PERSONAL ASSISTANTS IN THE PROMOTION OF INDEPENDENT LIVING FOR PERSONS WITH INTELLECTUAL DISABILITY: A BASIC AND APPLIED INVESTIGATION

Asistencia personal en la promoción de vida independiente para personas con discapacidad intelectual: una investigación básica y aplicada

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Abstract: *Background*: The personal assistant is a support figure aimed at improving the autonomy and independence of persons with intellectual disability, and is coherent with the new models of intervention with such groups. *Method*: Two sub-studies were conducted. The first one, comprising 120 persons with intellectual disability and 147 relatives, was aimed at identifying perceptions on support needs for independent living. The second was a case study with 4 participants who received support from personal assistants. *Results*: In the first sub-study, persons with intellectual disability showed a clear preference for a greater degree of autonomy and self-determination in their life projects. The second one highlights the effect of personal assistance on the

individuals' empowerment and the improvement of their autonomy. *Discussion*: The results are used to suggest a competency profile of the personal assistant, including ten key competencies, and a critical analysis of the most relevant findings is made.

KEY WORDS: intellectual disability; families; personal assistant; autonomy; independent living

RESUMEN: *Planteamiento del problema*: El asistente personal es una figura de apoyo a la mejora de la autonomía y la vida independiente, coherente con los nuevos modelos de intervención con personas con discapacidad intelectual. *Método*: Se desarrollan dos subestudios. El primero cuantitativo, con 120 personas con discapacidad intelectual y 147 familiares, tiene el objetivo de conocer la percepción de las necesidades de apoyo para la vida independiente. La segunda fase es un estudio de casos con 4 participantes, en los que se aplica la figura del asistente personal. *Resultados*: Destaca del primer subestudio la clara disposición de las personas con discapacidad intelectual a tener más autonomía y autodeterminación en sus proyectos de vida. En el segundo subestudio resalta el impacto de la asistencia personal en el empoderamiento y en la mejora de la autonomía. *Conclusiones*: Con base en los resultados, se propone un perfil competencial del asistente personal con diez competencias clave y se realiza un análisis crítico de los hallazgos más relevantes.

PALABRAS CLAVE: discapacidad intelectual; familias; asistente personal; autonomía; vida independiente.

1. Introduction

IMPROVING THE AUTONOMY OF PERSONS WITH INTELLECTUAL DISABILITY (henceforth ID) has been a concern of research and professional practice for a long time. However, in the last decades there has been a paradigm shift as regards the research and intervention approaches and models that address this objective. More specifically, 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). This perspective addresses the improvement of autonomy and independent living of individuals with ID by applying the basic principle of "giving voice" to them, as well as understanding their behavior through the lens of an ecological analysis of their daily interactions. It is, in sum, the model that is most coherent with the figure of the personal assistant, and which provides this research with its conceptual underpinnings.

In recent years, there has been a greater emphasis on the promotion of independent living for people with ID coming from both practitioners and researchers (Ahlstrom and Wadensten, 2011; Egard, 2011; Karin, 2015; Roos, 2009; Schelly, 2008). The gradual increase in life expectancy, together with advances in the recognition of the rights of persons with ID, have influenced the development of supports that serve to enhance their autonomy and promote their independent living. As a result of this

growing concern, 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.

Prior to analyzing the role of personal assistants, the concept of independent living must be discussed. Today, there are many barriers that limit equality of opportunities for persons with ID (Officer and Shakespeare, 2013), which in turn denies them a higher degree of autonomy and a better quality of life (Verdugo, Navas, Gómez and Schalock, 2012). 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). Among the most important milestones in the birth of this movement, are the actions of Ed Roberts, who had developed polio years ago, to further his education at the University of California. After a first refusal from the university, his insistence forced the university to accept him, residing at the university hospital because it was the only place accessible to him. From there, Ed Roberts and other students with disability, a group called "Rolling Quads", developed their actions until they were recognized and supported by through the "Psysically Disabled Students Program" (PDSP) (Oxford and McDonald, 1999). The development of this movement resulted in the gradual opening of different environments to them, as well as transference of some improvements in inclusiveness to other groups, such as individuals with ID. The independent living movement has continued its development to the present, moving towards a model of interdependence and supports to acquire a greater autonomy (White, Simpson, Gonda, Ravesloot and Coble, 2010).

