Person-Centred Planning in Centres of Activities for Inclusion

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Abstract
Person-centred planning includes the active social participation of individuals with intellectual and developmental disabilities (IDD) and is the fairest path towards assuring human rights and citizenship among people with IDD. Semi-structured interviews were undertaken with four technicians from centres of activities in Portugal, four family members, and four adults with IDD to observe the best practices that facilitate/hinder the implementation of person-centred interventions. Several discrepancies were identified regarding inclusive practices in centres of activities and capacity building, associated with the sense of mission, vision and perspective of technical structures, the bureaucratic weight that conditions the transition between intervention models, the participation and positioning of families regarding their representation of the centres, as well as the investment these centres make concerning effective and fair inclusion in surrounding communities. Still far from successful implementation, a person-centred approach must be considered and include all participants’ perspectives to build robust and integral life projects.

Keywords
CACI; capacity building centres; diversity; inclusion; intellectual disability; organisations; person-centred planning; Portugal

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1. Introduction
Disability inclusion is understood as the experience of participation, in different settings, of each person with disabilities, promoting human rights and creating more supportive structures that ensure equal access to all societal contexts (United Nations, 2019). The inclusion process is developed via a conceptual change from medical to biopsychosocial models (Purdue, 2009), stressing the human rights of the disabled person (Bray & Gates, 2000) and focusing not just on the obstacles to individual health/medical conditions, but on services and support, and on the external factors that surround an individual’s life (Koller et al., 2018). Broader expressions such as intellectual and developmental disabilities (IDD) are part of this inclusive approach (e.g., Schalock et al., 2019), combining the fields of intellectual disability and developmental disabilities. IDD comprises significant limitations in intellectual functioning and adaptative behaviour manifested before the age of 18 (intellectual issues) and/or chronic issues manifested before the age of 22, which results in substantial functional limitations in three or more life activities and requires long-term supportive services (developmental issues). In Portugal, youths and adults with IDD can be placed in social centres during the day with the intention of promoting their sense of belonging to the community and their skills by carrying out activities that enhance their self-determination, the establishment of interpersonal relationships, and the undertaking of valued social roles.

According to Simplican et al. (2015), community participation occurs in three different contexts: segregated,
semi-segregated, or mainstream. These social structures can, therefore, have different organisational practices, from those more focused on traditional models, more segregated from the community to practices based on person-centred planning and focused on achieving inclusion for all adults. However, research on this topic lacks greater depth, namely concerning how person-centred intervention has been implemented in organisations that support adults with IDD (Torres, 2015) and how these promote effective inclusion in the community.

Person-centred planning comprises tools and strategies to improve the quality of life of the patients/users and promote changes in these individuals’ lifelong project (Neto, 2019; Ratti et al., 2016). This systemic intervention, based on the biopsychosocial model (M. G. Pereira & Smith, 2006), is implemented in social centres that seek to meet the needs of each person in collaboration with their families and their community, constructing a project around patients’ participation in the centre with the goal of including them socially.

The construction of a life project can be defined as the construction of an individual’s identity in mapping possible future identities. Everyone, whether with disabilities or not, may build their identity through social relationships. Person-centred planning proposes that the work developed in social centres promotes a series of competencies that facilitates social interaction and individual growth: self-determination, interpersonal relationships, and valued social roles (Beadle-Brown et al., 2012; Kaehne & Beyer, 2014). These competencies’ aim has brought new challenges to organisations, shifting from work more focused on disability and behavioural interventions, based on the medical model, to core values of inclusion, providing service users and their families power over their lives (Iriarte et al., 2017), in a positive vision of the future, reinforcing strengths, preferences, and the capacity to gain new abilities (Holburn, 2002). Self-determination and interpersonal competencies, among other competencies, promote the most significant inclusion in the community (Santos, 2017). Wehmeyer et al. (2011) defined self-determination as the individual’s ability to achieve goals autonomously. In a centre with adults with IDD, self-determination can play a crucial role in finding a job outside the organisation, choosing the activities to be performed inside the centre, or joining a group of self-advocates (Heller et al., 2011). To contribute to self-determination in centres with person-centred approaches, Abery et al. (2008), assuming an ecological model of self-determination, developed, for this purpose, training for staff members. Results revealed that adults with intellectual disabilities living in community-residential settings exercise greater self-determination than peers in similar settings where staff have not been trained. Adults with IDD could also be trained in self-determination through self-directed support. In randomised trial studies, causal effects were observed with the training of adolescents with IDD in self-determination (see Wehmeyer & Abery, 2013).

