



**Trinity College Dublin**

Coláiste na Tríonóide, Baile Átha Cliath

The University of Dublin

# Decision Making for Adults Ageing with Intellectual Disability: Tools of Practice

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5 November 2020

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# Trinity Centre for Ageing and Intellectual Disability

Collaborating with the Sector

Trinity Centre  
for Ageing and  
Intellectual Disability

- The first dedicated Centre to investigate key issues in ageing, intellectual disability and the life course.
- Underpinned by the Intellectual Disability Supplement to The Irish Longitudinal Study on Ageing (IDS-TILDA).
- The Centre advances world-leading research, scholarship and training to identify the determinants of health and wellbeing for adults with an intellectual disability.

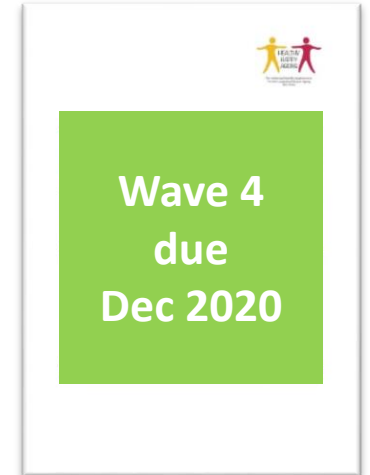
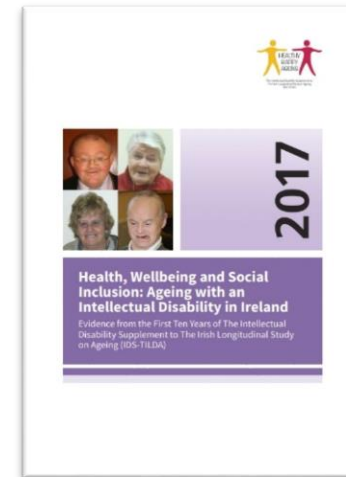
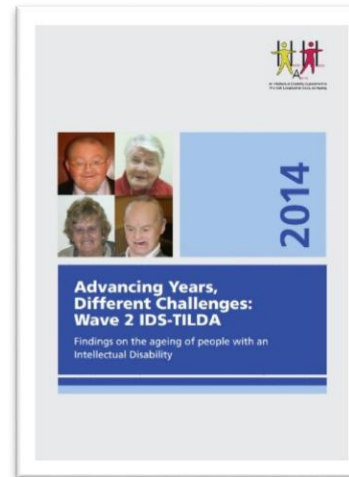




# The IDS-TILDA Story: 2007 – Present

Trinity Centre  
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Intellectual Disability

First nationally-representative longitudinal study on ageing with an intellectual disability comparable to the general population





# IDS-TILDA

## Objectives

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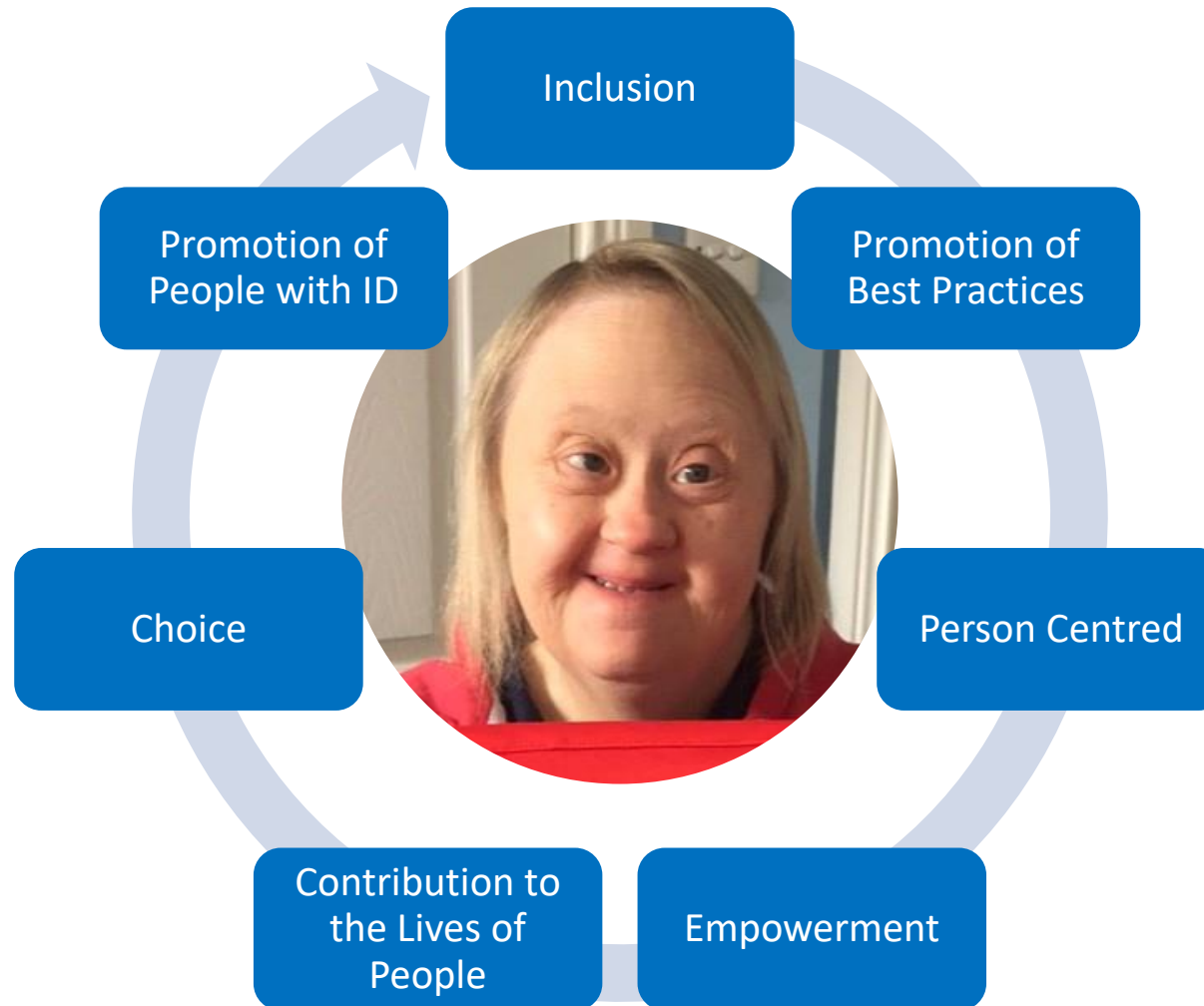
- **To understand the health characteristics** of people ageing with an intellectual disability;
- **To examine the service needs and health service utilization** of people ageing with an intellectual disability;
- **To identify disparities in the health status** of adults with an intellectual disability as compared to TILDA findings for the general population; and
- **To support evidence-informed policies, practices and evaluation.**



