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Universidad Autónoma
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The promotion of independent living in persons with Down syndrome and intellectual disability through the figure of the Personal Assistant

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Objective

The overall aim of the research was to contribute to the academic and practical development of the figure of the personal assistant as an aid for supporting the autonomy and independent living of individuals with ID.

More specifically, its objectives are:

- (a) to identify the perceived needs of support for independent living in individuals with ID and their families.
- (b) to analyze four cases of implementation of the figure of the personal assistant.

Background (I)

- There has been a shift from focusing on medical aspects related to deficit, to dealing with the person in a holistic way, through the bio-psycho-social, ecologic or interactive models (McKenzie, 2013).
- Personal assistants have appeared as a professional figure whose main function is to support and accompany individuals with ID in the process of achieving independent living.



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Background (II)

- Concept of independent living: support for independent living is not only identified as assisting service users in the daily tasks they are unable to perform but, also, as the learning of competencies that will allow them to become more autonomous and independent.
- The independent living movement was born in the 1970s, led by people with physical disabilities who demanded a more accessible and inclusive society (Arnau, 2009).



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Background (III)

- Personal assistants are professionals hired by persons with disabilities in order to provide them with supports that will promote their autonomy and independent living.
- A professional figure that will foster ecological supports within the community, aware of the high impact they may have in enhancing personal autonomy (Claes et al., 2012).



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METHOD – Research Design (2 sub-studies)

1. Descriptive cross-sectorial quantitative design

Perceptions regarding support needs of individuals with ID and their families.

2. Qualitative approach.
Cases study

Analyzed the application of the figure of the personal assistant through a multiple case study design.



SUB-STUDY 1 – Categories of analysis

Subcategory	Definition
User's and family's attitude toward independent living (1)	Desire to engage in activities related to independent living in an autonomous way
Obstacles encountered when trying to initiate independent living projects (2)	Personal and contextual barriers encountered by individuals with ID and their families
Perceived support and service needs (3)	All the supports and services that would be necessary for independent living
Forms of independent living (4)	Preferences considered by people with ID and their families in relation to the start of a more autonomous and independent life