As a result, independent living came to be linked not only to autonomy at home and emancipation, but also to all the policies and provision of supports directed at improving service users' autonomy and overall living conditions (Dollar, Fredrick, Alberto and Luke, 2012). From this point of view, 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. Such skills may of course center around the household and emancipation, but they also extend to other areas of support.

Moreover, it is necessary to give voice to the people with ID and their families in what regards their demands for support for independent living, as shown by research conducted by Jones and Gallus (2016) about families' perception of the fundamental supports needed by their children with ID in order to lead more independent lives. The main key aspects highlighted by respondents were: (a) respect for the opinions of the person and the family, (b) collaboration with families in the process of support for independent living, (c) provision of quality care, (d) supports of indefinite duration and consistent through time, and (e) fostering inclusion in the community. Another study (Soenen, Van Berckealer-Onnes and Scholte, 2016), conducted in Britain, suggested that a high number of individuals with ID that had sought a more independent lifestyle had not found the support of qualified services in their surroundings. The results of both studies highlight the need to create programs that will support individuals not only in narrowly specified areas of intervention, but also in wider spheres, such as autonomy and independent living, which may be present in a variety of contexts.

It is here that the figure of the personal assistant, rooted in evidence-based practice (Schalock, Verdugo and Gómez, 2011) becomes relevant. As defined by the European Network on Independent Living (2013), 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, Van Hove, Vandevelde, Van Loon and Schalock, 2012).

In recent years, several studies have analyzed the factors that contribute to the success of programs that promote the use of personal assistants. As Bexkens (2013) suggests, the first key factor may well be personalizing supports, and hence taking into account the person's characteristics when assessing the need for support. That is why analyzing the perceptions of individuals with ID becomes a critical element in the role of the personal assistant and, more generally, in any research directed at fostering autonomy and independent living. In this respect, personalizing the language assistant's function can have a significant effect on self-determination, one of the dimensions of the model of quality of life (Farmer, Allsoppa and Ferron, 2015; Schelly, 2008; Wang, Schalock, Verdugo and Jenaro, 2010). This is supported by Karin's (2015) qualitative study on the appraisal of personal assistance by individuals with ID, which found that user empowerment is one of the most significant benefits of assistance.

Indeed, the self-determination construct is clearly linked to processes of improvement of autonomy and independent living, understood in the framework provided by the model of individual quality of life (Shogren, Wehmeyer, Palmer, Rifenbark, Little and Todd, 2015). Self-determination involves both the possibility of making decisions in the individual's life, and the ability to develop effective competences that will help in the process of defining goals for his or her life project, as well as selecting the means that can be used to attain them (Shogre and Broussard, 2011). For this reason, as shown by the studies cited before, personal assistants can have a crucial role in improving self-determination in persons with ID (Farmer *et al*., 2015; Karin 2015).

This research has been complemented by other studies that have focused on the competency profile required of personal assistants. In a study conducted on individuals who received support from personal assistants, Roos (2009) found that the values that users ranked more highly in personal assistance were discretion and respect for the objectives of personal autonomy set by themselves. In this sense, a positive rapport between assistants and service users is highly advisable, and hence users should have a say on the choice of their assistants (Egard, 2011). Moreover, in another study, Williams, Ponting, Ford and Rudge (2009) used voluntary recordings to detect key competencies in the relationship between assistants and users. Some of the most relevant ones were: (a) ability to establish a non-directive communication style with the user, (b) ability for active listening, (c) non-verbal communication control, (d) respect for the time required by users to express themselves and share their views, (e) team work skills and the ability to coordinate support networks, and (f) respect for the user's personality.

The overall aim of the research presented in this paper 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 were: (a) to identify the perceived needs of support for independent living in individuals with ID and their families, and (b) to analyze four cases of implementation of the figure of the personal assistant.

2. Method

2.1. *Research Design*

The research was conducted in two phases, through two sub-studies that addressed the research objectives stated above. It was a mixed design, following a basic and quantitative approach for the first phase, and a qualitative one for the second. The first phase concluded with the creation of a Personal Assistant's Handbook, which was used in the implementation and subsequent validation of personal assistance in the second sub-study.