# IDS-TILDA: Values Framework

“Nothing about us, without us”

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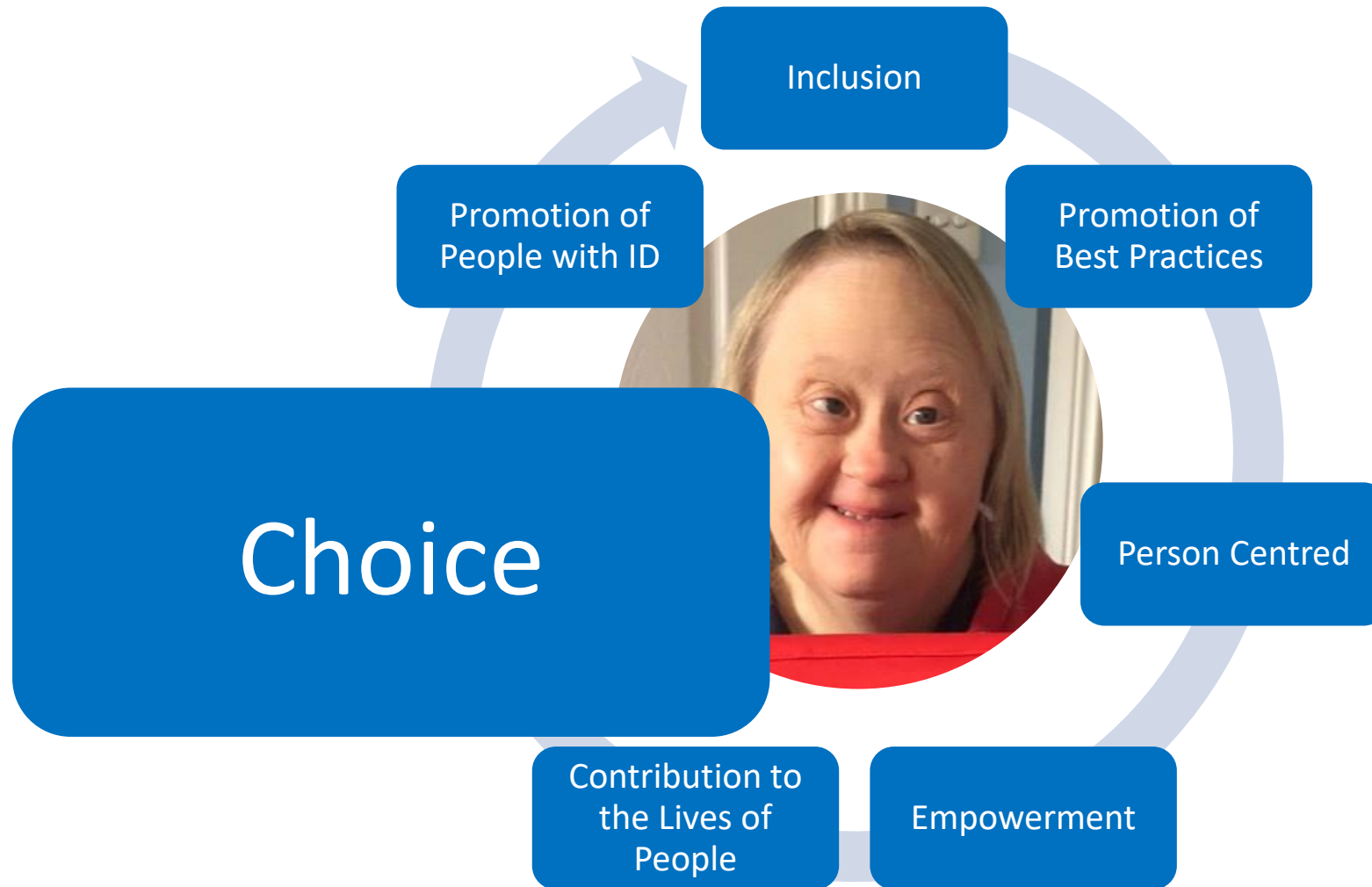




