



Inclusive research: How do we start?

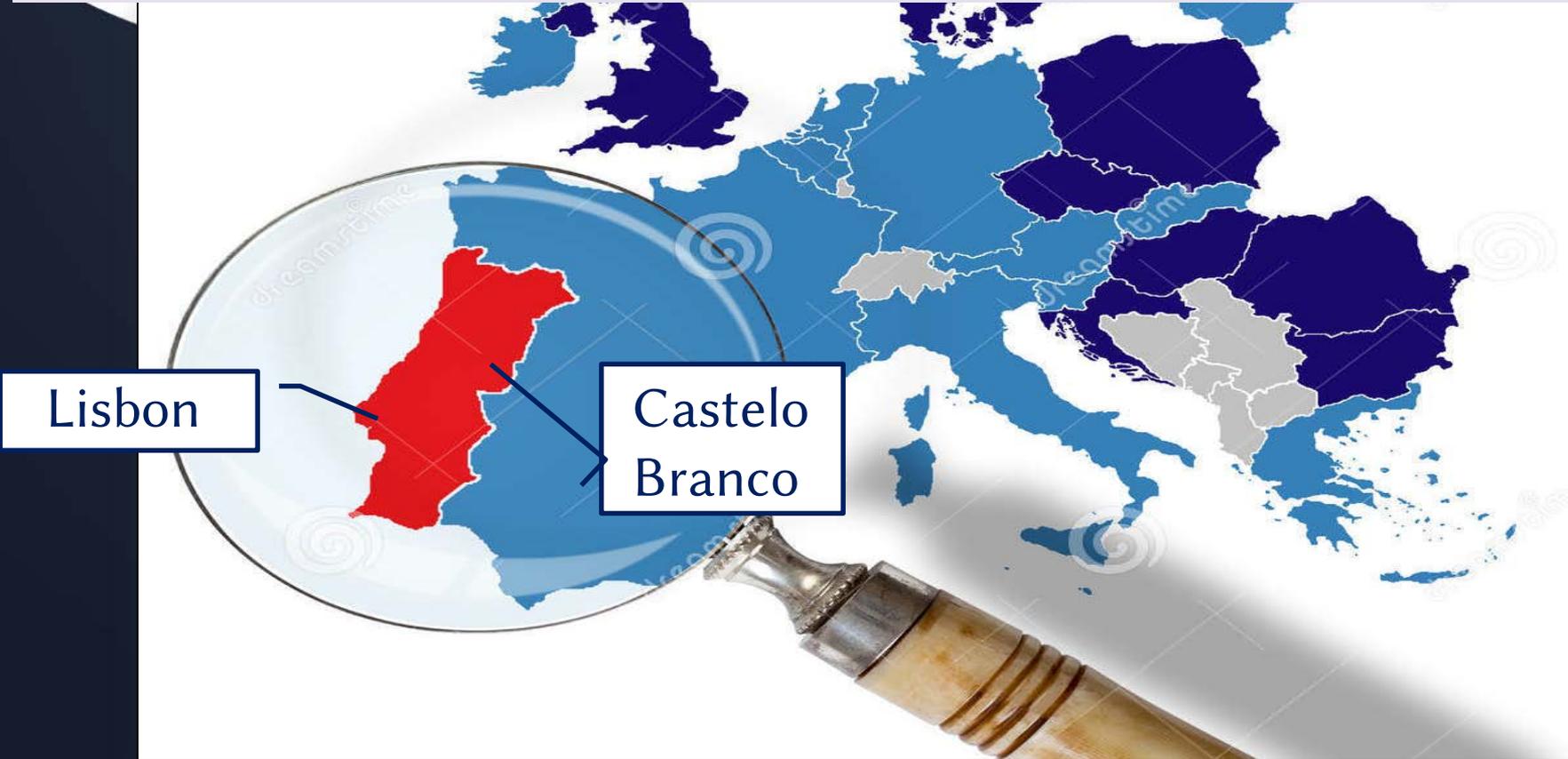
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Portugal

Portugal



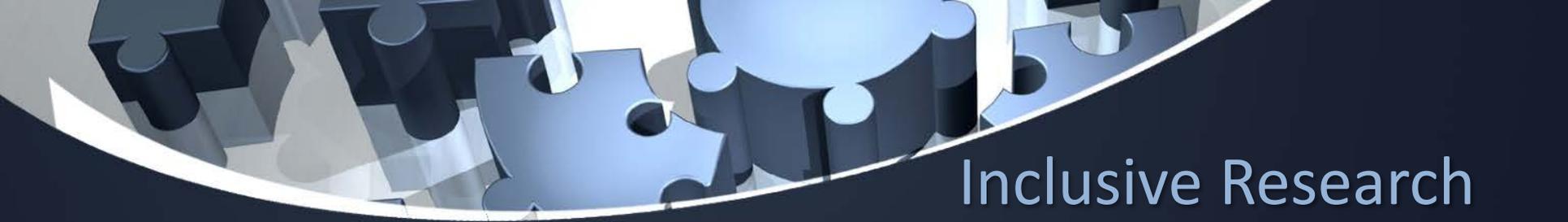
Lisbon

Castelo
Branco



**PORTUGUESE ASSOCIATION OF PARENTS AND FRIENDS OF CITIZENS WITH MENTAL DISABILITIES (APPACDM)
OF CASTELO BRANCO - PORTUGAL**





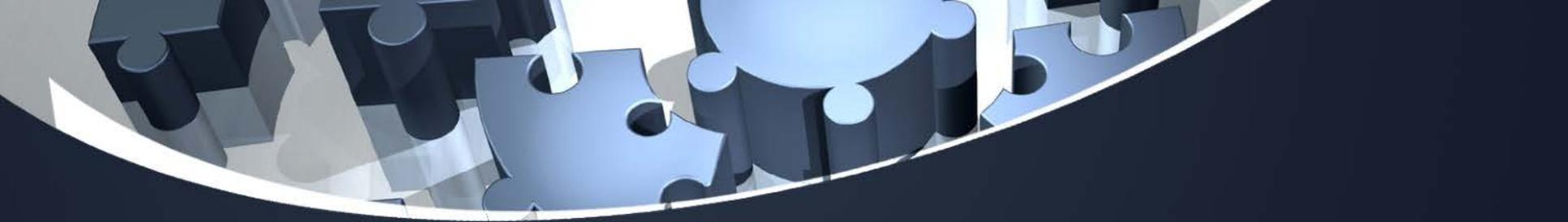
Inclusive Research

- The aim of this work is to describe the implementation process of an inclusive research project in a day care service provider in Portugal.