The first sub-study was conducted following a descriptive cross-sectional quantitative design. Hence, it is a non-experimental study, as it seeks to describe existing phenomena, namely, perceptions regarding support needs of individuals with ID and their families. The second sub-study analyzed the application of the figure of the personal assistant through a multiple case study design. This method facilitated an exhaustive assessment of the different experiences (McMillan and Schumacher, 2010), while maintaining an ecological approach (Stake, 2005).

Furthermore, the research followed the APA Ethics Code (2003) as regards ethical practices such as confidentiality, respect for participants, informed consent or participant access to information throughout the research. Finally, especially in the second sub-study, participants were involved in the research design and analysis of results, and were asked to suggest improvements to the Personal Assistant's Handbook in light of their experiences. Overall, we have attempted to conduct an inclusive investigation (Salmon, García Iriarte and Burns, 2017; O'Brien, McConkey and García Iriarte, 2014) in line with an ethical understanding of research.

2.2. *Categories of analysis*

In sub-study 1, the main category of analysis were the perceived needs regarding independent living of youth with ID and their families. Within this general category, previous research (e. g., Fitzgerald, 2010; Navallas and Verdugo, 2009) was used to identify four subcategories (see Table 1):

As regards the assessment of the application of personal assistants in sub-study 2, the main category of analysis was the set of independent living skills that were supported by the assistants. These skills, as applied to the four cases analyzed by the study, were the following: (a) personal hygiene, (b) diet, (c) trips and commutes,

TABLE 1. Categories of analysis of sub-study 1	
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

(d) new learning, (e) Information and Communication Technologies (ICT) skills, (f) money management, (g) autonomy at home, (h) future plans, (i) leisure, (j) emotional well-being and (k) safety.

2.3. *Participants*

The two studies described in this paper were conducted with the voluntary participation of individuals with ID and families in the Autonomous Community of Madrid (Spain). The participants were selected using purposive sampling, and were contacted through a non-profit organization whose aim is to support people with ID. This association conducts its support interventions in an urban environment –Madrid metropolitan area– and targets such areas as training, autonomy development, employment and leisure. In the case of participants who had been recognized as legally incapacitated, express authorization was obtained from their parents or guardians to participate in the investigation.

The first sub-study surveyed n = 120 youth with ID and 147 relatives. Participants with ID had the following characteristics (Tables 2, 3 and 4):

TABLE 2. Gender of participants with ID in sub-study 1	
GENDER	NUMBER OF PARTICIPANTS
Male	52
Female	68
Total	120

TABLE 3. Age of participants with ID in sub-study 1	
AGE	NUMBER OF PARTICIPANTS
Between 20 and 23	60
Between 24 and 28	45

TABLE 3. Age of participants with ID in sub-study 1 (cont.)	
AGE	NUMBER OF PARTICIPANTS
Between 29 and 33	9
Between 34 and 38	2
Between 39 and 47	4
Total	120

TABLE 4. Occupation of participants with ID in sub-study 1	
Current occupation	Number of participants
Occupational programmes	26
Job training	39
Employment in an ordinary company	43
Special employment	12
Total	120

In relation to participants' accommodation, 25 persons with ID live with at least one parent, 84 with at least one parent and one or more siblings, 8 with relatives other than their parents, 2 in supervised homes together with other persons with ID, and 1 lives in shared accommodation with a person without ID.

As regards the severity levels of intellectual disability of participants, 12 of them needed pervasive support, 14 extensive support, 55 limited and 39 intermittent. These needs were evaluated by the individuals' professional counsellors and followed the AAIDD's (2010) support scale. Turning to the 147 relatives who participated in the first sub-study, the survey was answered by 68 fathers/male guardians and 79 mothers/female guardians. The most common age range among relatives was 52-57, as can be seen in Table 5:

TABLE 5. Age of relatives who participated in sub-study 1	
AGE	NUMBER OF PARTICIPANTS
Between 40 and 45	2
Between 46 and 51	13
Between 52 and 57	74
Between 58 and 63	39
Between 64 and 69	14
Between 70 and 75	5
Total	147

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

It must be noted that all of the participants were able to communicate orally, although Participant 1 required Augmentative and Alternative Communication (AAC).