Furthermore, person-centred interventions reinforce interpersonal relationships, as having a prominent role in human development and learning (Marques, 2017). Activities promoting interpersonal relationships enable community proximity (McCausland et al., 2018). In this approach, individuals must engage in meaningful experiences from an early age with parents, friends, and the most prominent community members. In adulthood and organisational contexts, the interpersonal relationships of people with IDD are crucial on a daily basis (Marques, 2017), as relationships can often have an impact on the quality of life, as those who are included in a more significant number of networks and peer groups have a better outcome, avoiding situations of segregation and solitude (Fiori et al., 2006). People with IDD often have smaller social networks and participate less in friendship activities, as Emerson and McCVilly (2004) reported in their study with a sample of 1,542 adults with intellectual disabilities. The median interactions were two activities with other adults with intellectual disabilities and zero activities with friends without disabilities in a period of four weeks.

Moreover, interpersonal relationships are mainly maintained with the staff from centres, with literature on person-centred planning recommending informal relationships with staff and recognising the strengths and needs of the person with a disability (Iriarte et al., 2017). Clarkson et al. (2009) analysed the perceptions of a group of 11 adults with an intellectual disability concerning the support of the staff. Through semi-structured interviews, participants highlighted honesty, trust, and nurture as the most significant traits to build positive relationships.

The relationship between adults with IDD and family plays a crucial role in creating interpersonal relationships and may often be one of the most significant factors (Kozma et al., 2009) for the quality of implementation of person-centred planning (McCausland et al., 2021). Person-centred planning improves communication and family participation (Claes et al., 2010), reinforcing staff-family relationships. However, several potential barriers can arise in the staff-family relationship, when families are placed in a passive position (Rasheed et al., 2006), with only an occasional sharing of specific vocabulary with staff (Chambers & Childre, 2005) or of organisational procedures.

Besides self-determination and interpersonal relationships, valued social roles are also a priority in person-centred planning (Bradley, 1994). According to one of the precursors of social role valorisation (Wolfensberger, 1972, 1983, 2000), people generally define themselves according to the roles they occupy in the community. When only allowed to occupy marginal societal roles, adults with IDD feel undervalued (Fontes, 2016). Iriarte et al. (2017) presented significant support indicators for valued social roles through person-centred planning concerning paid employment or voluntary work. On the other hand, the social participation approach demands full community engagement and less...
segregated services, requiring monitoring systems and the support of individual needs (Bertelli et al., 2015).

Due to these changes in the social structures' working paradigm, this study aims to understand the practices and policies connected with implementing person-centred planning intervention (several competencies such as self-determination, interpersonal relationships and valued social rules), highlighting the facilitating aspects and constraints from the perspective of the technicians, families, and adults themselves, adopting an analysis from individual to organisational and intervention characteristics.

1.1. Centres of Activities and Capacity Building for Inclusion

There are several responses among centres to support youth and adults with IDD in Portugal, namely family foster care for adults with disabilities, home support, residential homes, and centres of occupational activities (CAOs, after the Portuguese centros de actividades ocupacionais; see Decreto-Lei n.º 18/89, 1989). According to the Portuguese Social Security, CAOs—later renamed CACI for centres of activities and capacity building for inclusion (after the Portuguese centros de actividades e capacitação para a inclusão)—have as their main aim the promotion of activities for adults with moderate disabilities. Ordinance Law no. 70/2021 (Portaria n.º 70/2021, 2021) describes CACI as social services with a community basis to develop occupational activities for adults with disabilities (18 years or older), seeking the promotion of their quality of life, access to the community, and to the resources and activities that support inclusion, based on their needs and capacities.