The starting point...

- Inter-university PhD programme in Psychology, speciality in Clinical Psychology, thematic version: Family and Family Intervention Psychology
- Main aim:
 - to understand the perspective of different family members about FQoL in families with members who have ID, including the perspectives of persons with ID themselves

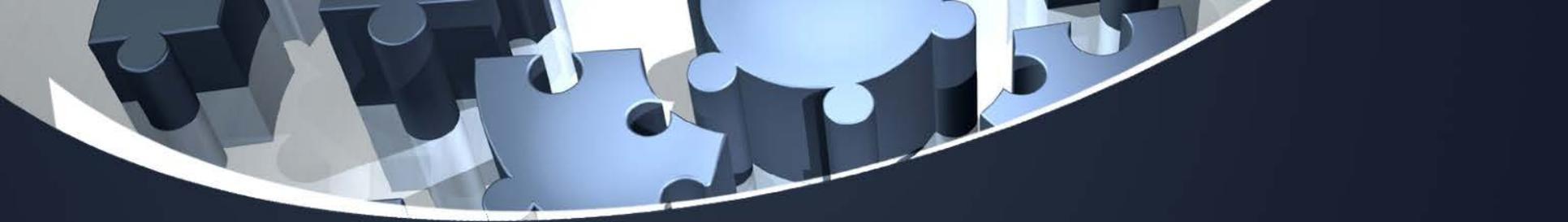


1st step:

give voice to persons with ID about their FQoL.



(Illustrative photo)

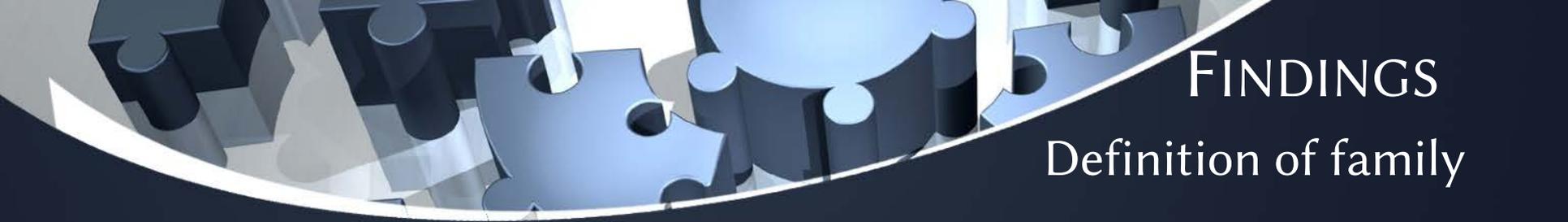


The MAIN AIM of this study is to give voice to persons with ID about their FQoL.

SPECIFIC AIMS

- a) to explore how persons with ID define family;
- b) to understand what people with ID consider important for them and their families to feel good together, i.e., to have good FQoL;
- c) to learn about the main concerns regarding family life identified from the point-of-view of persons with ID;
- d) to investigate the specificities of the perceptions of FQoL in older adults with ID.

☞ This study is part of a major project that seeks to understand different perspectives about FQoL: persons with ID, parents and siblings.



FINDINGS

Definition of family

1) FAMILY AS A SOCIAL STRUCTURE

a) Social roles associated with the family life

b) Consanguinity

c) Evolution in the family life

d) *Home*

e) Family activities and rituals

g) Geographic separation

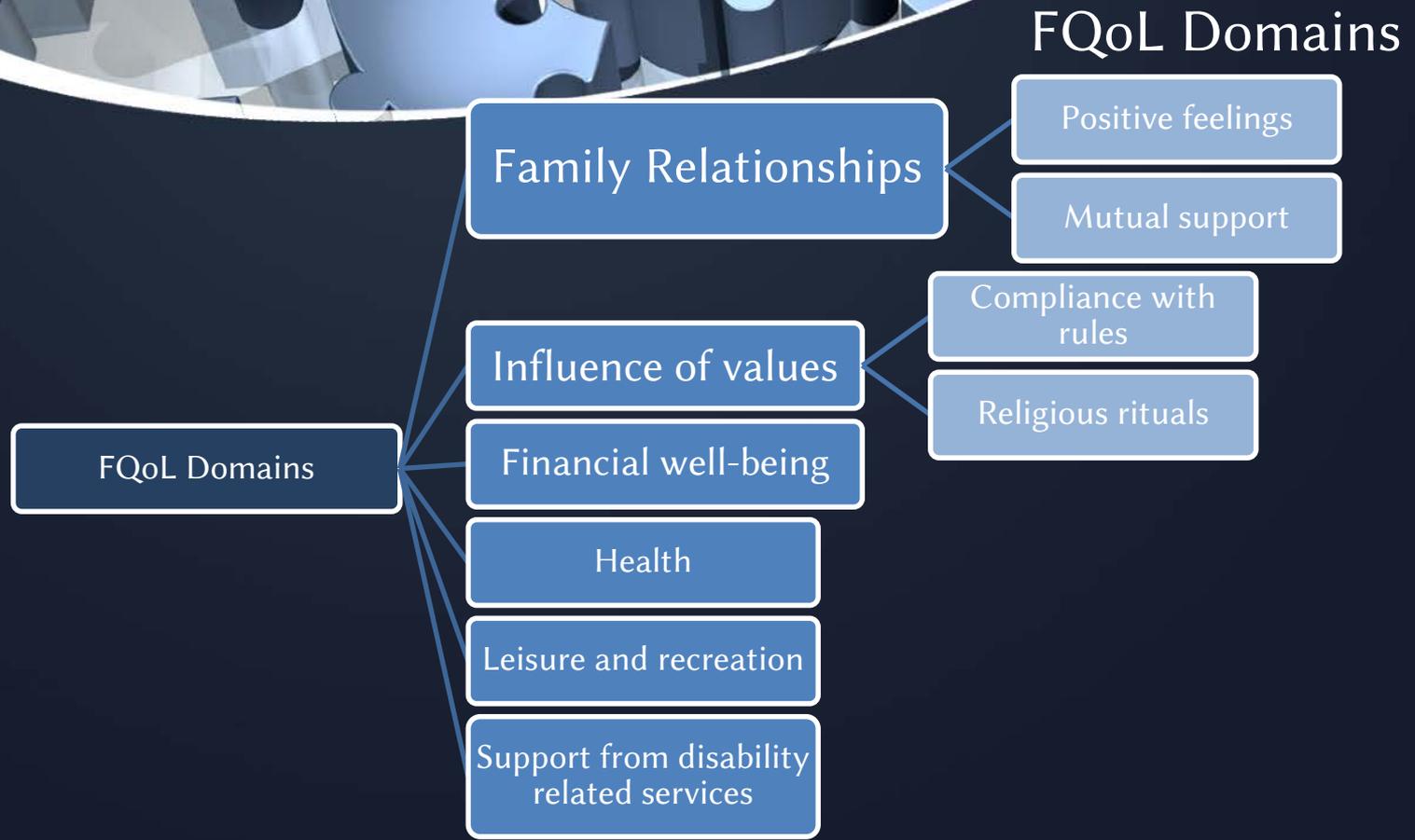
2) FAMILY AS EMOTIONAL AND RELATIONAL TIES