TABLE 6. Characteristics of participants in case study 2					
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 subling	Limited
4	Female	24	Ordinary employment	Shared accommodation with one person without ID	Limited

On the other hand, the four personal assistants employed in the study, who belong to the organization that supports the participants, received training based on the Personal Assistant's Handbook that was drafted upon completion of sub-study 1. Following the Handbook's structure, this training included the following modules: (a) the concept of personal assistance, (b) principles of intervention in personal assistance, (c) areas of support, and (d) guidelines for an effective rapport and communication between the assistant and the person with ID.

The training lasted 8 hours, and included instructional strategies such as teacher presentation, case resolution and practical debates. It was led by the research team, who also coordinated the process of implementing and assessing the four cases of personal assistance.

As regards the background of the 4 professionals who participated in the training, 1 had a degree in Pedagogy, 2 in Psychology and 1 in Teacher Training. Following Schelly (2008), a specific personal assistant was suggested to each person with ID, but it was them who decided who their assistant would be.

2.4. *Techniques and Instruments*

In the first sub-study, the following instruments were used:
- A survey study, with two questionnaires:
  – Persons with ID (QPID).

This questionnaire consisted of 37 close-coded dichotomous questions, with Yes/No answers. It followed 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). The questionnaire was administered with the aid of a professional, who, in 9 cases, read the questions to help the participants' comprehension.

– Parents or guardians of persons with ID (QF).

This questionnaire included 45 close-coded dichotomous questions, and was self-administered.

Both instruments were validated by five experts, who assessed each item for clarity and relevance. The questionnaire was also tested on 10 persons with ID and 10 relatives. As a result, the following changes were implemented: (a) the order of some items that appeared to be similar was modified, in order to avoid a feeling of repetition, (b) examples were provided in order to clarify some of the items, and c) the language of some questions that appeared too complex was simplified. Furthermore, Cronbach's alpha coefficient was used to test the reliability of the two questionnaire versions, obtaining scores of 0.865 for the one addressed to individuals with ID, and 0.807 for the version answered by relatives. Hence, it can be said that both questionnaires showed a high reliability.

In the case study corresponding to sub-study 2, the following techniques and instruments were used:
- 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.

In what regards the application of the personal assistant in the four cases, it followed the Handbook put together after the first sub-study. In all cases, the interventions had an approximate duration of four months.

2.5. *Data Collection*

The questionnaire and related materials were sent to the participants through their program tutors or support figures. In addition to the questionnaire, a brief description of the aims of the investigation, and a statement on voluntary participation and data confidentiality were included. Moreover, the tutors or support figures informed participants verbally about the above, as well as the procedure to answer the questionnaire. Whenever specific professional support was needed to apply the questionnaire –professionals reading and explaining questionnaire items to respondents– authorization was requested from the participants' families. The completed questionnaires were collected within a period of two weeks from the date they were sent to the persons with ID.

As to the second sub-study, data were collected during the 4-month period of application of personal assistance, but also in the three weeks following the end of assistance, by means of interviews with the participants with ID, the families and the personal assistants. Whereas the persons with ID were interviewed in their own homes, the interviews with the personal assistants were conducted in the association that supports the persons with ID. In both cases, the duration of the interviews was between 40 and 60 minutes.

2.6. *Data Analysis*

Data obtained from sub-study 1 were imported to the programs, *Statistical Package for the Social Sciences (SPSS 21.0)*, which was used to conduct a descriptive analysis of frequencies and percentages. Moreover, the Chi-Square ($\chi2$) test was applied on selected items that were chosen in order to assess the possible relevance of the support programmes or service used by individuals with ID in the responses given. These tests allowed us to analyze the four subcategories identified in sub-study 1.

In turn, data collected in the second sub-study were analyzed using content analysis. The following procedure was followed: (1) transcribing the data obtained from interviews, participant observation records and field journals, (2) incorporating it to the software, Atlas.ti, (3) codifying the data by grouping it by cases and skills developed by personal assistance, and (4) using the software to interpret the codified data. Moreover, the variety of data sources and the techniques employed to obtain them facilitated the triangulation of data in order to assure the validity of the research conducted. Given the limited space available, only the most relevant findings are presented here.

