

BUILDING CIRCLES OF SUPPORT FOR PEOPLE WITH INTELLECTUAL DISABILITIES

LET'S MAKE IT HAPPEN



The Intellectual Disability Supplement to
The Irish Longitudinal Study on Ageing
(IDS-TILDA)

INTRODUCTION

<https://youtu.be/TAYKmdBVmYk>



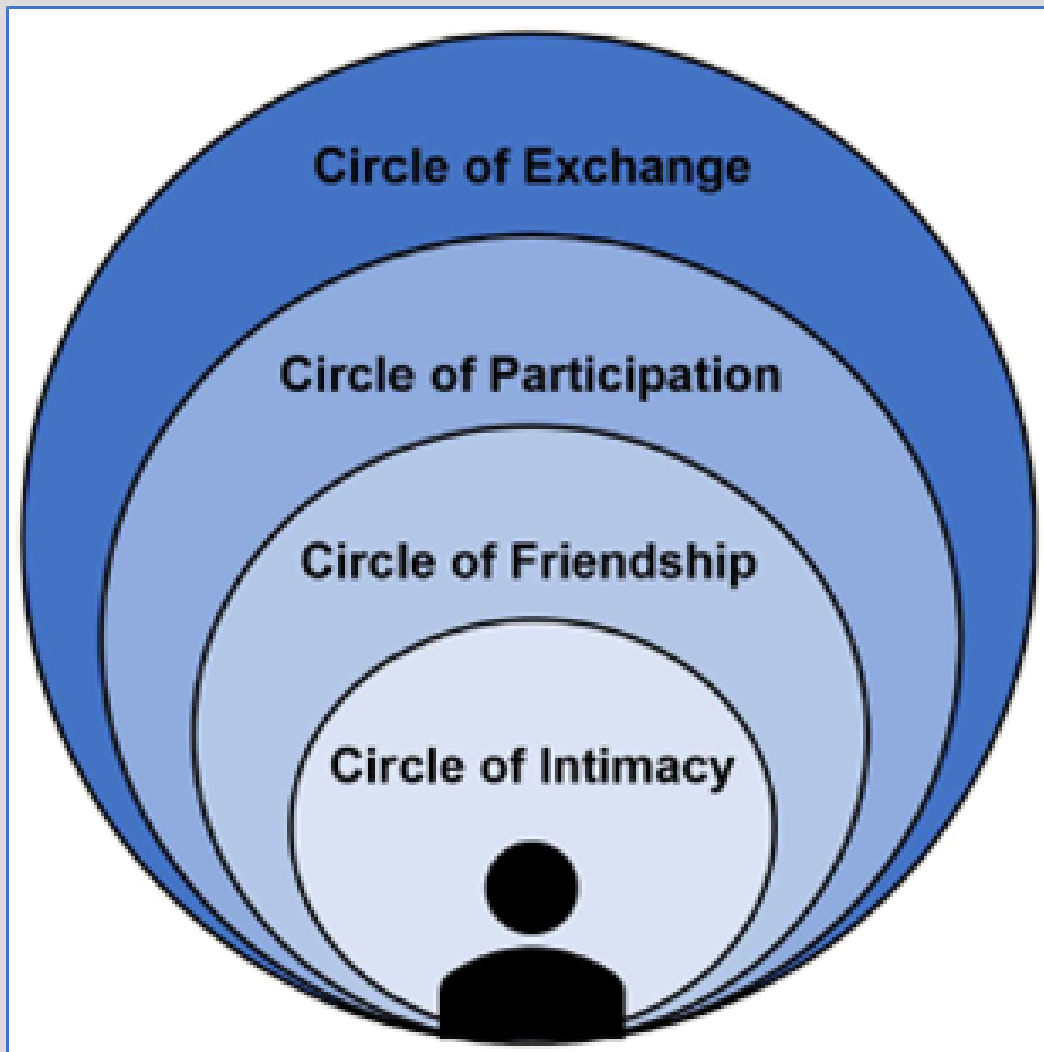
I am delighted to welcome you to our guide to Building Circles of Support for People with an Intellectual Disability.

This project was funded by the Health Research Board as an extension of the Intellectual Disability Supplement to the Irish Longitudinal Study on Ageing (IDS-TILDA), with the aim to translate what IDS-TILDA has learned about Circles of Support into practical resources.

Circles of Support is a concept that has been around for some decades now. It simply recognises that people with intellectual disabilities may draw support from different types of people in their lives – the different circles around them.