a) Positive feelings

b) Positive memories

h) Conflict

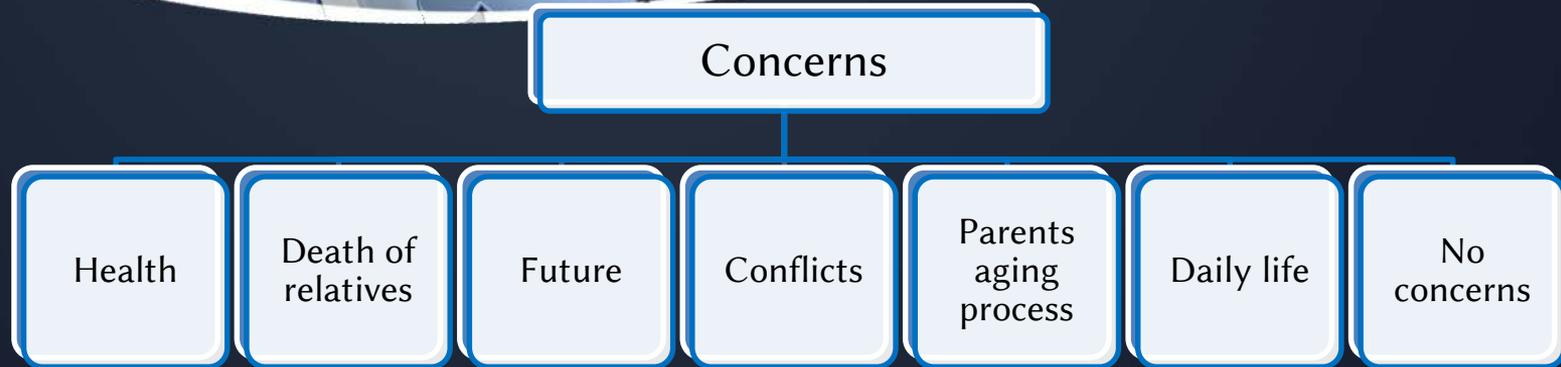
FINDINGS



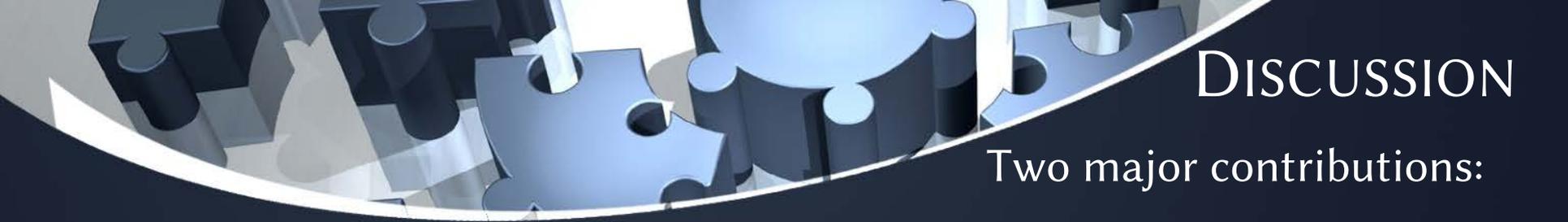


FINDINGS

Concerns



- Concerns about the future and about the ageing process are only present in the discourses of older adults.
- Concerns with family conflict, daily life issues and absence of concerns are only found in the discourses of younger adults.
- Concerns about health and about the death of relatives are found in both groups.



DISCUSSION

Two major contributions:

■ Show that family relationships are extremely important for persons with ID.

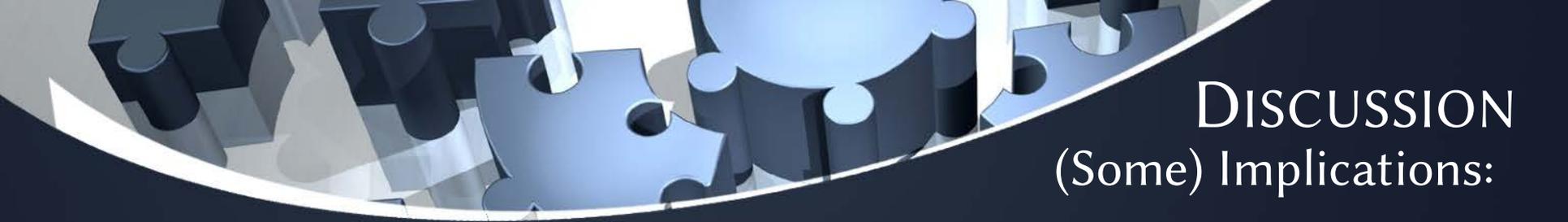


consistent with a study where the Family relationships domain was rated highest overall by main caregivers (Werner, Edwards, Baum, Brown, et al., 2009).