# IDS-TILDA: Values Framework

“Nothing about us, without us”

Trinity Centre  
for Ageing and  
Intellectual Disability







# The right to choose

UN Convention on the Rights of People with Disabilities

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## Article 19 – Living independently and being included in the community

States Parties to the present Convention recognize the equal right of all persons with disabilities to live in the community, with choices equal to others, and shall take effective and appropriate measures to facilitate full enjoyment by persons with disabilities of this right and their full inclusion and participation in the community, including by ensuring that:

- a) Persons with disabilities have **the opportunity to choose their place of residence and where and with whom they live on an equal basis with others** and are not obliged to live in a particular living arrangement;
- b) Persons with disabilities have access to a range of in-home, residential and other community support services, including personal assistance necessary to support living and inclusion in the community, and to prevent isolation or segregation from the community;
- c) Community services and facilities for the general population are available on an equal basis to persons with disabilities and are responsive to their needs.



# What IDS-TILDA Teaches Us

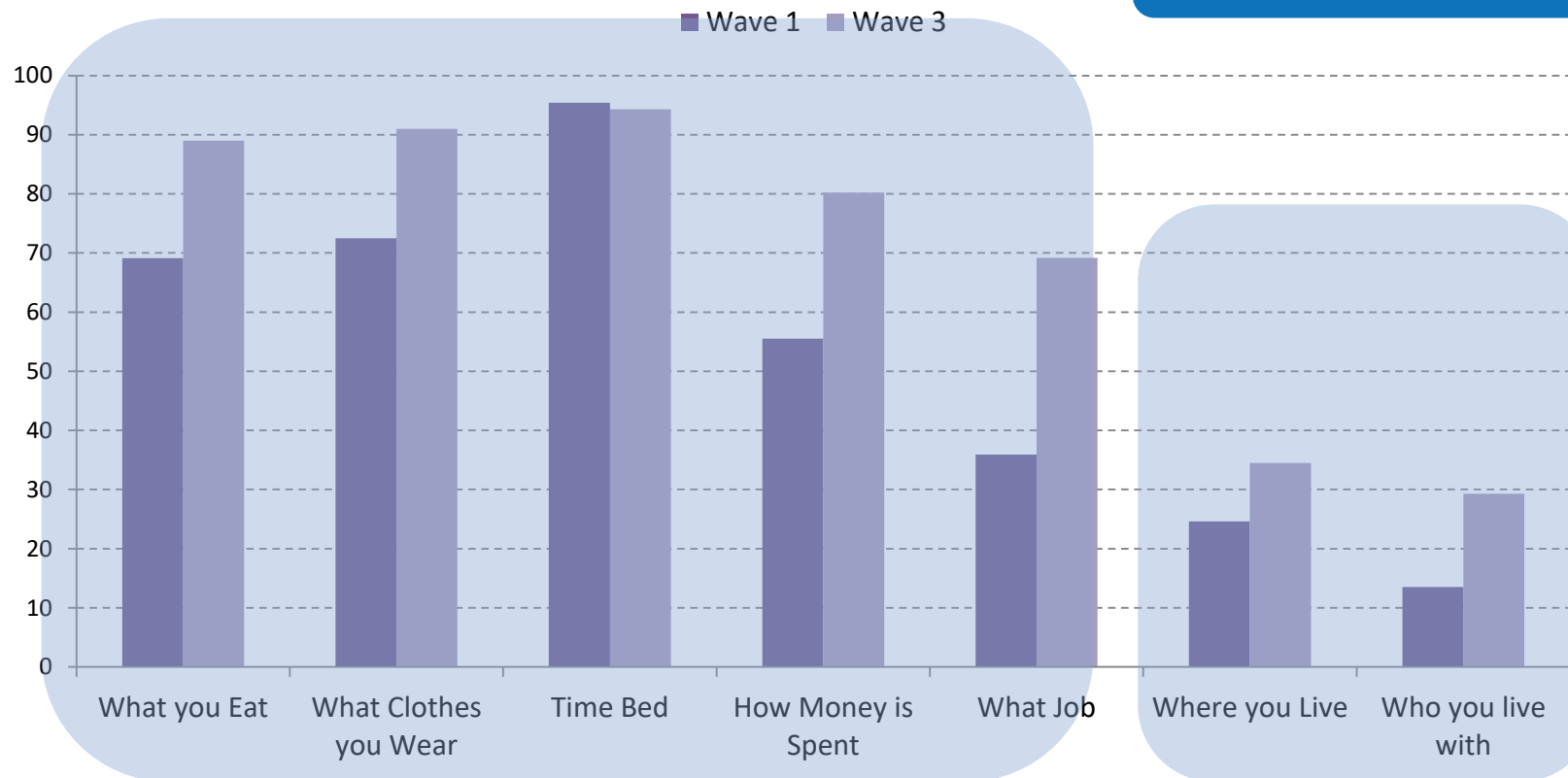
## Choice and Supported Choice

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Level of Choice increased between Wave 1 and Wave 3

Level of choice for day-to-day activities

Improvements but only  
for some







# What IDS-TILDA Teaches Us

Choice and Supported Choice about Money

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- **24.4%** chose how to spend their money
- **56.8%** were supported in their choices
- **19.8%** had no choice, or choice was made on their behalf, about their money

On where they **kept** their money:

**17.2%** reported that they chose where it is kept

**47.2%** reported no choice or choice made on their behalf



# What IDS-TILDA Teaches Us

## Exercising Choice

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The Assisted Decision-Making (Capacity) Act 2015 will provide more formal supports to be able to help people to make decisions.

But decision-making is a 'muscle' – we must understand whether people have the opportunity to make choices every day if we expect them to make big life-choices.

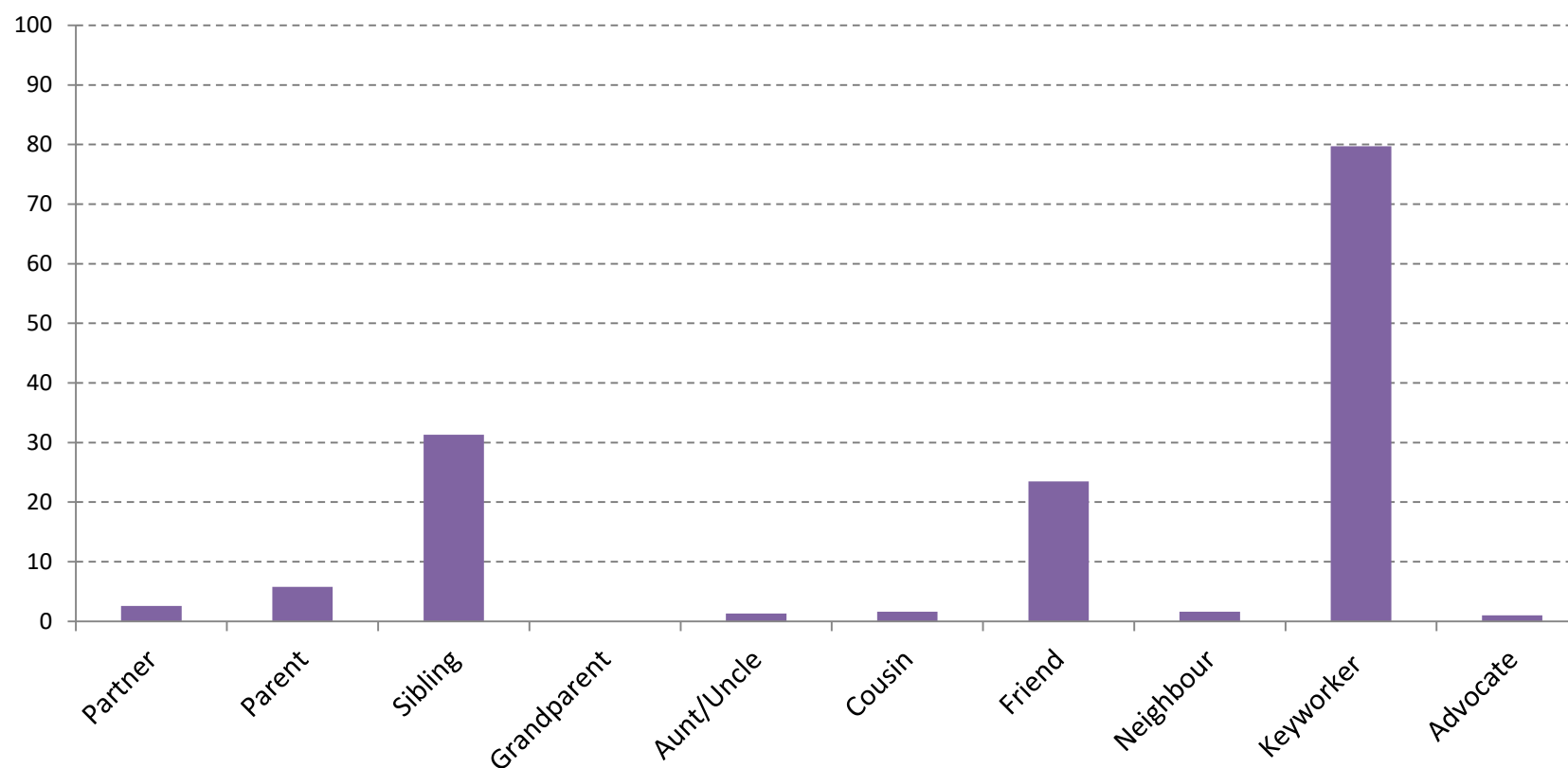


# What IDS-TILDA Teaches Us

## Trust & Safeguarding

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### Who do you confide in?

