

elSSN: 1989-9742 © SIPS. DOI: 10.7179/PSRI_2020.35.10 http://recyt.fecyt.es/index.php/PSRI/ Versión en español: https://recyt.fecyt.es/index.php/PSRI/article/view/73999/47960

PERSONALIZED SUPPORT FOR PEOPLE WITH INTELLECTUAL DISABILITIES: FUNCTIONS AND TRAINING OF SOCIO-EDUCATIONAL PROFESSIONALS FOR SOCIAL INCLUSION

EL APOYO PERSONALIZADO A PERSONAS CON DISCAPACIDAD INTELECTUAL: FUNCIONES Y FORMACIÓN DE LOS PROFESIONALES SOCIOEDUCATIVOS PARA LA INCLUSIÓN SOCIAL

O APOIO PERSONALIZADO A PESSOAS COM DEFICIÊNCIA INTELECTUAL: FUNÇÕES E FORMAÇÕES DE PROFISSIONAIS SOCIOEDUCATIVOS PARA A INCLUSÃO SOCIAL

Maria PALLISERA DÍAZ Universidad de Girona

> Received date: 29.VIII.2019 Reviewed date: 21.IX.2019 Accepted date: 26.XI.2019

KEY WORDS:

professional functions personalization people with intellectual disabilities training of professionals ABSTRACT: The transformation of the institutional model of care for people with intellectual disabilities to the community-based and inclusive model generates new professional roles and poses challenges related to their training. The objectives of the research were: to deepen the role of professionals who offer support to people with intellectual disabilities from the perspective of personalization and the rights model; and establish the training priorities that enhance the development of this role. Qualitative research was developed based on interviews that were applied to 12 professionals selected for developing good support practices. The analysis was carried out through thematic content analysis. According to the participants, promoting social inclusion and connections of people with disabilities requires completely personalized support formulas and correctly managing the partnership with community agents, where the socio-educational work scenario is established. Regarding training, the participants defended the need to base the training on the person-centered model, and on basic values of the educational relationship based on respect, trust and confidentiality. The importance of having the testimony and experience of people with disabilities in the training processes was also indicated. From the study carried out, there is a need to involve in the transformation of the support to the organization as a whole, promoting training activities that incorporate

CONTACT WITH THE AUTHORS

MARIA PALLISERA DÍAZ. E-mail: maria.pallisera@udg.edu

the rights model to the perspective of disability, and to transfer the scenario of support to the community. Concerning the training, professional competencies to evaluate community spaces and establish social connections that contribute to enrich the social relationships of people with disabilities should be strengthened.

PALABRAS CLAVE:

funciones
profesionales
personalización
personas con
discapacidad
intelectual
formación de
profesionales
de la acción
socioeducativa

RESUMEN: La transformación del modelo institucional de atención a personas con discapacidad intelectual al modelo basado en la comunidad e inclusivo genera nuevos roles profesionales y plantea retos relacionados con su formación. Los objetivos de la investigación eran dos: profundizar en el rol de los profesionales que ofrecen apoyo a personas con discapacidad intelectual desde la perspectiva de la personalización y el modelo de derechos; y establecer las prioridades formativas que potencien el desarrollo de este rol. Se desarrolló una investigación cualitativa basada en entrevistas que se aplicaron a 12 profesionales seleccionados por desarrollar buenas prácticas de apoyo. El análisis se realizó mediante análisis de contenido temático. Según los participantes, potenciar la inclusión social y las conexiones de las personas con discapacidad requiere fórmulas de apoyo completamente personalizadas y gestionar correctamente el partenariado con agentes de la comunidad, donde se establece el escenario de trabajo socioeducativo. En cuanto a la formación, los participantes defienden la necesidad de fundamentar la formación en el modelo centrado en la persona, y en valores básicos de la relación educativa basados en con el respeto, la confianza y la confidencialidad. También se indica la importancia de contar con el testimonio y experiencia de personas con discapacidad en los procesos formativos. Del estudio realizado se deriva la necesidad de implicar en la transformación de los apoyos al conjunto de la organización, potenciando para ello acciones formativas que incorporen el modelo de derechos a la perspectiva de la discapacidad, y a trasladar el escenario de apoyo a la comunidad. Desde la formación se deben potenciar las competencias profesionales necesarias para evaluar los espacios comunitarios y establecer conexiones sociales que contribuyan a enriquecer las relaciones sociales de las personas con discapacidad.

PALAVRAS-CHAVE:

funções profissionais personalização pessoas com deficiência intelectual formação de profissionais da ação socioeducativa RESUMO: A transformação do modelo institucional de atenção a pessoas com deficiência intelectual para um modelo baseado na comunidade e inclusão ocasiona novas funções profissionais e desafios relacionados à sua formação. A pesquisa apresentou dois objetivos: aprofundar a questão do papel destes profissionais que oferecem apoio a pessoas com deficiência intelectual desde a perspectiva da personalização e do modelo de direitos; e estabelecer prioridades formativas que potenciem o desenvolvimento desta função. Desenvolveu-se uma pesquisa qualitativa baseada em entrevistas que foram aplicadas a 12 profissionais selecionados para desenvolver boas práticas de apoio. A análise foi realizada mediante análise de conteúdo temática. Segundo os participantes, potenciar a inclusão social e a conexão de pessoas com deficiência requer fórmulas de apoio completamente personalizadas e gerir corretamente a parceria com agentes da comunidade, na qual se estabelece o cenário de trabalho socioeducativo. Quanto à formação, os participantes defendem a necessidade de fundamentar a formação no modelo centrado na pessoa, e em valores básicos da relação educativa baseados no respeito, confiança e confidencialidade. Também se destaca a importância de contar com o testemunho e experiência de pessoas com deficiência nos processos formativos. A partir do estudo realizado, evidenciou-se a necessidade de um maior comprometimento na transformação dos apoios ao conjunto da organização, maximizar ações formativas que incorporem o modelo de direitos à perspectiva da deficiência, bem como transladar o cenário de apoio à comunidade. Desde a formação, deve-se potencializar as competências profissionais necessárias para avaliar os espaços comunitários e estabelecer conexões sociais que contribuam para o enriquecimento das relações sociais das pessoas com deficiência.