■ Reveal important differences between younger and older generations, with older persons with ID denoting greater concern with the future and ageing process than younger persons.



In line with research that identified the same concern from the perspective of older parents of persons with ID (Jokinen & Brown, 2005; Carr & O'Reilly, 2007; Marshak, Seligman & Prezant, 1999).



DISCUSSION (Some) Implications:

RESEARCH

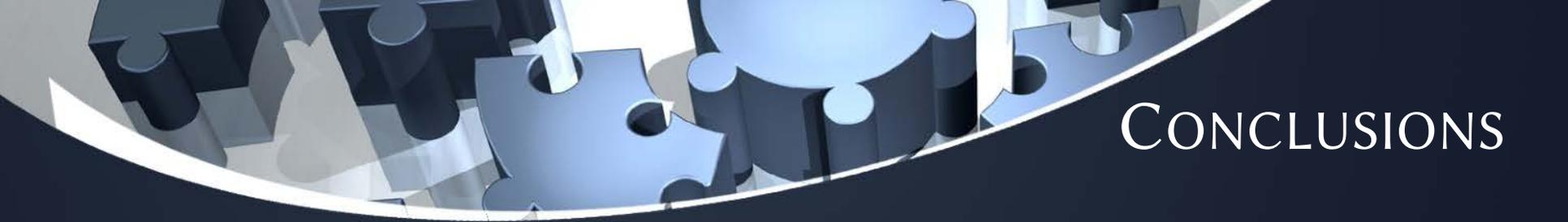
- ◆ Use of qualitative research and focus groups to study the population with ID proved to be useful and relevant;
- ◆ The reduced number of participants in each focus group was another positive feature that helped to gain an understanding about personal experiences.

INTERVENTION

- ◆ The importance of family relationships for persons with ID points to the need to create more opportunities to foster them;
- ◆ Need to address anxiety about the future and the process of ageing experienced by older adults.

SOCIAL FIELD

- ◆ Opportunity to empower persons with ID, by offering them the chance to express their perceptions, opinions and views about different aspects of their lives. The focus is on the person's abilities and resources.



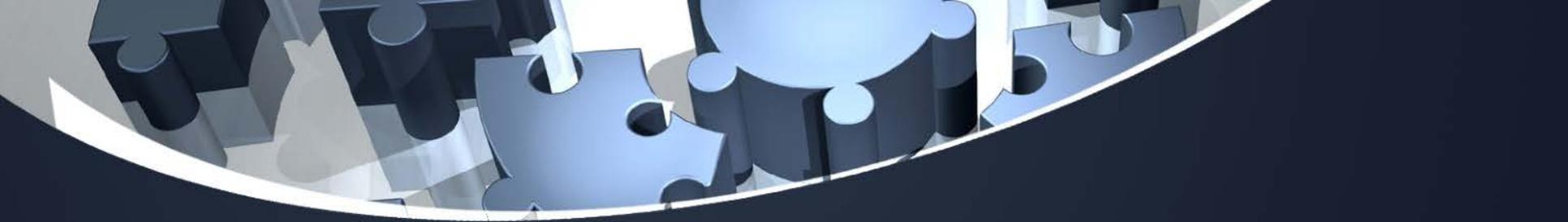
CONCLUSIONS

IN CONCLUSION...

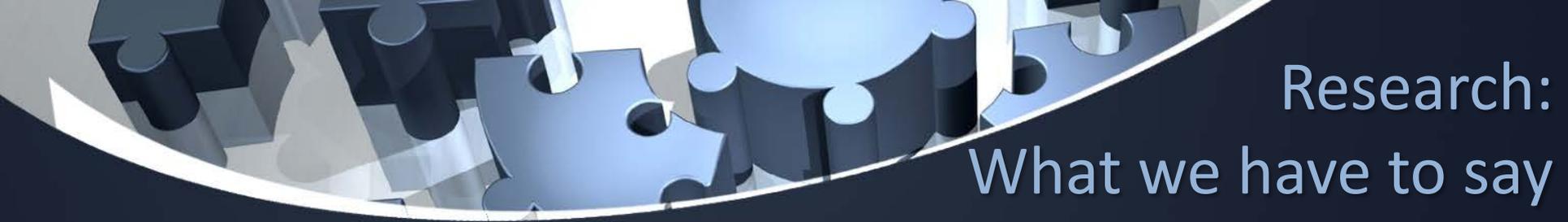
... the perspective of persons with ID can provide a fundamental and enriching contribution to research, particularly on issues related to FQoL areas.



It is an essential research decision to give voice to persons with ID and learn from their perspectives and opinions.

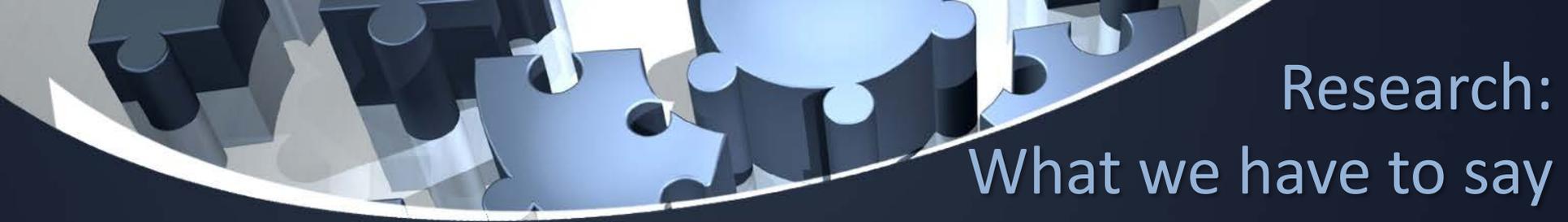
A circular inset at the top of the slide shows several interlocking 3D puzzle pieces in shades of blue and grey, set against a light background. The pieces are arranged in a way that suggests a complex, interconnected system.