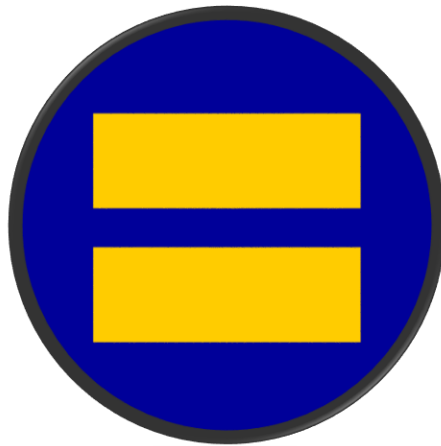




# What IDS-TILDA Teaches Us

## Access to Advocacy

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- **51.3%** said they had an independent advocate
- **72.0%** said they had access to an independent advocacy service



# The right to choose

UN Convention on the Rights of People with Disabilities

Trinity Centre  
for Ageing and  
Intellectual Disability

## Article 21 – Freedom of expression and opinion, and access to information

States Parties shall take all appropriate measures to ensure that persons with disabilities can **exercise the right to freedom of expression and opinion**, including the freedom to seek, receive and impart information and ideas on an equal basis with others and through all forms of communication of their choice, as defined in article 2 of the present Convention, including by:

- a) Providing information intended for the general public to persons with disabilities in **accessible formats** and technologies appropriate to different kinds of disabilities in a timely manner and without additional cost;
- b) Accepting and facilitating the use of **sign languages, Braille, augmentative and alternative communication**, and all other accessible means, modes and formats of communication of their choice by persons with disabilities in official interactions;
- c) Urging private entities that provide services to the general public, including through the Internet, to provide information and services in **accessible and usable formats** for persons with disabilities;
- d) Encouraging the mass media, including providers of information through the Internet, **to make their services accessible** to persons with disabilities;
- e) Recognizing and promoting the use of **sign languages**.



# Glancing Back, Planning Forward

Accessible Planning Tool for People with ID

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
# Glancing Back, Planning Forward

Accessible Planning Tool for People with ID

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A tool for the person to be able to record their end-of-life wishes and preferences.

**Accessible Planning Tool**  
Glancing Back Planning Forward

**The tool** 

**Tell us what you want to do**

If you were sick how much information would you like to know about sickness? ☐ None ☐ A little ☐ A lot

If the doctor had to tell you news about your health who would you like to be with you

Name of the person

His/her phone number

If you were very sick and the doctor said you would not get better where would you like to be cared for?

☐ Put 1 beside your first choice  
☐ Put 2 beside your second choice  
☐ Put 3 beside your third choice  
☐ Put 4 beside your fourth choice

☐ At home  
☐ In Hospital  
☐ In a Hospice  
☐ In a Nursing Home



# Glancing Back, Planning Forward

Accessible Planning Tool for People with ID

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## Accessible Planning Tool

Glancing Back Planning Forward



### About this guide

- This is information to help you prepare for the future
- This information will help you to make decisions so your friends, family and staff will understand your wishes
- Sometimes you make decisions that are easy like what you would like to eat
- Sometimes you make decisions that are difficult like what will I do if I get very sick
- By planning ahead you will know who will help you and they will know what you want



## Accessible Planning Tool

Glancing Back Planning Forward



### About this tool

- This is a planning tool to help you let everyone know what you want if you get very sick and will not get better
- It can be filled out when you are ready to do so
- You can change anything you write in the tool any time you want





# Glancing Back, Planning Forward

Accessible Planning Tool for People with ID

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## Accessible Planning Tool

### Glancing Back Planning Forward

#### The tool

#### Personal Details

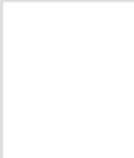
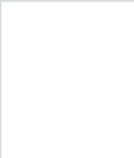

My name is

Insert your photo here 

I live in

My Carer is


Picture(s) of carer  
My parent/sister/  
brother/key worker



## Accessible Planning Tool

### Glancing Back Planning Forward

#### The tool



#### Tell us what you want to do

If you were sick how much information would you like to know about sickness?

☐ None ☐ A little ☐ A lot

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■ Put 3 beside your third choice  
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# Glancing Back, Planning Forward

Accessible Planning Tool for People with ID

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## Accessible Planning Tool

### Glancing Back Planning Forward

**The tool**



**Tell us what you want to do**

If you were very sick is there someone from your church or religious group you would like to tell

Priest/Minister/Other [Name and details]  
Do not have a religious preference

Phone number

**Think and answer when you are ready**

**The next questions are about if you got very sick and you would not get better**

Are there any things you would like in your last days of your life?