1. Introduction

Attention to people with intellectual disabilities has traditionally been determined in recent decades by organizing social care based on institutional approaches that have given users little control and have not sought personalized solutions (Duffy, 2011). The basis of this model is that users are passive recipients of the services and that professionals know what care they need, attention that is organized and offered in an institutional environment. The institutional model began to transform into community models a few decades ago, beginning in the Anglo-Saxon context, due to the

incorporation of the social model in the conceptualization of disability that prioritizes the organization of support in inclusive contexts (Mansell and Beadle-Brown 2010). However, although the presence of people with disabilities in the community has increased, along with the progressive incorporation of person-centered approaches, little progress has been made in increasing the participation of people with intellectual disabilities in the community, the neighborhood and in society in general (Bigby, Anderson and Cameron 2018). People with intellectual disabilities (ID) continue to have fewer social connections than the general population and other groups of people with

other disabilities (McCausland, McCallion, Cleary and McCarron, 2016). The support professionals seems to play an important role in creating opportunities to increase the social opportunities of people with ID; When professionals offer more attention to people, they develop more community activities and receive support to establish social ties (Amado, Stancliffe, McCarron, and McCallion, 2013; Verdonshot, de Witte, Reichrath, Buntinx and Curfs, 2009).

The Convention on the Rights of Persons with Disabilities (United Nations 2006) constitutes a turning point not only in the vision of people with disabilities as subjects of rights, but also in raising the need to distribute support taking into account the needs and requests of each person, based on the right to individual decision making. Similarly, the European Strategy on Disability 2010-2020 (European Commission, 2010) underlines the promotion of participation and accessibility, among others, as areas of action, pointing out the need to promote the transition from institutional assistance models to community ones. With this, the need to rethink the way of distributing support is underlined, both from an organizational perspective and from the action of professionals responsible for socio-educational action. That is to say, the concept of more personalized social services that enhance social inclusion in all its dimensions suggests new roles for users and professionals and is based on a change in the relationships between policymakers and consumers of the services (Jacobs et al, 2013, Moriarty, Manthorpe and Cornes, 2014).

Spicker (2013) introduces three interpretations of the concept of personalization: the first refers to individualized evaluation and responses (the idea of "tailor-made" services); the second is based on the expression of user preferences, rather than an evaluation process. Here, the user's choice, their demands and preferences, acquire a preponderant role. The third model tries to reconcile professionals and users so that they work together in the management of risks and resources. In the three models there is a transformation of the traditional service distribution model based on a vertical relationship between organization-professionals and users, towards a model that has the person at the center and is oriented as a result the decisions this person makes. Although personalization can be criticized as being an individualistic philosophy, based on neoliberal approaches that place the "user" as an isolated individual and autonomous consumer (Williams, Porter and Marriott, 2014), authors such as Houston (2010) insist on the need to go beyond this conception and to recognize the value of social connection, and the interaction of the environment in the configuration and construction of personal projects. The personalization fits, according to different authors (Sowerby, 2010), in the objectives of the professionals that are encompassed in the socio-educational intervention, among them the professionals of social education.

The new perspectives are incorporated into the social policies of different countries by configuring service / support models that tend towards or seek control by the person. Sowerby (2010) indicates that offering personalized support requires fundamental changes in the welfare system. It requires a transformation of the system at different levels: rebalancing objectives through the support of people so they can live the life they want; new financing and decision-making structures, openness regarding resources and opportunities, new partnerships with people who want support, and a wider and more flexible range of local / community options to choose from.

This transformation leads to a rethink of the role of support professionals. The professionals do not exercise their action within the framework of institutions and in group contexts, but rather, different social spaces (leisure centers, cafeterias, civic centers, training centers, the person's own home) are configured as new scenarios to implement personalized socio-educational actions. Social inclusion in its different dimensions (labor, relational, community participation, etc.) generates new, ambitious intervention objectives. Therefore, new professional functions are configured related to strengthening the connection with community spaces (Duggan and Linehan, 2013) and the domain of competences linked to the analysis of community contexts to identify sources of support and the design of strategies that allow people with disabilities to expand their natural support network (García Iriarte, Stockdale, McConkey and Keogh, 2016). However, rethinking the contexts, objectives and methodologies is not an easy task, but in fact rather a challenge for support professionals. As commented by García Iriarte, Stockdale, Mc-Conkey and Keogh (2016), the Convention on the Rights of Persons with Disabilities constitutes the framework for new professional roles that may conflict with institutional procedures and priorities, so it is necessary to transform the perspective at all organizational levels so that the personalized support model, in inclusive contexts, can be implemented. The support offered by professionals is linked to their perception of the role, and concerns about the risks associated with the assuming of autonomy can limit the empowering actions of professionals (Duggan and Linehan, 2013; Windley and Chapman 2010). The competencies that professionals need to support people with disabilities from a personalization perspective have hardly been investigated (Jacobs et al 2013, Moriarty et al 2014). Along these lines, Van Asselt-Goverts, Embregts, Hendriks, and Frielink (2014) and Bigby and Wiesel (2015) indicate that research on community participation and social inclusion of people with ID should include study on the organizational and cultural context from which that support is offered (including the training of professionals and the management of support) to determine to what extent they enhance the development of social ties.