3. Results

3.1. *Sub-Study 1. Support Needs for Independent Living*

This section discusses the main findings of the survey conducted on persons with ID (QPID) and families (CF) (Figures 1 and 2). With the aim of presenting the results in a clear and straightforward way, only the results of the most relevant items for the implementation of personal assistance are described.
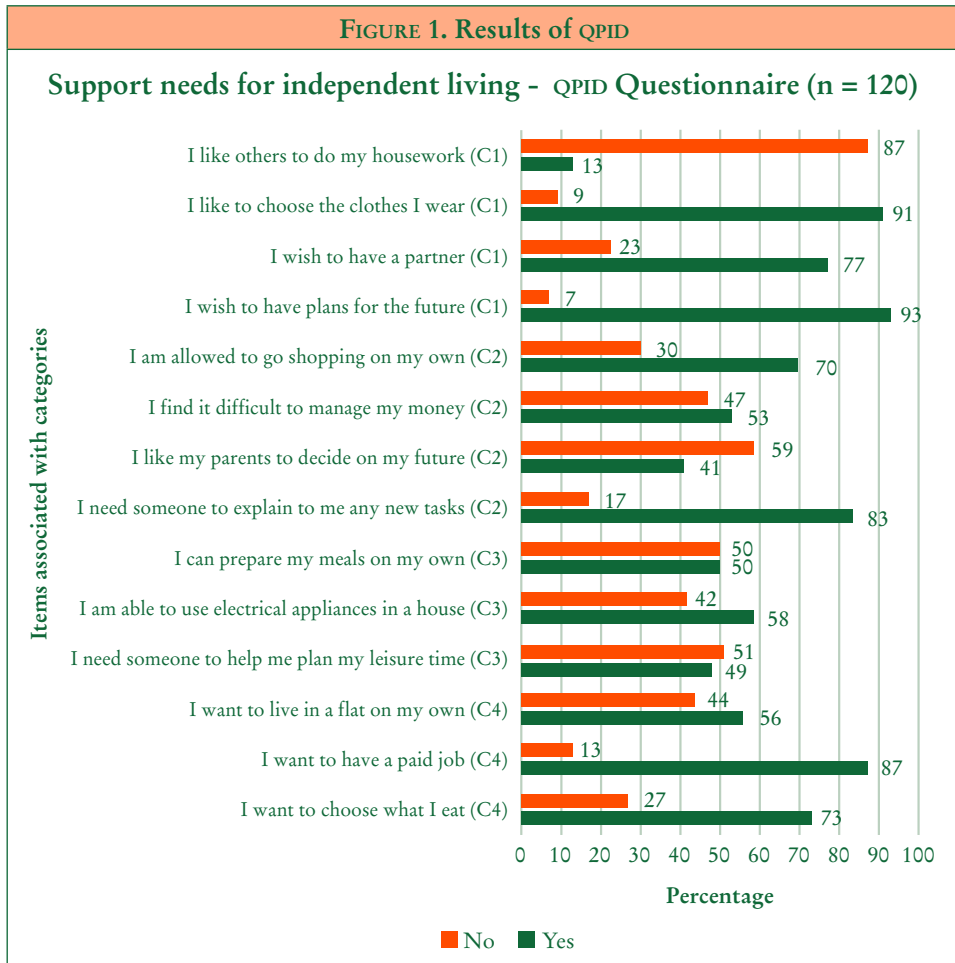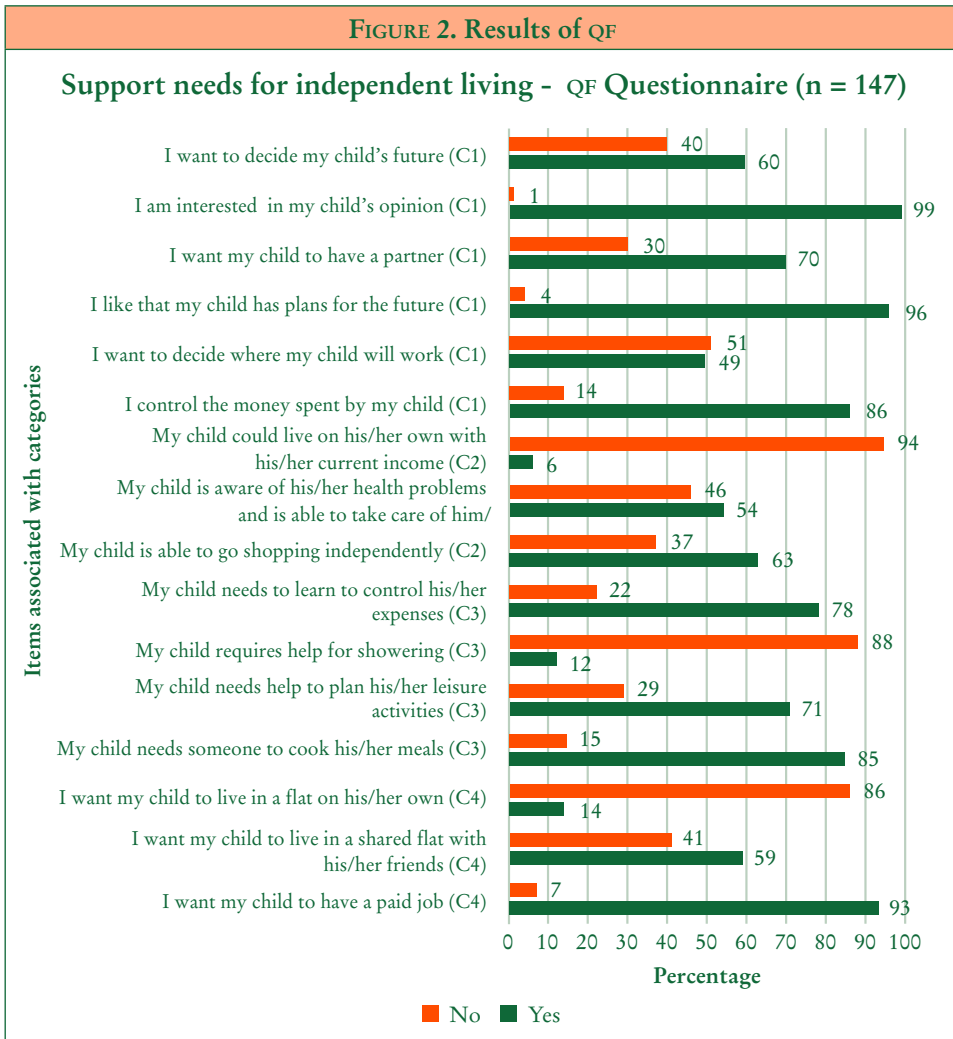