SUB-STUDY 1 – Participants

- The first sub-study surveyed n = 120 youth with ID and 147 relatives

Gender	Number of participants
Male	52
Female	68
Total	120

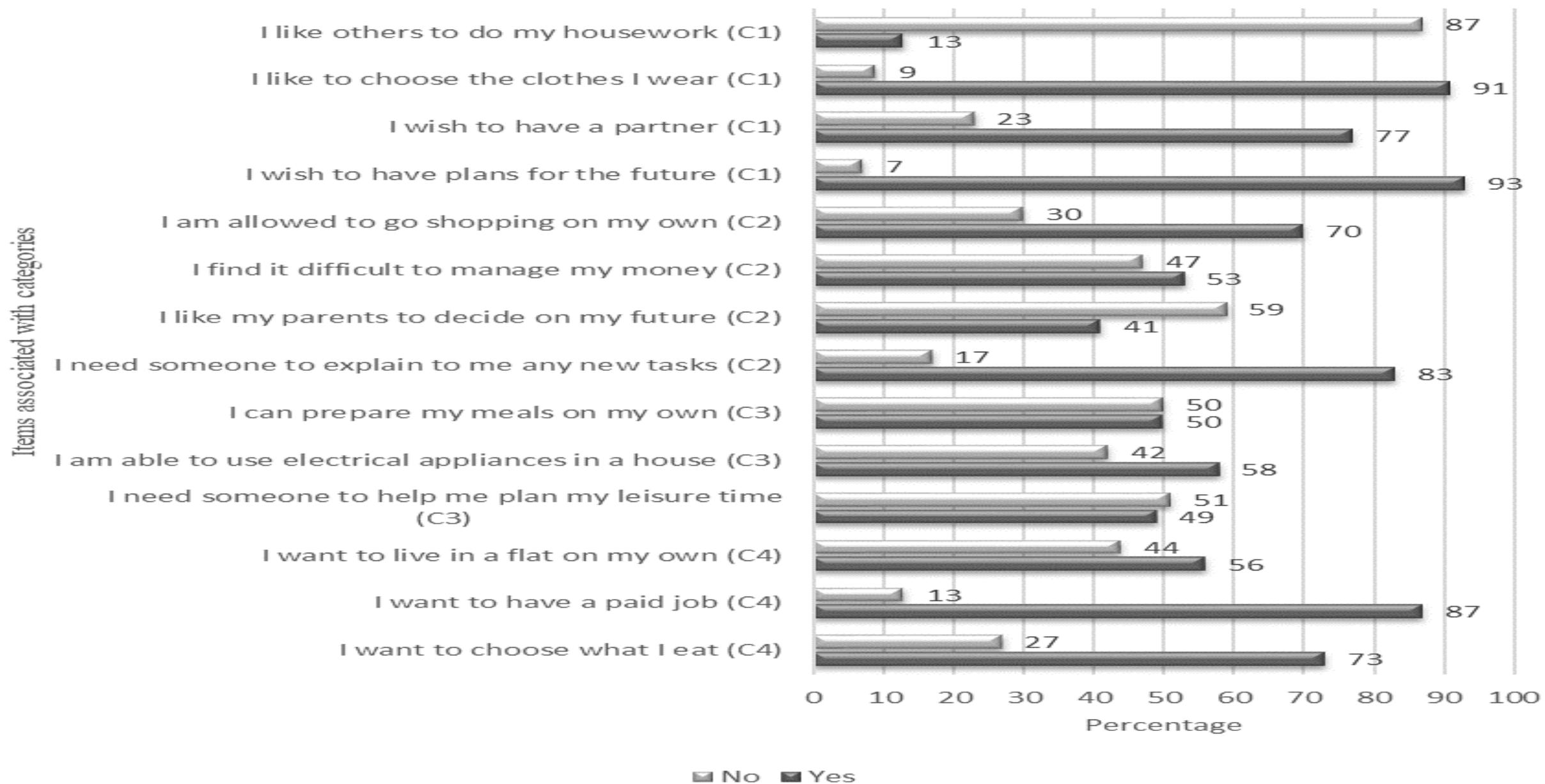
Age	Number of participants
Between 20 and 23	60
Between 24 and 28	45
Between 29 and 33	9
Between 34 and 38	2
Between 39 and 47	4
Total	120

Current occupation	Number of participants
Occupational programmes	26
Job training	39
Employment in an ordinary company	43
Special employment	12
Total	120