As centres of occupational activities, these structures can offer several activities: occupational and therapeutic, socially valuable, interaction with the social context, and qualification for social and professional inclusion. Centres have different spaces, commonly divided into occupational rooms and socially valuable rooms. The work developed in these rooms has distinct objectives to respond to different challenges. The occupational rooms aim to ensure that individuals with IDD remain active and interested in performing previously defined activities (Veiga et al., 2013). As for the socially valuable rooms, the aim is to further adults' professional integration into the labour market, promoting social and professional abilities. Nevertheless, according to article 8 of Law no. 70/2021, socially valuable activities should be preferentially implemented in the community and not in the centre, as practised commonly.

To guarantee the quality of the implementation of person-centred interventions, factors that hinder and facilitate intervention have already been investigated in several social and health contexts (Collins, 2014; de Silva, 2014; Morgan & Yoder, 2012). However, according to Scholl et al. (2014), research results concerning the effectiveness of person-centred interventions are contradictory. These results' inconsistency could be explained by the different methodologies used to analyse the effectiveness of an intervention (Damschroder et al., 2009). Hower et al. (2019) analysed the implementation of patient-centred care intervention, identifying the organisational determinants considered by decision-makers as barriers/facilitators based on the Consolidated Framework for Implementation Research (CFIR; for a complete description see the Supplementary File), which was also implemented in the present study.

Therefore, the following research questions were formulated: Which competencies (self-determination, interpersonal relationships, valued social roles) are the most worked on within person-centred planning in CACI? What are the factors that facilitate/hinder the implementation of person-centred planning at different levels (perceptions of intervention characteristics, the organisational level, and the individual level)?

2. Method

2.1. Participants

The sample of the study is composed of 12 participants, namely four technicians (A-D), four family members (A-D), and four adults with IDD aged between 20 and 40 years old (A-D). These participants are connected to four CACI in the north/centre of Portugal, selected by convenience through a list of institutions previously analysed. The directors of each CACI indicated the technician to be a participant in the study, and the technician named the adult with IDD and the member of the family who had more contact with the centre. The technicians have a background in psychology and social education. Technician A has a background in clinical psychology in the health area, as a specialist in psychological intervention in mental illness, with five years of work in a CACI. Technician B has a degree in clinical psychology, in the branch of systemic and family intervention, with six years of training in disability. Technician C has a degree in social education and has been working at a CACI for one year. Technician D has a degree in psychology and a post-graduation in management of social enterprises. Technicians A and B are females, C and D are males.

Family members are listed as Family Member A, Family Member B, Family Member C, and Family Member D. Family Member A (male) is a car upholsterer with primary schooling (four years of schooling). Family Member B (female) is a technical assistant in a higher education institution with secondary education (12 years of schooling). Family Member C (female) is a manager of a cosmetics shop, who attended the first year of a nutritional sciences degree (degree not completed). Family Member D (female) is a dental assistant with a degree in environmental engineering. The adults were listed as Adult A (male aged 34, 16 years in a CACI), Adult B (male aged 23, three years in a CACI), Adult C (male aged 32, nine years in a CACI), and Adult D (female aged 37, 19 years in a CACI).
2.2. Data Collection

The data collection instruments used in this research study were interviews conducted by the same researcher. Due to pandemic contingencies, the interviews took place face-to-face, through videoconference. Three different scripts were created, one for the technicians (14 questions), one for the adults with IDD (13 questions), and the other for their family members (12 questions). The questions focused on categories such as the role played by adults with IDD in the CACI; the influence of self-determination skills, interpersonal relationships, and valued social roles in the way the CACI operates; the implementation of activities at the CACI based on the person-centred intervention; the participation of the community in the CACI’s activities; the role of the family in the way the CACI works; the construction of life projects. These interviews were previously tested with a technician, an adult with IDD, and a family member to validate the questions and to adapt language. For adults with IDD, the questionnaire was adapted with several examples to assist in the understanding of the questions, the interviewer was trained previously, and staff from the centre/members of the family assisted in the preparation of the online session, easing the communication process.

The directors of the CACI signed a favourable authorisation to implement the research study. To implement the research study, a request for collaboration and informed consent was made to family members and senior technicians, as reference figures of adults with IDD. A request for consent was also made to the adults, and oral authorisation was requested for the recording of the interview, given the possibility that they might not master reading and writing skills, and in conjunction the favourable opinion of their legal guardians was sought.

