











Building Circles of Support for People with an Intellectual Disability



#### **RESEARCH TEAM**



Professor Mary McCarron Principal Investigator



**Dr Darren McCausland Project Lead** 



Ms Iara Faria Synott Research Assistant

#### **COLLABORATORS**

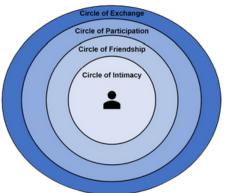
- Stewarts Care
- TCAID PPI Panel
- National Federation of
   Voluntary Service Providers
- Health Service Executive (HSE)
- Temple University Institute on Disability, Philadelphia (USA)

#### **FUNDED BY:**

Health Research Board (HRB) Knowledge Translation Award 2022

#### **PROJECT OVERVIEW**

Building Circles of Support for People with Intellectual Disabilities, a Health Research Board (HRB) funded knowledge translation project, aims to showcase exemplary Circles of Support through positive case studies of participants' lived experiences. Over 15 years, IDS-TILDA research has underscored the pivotal role of individualised Circles of Support in fostering social inclusion and community participation for older adults with intellectual disabilities. A Circles of Support (COS) model describes how people receive support from different types of relationships - through Circles of Intimacy, Friendship, Participation, and Exchange. IDS-TILDA data supports research internationally in finding that people with intellectual disabilities sometimes have inadequate Circles of Support, frequently with gaps in their Circles of Friendship and Participation in particular. These deficiencies in their COS have been associated with diminished social inclusion and poorer quality of life.



Snow (1998) Circles of Support Model

Project partner, Stewarts Care, identified a need to improve participation in its person centred-planning process by the Circles of Support of adults with intellectual disability supported through day service programmes. As a critical component of New Directions policy governing day service provision, person-centred planning facilitates an individualised approach to building service supports around the wishes, dreams and goals of individuals. The international literature and the HSE's Person Centred Planning Framework have identified that the best person-centred plans (PCPs) are built upon participation by the individual's Circles of Support.















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#### **PROJECT AIMS AND OBJECTIVES**

The project aimed to create accessible resources to help individuals with an intellectual disability, their families and support services to grow and strengthen Circles of Support of individuals with intellectual disability.

Key objectives included:



#### **Key Principles for Developing COS**

Consolidate key principles, approaches, and methods for developing and supporting COS and natural supports for person-centred planning, for inclusion in educational and informational materials.



#### **Case Studies of COS Practices**

Produce 6 individual case studies of good practice in COS, for individuals with varying degrees of intellectual disability and their COS, using video and plain language documentation.



#### Multimedia Resources for COS Development

Produce an overall multimedia package of educational and guidance resources for developing and sustaining COS for person-centred planning with individuals with all levels of intellectual disability, utilising plain language instruction and video illustrations of case studies of good practice.



#### Outreach Strategy for Engaging COS

Develop, test and implement an outreach strategy that includes approaches and media for reaching services and potential COS members.

#### **IMPACT AT A GLANCE**

Directly influences current policy on person-centred, individualised approaches to day service provision in Ireland, contained in New Directions and the HSE's National Framework for Person-Centred Planning in Services for Persons with a Disability.





Promotes improved social inclusion and participation for adults with an intellectual disability by building deficits in their Circles of Supports.

"This grant will help to translate what we have learned about social networks through IDS-TILDA into practical resources to improve Circles of Support for people with an intellectual disability.

By partnering with Stewarts Care, we can also ensure that these resources have an immediate impact for the individuals they support and their families.

Additional partnership with the National Federation and Temple University will also help to increase the reach of the project both nationally and internationally." – Dr. Darren McCausland, Senior Research Fellow















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#### **APPROACH**

- Case study approach an in-depth qualitative research methodology, to bring examples of good practice to life.
- Ethical approval from TCD Faculty of Health Sciences and Stewarts Care Research Ethics Committees.
- Invitation issued to all individuals supported by Stewarts Care Day Services.
- Six participants with an intellectual disability and their COS selected to participate.
- Participating COS members included family members, friends, partners, and support staff.
- Participants and members of their COS were invited to participate in an interview.
- Following analysis and PPI panel review, participants/COS invited for video recording session.

As a project partner, the **TCAID PPI Panel** strongly influenced the direction of the project and final resources that were created. Members of the PPI panel were passionate about this topic as it resonated deeply with their own lived experiences.

#### **IMPACT AT A GLANCE**

"We want to see their connection! We want to see them doing something together!"

PPI Panel Member

## The PPI Panel's contributions extended to

**Review of resources** 

**Consultation and collaboration** 

Impact on how videos were created









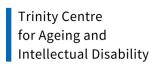












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#### **IMPACT AT A GLANCE**

### **Overarching Themes**

**Reciprocal Support** 

**Remote Support** 

**Confluence of Support** 

**Cascade Effect** 



Adopted by partner service provider as a resource to support adults with intellectual

disabilities attending their services.



#### PROJECT OUTPUTS (A-MULTI PLATFORM APPROACH)

In meeting the project aims and objectives, accessible resources were created:



A dedicated web page on the TCAID website to host project resources <a href="https://www.tcd.ie/tcaid/research/">https://www.tcd.ie/tcaid/research/</a>
<a href="buildingcirclesofsupport.php">buildingcirclesofsupport.php</a>



A series of accessible videos hosted by Ms Mei Lin Yap, Chair of the TCAID PPI Panel.



An accessible handbook 'Let's Make it Happen!', outlining the case studies and strategies to develop and maintain Circles of Support











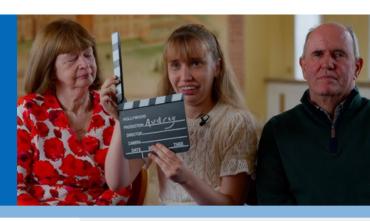








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# A series of events were held to launch and showcase the project resources.

- Pre-launch screenings of the video case studies were held in TCAID and Stewarts to present the final resources to the PPI Panel and participants with intellectual disability and their Circles of Support.
- In December 2023, TCAID hosted a webinar with national and internation partners to officially launch the website and project resources.



- In Spring 2024, the video case studies were presented to over 500 adults with intellectual disabilities who attend Stewarts Care day services.
- The project and resources were presented to the Stewarts Care Family Network in May 2024.



- Project findings and resources were presented to two scientific conferences:
  - Trinity Health and Education International Research Conference (THEconf, Trinity College Dublin, March 2024)
  - Word Congress of the International Association for the Scientific Study of Intellectual and Developmental Disabilities (IASSIDD World Congress, Chicago, August 2024)

#### **IMPACT AT A GLANCE**



Over 1500 engagements with accessible project resources.

The videos were presented at Stewarts Care to

Over 500 adults with intellectual disabilities





"This is what Inclusion, partnership and co-researching looks like!"

-Prof Philip McCallion

#### **UN Sustainable Development Goals**