Therefore, it is necessary to address this issue in order to raise the possibility of training activities, both initial and continuing, of professionals who perform accompaniment functions for people with disabilities. The objective of the research presented in this article is precisely to go into greater depth regarding the role of professionals who offer support to people with intellectual disabilities from the perspective of personalization, the rights model and community inclusion, to establish the training priorities that enhance the development of this role. This issue is of special relevance in the Spanish context, where support for people with intellectual disabilities is organized according to Law 1/2013 on the Rights of Persons with Disabilities and their Social Inclusion following a model that combines institutional care with some community-based initiatives. As Verdugo and Jenaro indicate in their report on independent living and community inclusion (2019), in Spain the emphasis has been placed on residential supports rather than those based on the community which foster people's independent living and social inclusion. The report indicates that little progress has been made in deinstitutionalization and recommends implementing resources to develop personalized support for all people with disabilities. Having more information about the functions developed by support professionals from models that prioritize inclusion and a personalized perspective will allow the training of these professionals to be properly focused, which should have an impact on the quality of support received by people with disabilities in their processes of social inclusion.

The role of support professionals for people with intellectual disabilities: research approach

Sowerby (2010) develops research focused on the role of support professionals in which he explores two dimensions: the type of relationship and / or support that allows people to gain control of their

lives, and the changes that organizations can make to incorporate actions based on customization. As for the first, it underlines the possibilities of the Circles of Support (Burke, 2015) that include people who are close and who appreciate the person receiving support in the distribution of informal supports, in a process led by the individual with disabilities. In addition, it argues that all people, regardless of disability, have preferences and should be able to express them, so it is a task of the support person to find a good system to ask the person what they want, help them understand, and be able to interpret the answer. It is necessary for the support person to spend enough time with the person receiving the support to get to know them and learn to communicate well with them. Along the same lines, the research by Williams, Porter and Marriott (2014), focused on people who receive support, highlights their need to be heard and that the support professional understands their needs. They value the fact that they spend time and help them think about alternatives and new possibilities.

As for organizations, their role cannot be ignored because it greatly conditions the actions of professionals. Sowerby (2010) points out the possibility that organizations do not give up control and experience resistance to changes, making it difficult for professionals to feel supported in the development of personalized support relationships. Some studies agree on this issue, highlighting the existence of tensions between organizations and professionals due to the difficulties for the institution to transform the institutional culture towards that of the personalized support model (Clement and Bigby, 2012; Duggan and Linehan, 2013; Mc-Conkey and Collins, 2010). Institutional concerns regarding the risks involved in assuming autonomy can limit the empowering actions of professionals (Duggan and Linehan, 2013; Windley and Chapman 2010). As shown by the research carried out by the European Union Agency for fundamental Rights (FRA) (2013), the paternalistic attitudes of professionals and organizations often erect barriers to the ability of people with intellectual disabilities to establish community networks and to advance in their social inclusion.

Brophy, Bruxner, Wilson, Cocks and Stylianou (2015) also highlight the need for the socio-educational professional to work in partnership with families and other informal agents, developing creative and innovative supports that respond to personal needs and demands. Establishing coordination processes with other formal and informal community resources is configured as a key strategy among their functions. From this perspective, personalization offers socio-educational

professionals the potential to establish relationships with people and work with them in a more meaningful way.

Few studies in our context address the analysis of the role of professionals in the socio-educational field linked to personalized support for people with disabilities. In the work by Oliveras and Pallisera (2019) a qualitative study is conducted aimed at deepening the perceptions of support professionals about their own role in supporting people with intellectual disabilities in housing contexts. The results indicate the willingness of professionals to advance in support practices based on the active listening to people and the commitment to respect their decisions. Professionals value the importance of professional skills linked to the educational relationship (empathy, listening, respect for personal differences) and the need to respect people's decisions and their lifestyle.

Pallisera et al (2018) analyze the role of support professionals in independent living contexts in research based on interviews with professionals responsible for the distribution of support and discussion groups with self-managers (people with intellectual disabilities). Both groups demand a central role for people in the support process; However, the former point out that there are numerous difficulties in transforming the institutional model based on care into a model centered on personalized support. Self-managers value, above all, the emotional support received by support professionals and, consequently, the professional skills most valued by them are patience, listening skills, respect, and availability.

This research aims to go into greater depth regarding the role of professionals who offer personalized support, through the narratives of professionals with proven experience, and which is recognized in their environment as good practice in the support of people with intellectual disabilities in social inclusion contexts. This will allow to look more deeply into the basic functions of the support professionals, as well as establish the basic training axes that prepare them for these functions.

3. Methodology

A study based on interviews with support professionals with extensive experience in facilitating social inclusion processes is carried out. The study is carried out in Ireland, a context where there has been a significant advance in the processes of deinstitutionalization of people with ID in the last decade and in the development of practices based on personalized and flexible support through the issue of institutional documents that

recommend them, based on individual needs and seeking the objective of full inclusion (McConkey, Bunting, Ferry, García-Iriarte & Stevens, 2013). In line with the Convention on the Rights of Persons with Disabilities (United Nations, 2006), there has also been a transformation of the vision of people with disabilities recognizing their experiential knowledge and enhancing their inclusion in research processes and evaluation of the services and support. Ireland is currently one of the contexts in which there is a national network of inclusive research composed exclusively of people with intellectual disabilities who, with the support of researchers from different universities, act as researchers in processes aimed at analyzing and improving their lives. In this sense, the recognition of the rights of people with intellectual disabilities is generating a significant transformation of social policies, research and support practices (Salmon, Barry & Hutchins, 2018).

The intention is for the story and the reflection of the professionals themselves on the innovative practices that are being carried out in the Irish context allows the definition of both the new support roles and the training practices that can contribute to strengthening them in different territorial contexts. The study objectives are to:

- Explore the role of professionals in the personalized support offered to people with ID in contexts of social inclusion, from the point of view of professionals.
- Discover the opinions of the professionals about the necessary training to carry out these functions.