All ethical issues were safeguarded, and all participants were duly informed of the study’s aims. The ethical committee from the university approved the present study. The interview with technicians took an average of 40 minutes, the family member interview took an average of 30 minutes, and the interview with adults with IDD took an average of 10 minutes.

2.3. Data Analysis

All the interviews were transcribed and qualitative content analysis (Bardin, 1977) explored participants’ perspectives. Categories were extracted from the questions asked. We also based our analysis on the CFIR (Damschroder et al., 2009), a coding frame including core elements of person-centred intervention, combining deductive and inductive approaches. The CFIR is a well-established framework that proposes a list of constructs that influence (positively or negatively) the effectiveness of an intervention. The CFIR comprises five significant domains: intervention characteristics; outer settings; inner settings; characteristics of the individuals involved, and the implementation process. Two trained researchers assessed all transcribed interviews (L. C. and L. A.). Disagreements were solved through discussion. The final version is presented in Section 3, with a short definition and textual fragments of participants’ narratives to exemplify. The textual fragments were translated into English.

3. Results

A total of 12 interviews were analysed and the results are structured according to the research questions and CFIR domains, enabling the following categories: (a) intervention characteristics, (b) outer setting, (c) inner setting, and (d) characteristics of the individuals involved. These are described and explained in detail in the following sections, with the results for every group of interviewees.

3.1. Intervention Characteristics

In what concerns the intervention implemented in each CACI, several subcategories were found and consolidated to deepen and clarify the analysis of the results.

3.1.1. Strength, Quality, and Adaptability

This subcategory refers to the perception of the quality and validity of the intervention undertaken in each CACI to achieve the expected results and the extent to which it can be adapted to meet specific needs. Our results clearly show concern on the part of the technicians associated with ensuring multidisciplinary work and with providing varied experiences to the CACI’s users. Some of them try to make these users aware of all the services of the CACI, with the perspective of users’ active participation in preparing the respective allocations and selection of activities, but always with the need to justify that they also benefit from those moments to assess the skills and needs of the users “to allocate them better”: “We have a very, very large multidisciplinary team with different areas of expertise, which enables us to meet what they ask us to do, but also to meet the needs we identify” (Technician A).

Furthermore, families and the users themselves seem to have little involvement and little critical approach regarding the strength, quality, and adaptability of the intervention provided, as only one family member commented on having felt improvements in the general behaviour of her family member, as mentioned by Family Member C: “I have lost count, but he has been there for many years. I have noticed that he has become more agile; he improved without a doubt.”

3.1.2. Complexity

The subcategory analysed here refers to difficulties in implementing the intervention. Our results reflect not only the immediate difficulties and concerns, depending
on the type of interviewee, but also a wide variety of barriers and potential inhibitors to the intervention’s success.

Besides the complexity associated with the intervention, other difficulties experienced are linked to the diversity of the characteristics of users (high heterogeneity), the dimensions of the CACI itself, the management of expectations regarding the results of the intervention (namely on the part of family members and sometimes of the users themselves), and an unfavourable ratio between technicians and users (high number of users), reflecting a panorama of global disinvestment in the social and disability area:

Then there is the bad habit of the state...of thinking that a methodology that works very well in Finland, Norway, or Denmark, will also work very well here [Portugal]. However, they are given 1000 euros per month in support, and we have 200 euros. They have technicians and support staff of almost one-to-two, or one-to-one many times, and here we have one-to-ten. (Technician D)

Family members recognise the challenges associated with the intervention and appreciate the work undertaken by technicians with their relatives. However, they also signal their need for knowledge associated with the nature of the intervention itself. According to Family Member A:

So, I know he has support, he has various kinds of support, but sometimes I do not know what subjects he has, what support he has. Yes, I cannot decipher what they are, he sometimes tells me, he shows me the papers, so I can read them, but there are so many things.