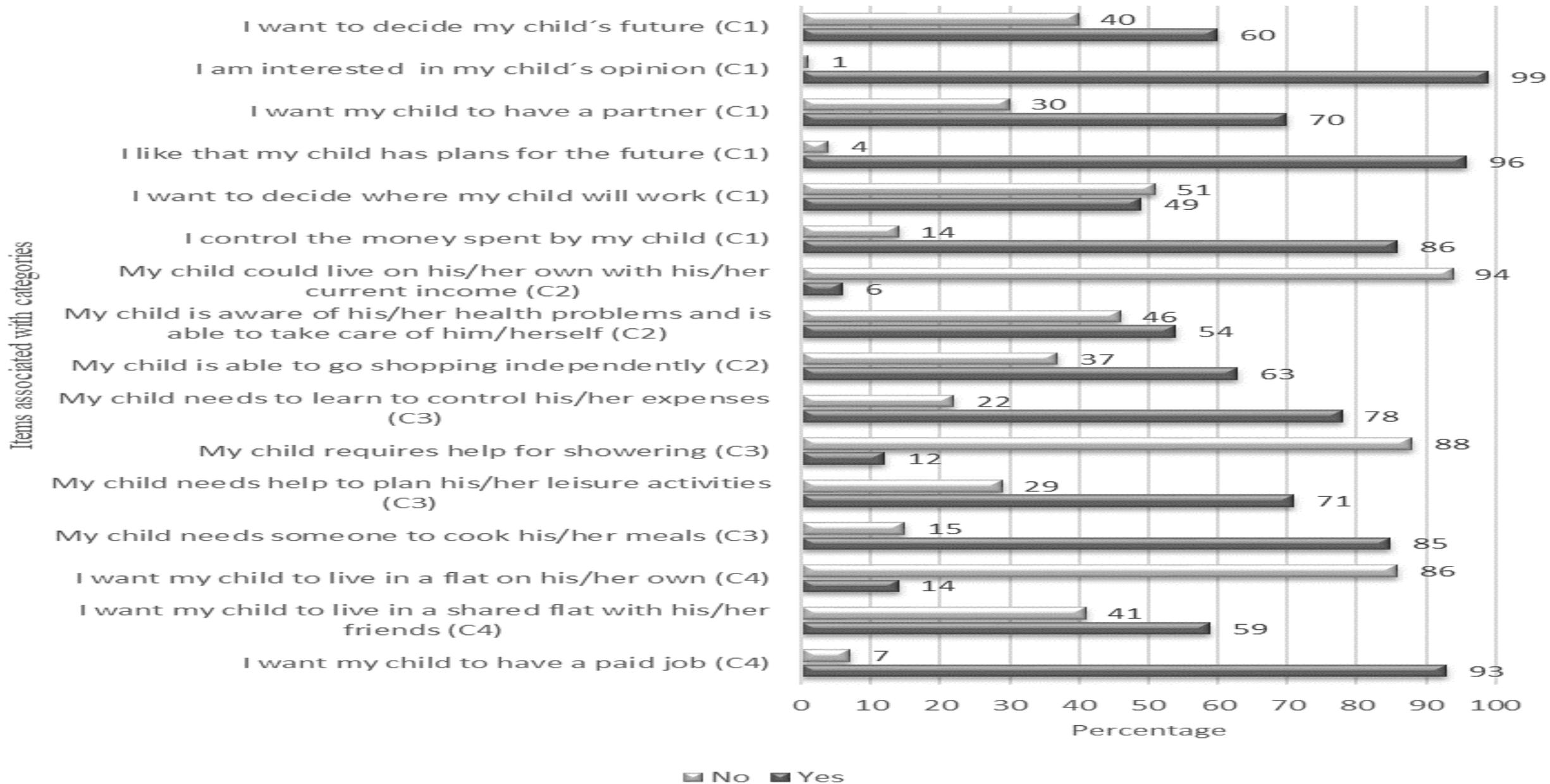
SUB-STUDY 1 – Instruments

- 2 questionnaires:
 - **Persons with ID (QPID)**. This questionnaire has 37 close-coded dichotomous questions, with Yes/No answers. It follows the criteria stated in Freyhoff et al.'s *Make It Simple: European Guidelines for the Production of Easy-to-Read Information for People with Learning Disability* for authors, editors, information providers, translators and other interested persons (1998).
 - **Parents or guardians of persons with ID (QF)**. This questionnaire includes 45 close-coded dichotomous questions, and was self-administered.

Support needs for independent living - QPID Questionnaire (n=120)



Support needs for independent living - QF Questionnaire (n=147)



SUB-STUDY 2 – Categories of analysis

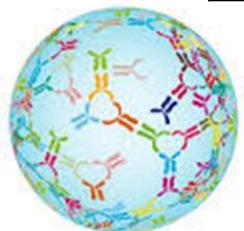
(a) personal hygiene	(f) money management
(b) diet	(g) autonomy at home
(c) trips and commuting	(h) future plans
(d) new learning	(i) leisure
(e) Information and Communication Technologies (ICT) skills	(j) emotional well-being and
	(k) safety



SUB-STUDY 2 – Participants

- The case study of sub-study 2 was conducted on four persons with ID, who presented the following characteristics

Participant	Gender	Age	Current occupation	Type of accommodation	Support needs
1	Male	21	Occupational programme	Family home, with parents and 3 siblings	Pervasive
2	Male	21	Occupational programme	Family home, with parents and 2 siblings	Extensive
3	Male	21	Job training	Family home, with parents and 1 sibling	Limited
4	Female	24	Ordinary employment	Shared accommodation with one person without ID	Limited



SUB-STUDY 2 – Personal Assistants

- 4 personal assistants employed in the study.
- The training received was based on the Personal Assistant's Handbook that was drafted upon completion of sub-study 1.