Participants

We are interested in deepening our understanding of the vision of professionals with proven experience in good practice of personalized support in processes of social inclusion of people with intellectual disabilities. Following Yurrebaso (2017), good practices can be defined as innovative, effective, sustainable, flexible and transferable actions that produce progress or improvement of results in a given area. In order to select professionals who can give an account of good practices of personalized support in inclusive contexts, a preliminary phase was carried out in which the objective of the research was reported to university experts in the field of intellectual disability, all of them with experience in applied research and therefore with knowledge of organizations, projects and professionals that provide support. These experts were consulted about projects, services and / or professionals that developed good practices in the field of study. Based on the suggestions of these

experts, contact was made with the 12 people who participated in the research. These are 9 women and 3 men, who work in different support organizations (7 in total) except one of the participants, who is hired directly by the person receiving the support through a pilot program. 11 people have a work experience of more than 15 years working with people with disabilities, and one of 7 years. The contact with them was initially made by email, briefly indicating the objectives of the project, and once the person showed their interest, a brief document was sent with information about the project and an informed consent form and finally a date for a meeting was set. The 12 people agreed to conduct the interview, which was carried out in person at a place where they suggested.

Instrument

The exploration of the objectives based on opinions and experiences of support professionals led us to design a semi-structured interview with open questions, considering that this strategy would allow us to go into greater depth on the subject of study by allowing participants to discuss freely (Seidman, 2006). The interview was organized into the following topics: functions of the support professional, role of organizations, training of support professionals and was based on the following script:

- 1) Functions of the support professional:
 - a. Indication of the main functions developed at present, and differences with the previous ones, if this is the case.
 - The role of the person with disabilities in the support process: current role and how the support materializes. Spaces, main strategies, facilitators and barriers.
- 2) Role of organizations:
 - a. Facilitators and barriers from the organization to offer personalized support.
 - b. Organization-professional relationship
- 3) Training of professionals:

- a. Appropriate abilities to offer personalized support
- b. Training strategies that they value as being appropriate

Procedure

The interviews took place either in the professional's workplace or in an alternative space chosen by the professional. Before beginning the interview, each participant was told of the objective of the investigation, and they were required to sign an informed consent form that guaranteed anonymity and the possibility of leaving the interview at any time they wanted. Two people preferred not to be recorded, but accepted that the interviewer take notes during the interview. The average duration of the interviews was approximately 80 minutes. The interviews took place between October and December 2018 in 6 Irish cities.

Data analysis

The interviews that were recorded were transcribed and analyzed through thematic content analysis, in accordance to Braun and Clarke (2006), to identify, analyze and report on the topics that appear in a data set based on patterns or topics that repeat and a coding process based on the analysis of the different topics was developed (Gibbs, 2012). Following the procedure indicated by these authors, and based on the initial topics, various readings of the transcripts were made by adding new emerging codes related to the object of study. Once all the data were encoded, the main topics and sub-topics that included all the codes and their relationships with each other were established (Braun & Clarke, 2006). Table 1 shows the final list of subtopics used to thematically classify the emerging information of the 12 interviews:

Table 1: Topics and subtopics				
Topics	Subtopics			
1. Professional functions	-Relationship with the person: listen to their needs and support their decisions -Connection with the community -Make the community the work scenario -Risk assessment			
2. Role of organizations	-Transform the vision / center the person -Support for professionals -Establish clear guidelines			
3. Training of professionals	- Person centered model -Ability to plan personalized actions according to individual capabilities - Strengthen the connection with the community and social networks -Training throughout life			

Results

The research results are presented in an orderly manner according to the thematic blocks mentioned in the table.

Topic 1: Functions of professionals

The first subtopic analyzed corresponding to professional functions could be briefly summarized in the following sentence: "All work really begins with the person" (P1). Participants agree that support must be absolutely person-centered, based on the preferences and requests made by each of the people to whom they offer support. The first step, therefore, is to ask people what they want to do; that is to say, "sit with the person, listen to their hopes, their dreams and ambitions" (P3). People's demands generally do not consist of attending day centers or services, but rather, they ask to work, or train for it, or participate in community activities. Therefore, professionals must constantly reflect on how to respond to these individual demands:

"Everyone has their likes and dislikes, everyone has strengths, and things they have never tried to do, or would like to do, so... we are constantly.... Reflecting, thinking how to respond to this" (P4).

In addition, the need to enhance and support people's decision-making is highlighted: "Good support provides information, allows the person to make the decision, and supports them in their attempts" (P10).

Ingenuity and creativity come into play to answer each person's requests; in some cases, this will require thinking about forthcoming experiences, while in others the response may be more

direct by connecting with training or social opportunities in the locality, for example. Sometimes prior work with the person is required, through role playing or simulations; in others direct support consisting of accompaniment, or contact with an external person who acts as a point of reference. There is also insistence that "people should receive support when they need it" (P5). In this process, flexibility is essential both in hours and in work spaces.

With this, we connect with the second subtopic related to professional functions, directly referring to the need to make the community the work scenario: "We connect with the (educational) opportunities offered by the community" (P3, P5, P7, P8). The main strategy to answer individual demands is to establish links with community entities and services that offer training and learning opportunities: university, adult education centers, volunteer groups. This implies having enough knowledge of the community to assess the possibilities of participation and, once established, organize and distribute the necessary support to make it possible. It is also essential to know the resources that the person can have available to move into the community, and how they can access them. "We are constantly working in a network exploring what is around us, and we share this information, what is good..." (P7). Supporting the creation of social ties implies moving the scenario of support to the community itself, taking into account spaces where the supported person feels safe and comfortable. This has implications for the work spaces of professionals; as indicated by some of the professionals "I don't have an office" (P1, P6).

Working from personalization and in inclusive contexts requires significant dedication to risk αs -sessment, which means prior work in the analysis

of situations that may occur in the processes developed by the person receiving the support, and to document widely to what extent the possible risks and the control measures implemented to avoid them have been taken into account. The professionals with more experience underline that this function has gained significant relevance in recent years, to the extent that community spaces have been the usual life scenario.