Inclusive research,
why not?!



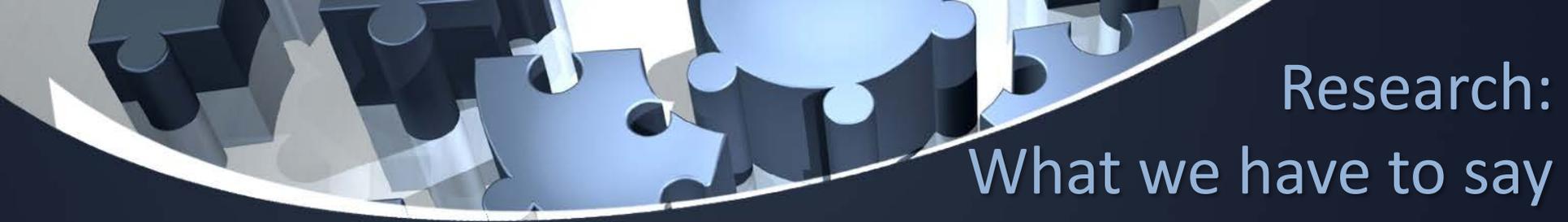
Research: What we have to say

- **MAIN AIM:**
 - to know the perceptions of persons with ID about the research process
- **SPECIFIC AIMS:**
 - To explore how persons with ID define research/ doing science;
 - To understand the interest of persons with ID in doing research.



Research: What we have to say

- Individual interviews
- 12 persons with ID (6 younger adults and 6 old adults)
- Interview guide with two parts:
 - perceptions about what is to research/ to do science and how the process is carried out
 - the interest in participating in other studies, both as subjects and as researchers
- The interviews were recorded in audio format and full transcribed , and NVivo 10 software was used to analyze the data.



Research: What we have to say

“seeing things”
(Nuno, 27 anos)

“inventing something”
(Andreia, 44 anos)

“discovering things we
don’t know”
(Natália, 52 anos)

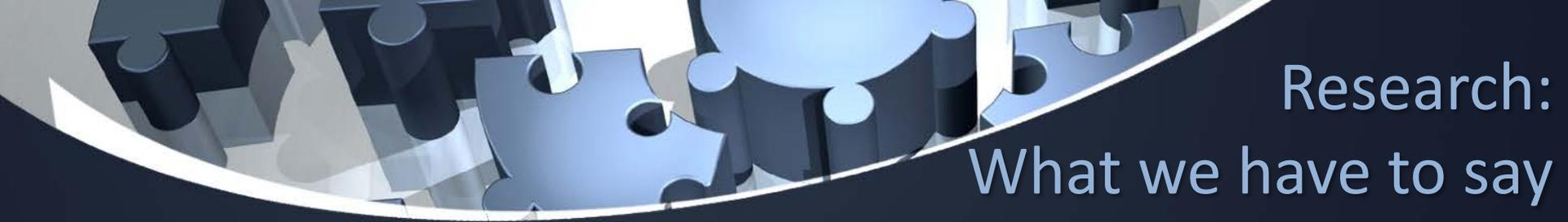
“a person looks for something and then uses a magnifying glass and write, ask, and for example go to computers, on the internet, and go to books” (Natália, 52 anos).

“to find things that
are good to know”
(Celeste, 53 anos)

“doing experiments”
(Edite, 24 anos)



RESEARCH



Research: What we have to say



is necessary to "have a uniform, mask, glasses, have the right equipment" (Rita, 20 years old)

"papers, write" (Celeste, 53 years old)

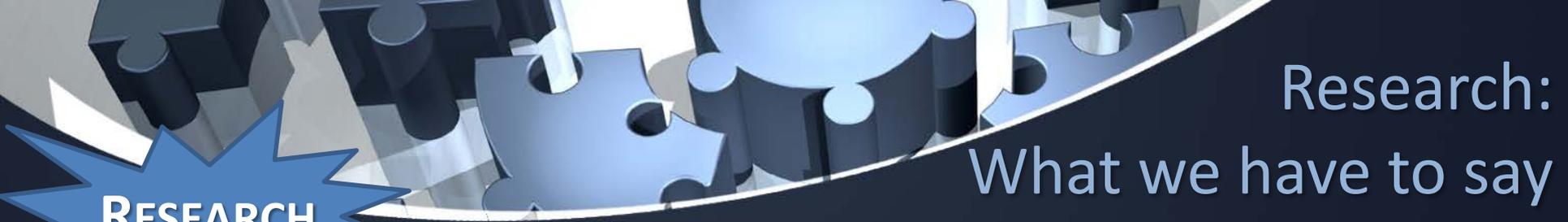
"it is for us to feel good, so we do not have many health problems and so" (Natália, 52 years old)

"we have to work for this, we have to work hard" (Nuno, 27 years old)

"must have a researcher's course" (Edite, 24 years old)

"They have to be experts, not us" (Paulo, 44 years old)

"you have to take lessons, take a training" (Andreia, 44 years old)



Research: What we have to say



RESEARCH

Positive aspects

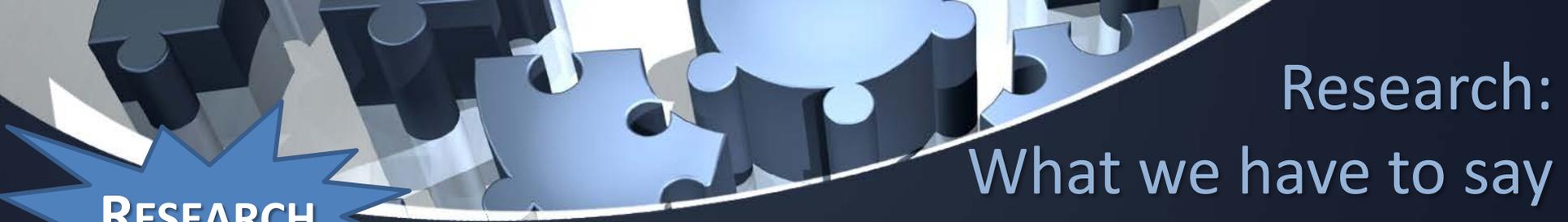
- "It's good" (Nuno, 27 years old)
- "it's useful" (Paulo, 44 years old),
- "it's very cool" (Andreia, 44 years old)
- "it's very important" (Júlia, 20 years old)
- "it's fun" (Rui, 20 years old)