SUB-STUDY 2 – Techniques and Instruments

- Semi-structured interviews with the participant individuals with ID, their relatives and personal assistants.
- Participant observation in the participants' own natural environments.
- Field journals recorded by the personal assistants.

SUB-STUDY 2 – Case 1. Self-care and personal image

- It was the family that requested the support services.
- The user wished to improve his independence and autonomy related to his dressing habits.
- After four months, in which the personal assistant coordinated the different supports, the user was able to fasten his trousers while observing someone else modelling the task.
- The person with ID valued very highly the support received from a female peer in his occupational programme, even higher than that provided by his supervisors.

SUB-STUDY 2 – Case 2. Managing money and personal finances

- This case focused on a 21 y.o. young male with ID, user of an occupational programme, who demanded support in order to improve his money management.
- The plan was designed by the personal assistant together with the user's occupational programme supervisor, and targeted different environments: the occupational programme, family life -with special participation of the user's siblings- and other natural settings such as shops, restaurants and supermarkets.
- The intervention resulted in an improvement in the set objectives.



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SUB-STUDY 2 – Case 3. Personal planning and organization

- This case centered around a student with ID in an employment training programme who, due to difficulties in following his studies, requested help from his supervisors in the area of personal planning and organization.
- During several weeks, the assistant accompanied the person with ID in his different environments in order to observe any support needs related to planning and organization.
- Personal assistance resulted in better personal planning through the use of the diary, with a positive impact in the user's different environments.

SUB-STUDY 2 – Case 4. Advice for independent living

- In this case, personal assistance was applied to support a 24 year-old-woman with ID who works in a regular paid job.
- It was agreed with the service user that the personal assistant's mission would be to counsel both housemates in order to improve the cohabitation and hence the chances of success of this experience of independent living that had been promoted by the parents.
- Some obstacles were found by the Personal Assistant.



DISCUSSION (I)

- By incorporating the voices of both service users and families, the results of the two sub-studies conducted offer significant contributions to an analysis of the support needs for improving independent living in persons with ID.
- All participants desire a higher degree of autonomy and independence.
- The variety of their support needs is significant.

DISCUSSION (II)

- Families are concerned about their children's future, with 59% of participant families claiming that they would like their children with ID to live with friends while receiving the necessary supports.
- Need to create and implement programmes of personal assistance that will aim at achieving transversal objectives in relation to users' autonomy and independent living.
- The personal assistant is not just necessarily someone who intervenes with direct support to users, but rather someone who develops an awareness of who the users and their natural environments are, and uses this awareness to provide relatives and other professionals with the necessary skills to work toward the plan of increased personal autonomy that has been designed with users in the first place.



KEY COMPETENCES (I)

- (1) Possess a critical knowledge of the different intervention models in ID and their application in different contexts.
- (2) Have a comprehensive understanding of the support networks available to individuals with ID, as well as the different existing services and programmes.
- (3) Be aware of, and have the ability to research, the different resources and opportunities that can be provided by the user's family and closer community.
- (4) Communicate effectively with persons and practitioners of different profiles, such as the users themselves, relatives or support professionals.
- (5) Be able to conduct effective interviews with families and professionals suited to the user's needs.

KEY COMPETENCES (II)

- (6) Show an awareness of the main principles of intervention in the user's natural environments, such as home, workplace or training institutions.
- (7) Reflect on the ethical foundations of personal assistance, and incorporate them in professional practice.
- (8) Show an acquaintance with theories of cognitive, social and affective development of persons with ID, and incorporate their insights to intervention cases.
- (9) Be able to maintain emotional balance while accompanying users in their decision-making process.
- (10) Consider the variety of ways to promote autonomy and independent living in persons with different support needs.

LIMITATIONS AND FUTURE CHALLENGES

The research took place in a very specific context, namely, urban environments, and with largely middle-class families.

The study only surveyed participants who were able to communicate verbally - even with the aid of supports- leaving aside those whose degree of intellectual disability precluded this form of communication.



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