"You need to evaluate the risks, this does not mean preventing the person from doing things, but you must document that you have previously considered the possible risks and that you have taken into account the control measures so that if something happens, you are covered..." (P11)

Topic 2: The role of support organizations

Participants agree that the traditional support distribution system based on large organizations that offer all kinds of services to people with disabilities should be radically transformed. Some of these organizations have evolved, generating new support roles and work processes centered on the person. Alongside these services, new support services that are based on personalized approaches have emerged. Regardless of the organizational model in question, those interviewed are in agreement in raising the question of the need for the organization to understand that the person with disabilities and their rights are the focus of their work and that the organizational context must fully support professionals.

The organizational context is greatly valued by support professionals. Offering support that really enhances social inclusion requires transforming both scenarios and work methodologies, and it is essential that the organization makes it easier for the professionals to take initiatives, supports them and at the same time demands guarantees that the possible risks in the processes have been analyzed in inclusion processes. As one of the participants says: "I would never have been able to do what I do alone" (P3). In addition, "if you don't feel supported, you're not going to take risks" (P5).

Having good support in the form of supervision is another element valued by professionals, both for what it represents as a reflection on the intervention itself as well as a space for personal care.

It is important that the organization establishes a policy as a center in which the guidelines are clear and explicit, guaranteeing the rights of persons with disabilities and guiding the response of professionals in accordance to them. For example, participant P7 comments that the organization in

which she works openly recognizes the right to affective-sexual relations for her clients. In addition to proposing training activities aimed at people who receive support, the organization publishes the regulations that apply to make it possible for users to enjoy their privacy, in accordance with their wishes, in the independent life support services that manage on its intranet. These regulations are mandatory for all professionals, regardless of their criteria or opinion.

The organization also plays an important role in the in-service training of professionals. For example, on subjects in which professionals must be informed in order to offer good support, such as the use of ICT.

The organization must include the voices of people with disabilities in its operating structure, not just symbolically but really.

Topic 3: The training of professionals

The participants defend the need to base the training on the person-centered model, and on basic values of the educational relationship based on respect, trust and confidentiality. Training must be "absolutely person-centered", contemplating the strategies and methodologies that facilitate the personalization of the supports, in addition to taking into account the involvement of people in the environment in these supports. In this sense, the importance of strategies such as "circles of support" is pointed out. It consists of a strategy to activate informal support, through setting objectives and delegating support, timing the follow-up of the actions and providing feedback for the process. "When I give support, I do it because it is my job, and I get paid for it, not because I really like the person, so for professionals this system (circles of support) is really sustainable, and has good results. Because it brings into play other people who are related to the person you support. And the professionals can position themselves in the background, allowing informal support to be activated". (P1)

In addition, professionals must be able to differentiate personal needs and abilities, and to face the teaching of different capacities, by proposing strategies that can respond to different learning rhythms. In order to sensitize future professionals to the need to plan and carry out personalized actions, the relevance of using real stories is indicated, which makes students reflect on real needs and demands, as well as incorporating people with disabilities into formative processes.

Several people interviewed raise the importance of online social networks in youth relationships. The use of technologies as support to initiate and maintain social contacts is essential, so it is necessary to know how to teach people with disabilities to use them safely. From another service they indicate with an example the importance of the person being independent to be able to contact the people they want, which highlights the role of information and communication technologies.

Several professionals highlight the need for tools that allow working in close connection with the community: knowing how to evaluate the services, the different spaces of the community (work, leisure, training, volunteering, etc.) to be able to link people with these scenarios.

Finally, the need to continue training once the initial training is completed, connected with the support needs experienced by the people they accompany, is not forgotten.

Discussion and conclusions

This research was oriented towards two related objectives: the first one sought to go into greater depth into the role of professionals in personalized support offered to people with intellectual disabilities in social inclusion contexts; and the second to explore the training necessary to carry out these functions. Professionals with recognized experience in offering personalized support in inclusive contexts that can be considered good practice in the field participated in this study, based on their opinions and reflections on their professional practice.

Regarding the professional role, the study participants highlight the need to organize the person-centered supports and take into account their needs and preferences. This coincides with the first two meanings of personalization indicated by Spicker (2015). It also aligns with the commentaries from Van Asselt et al. (2014), which indicate that the professional must take into account the needs of the people who receive support, as well as the preferences they show about desired activities and relationships. According to Houston (2010), participants indicate that it is necessary, in addition to focusing support on the person, to focus on social inclusion by enhancing connections in community settings. Planning and developing personalized interventions in these environments implies knowing what the training, leisure, labor, etc., resources are in the territory and being willing to work with community agents to build inclusive processes. The professionals interviewed have stressed the need to make the community the priority work scenario, coinciding with Bigby and Wiesel (2015) when they point out that these professionals play a key role in promoting meetings that involve recognition and appreciation of the person with ID.

In summary, in relation to objective 1, the results obtained in the study coincide with the literature about the facilitating supports for the social inclusion of people with intellectual disabilities. Enhancing the social inclusion and connections of people with disabilities requires completely personalized support formulas and their development in community settings. Therefore, the emphasis, rather than on services, should be placed on individually supporting access to desired environments and building relationships in the community (Power and Bartlett, 2018). This implies a transformation of organizations; as indicated by, among others, Duggan and Linehan (2013), Sowerby (2010), and Windley and Chapman (2010), organizations play a fundamental role as facilitators and enhancers of the support exercised by professionals. The participants in the study have stressed the need to feel supported by the organization where they work to be able to make personalized support in inclusive contexts, enhancing connections and social interactions. In this regard, they agree on the need for organizations to promote creative support strategies for social inclusion, instead of restricting their work through the imposition of rigid standards (Hemrsen, Embregts, Hendriks and Frielink, 2012). What is made clear from the manifestations of the participants in the study is the importance of organizations in clarifying positions, thereby facilitating coherent actions by professionals, and establishing reasonable protocols for risk assessment, without impeding progress in inclusion processes in the community.