FIGURE 1. Results of QPID

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

FIGURE 2. Results of QF

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

The Chi-square (χ2) test was applied to selected items in order to analyze a possible dependence of the responses on other variables. For instance, the item "I want my child to have a paid job" (C4) showed a statistically significant relationship with the current occupation of the individuals with ID ($p < 0.01$). It was found that, as children have greater support needs and therefore enter occupational programmes, parents are less concerned about them securing paid employment. In fact, 75% of parents who answered "no" to this question have children with ID in occupational programmes. Something similar occurs with the item, "My child requires help for showering", where a statistically significant relationship ($p < 0.01$) was also found, as 72% of parents who answered "yes" have children in occupational programmes.

3.2. *Sub-Study 2. Case Study on the Figure of the Personal Assistant*

3.2.1. Case 1. Self-care and personal image

This intervention involved the personal assistant of a twenty-one-year-old man with ID, pervasive support needs, and who is a user of an occupational programme. In this case, it was the family that requested the support services. Interviews were conducted with the user, his family at home, his occupational programme supervisor, and the mediator in the leisure programme he participates in. The personal assistant accompanied the user in his daily routines for several days. The user wished to improve his independence and autonomy as regards his dressing habits. As a result, the personal assistant designed a sequence for task acquisition based on Ghaleb's research (2015), targeting the user's occupational and family environments, and which set the goal of helping him learn to fasten his shirts and trousers. 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.

It is worth noting that, when assessing the process, 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. This result reinforces the principle that the assistant's support must take place within the user's ecological and natural context, and rely on those individuals who are most meaningful for his or her learning. Furthermore, when interviewed, the user's parents claimed to have noticed a change of attitude in their son, who showed an increased willingness to engage in autonomous self-care tasks. In fact, the personal assistant's intervention had a positive impact on the categories personal hygiene, new learning, autonomy at home and safety.

