involving vulnerable groups in research is their protection from exploitation and harm (Dalton & McVilly, 2004), such as occurred during the Willowbrook experiments. The very notion of protection, however, invokes paternalistic protectionism, with a concomitant risk of non-inclusive and discriminatory decisions by institutional ethics committees. The benefits of requiring researchers to follow internationally endorsed ethical standards, such as the Declaration of Helsinki, are evident. There is, however, a danger of increasing conservatism creeping into ethics committees, such that the types of research approved for participation of people with intellectual disability or the requirements for their participation become overly restrictive.

This movement toward such a paternalistic stance may arise from *reactive dynamics*, a term coined by MacDonagh (1958; cited in Pettit, 1992), which Pettit argued can be seen in the evolution of the process of research ethics review. Reactive dynamics was described by Pettit as government regulation arising as a result of a four-step process: (1) an evil occurs that needs to be dealt with; (2) the evil is exposed in a sensational manner; (3) there is popular outrage; and (4) governments react by putting in place legislation or administrative strategies to ensure a similar evil will not recur. Such a process could be argued to have been the basis for the Nuremburg Code and the Declaration of Helsinki,