The second objective of the study was to explore how training processes can adequately prepare professionals in the socio-educational field so that they can develop support functions consistent with personalization and the creation of social connections in inclusive contexts. From the manifestations of the professionals it can be deduced that the specific training actions on personalization and social inclusion from the rights model should not be directed only to support professionals, but to all professionals responsible for managing support at different levels. Only in this way will the organization commit globally and develop leadership that leads to work methods based on personalization and aimed at promoting social inclusion (Clement and Bigby, 2012; McConkey and Collins, 2010; Pallisera et al, 2018). The balance between risks and opportunities, in the context of the rights model guided by the Convention on the Rights of Persons with Disabilities and the European Strategy on Disability 2010-20, presupposes that support professionals receive

adequate training and are able to offer good personalized support that respects the right to make decisions of the people they help (Hawkins, Redley and Holland, 2011), building an educational relationship that respects the needs and demands of people (Salmon, Holmes and Dodd 2013).

Professionals are no longer the experts who make decisions alone about the actions to be designed or evaluated. They empower participants, and support them so that they can contribute with the value of their experience and hand over power to them. The change in the role of professionals implies the need to prioritize the competences related to the development of collaborative and partnership processes from organizations in their training. The incorporation of people with disabilities as teachers in the initial training processes, a strategy indicated by some of the participants in the study, constitutes a strategy formally recognized in some contexts such as in the United Kingdom. There are already several experiences that provide valuable insights on how these can contribute to promoting, through the creation of shared learning and growth spaces, the dialogue between professionals and users and sharing positions of power (Casey, 2018; Pendred and Chettle, 2006; Ward, Raphael, Clark and Raphael, 2016). Other studies indicate that participants in such training processes perceive improvements in skills such as empathy, understanding of individual particularities, and other competencies linked to personalized support (Unwin, Rooney, Osborne, and Cole, 2017).

In summary, the experiences of professionals coincide with the literature in terms of confirming that offering support in the community by creating inclusive experiences that have an impact on the establishment of powerful social ties implies developing new roles that enhance the connection with the community, as well as networks of informal support that professionals can complement (Duggan and Linehan, 2013). At the training level, together with the basic socio-personal skills related to the establishment of empathy and trust with the person to whom support is offered (Sowerby, 2010; Pallisera et al, 2018), there is an indication of the need to enhance skills of community development such as mapping local resources and networking with community resource professionals (Bigby, Wilson, Stancliffe, Balandin, Craig, and Gambin, 2014). Training is a key dimension for the transformation of supports, so we propose, based on the research carried out, axes that can articulate the training processes to provide professionals with the skills that allow them to support people with DI in their community participation and the improvement of their social ties:

- Axis 1: Knowledge about Personalization and Person-centered Planning concepts: origin, and development in the model of the Rights of Persons with Disabilities (United Nations, 2006). This axis would include the work of communication strategies, as well as methods and work strategies centered on the person: Circles of Support, PATH (*Planning Alternatives for Tomorrow with Hope*), etc.
- Axis 2: Skills to establish connections with the community. The objective is to allow professionals to explore the local community, both known spaces and new places to observe their potential in relation to establishing new social and personal links. This axis would incorporate the skills for the analysis of the barriers and enhancers of social inclusion (with the objective of analyzing the role of the community and professional practices themselves to determine to what extent they enhance inclusion and to establish real support practices); skills to plan outings and meetings in the community (including risk analysis and management, as well as the provision of the necessary support at the level of communication, mobility or economic resources); and skills to assess the taking of initiatives in relation to the management of the meetings. At the methodological level, promoting direct contact with people with disabilities through their incorporation into training contexts is a priority strategy to enhance significant learning in future professionals.

Undoubtedly, the training of professionals, whether in the initial stage or in service, is a key element for the enhancement of their professional activities, from personalized perspectives, the community participation of people with intellectual disabilities, the strengthening of their social networks and definitive social inclusion. However, we cannot ignore the role that social policies play in the structuring of services, nor the power of the underlying institutional culture in the work of organizations in the disability sector. In our context, as we have pointed out, the current legislation has not promoted a significant transformation of the structures (Verdugo and Jenaro, 2019), so this transformation of the institutions both physically and with respect to the distribution of supports falls to the willingness and possibilities of the entities themselves and the professionals within them. From the field of social policies, there has not been an adoption of documents that clearly guide towards a transformation of institutions and support that advocate the need to work in and from the community, based on personalized

approaches, as has happened in other countries that have made progress in this regard, such as Ireland (Salmon, Barry & Hutchins, 2018) or the United Kingdom (Kaehne & Beyer, 2014). Without a clear position from the administration strongly supporting the inclusion of people with intellectual disabilities in the community, and proposing the organizational and professional strategies that can contribute to it, it is difficult to make the necessary

transformations, both at the institutional level and regarding the socio-educational action itself. The training in rights of persons with disabilities themselves is a key factor to help them claim the enjoyment of these rights, and thereby contribute to a necessary change of perspective of the administration in the establishment of clear guidelines that support, give economic help and urge organizations to promote personalized actions.

Note

^{1.} Specifically, 3 Disability expert teachers linked to Trinity College (Dublin) were interviewed; 1 professor at University College Cork; 1 professor at the University of Limerick; and 1 professor at the Dublin Institute of Technology.