Some of these things might be:

- People you would like to see
- Places you would like to go
- Being kept comfortable
- Doing everything the doctor or nurse can think of to make you feel better

## Accessible Planning Tool

### Glancing Back Planning Forward

**The tool**

Are there any things you would NOT like to do in the last days of your life?

Some of these things might be:

- Going into hospital
- Doctors or nurses doing things that might be painful

Are there any things you would like to do if you were able to?

Is there any person you would like to see or talk to? Please write their name(s) and phone number(s).

Would you like to be in a quiet place or a place with activity around?

Would you like lots of visitors or just a few close friends?



# Glancing Back, Planning Forward

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## Accessible Planning Tool

### Glancing Back Planning Forward

#### The tool

Think and answer when you are ready

#### Questions about when you die

Would you like to make a will?

☐

Yes

☐

No

After you die are there any  
particular people that you would  
like to be told about your death?

## Accessible Planning Tool

### Glancing Back Planning Forward

#### The tool

After you die are there any clubs  
or groups that you would like to be  
told about your death?

[name and details]

None

☐

Tell me the name of the person  
who you would like to make your  
funeral arrangements

[name and details]

I don't mind

☐

Would you like to be buried or  
cremated?

☐

Buried

☐

Cremated



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## Accessible Planning Tool

### Glancing Back Planning Forward

#### The tool

Where would you like to be buried?  
Check with family or service re plot

[name place and details]

Where would you like to have  
your ashes placed  
Check with family or service re plot

[name place and details]

Is there a particular celebrant you  
would like to do your funeral?

Please list anything else you would  
like in your funeral service or  
ceremony such as a favourite piece  
of music or poem?

## Accessible Planning Tool

### Glancing Back Planning Forward

#### End of Life Planner Checklist

- I have thought about the things I want to happen at the end of my life ☐
- I have thought about the care I want to receive at the end of my life ☐
- I have talked about these things with people I trust ☐
- I have filled out this form with someone I trust ☐
- I am happy with the plans I have made on this form ☐

#### Signed:

My signature: \_\_\_\_\_

The signature of the person supporting me : \_\_\_\_\_

Relationship of this person to me (e.g., family, friend, keyworker): \_\_\_\_\_

Date: \_\_\_\_\_

#### Review

- I have reviewed this document with someone I trust ☐
- I am happy with changes I have made to this document ☐

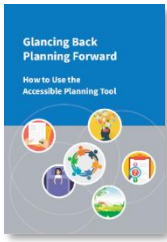
#### Signed:

My signature: \_\_\_\_\_

The signature of the person supporting me: \_\_\_\_\_

Date: \_\_\_\_\_





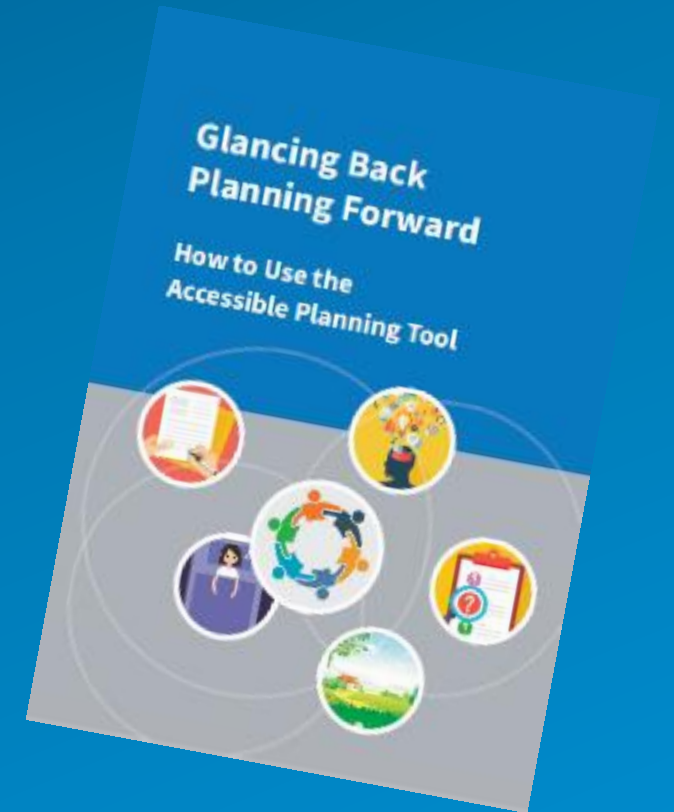
# Glancing Back, Planning Forward

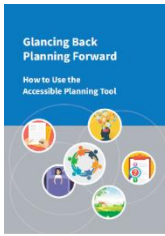
Using the Tool

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Prompts to help people with ID to:

- **Think** about the future and what they would like
- **Talk** to people they trust about the issues
- **Write** down what they want
- **Revisit** it whenever they wish





