

Enhancing Social Inclusion for Youth with Intellectual Disabilities: A Multi-site and Social Media Study (ESISM study)

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Background

Social inclusion has been noted as an important determinant of health and understood to be inclusive of all individuals on an equal basis and without discrimination.

- Defining social inclusion – based on an ecological model and defined as the interaction of two major life domains, that of **interpersonal relationships and community participation** (Simplican et al, 2015)

However, people with disabilities including young people with intellectual disabilities (ID) experience stigma, discrimination, lack of access to basic services and they are often excluded from ordinary activities in society thus depriving them the opportunity to build meaningful relationships.

This warrants our collective response to investigate and conduct research that evaluates interventions that promote social inclusion for youth with ID.

Purpose

The purpose of the research study is to determine to what extent social inclusion initiatives for young people with ID can be sustained over time.

The proposed project aims to build on the social intervention previously implemented by Whitehouse et al (2001) by replicating the study and modifying the design as follows:

- study population – **young people (18 – 24)** with intellectual disabilities
- facilitation of **social inclusion activities** using information communication technology (ICT) via a **mobile application, a social media component and photovoice** technique

Method

A **participatory action research (PAR)** approach will be implemented targeted towards planning and conducting the research process with those 'people whose life-world and meaningful actions are under study' (Bergold, J. & Thomas, S. 2012).

PAR involves practitioners and participants in the research process from the initial design of the project through data gathering and analysis to final conclusions and actions arising out of the research .

Recruitment will be done within the community of Ireland particularly within **the DoC network**

Facilitated social activities will be loaded on tablets or android smart phones and implemented over **12 intervention sessions**.

Data Collection

- Data collection will include a **mixed-method approach** (qualitative and quantitative techniques) that includes focus groups, interviews, photovoice, questionnaires and participant observation schedule.
- **Multiple sites** will include participants living independently and with their families accessing various forms of day services offered within the community.

Tools & Analysis

Pre/ post measures - San Martin Scale , Sue Spence Social Skills questionnaire, Participant Observation schedule completed by family members and staff.

- ❖ **Grounded theory:** ATLAS. ti or NVivo
- ❖ **Inferential statistics:** - STATA/ SPSS

The Intervention – ESISM study

During each session, two research assistants will facilitate the session:

- the first research assistant will guide each 40 minute session by providing prompts or cues to participants while they engage in the steps of each social activity,
- the second research assistant will manually record the quantity of social interactions (2 minutes for each person) and code the interactions on a participant observation schedule.

All 12 sessions will be done using the mobile app loaded with guided instructions for each of the social inclusion activities.



Participants in the social media groups will be asked to take pictures of their interactions during and after the sessions.



The pictures will be uploaded and share among invited family members on the social media platform. Families participating as case studies will be asked to write narrative stories of their experiences based on the pictures.



After each session, both research assistants will write field notes and code their observations during each session.

Ethical considerations

- ❖ Participants will be well informed of the purpose of the study.
- ❖ Data will be kept confidential and possible risks and benefits will be made explicit.
- ❖ All data will be kept on a password protected laptop in encrypted folders with all participant identifiers removed.

Impact of study

For young people with ID:

The efficacy of a research project that use ICT, social media and photovoice as a unique and innovative method to reveal real life experiences and enhance social relationships will empower marginalized individuals such as young people with intellectual disabilities immensely.

Fieldwork

PHASE 1

Planning and set up:

- ❖ Obtain ethical approval
- ❖ Conduct systematic literature reviews
- ❖ Finalise mobile application with guided social inclusion interactions/ activities

PHASE 2

Residential intervention:

LEVEL 1:

Day service (social media + non-social media group)

LEVEL 2:

Independent living (social + non-social media group)

LEVEL 3:

Case studies (Families)

PHASE 3

Community intervention:

- ❖ Staff members working for local service providers will be allocated to social media + non-social media groups.
- ❖ The service providers will provide input related to the weekly social activities to be included on the app and implemented thereafter.
- ❖ Research assistants will be trained and employed to facilitate individual sessions.
- ❖ Follow up for all groups on a bi-monthly basis.

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