Bibliography

- Amado, A. N., Stancliffe, R. J., McCarron, M., & McCallion, P. (2013). Social inclusion and community participation of individuals with intellectual/developmental disabilities. Intellectual and Developmental Disabilities, 51(5), 360-375. https://doi.org/10.1352/1934-9556-51.5.360
- Bigby, C., Anderson, S., & Cameron, N. (2018). Identifying conceptualizations and theories of change embedded in interventions to facilitate community participation for people with intellectual disability: A scoping review. Journal of Applied Research in Intellectual Disabilities. https://doi.org/10.1111/jar.12390
- Bigby, C., & Wiesel, I. (2015). Mediating Community Participation: Practice of Support Workers in Initiating, Facilitating or Disrupting Encounters between People with and without Intellectual Disability. Journal of Applied Research in Intellectual Disabilities, 28(4), 307-318. https://doi.org/10.1111/jar.12140
- Bigby, C., Wilson, N. J., Stancliffe, R. J., Balandin, S., Craig, D., & Gambin, N. (2014). An effective program design to support older workers with intellectual disability to participate individually in community groups. Journal of Policy and Practice in Intellectual Disabilities, 11(2), 117-127. https://doi.org/10.1111/jppi.12080
- Braun, V. and Clarke, V. (2006). Using thematic analysis in psychology. Qualitative Research in Psychology, 3(2), 77-101. https://doi.org/The publisher's URL is: http://dx.doi.org/10.1191/1478088706qp0630a
- Brophy, L., Bruxner, A., Wilson, E., Cocks, N., & Stylianou, M. (2015). How social work can contribute in the shift to personalised, recovery-oriented psycho-social disability support services. British Journal of Social Work, 45(October), i98-i116. https://doi.org/10.1093/bjsw/bcv094
- Burke, C. (2015). A Guide to Circles of Support. Foundation for People with Learning Disabilities. London: UK.
- Casey, H. (2018). Transforming professional training and education –a gap mending approach: the PowerUs European Partnership. En Beresford, P. y Carr, S. (Eds.). Social policy first hand. An international introduction to participatory social welfare. Bristol: Policy Press. 349-354.
- Clement, T., & Bigby, C. (2012). Competencies of front-line managers in supported accommodation: Issues for practice and future research. Journal of Intellectual & Developmental Disability, 37, 131-140. https://doi.org/10.3109/1366825 0.2012.681772
- Comisión Europea (2010). Estrategia Europea sobre la discapacidad 2010-2020: un compromiso renovado para una Europea sin barreras. https://www.mscbs.gob.es/ssi/discapacidad/docs/estrategia_europea_discapacidad_2010_2020. pdf (consulta 20 de noviembre del 2019).
- Duffy, S. (2011). Personalisation in social care what does it really mean? Social Care and Neurodisability, 2(4), 186-194. https://doi.org/10.1108/20420911111188434
- Duggan, C., & Linehan, C. (2013). The role of "natural supports" in promoting independent living for people with disabilities; a review of existing literature. British Journal of Learning Disabilities, 41(3), 199-207. https://doi.org/10.1111/bld.12040
- European Union Agency for Fundamental Rights (FRA) (2013). Choice and control: the right to independent living. Experiences of persons with intellectual disabilities and persons with mental health problems in nine EU Member States. Luxembourg: Publications Office of the European Union.
- Garcia Iriarte, E.; Stockdale, J.; McConkey, R. & Keogh, F. (2016). The role of support staff as people move from congregated settings to group homes and personalized arrangements in Ireland. Journal of Intellectual Disabilities, 20(2), 152–164. doi:10.1177/1744629516633966