3.2.2. Case 2. Managing money and personal finances

This case focused on a young male with ID aged 21, user of an occupational programme, who demanded support in order to improve his money management. When interviewed, he stressed the importance of family, and especially siblings, in his daily life. This claim was confirmed in an interview with his family, who agreed with the assistant on the need for a plan to improve their son's money management skills. This plan was meant to be functional and adapted to the person's needs (Henderson, 2009), and was based on a thorough analysis of his money management habits and skills prior to the intervention.

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. In the user's own words, "I have enjoyed being able to better manage my money; it makes me feel good inside"; "I believe that I am not yet able to fully manage my money; there are

still some areas that I need to work on with my assistant, if she wants to"; "I used to be afraid of going to shops for fear of being tricked; now I have a better idea of what change I'll be given, or whether I'm giving a lot or little money". The intervention contributed to the following areas: new learning, ICT skills, money management, future plans, emotional well-being and safety.

3.2.3. Case 3. Personal planning and organization

This case centered around a student with ID in an employment training programme who, owing to difficulties in following his studies, requested help from his supervisors in the area of personal planning and organization. The specific features of this case made us consider it as suitable for our research on personal assistants. 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. In agreement with the student, the assistant designed a plan to be implemented in the training programme, family life and in the leisure programme. The main aim of this intervention was to improve the person's use of his diary and, as a result, the development of his executive functions, of crucial significance in personal planning (Sastre-Riba, Fonseca-Pedrero and Poch-Olivé, 2015). Personal assistance resulted in better personal planning through the use of the diary, with a positive impact in the user's different environments. The plan contributed to the following categories: trips and commutes, new learning, future plans, leisure, and emotional well-being.

3.2.4. 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. At the time of the investigation, she had been sharing a flat for one year with a female student without ID, who accepted to live with her, and attend to her needs, in exchange for free rent. It was this student who requested help in order to improve her relationship with the woman with ID and be better equipped to support her. 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. Specific advice, which was offered during interviews with the person with ID, her housemate and the parents, focused on three areas: (a) designing specific objectives of improvement of autonomy and independent living, (b) reducing the amount of support offered by the housemate as the user attained higher degrees of autonomy, and (c) establishing personal spaces for both. The assistant monitored the situation, improving daily coexistence at early stages of the process, but finding significant obstacles for the improvements to consolidate in the medium run.

After evaluating the case, it was found that some of the obstacles that may have mitigated the impact of the personal assistant's action were: (a) the fact that the experience of independent living was fostered primarily by the user's parents, and did not follow her own request, and (b) behavioral problems in the person with ID, which required their own supports at the therapeutic level. The case study, which was concerned with the areas, diet, autonomy at home, future plans, emotional well-being, and safety, is therefore also interesting for an analysis of those factors which may negatively affect the implementation of personal assistance.

4. Discussion

As we have seen, 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. These findings can, in turn, serve to improve the professional practice of personal assistants.

The first sub-study highlights the readiness of individuals with ID to enjoy a greater autonomy and design their own life projects. This is shown in the answers to the items, "I like others to do my housework", with a high 87% of negative responses, and "I wish to have plans for the future", with which 93% of respondents agreed. People, notwithstanding their support needs, wish to have a greater degree of autonomy and to be able to make important decisions in their lives. This result supports the need for personal assistance to go beyond the idea of "doing what users cannot do", and rather, develop in them the necessary skills to gradually become more autonomous (Shogren *et al*., 2015).

It is interesting to compare these responses to the ones obtained in the CF questionnaire applied to families. The responses appear to contradict each other, but this contradiction may reflect a compatible set of opinions, attitudes and assumptions. In this sense, almost all participant families claimed to be interested in their children's opinions, like them to have future plans but, on the other hand, 40% would like to be the ones deciding on their future. In other words, they desire a greater autonomy and self-determination for their children, but also to keep controlling their future. Such attitudes show the complex range of feelings that may be present in parents of adult individuals with ID. Indeed, seeing the action of the personal assistant as a loss of control over their children can generate opposition to certain interventions or reactions that could hinder the process of increased autonomy and independent living in their children with ID. In this sense, the findings of this study are consistent with those of Jones and Gallus (2016) about the relevance of family collaboration in the process. In addition, they suggest that one of the main functions of the personal assistant is to gain the user's family's trust, respecting its voice as a key agent in the development of the person with ID, and empowering it in the decision-making process. It is significant that participants with ID value the role of their families in decision-making, as can be seen in the responses to the item, "I like my parents to decide on my future".

