



# USING PROXIES

to assist people with Intellectual Disabilities participate in research.

Proxies are often used in research with vulnerable populations such as children and individuals with cognitive impairment.



Examples of when a proxy may be required with an individual with intellectual disabilities includes severe communication difficulties, maladaptive behavioural issues and/or the presence of a severe/profound intellectual disability.

## DEFINITION OF 'PROXY'

Proxies are individuals who speak on behalf of others or about others and decide whether to consent to their participation in research.

As well as responding on behalf of the individual, a proxy can support and assist the individual to participate in research.

## WHY IS THE ROLE IMPORTANT?

The proxy can ensure the inclusion of those individuals with intellectual disabilities who otherwise might be excluded from having their voice heard through research. Equally it can ensure that individuals who do not wish to participate in research studies have their preference recognised.

The proxy can help the individual to understand information regarding the research study and what is involved in participating in the study.

## CRITERIA FULFILLING THE ROLE OF 'PROXY'

- 1 Identified by the individual with intellectual disabilities as their chosen proxy.
- 2 Frequent day to day contact with the individual with ID.
- 3 Working in close proximity with the individual on a regular basis at least 2 days per week in the previous 6 months.
- 4 Regular interaction with the individual with intellectual disabilities necessitating face-to-face communication at least 2 days per week in the previous 6 months.



Trinity  
College  
Dublin

The University of Dublin

IDS TILDA

The Intellectual Disability Supplement to  
The Irish Longitudinal Study on Ageing