- Gibbs, G. (2012). El análisis de datos cualitativos en investigación cualitativa. Madrid: Morata
- Hawkins, R.; Redley, M.& Holland, J. (2011). Duty of care and autonomy: how support workers managed the tension between protecting service users from risk and promoting their independence in a specialist group home. Journal of Intellectual Disability Research: JIDR, 55(9), 873-84. doi:10.1111/j.1365-2788.2011.01445.x
- Hermsen, M. A., Embregts, P. J. C. M., Hendriks, A. H. C., & Frielink, N. (2014). The human degree of care. Professional loving care for people with a mild intellectual disability: An explorative study. Journal of Intellectual Disability Research, 58(3), 221-232. https://doi.org/10.1111/j.1365-2788.2012.01638.x
- Houston, S. (2010) 'Beyond Homo economicus: Recognition, self-realization and social work', British Journal of Social Work, 40(3), pp. 841-57. https://doi.org/10.1093/bjsw/bcn132
- Jacobs, S., Abell, J., Stevens, M., Wilberforce, M., Challis, D., Manthorpe, J., ... Netten, A. (2013). The personalization of care services and the early impact on staff activity patterns. Journal of Social Work, 13(2), 141-163. https://doi.org/10.1177/1468017311410681
- Kaehne, a, & Beyer, S. (2014). Person-centred reviews as a mechanism for planning the post-school transition of young people with intellectual disability. Journal of Intellectual Disability Research: JIDR, 58(7), 603-13. https://doi.org/10.1111/jir.12058
- Ley 1/2013 de Derechos de las personas con discapacidad y su inclusión social (Madrid, BOE, 3 de diciembre del 2013). Mansell, J. & Beadle-Brown, J. (2010). Deinstitutionalisation and community living: Position statement of the comparative policy and practice special interest research group of the international association for the scientific study of intellectual disabilities1. Journal of Intellectual Disability Research, 54(2), 104-112. http://doi.org/10.1111/j.1365-2788.2009.01239.x
- McConkey, R., & Collins, S. (2010). The role of support staff in promoting the social inclusion of persons with an intellectual disability. Journal of Intellectual Disability Research, 54, 691-700. https://doi.org/10.1111/j.1365-2788.2010.01295.x
- McConkey, R., Bunting, B., Ferry, F., García-Iriarte, E. & Stevens, R. (2013). An evaluation of Personalised Supports to Individuals with Disabilities and Mental Health Difficulties. Belfast: University of Ulster.
- McCausland, D., McCallion, P., Cleary, E., & McCarron, M. (2016). Social Connections for Older People with Intellectual Disability in Ireland: Results from Wave One of IDS-TILDA. Journal of Applied Research in Intellectual Disabilities, 29(1), 71-82. https://doi.org/10.1111/jar.12159
- Moriarty, J., Manthorpe, J., & Cornes, M. (2014). Skills social care workers need to support personalisation. Social Care and Neurodisability, 5(2), 83–90. https://doi.org/10.1108/SCN-12-2013-0042
- Naciones Unidas (2006): Convención Internacional sobre los Derechos de las Personas con Discapacidad. Nueva York: ONU.
- Oliveras, M., & Pallisera, M. (2019). Avananzando en la vida independiente de las personas con discapacida: el rol de los profesionales de apoyo. Educación Social. Revista de Intervención Socioeducativa, 71, 164-180.
- Pallisera, M., Vilà, M., Fullana, J., Díaz-Garolera, G., Puyalto, C., & Valls, M.-J. (2018). The role of professionals in promoting independent living: Perspectives of self-advocates and front-line managers. Journal of Applied Research in Intellectual Disabilities, 31, 1103-1112. https://doi.org/10.1111/jar.12470
- Pendred, B., & Chettle, K. (2006). What Being a Trainer Means to Me. Social Work Education, 25(4), 415-417. https://doi.org/10.1080/02615470600593832
- Power, A., & Bartlett, R. (2018). Self-building safe havens in a post-service landscape: how adults with learning disabilities are reclaiming the welcoming communities agenda. Social and Cultural Geography, 19(3), 336-356. https://doi.org/10.1080/14649365.2015.1031686
- Salmon, R., Holmes, N., & Dodd, K. (2013). Reflections on change: Supporting people with learning disabilities in residential services. British Journal of Learning Disabilities, 42, 141-152.
- Salmon, N., Barry, A., & Hutchins, E. (2018). Inclusive research: An Irish perspective. British Journal of Learning Disabilities. https://doi.org/10.1111/bld.12247
- Seidman, I. (2006). Interviewing as a qualitative research. A guide for researchers in education and the social sciendes. Teachers College, Columbia University: New York and London.
- Sowerby, D. (2010). What sort of helping relationships are needed to make Personalisation happen and how can organisations be developed to support this? Journal of Social Work Practice, 24(3), 269-282. https://doi.org/10.1080/02650533.2010.500119
- Spicker, P. (2013). Personalisation falls short. British Journal of Social Work, 43(7), 1259-1275. https://doi.org/10.1093/bjsw/bcs063
- Unwin, P. F., Rooney, J. M., Osborne, N., & Cole, C. (2017). Are perceptions of disability changed by involving service users and carers in qualifying health and social work training? Disability and Society, 32(9), 1387-1399. https://doi.org/10.1080/09687599.2017.1322498

- Van Asselt-Goverts, A.E., Embregts, P.J.C.M.; Hendriks, A.H.C. & Frielink, N. (2014). Experiences of support staff with expanding and strenghthening social networks of people with mild intellectual disabilities. Journal of Community & Applied Social Psychology, 24, 111-124. https://doi.org/10.1002/casp.2156
- Verdonschot, M. M. L., de Witte, L. P., Reichrath, E., Buntinx, W. H. E., & Curfs, L. M. G. (2009). Community participation of people with an intellectual disability: a review of empirical findings. Journal of Intellectual Disability Research, 53(4), 303-318. https://doi.org/10.1111/j.1365-2788.2008.01144.x
- Verdugo, M.A., & Jenaro, C. (2019). ANED country report living independently and being included in the community. Spain. Academic Network of European Disability experts. Retrieved from (https://www.disability-europe.net/the-me/independent-living) (accessed the 20th November 2019)
- Ward, N., Raphael, C., Clark, M., & Raphael, V. (2016). Involving People with Profound and Multiple Learning Disabilities in Social Work Education: Building Inclusive Practice. Social Work Education, 35(8), 918-932. https://doi.org/10.1080/02615479.2016.1239705
- Williams, V., Porter, S., & Marriott, A. (2014). Your life, your choice: Support planning led by disabled people's organisations. *British Journal of Social Work, 44*(5), 1197-1215. https://doi.org/10.1093/bjsw/bct005
- Windley, D. & Chapman, M. (2010). Support workers within learning / in- tellectual disability services perception of their role , training and support needs. British Journal of Learning Disabilities, 38, 310-318. http://doi. org/10.1111 /j.1468-3156.2010.00610
- Yurrebaso, G. (2017) Buenas prácticas en transición a la vida adulta de jóvenes con DI desde las aulas de aprendizaje de tareas en la CA del País Vasco. Tesis doctoral, Bilbao: Univ. Deusto

HOW TO CITE THE ARTICLE

Pallisera. M. (2020). El apoyo personalizado a personas con discapacidad intelectual: funciones y formación de los profesionales socioeducativos para la inclusión social. *Pedαgogía Social. Revistα Interuniversitaria*, 35 119-131. DOI:10.7179/PSRI_2019.35.10

AUTHOR'S ADDRESS

MARIA PALLISERA DÍAZ. E-mail: maria.pallisera@udg.edu

ACADEMIC PROFILE

MARIA PALLISERA DÍAZ. Profesora Titular del Departamento de Pedagogía, en la Universidad de Girona. Miembro del Instituto de Investigación Educativa de esta universidad. Coordinadora del Grupo de Investigación en Diversidad. Docencia en el Grado de Educación Social, Trabajo Social y el Máster en Atención a la Diversidad en una Educación Inclusiva de esta universidad. Línea de investigación en Inclusión educativa y social de personas con discapacidad. Investigadora Principal, junto con Judit Fullana, del proyecto EDU2017-84989-R (Construcción y gestión de las redes sociales de apoyo de personas con discapacidad intelectual: Diagnóstico, buenas prácticas y diseño inclusivo de proyectos de mejora). Actualmente es coordinadora del Programa de Doctorado en Educación de esta universidad.