If all participants desire a higher degree of autonomy and independence, the variety of their support needs is significant, as revealed by both the individuals with ID and their families. This means that, even if intervention must necessarily be guided by a number of generic competencies and common principles of professional practice, it must also be wholly tailored to each user. Furthermore, the second sub-study also reveals a divergence in the users' support needs, as each case required personal assistance in very different areas, such as independent living at home, personal planning, self-care or money management. Thus, this principle of intervention is consistent with Bexkens's (2013) research to the effect that assistants must respect the user's decision-making process with respect to the objectives of autonomy improvement, which are set with the collaboration of family and other relevant figures. Furthermore, this case study proves that, in the participants' opinion, personal assistance fosters a greater degree of empowerment (Karin, 2015).

In what regards the forms of independent life described by persons with ID and their families, it was found that employment is a vehicle for accessing opportunities of improvement and therefore enjoying a more autonomous life, as confirmed by a great majority of participants. However, families also feel that, even when employed, their children will find it difficult to become emancipated. Indeed, low salaries are one of the main obstacles to the effective emancipation of adults with ID (Izuzquiza and Rodríguez Herrero, 2016). Moreover, 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. In this sense, the fourth case discussed above highlighted the importance of a process of emancipation that is driven and demanded by the individual with ID rather than predominantly by the family or professional environment, for the latter cases seem to entail a higher probability of failure.

The second part of the research, conducted through a number of case studies, also justifies the need to create and implement programmes of personal assistance that will aim at achieving transversal objectives in relation to users' autonomy and independent living. For it is hard to see such objectives reflected in the agendas of the individualized programmes designed by services whose scope of action may be too narrow. Hence, there is a need for an organizational change that will place the emphasis on the user rather than on the different fields of intervention (Schalock and Verdugo, 2013). This change must come hand in hand with the implementation of professional figures such as the personal assistant, with the role of coordinating the different supports received by the person with ID. Indeed, the case study conducted has shown how 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.

This new role brings with it a difficulty, namely, managing the variety of challenges that can be encountered by the personal assistant when supporting different individuals with ID. At the same time, we believe that assistance must be evidence-based

(Schalock *et al.*, 2011). Practitioners cannot master all the techniques and be knowledgeable of the results of research coming from a wide range of fields; however, they must have a scientific attitude that will lead them to seek evidence and work with other practitioners in the design of intervention plans. This has been the approach in the four cases of application of personal assistance discussed above, contributing to more rigorous interventions. Moreover, the results of this research suggest that programmes of personal assistance could gain from being coordinated by practitioners in line with these values, principles and competences.

When defining such as complex and multi-dimensional professional profile, it is a major challenge to select the specific competences that will help clarify the personal assistant's role. Building on the work of Williams *et al.* (2009) and the findings presented here, especially those in relation to the application and assessment of personal assistants in the case study, we propose the following ten key competencies for this professional figure:

(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.
(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.

In sum, we believe that this competency profile can aid the design of programmes aimed at training professionals from the Social and Health sciences to work as personal assistants.

While this study has attempted to achieve a broad scope that would include both the perception of the persons with ID and their families, as well as applied research in the form of a case study, there are some limitations in the research design that should nevertheless be highlighted. The first one is the fact that the research took place in a very specific context, namely, urban environments, and with largely middle-class

families. This means that, while the results obtained from this investigation may be helpful to interpret similar scenarios in other Western countries, they could fail to shed light on users or families from different socio-economic backgrounds. A second limitation is that 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.

In any case, we believe that this investigation can contribute to the field by opening new lines of research on the figure of the personal assistant, such as their own perception of the assistance process, the validation of training programmes following the competency profile outlined above, or an analysis of personal assistants' support with multiple disabilities and serious communication difficulties. Furthermore, it makes a practical contribution to one of the challenges faced by support organizations today, namely, becoming institutions whose ultimate goal is to support persons with ID by considering them integrally and paying close attention to the effect on their quality of life of the different natural environments where their daily interactions take place.

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