Learning context

- "At least I learn something" (Nuno, 27 years old)
- "To know things we do not know" (Natalia, 52 years old)
- "to learn more" (Madalena, 48 years old)

Social interaction

- "I like to participate with my colleagues, to be here with my colleagues" (Gonçalo, 22 years old)



Research: What we have to say

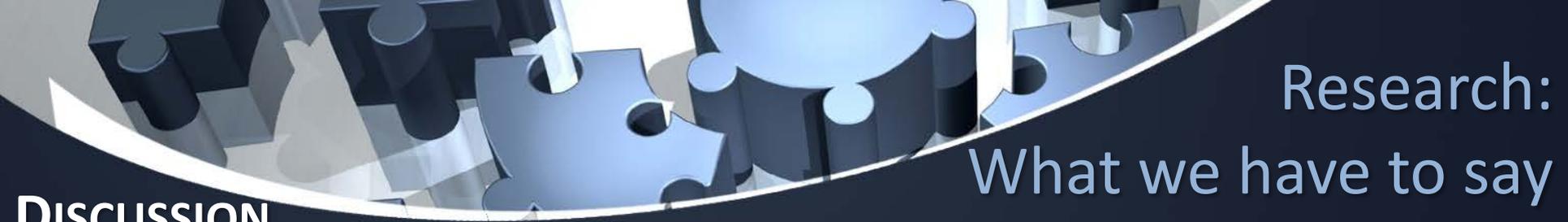
RESEARCH

All of the participants were willing to participate in new studies.

When asked if they would like to participate as researchers:

- 8 said yes,
- 2 only if they had the opportunity to have a first experience,
- 1 said that only if they had some preparation in advance and
- 1 said that they didn't like to participate as a researcher because "it is very complicated to do this" (Rui, 20 years old).

One of the participants stated that the topic she would like to investigate was "how the future will be" (Andreia, 44 years old).



Research: What we have to say

DISCUSSION

Persons with ID

- conceptualize research as something **positive**, and they like and would like to participate, which is in line with the study by Abell et al. (2007) that describes an inclusive research group that was initiated by the great interest of the people with ID.
- considered the research process **difficult**, being necessary to study, to learn and to prepare previously. Strnadová et al. (2014) considered the research training an important element to implicate the persons with ID.
- highlighted the importance of **learning** in the research process as well as the **social interaction** they established with their **colleagues**. For persons with ID to learn and make friends is as important as finding answers to research questions (Strnadová et al., 2014).

Persons with ID might not be aware that they could really make a difference by being involved in a research process as researchers, so it is important to disseminate this information
(Strnadová et al., 2014).

SEARCHING



Books:

Nind, M. (2014). *What is inclusive research?* London: Bloomsbury.

Walmsley, J., & Johnson, K. (2003). *Inclusive research with people with learning disabilities: Past, present and futures.* London: Jessica Kingsley.

(...)



Articles and reports that describe inclusive research experiences:

Abell, S., Ashmore, J., Beart, S., Brownley, P., Butcher, A., Clarke, Z., ... Wilson, D. (2007). Including everyone in research: The Burton Street Research Group. *British Journal of Learning Disabilities*, 35, 121-124.

National Institute for Intellectual Disabilities (2009). *All We Want to Say: Life in Ireland for people with Intellectual Disabilities Report*, Trinity University Dublin.

Nind, M., & Vinha, H. (2012). *Doing research inclusively, doing research well?* University of Southampton.

Salmon, N., Carey, E., & Hunt, A. (2014). Research skills for people with intellectual disabilities. *Learning Disability Practice*, 17 (3), pp. 27-35.

Strnadová, I., Cumming, T., Knox, M., Parmenter, T., & Welcome to Our Class Research Group (2014). Building an inclusive research team: the importance of team building and skills training. *Journal of Applied Research in Intellectual Disabilities*, 27, 13–22.

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SEARCHING



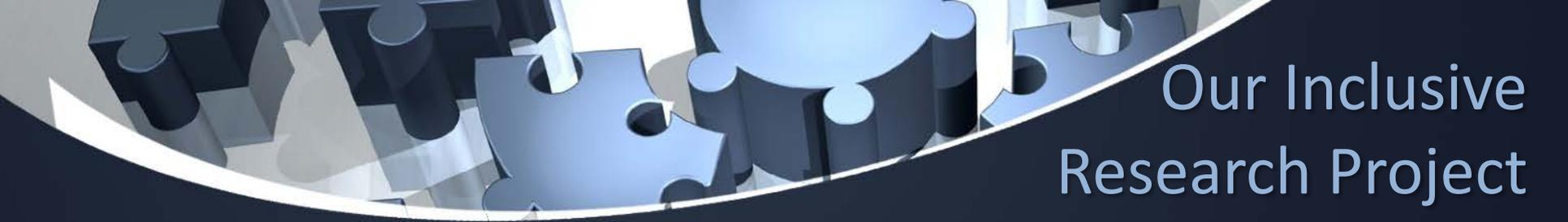
Inclusive articles:

Abell, S., Ashmore, J., Beart, S., Brownley, P., Butcher, A., Clarke, Z., ... Wilson, D. (2007). Including everyone in research: The Burton Street Research Group. *British Journal of Learning Disabilities*, 35, 121-124.

Bane, G., Dooher, M., Flaherty, J., Mahon, A., Donagh, P., Wolfe, M., ... Shannon, S. (2012). Relationships of people with learning disabilities in Ireland. *British Journal of Learning Disabilities*, 40, 109-122.