In five waves of IDS-TILDA to date, we have learned so much about the importance of social networks of people with an intellectual disability including family and friends.

We have also highlighted the importance of other supports, including services that support people with intellectual disabilities and their families, as well as support from the wider communities in which individuals live.



Circles of Support Model (Snow, 1988) [1]



[1] Health Service Executive. (2020). A Guide to Circles of Support.
tinyurl.com/HSEguideToCirclesOfSupport

IDS-TILDA has found that, while many people with intellectual disabilities have very strong and diverse Circles of Support, this is not always the case.

Many people with intellectual disabilities have a very strong Circle of Intimacy, with great support from their close family, and a very strong Circle of Exchange, with support from a disability service provider.

However, for some, there are critical gaps in their wider Circle of Friendship and in their Circle of Participation.

Circles of Support are also critical to helping services develop a person-centred approach and culture, for example, in helping individuals to identify and achieve their personal goals through person-centred planning.

We hope that these resources will be of benefit to people with intellectual disabilities and the people who support them – including their families and services.

Our aim was to demonstrate and showcase positive examples of Circles of Support, and the strategies individuals use to build and maintain those relationships.

We feel that others can learn from the wonderful examples of supportive relationships that our participants have demonstrated in these videos – and take some of the strategies to help build their own Circles of Support.

We have worked closely with Stewarts Care in Dublin to develop these resources and have been supported by other partners including the HSE, the Federation of Voluntary Service Providers, and Temple University in the United States.

I wish to thank all of them for their support of this important project.

Many thanks, and I hope you enjoy these resources and videos.

Prof. Mary McCarron.

Prof. Mary McCarron
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PROJECT GUIDE

https://youtu.be/VUtWoVpbm_k



My name is Mei Lin Yap, Ambassador Liaison Officer at the Trinity Centre for Ageing and Intellectual Disability. I will be your guide to Building Circles of Support.

This project aimed to demonstrate and showcase positive examples of support for individuals from their Circles of Support, and the strategies they have used to build and maintain those relationships.

The model behind Circles of Support explains the circles as different layers of support made up by the people you know. These Circles include:

Circle of Intimacy

These are the very close relationships in our life.

Circle of Friendship

They are our friends and family that we see often but not all the time.

Circle of Participation

They are the people in our community groups, clubs, work, and classmates.

Circle of Exchange

They are the people in our life that are paid to support us.

LET'S MEET OUR PARTICIPANTS

Audrey



I live with mum and dad. I go to day services in Stewarts twice a week and I work in a solicitor's office. I swim with Special Olympics and play bocce. I like going out shopping or for coffee. I like to go to the theatre and relaxing at the weekends.

People in my circles are my mum, dad, and brother. My cousins, auntie, colleagues and friends from clubs and work.

Pat & Joe



Joe: I am 44, work in Musgraves, and I play a bit of sport too. In my work I help people with the shopping trolleys and their bags. I work 3 times a week. Wednesday is my day off. I play football, tag rugby, badminton and sometimes tennis.

Pat: I work in the farm in Kilcloon. I enjoy planting and grass cutting. I also do horse-riding on Tuesdays. I like swimming, squash, badminton, basketball and running.

Martin



I'm 36 years old and live with my mum. I go to day services in Stewarts. I like knitting, painting, drawing, making cards, woodwork and help with the horses at the Equestrian centre.

People in my circles are my mum, 4 sisters, nieces and nephews, my friend Tommy, and staff from Stewarts.

Theresa



I'm 42 years old and I live with my mum and dad. I try to be as active as I can. I go to Rossecourt and enjoy horse riding, bowling, swimming, arts and crafts.

On Saturdays I go for a walk with my uncle. I am happy with the support I have from my family, friends, and staff in Stewarts.

Una



I'm 40 now. I live with my dad and my dog. I have 2 jobs working in admin. I take part in Special Olympics, in bowling. I go to the gym and swimming. On the weekends I go shopping or meet my boyfriend for a coffee or cinema. We hang out! The people in my circles are my dad, sisters, my boyfriend, and friends.

CIRCLE 1 – CIRCLE OF INTIMACY

https://youtu.be/wRDa_CcmOLM

The Circle of Intimacy includes the people very close to us, sometimes living with us, and who we share private information with. They are the people we would miss a lot if they were not around.

Our participants highlighted the special importance of family in their Circles of Intimacy.

But other people, such as partners, boyfriends/girlfriends, or very close friends may also be important members of this Circle.



Audrey spoke about how her mum supports her healthcare appointments and guides her with directions and transport.