# Glancing Back, Planning Forward

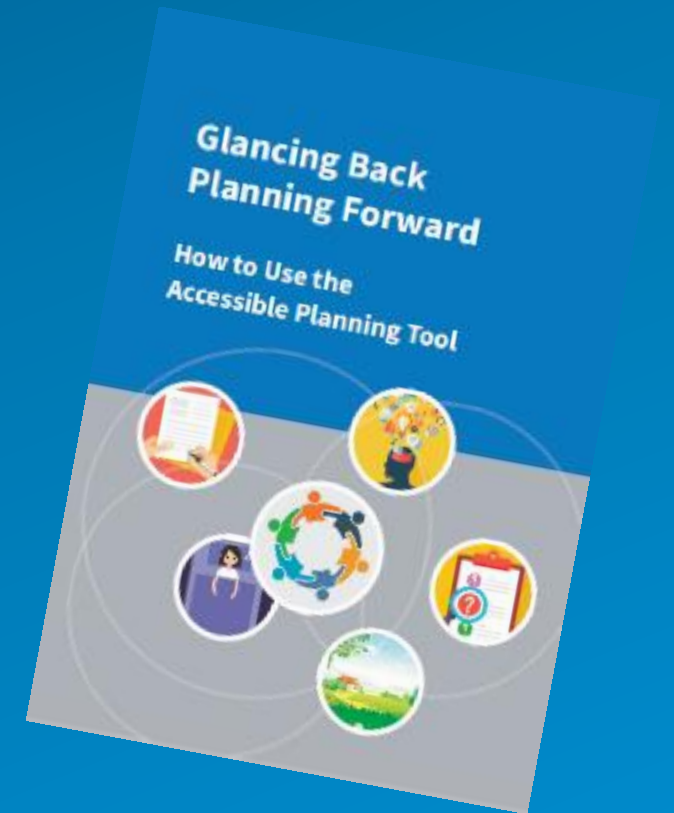
A Guide for Carers

Trinity Centre  
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## Starting the Conversation:

- When family members or friends die
- Incidental opportunities, e.g. when death is on TV
- When the person is dying

**Remember to use simple, concrete language: metaphors like 'passed away' or 'gone to sleep' can be confusing.**





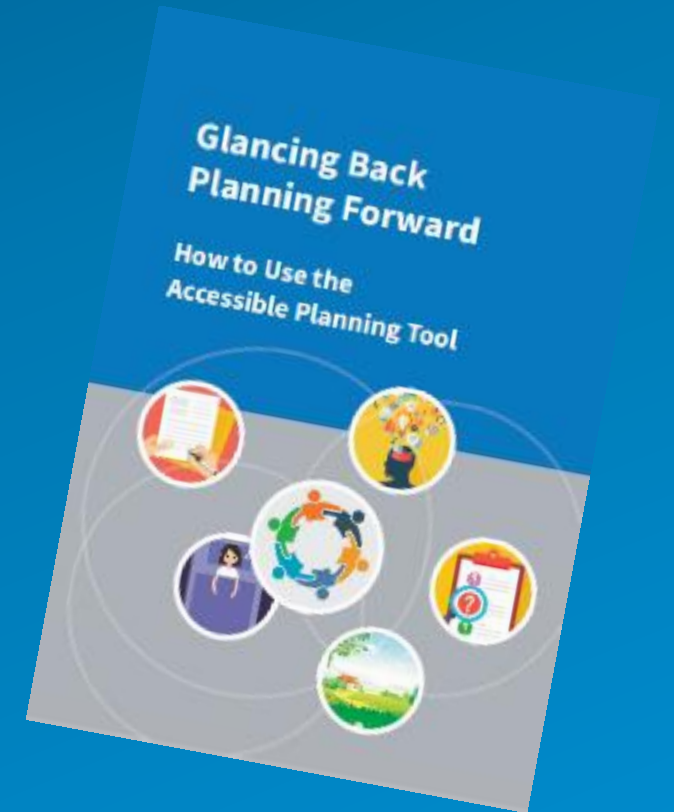
# Glancing Back, Planning Forward

A Guide for Carers

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## A Care Conversation:

- Builds knowledge
- Works with the person's capacity
- Connects to other people's conversations
- Provides support to the person at difficult times