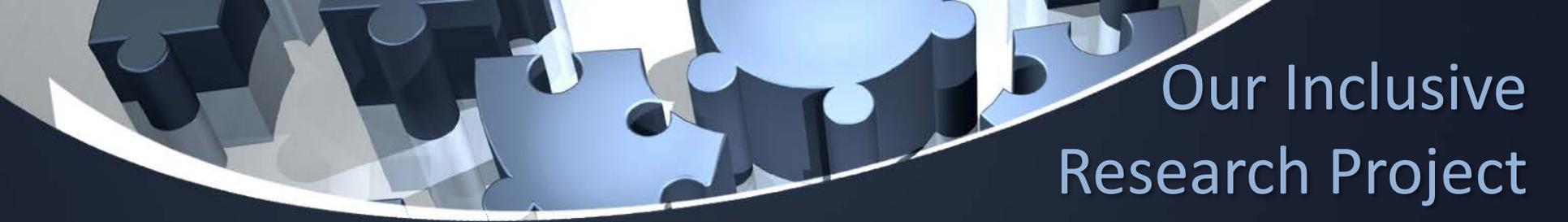
Deguara, M., Jelassi, O., & Callus, A. (2012). How we like to live when we have the chance. *British Journal of Learning Disabilities*, 40, 123-127.

(...)



Our Inclusive Research Project

- The participants of the project are five persons with ID and a clinical psychologist which is also a Ph.D. student.
- The participants with ID attend the occupational center of a day care service provider.
- The **main aims** are
 - increase their autonomy and exercise of choice;
 - develop their cognitive abilities;
 - promote their empowerment.



Our Inclusive Research Project



**The sessions will happen in a
higher education school.**



Instituto Politécnico de Castelo Branco
Escola Superior de Educação



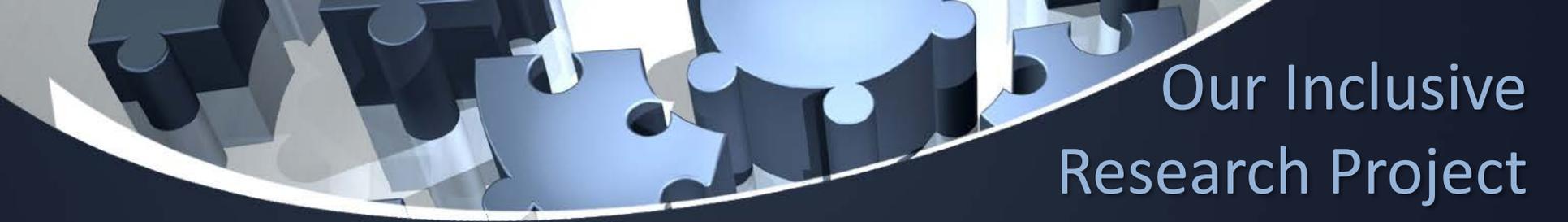
Our Inclusive Research Project

1ST PHASE

- **Inclusive research training**
- explore the importance of research, why we should do that
- learn research skills

2ND PHASE

- **Development of an inclusive research**
- The participants will choose the theme(s) to research
- They will be involved in every steps of the research process

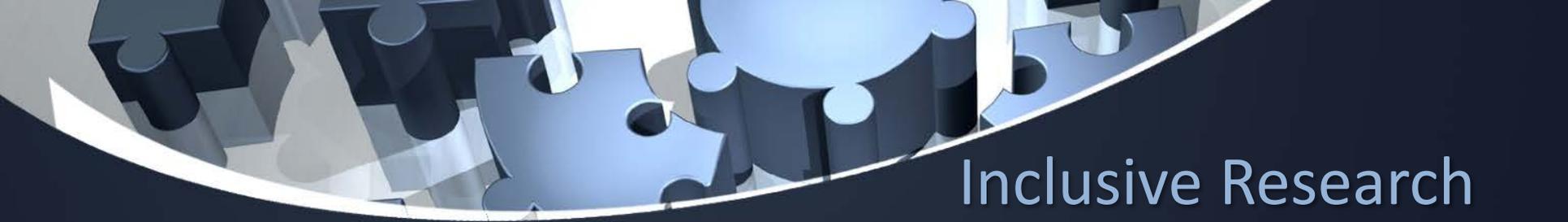


Our Inclusive Research Project

THE FIRST PHASE, THE RESEARCH TRAINING

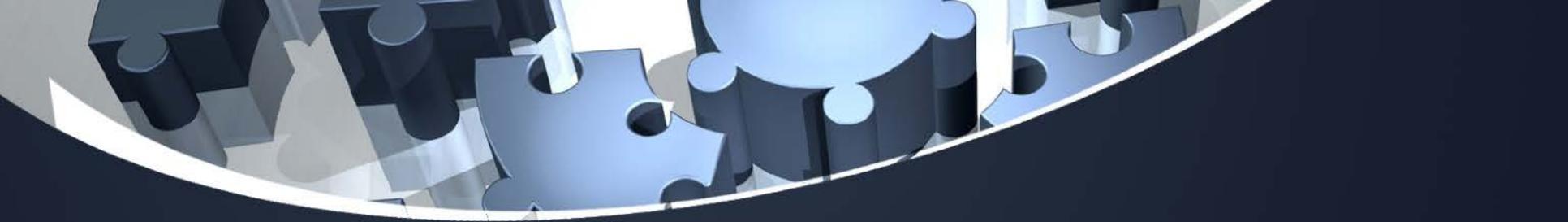
- 12 sessions
- 2 hour/session
- (Some) themes:
 - ✓What is research;
 - ✓The research process and its phases;
 - ✓How to do research – some methods;
 - ✓Ethic principles;
 - ✓Group dynamics.

At the end of all sessions, the participants will do a report and a reflection.



Inclusive Research

- Persons with ID should have the opportunity to active participate in inclusive research projects.
- It is important applying different and active methods, and use accessible language.



OBRIGADA!