Audrey's dad talked about supporting her getting to work and social activities such as the cinema, sports, and theatre.

Audrey's mum said how their ***“whole thing in life is to make sure she's happy and healthy, and just encourage her to get out there and do as much as she can”***.



Una noted that her boyfriend is her “***biggest supporter***”, and she also gets lots of day-to-day support from her dad and other close family members.

Una’s dad spoke about how they get on as a normal family doing day-to-day stuff, and his role supporting Una with household activities and transport.



Theresa is independent in many ways. Her mum supports her with some of her activities of daily living. She helps her to get ready in the morning and to have her breakfast, in time to leave for her day service each day.



Martin's mum also plays a key role for Martin, but his Circle of Intimacy also includes important support from the close-knit family including his sisters.

One of his sisters lives nearby and is always around, and the other sisters are also regular supports.

This takes some of the pressure off Martin's mum as the primary support.

CIRCLE 2 – CIRCLE OF FRIENDSHIP

<https://youtu.be/fO-jlEq1r8>

Outside the Circle of Intimacy is our Circle of Friendship.

In the Circle of Friendship are the people we share things in common and meet socially. Our friends and family that we see often but not all the time.

Our participants highlighted how special it is to have friends, someone who knows you well and who you can count on for support outside family and the support service.



Pat and Joe originally met through shared interests in sport and got on great together, building their friendship over the next 20 years.

They spoke about the importance of their support for each other.

They said it was important to be there for your friend, but also to allow them their own space.



Martin's sister spoke about how she goes bowling with Martin every Friday. Others in Martin's Circle of Friendship also help to support his activities, including another sister, Gina, and friend Tommy.



Una said she has lots of friends including different types of friends. Her friends are very special and important to her.

Una keeps in contact with her friends by phone and text messages, as well as meeting up.



Theresa's Circle of Friendship includes her uncle, Dominic, who takes her out on Saturdays. This supports Theresa's interests and participation as well as supporting her parents. Theresa also spoke about getting out to see her other friends, especially at the weekends doing bowling.



Audrey's aunt and cousin, Mary, are important members of her Circle of Friendship. They provide great support for both Audrey and her family.

Audrey has a great group of friends through her activities in Special Olympics, who always look out for each other.

Audrey also spoke about the importance of her friends in college in Rossecourt, who she meets up with for a cup of tea and a chat.

CIRCLE 3 – CIRCLE OF PARTICIPATION

<https://youtu.be/JSBW06ROdts>

After the Circle of Friendship, comes the Circle of Participation, which includes the people we interact with frequently.

Our participants mention the importance of feeling part of the community *“like everybody else”* when having people in this circle.



Joe got a job in Musgraves with support from Stewarts. He says: *“I love it”*. He really enjoys his tasks helping customers and feels part of the team. Pat enjoys all his social activities. He brings back strawberries to his friends in Kilcloon farm after respite.

Joe’s keyworker Orlaith spoke about all the activities and weekly meetings in JASS to support employment and promote social interaction and fun time together.

Both Joe and Pat mentioned having an enjoyable busy weekly scheduled. They both like taking part in their groups and sports.

Pat’s keyworker Bridget mentioned naturally Joe and Pat include others to make sure new members feel part of the group. Their friendship helps others to belong to the group.



Audrey mentioned her job and how much she feels part of the team. She helps in admin tasks and events. Audrey's sense of belonging is very strong, she says they are like a ***"family, a different family, they include me in everything"***.

Audrey also spoke about taking part in an event at work to celebrate difference. She had the opportunity to explain to her workmates her abilities and support needs. ***"It is easier to work together once they know more about me"***.



Una works in Musgraves for over 15 years and Campion Insurance for 5 years. She enjoys her roles and feels supported. Una ***"loves"*** dressing up smart for work like everybody else in her role.



Theresa enjoys her tea breaks with her colleagues in Rossecourt and going out for bowling. She says: ***“I enjoy it even if it is only for a couple of hours”.***



Martin goes bowling with his friends on Fridays after Stewarts. His family or friend Tommy, members of other circles, help to facilitate his participation and interaction in this circle.

CIRCLE 4 – CIRCLE OF EXCHANGE

https://youtu.be/WRWTzDli_Ns

In the Circle of Exchange are the people in our life that are paid for their time, for example staff from support services, doctors, and therapists.

Our participants spoke about the importance of this close relationship and open communication with staff from services, and how this supports a person-centred approach.

They also mentioned how important it is to have people from this Circle also supporting their Circle of Intimacy.