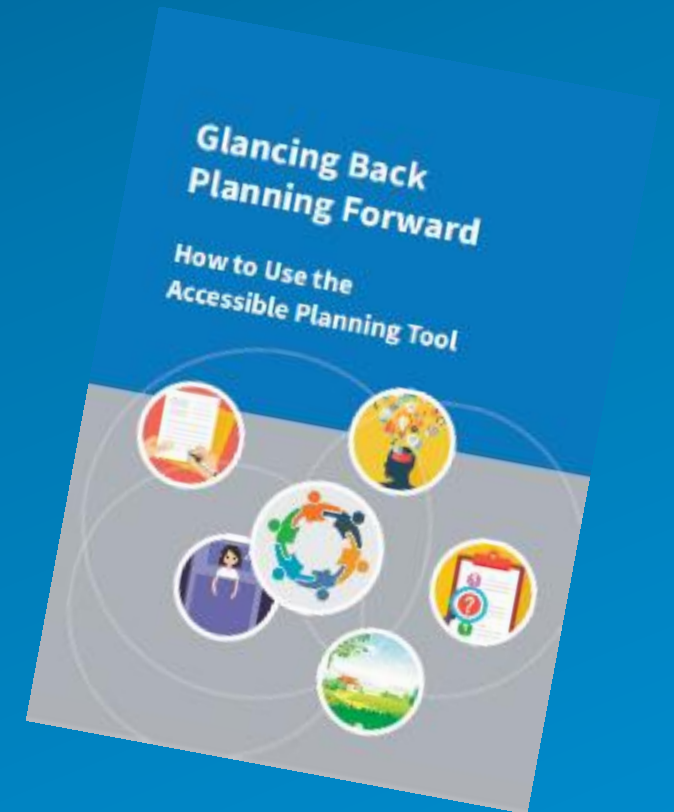
# Glancing Back, Planning Forward

A Guide for Carers

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for Ageing and  
Intellectual Disability

## Barriers to a Care Conversation:

- Misguided desire to 'over-protect'
- Preventing distress
- Too difficult for bearer of bad news
- Bearer of bad news lacks knowledge of illness
- Lack of sense of time
- Conflicting views of stakeholders





# Future Care Road Map

Accessible Planning Tool for People with ID

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# Future Care Road Map

Accessible Planning Tool for People with ID

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## Supporting the Conversation about Future Care

- **Making the interview process accessible:**  
Understanding what constitutes accessible information for the participant and what is their preferred communication method. Also, using accessible language that has been checked by people with ID
- Focusing on the present:
- Making the future relatable:





# Future Care Road Map

Accessible Planning Tool for People with ID

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## Supporting the Conversation about Future Care

- **Focusing on the present:**  
Framing the conversation in what is already understood by the individual. The future, as a concept, can be very abstract for some.
- **Making the future relatable:**  
Using simple phrases such as “when you’re a bit older” or “in a few years’ time” can make the future more relatable.



# Future Care Road Map

Accessible Planning Tool for People with ID

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## Supporting the Conversation about Future Care

- **Managing sensitive topics:**  
Understanding that discussions about the future must, by necessity, also include difficult topics such as the death of a parent or primary carer
- **Emotional support:**  
Highlighting to the individuals involved that there may be a need for emotional support and identifying where that support can be reached



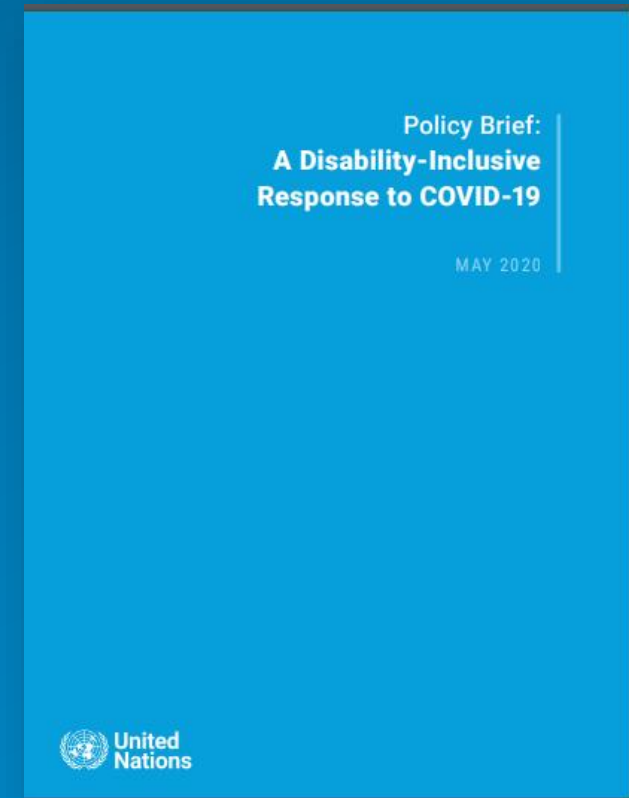
# An Opportunity during the Pandemic

## Building Back Better – UN Policy Paper

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While building back better, it is critical that **persons with disabilities are part and parcel of the response** which countries... are preparing.

These responses, if well designed, can address the exclusion and discrimination faced by persons with disabilities, thus creating more resilient communities and systems.







# The TCAID Team

Trinity Centre  
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# IDS-TILDA

## Acknowledgements

Trinity Centre  
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Intellectual Disability

The IDS-TILDA Team extends grateful appreciation to:

- Participants, Families and Carers
- The IDS-TILDA Steering Committee and International Scientific Advisory Board
- Advisors and Advisory Groups
- Our Funders





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The Trinity Centre for Ageing and Intellectual Disability is an international and multi-disciplinary research centre examining key issues in ageing and the life course, informing policy and debate at the national and local level.

ABOUT

IDS-TILDA



Participant  
Involvement



Research  
Themes



Education and  
Knowledge  
Transfer



PPI Ignite@TCD



[www.tcd.ie/tcaid](http://www.tcd.ie/tcaid)





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## Thank You

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