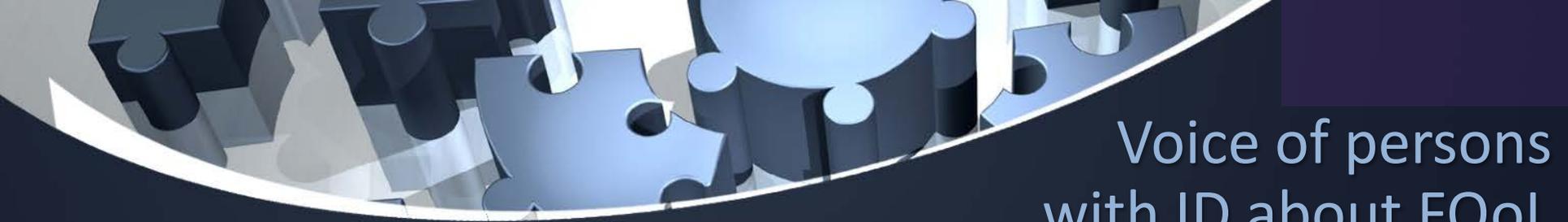
THANK YOU!

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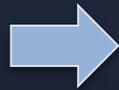






Voice of persons with ID about FQoL

How persons with ID and their relatives evaluate their FQoL?



Understand the perceptions about FQOL of...



... parents of persons with ID



... siblings of persons with ID

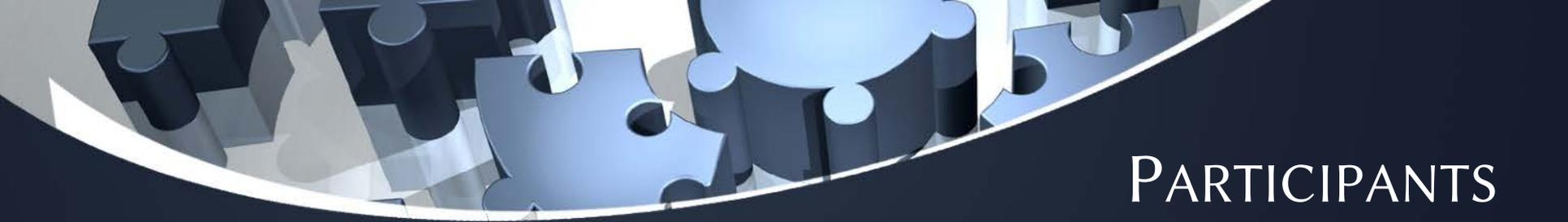


... persons with ID



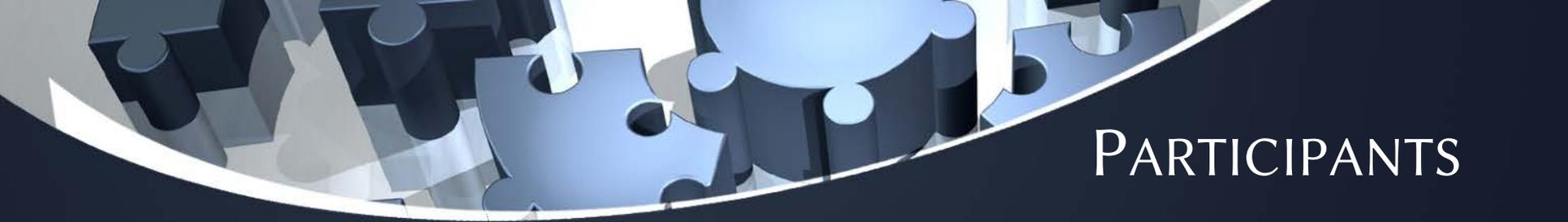
Increase the knowledge about the FQoL of persons with ID





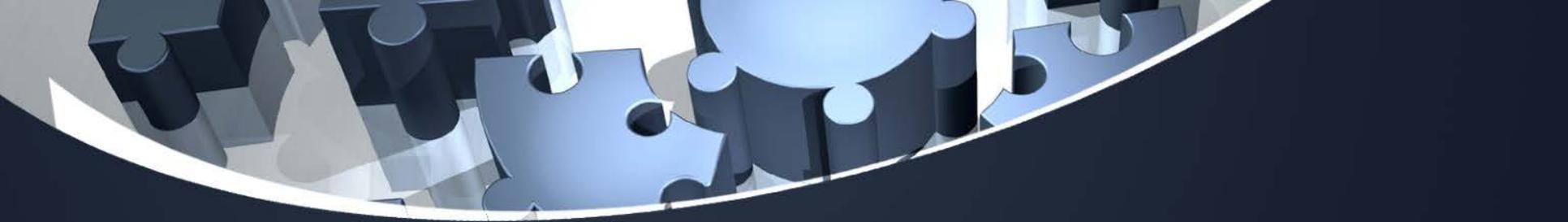
PARTICIPANTS

- 17 persons with ID
- Ages between 16 and 53 years old (mean age = 33.2),
- 9 were women and 8 were men.
- All participants were recruited in three day care programs for persons with ID of a service provider organization for persons with ID, located in a rural region of Portugal.
- At the time of the data collection, all the participants were living with their family (mostly parents) at home.
- The participants were selected by the staff of the organization, taking into account their availability and oral capacity.



PARTICIPANTS

FOCUS GROUP	PARTICIPANT	GENDER	AGE	FOCUS GROUP	PARTICIPANT	GENDER	AGE
A	A1	Female	47	B	B1	Female	20
	A2	Female	53		B2	Male	27
	A3	Male	51		B3	Female	20
	A4	Female	52		B4	Male	20
C	C1	Female	48	D	D1	Female	24
	C2	Female	38		D2	Male	21
	C3	Male	44		D3	Male	16
	C4	Female	44		D4	Male	22
					D5	Male	18



Focus groups technique



express their experiences,
opinions and views, in an open
and comfortable setting.



Focus groups

Groups	Category	Number of participants	Duration
1	Adulthood (38-53 years old)	4	1h 10min
2	Young adulthood (16-27 years old)	4	48min
3	Adulthood (38-53 years old)	4	1h 21min
4	Young adulthood (16-27 years old)	5	53min

☞ The reduced number of participants in each focus group makes it possible that more time is given to each one, as well as more opportunities to talk and better support.