Participants mentioned how important the Circle of Exchange is in enabling their routines – for example, allowing important breaks for the individuals and also their families.



Pat spoke about how important it is to have the time away from home to break the routine. ***“I need a break and so does my family”***. Pat enjoys and ***“feels relaxed”*** knowing he has the support from his service. ***“They will do anything for you”***.



Martin's mum Helen mentioned how happy he feels going to day services because he knows he can talk to staff, and they know him very well. Helen also spoke about the person-centred approach Martin receives from staff giving him time and the opportunity to talk and be heard.

Martin's sister Martina also highlighted how having a break is important for her mum. ***"She needs to have her own space but knowing Martin is comfortable and happy"***. Martina also spoke about how the relationship with the service has improved and evolved over the years. ***"Open communication and trust develop over the years; it doesn't happen instantaneously"***.

Martin's keyworker, Aaron, spoke about encouraging families to communicate frequently and to be included in the delivery of the day service.



Theresa enjoys going out for a coffee with staff on the weekends and looking around the shops.

Theresa's mum Evelyn spoke about how important it is to have her own break and time for herself and Patrick, even though she wouldn't like that all the time.



Una's keyworker Orlaith mentioned the support Una can access from Employability and Jass. They have a range of weekly and monthly activities and opportunities to catch up with keyworker and colleagues to share new ideas or good stories and have fun.

OVERARCHING THEMES

https://youtu.be/0d79Fw_nP6Y

From speaking with our participants and their Circles of Support, some important themes emerged. These are important to think about for Circles of Support. And we think they are very important to share with you.

Person-Centred Approach

Having a person-centred approach was highlighted as being important by the participants and their Circles of Support.

This means ensuring that the individual and their wishes and preferences remain the primary focus. And this requires really getting to know the person over time, as mentioned by Martin's sister Martina and keyworker Aaron.

Audrey's mum Monica highlighted how important it is ask questions and to be open. ***"I want her to be challenged and be able to do anything she wants to do."***

Reciprocal Support

Meaning you give, and you receive, was also mentioned by several participants as an important way to start and develop relationships. Keyworkers Bridget and Orlaith highlighted this reciprocal support in the Circle of Exchange with Joe and Pat. ***"You need to be kind. Kindness is always important"***.

Remote Support

A lot of the participants spoke about how they maintain their relationships and contact with family members and friends using technology, phone, and computers. In this way, important supports can be provided even if family or friends live far away, as mentioned by Una and Audrey. They also highlighted how some family members help dealing with complex computer tasks - a valuable support spoken about by Theresa's mum, Evelyn.

Confluence of Support

Where support from different parts of the circles come together and combine to help one another for a better quality of life for the person with an intellectual disability and their circles. This was mentioned by all participants circles of support and emphasised by Audrey's mum Monica, Theresa's dad Patrick, and Martin's mum and sister.

Cascade Effect

Where existing people in different circles may grow into another layer. For example, Pat and Joe first met through playing basketball, but after became very good friends. The circles are constantly changing and growing, so their relationship moved from the Circle of Participation into the Circle of Friendship.

STRATEGIES FOR BUILDING CIRCLES OF SUPPORT

https://youtu.be/hBVRN_1Du2s

Finally, we asked our participants about strategies for how to start, grow and maintain their Circles of Support.

Here's what they suggested!

- Get involved in clubs and societies outside support services was suggested by Joe and Pat and their keyworkers Bridget and Orlaith as a great strategy for building circles.
- You must give to receive. This strategy was highlighted by most of our participants during the interviews and also by our expert TCAID PPI panel.
- Show you are interested and give time for people to get to know you was also highlighted by Pat and our expert PPI panel.
- Look for people that share the same interests; you might not like to play a sport, but you might like to watch it together. This strategy was mentioned by Joe and Pat and suggested by Una's boyfriend Ross.
- Start meeting in places that are easy to get to and accessible. Go for a walk or to a coffee shop was an example and strategy given by Audrey, Theresa, Martin and Una.
- Volunteering in your local community might help you meeting people in your neighbourhood. A strategy strongly supported by Audrey and her family.
- Meeting people once a week was mentioned by most of the participants as a great way to grow your circles.

ACKNOWLEDGEMENTS

<https://youtu.be/5x-EGRbzWQA>

The authors would like to thank all the participants in this study who took their time to share their lived experiences. The stories they communicated gives us positive examples of Circles of Support and valuable strategies to build and maintain social connections.

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Scan the QR code below to access resources from the Building Circles of Support project and to watch the videos.



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