3.1.3. Planning of an Intervention: Change of Paradigm

Regarding the perception of innovation in the intervention paradigm, our results point to a progressive (though slow) replacement of the traditional biomedical intervention paradigm by the person-centred model, adjusted to emotional and motivational needs and personal preferences. These results show that this is a transversal perspective of technicians and families:

I think there is this change, and we are thinking about it and what I said to you during the interview. We are increasingly valuing the tastes, the choices of the person, and not focusing so much on what the technical part thinks. (Technician B)

She [the user] always had the opinion, the final decision has always been hers, however much they may sometimes disagree, they [the technicians] may try to make her understand. However, the final decision is always hers. (Family Member D)

3.2. Outer Setting

Several subcategories also emerged when considering the local community and social context.

3.2.1. Social Inclusion and Stereotyping

Despite the shortage of detailed data, our results point to the existence of prejudice against people with IDD, namely within the family itself:

Because he [the user] had problems, the other brother was smarter than him, and sometimes there was interference because one knew more and the other knew nothing. Moreover, he began to feel inferior to his brother and put himself aside. Moreover, I always tried to...call him...pulled him to the other side, so he did not care too much about that. (Family Member A)

Technicians are the ones who position themselves most critically, reflecting on the implementation of the inclusion model in other places that impact lifelong development, such as schools:

At this moment, it is the phase of integration in schools that they call inclusion, which for us often makes no sense because we are talking about a relative inclusion. We are talking about schools with a little room called multi-disability room where young people are placed and do little, but they call it inclusion, unfortunately. (Technician D)

3.2.2. External Policies in Disability

In terms of government policies and regulations, technicians refer to the weight of bureaucracy—besides lack of financial investment—as negatively impacting processes associated with the work of the CACI in terms of promoting a person-centred intervention:

Here [Portugal], getting a wheelchair is a lengthy process, a complex process, which often fails to produce results, and maybe abroad they have the right and the facilities, and then have an adapted wheelchair that costs 3,000 or 4,000 euros. (Technician D)

3.2.3. Rights of Adults With IDD

Although not consistent or conclusive, our data concerning this matter indicates some failures in the assertion of some rights of people with IDD, often associated with a certain paternalism:

From the general population of our CAO, the dimensions that are most worked on are, I think, the emotional well-being dimension and the physical well-being dimension. The dimension we have the
most difficulty working on is the person’s rights. (Technician A)

3.2.4. Peer Pressure and Similar Centres
Regarding the competitive pressure to implement an intervention, because another similar centre is also implementing it, our results are consistent concerning the absence of this comparison. Each CACI is centred on its own reality and users’ characteristics, developing a network of activities for them.

3.2.5. Adults With IDD’s Engagement With the Community
When considering the involvement and inclusion of people with IDD in the communities, two approaches emerge. On the one hand are the efforts that derive from strategies undertaken by centres and headed by the technicians, which seek to promote these realities—whether in more concerted initiatives, or occasional events:

We will always seek to provide answers outside our micro-community...because the goal is that....[In the centre] it’s inclusion, work on the skills and meet the[ir] needs, but it is a false inclusion. So, we try to take them and insert them into the community, which is real inclusion. We have an excellent relationship with the community: local businesses, vets, city council, bakeries, factories. (Technician A)

Along the same line is the positive recognition by families concerning the CACI for all these initiatives:

Certain projects that they create, like this one, for example, about the integration of the disabled into society, which makes them, now I am missing the word, which makes them value themselves even more. (Family Member D)

On the other hand, the users of the CACI do not recognise or cannot position themselves as actively participating members of their surrounding communities:

Interviewer: Do the activities essentially take place in the centre, or do you also do them around your community?

Adult D: In the centre, we have an event that we do every year involving the whole community.

An exchange with another participant resulted in the following dialogue:

Interviewer: Are the activities you usually do always in the centre, or do you also do activities in the community, in the area where you live?

Adult C: No. It is only in the centre.

Interviewer: You never had activities with the community?

Adult C: No. Not that I remember.

3.3. Inner Setting
Regarding internal context, organisational structures, and characteristics of the CACI, we present here the categories found.

3.3.1. Structural Characteristics and Organisational Resources
Analysing the interviewees’ perspective on the characteristics of the CACI, aspects such as social architecture, age, maturity and size of the centre, resources, and work management are co-articulated for a global service. We found indicators that allow us to assume a convergence between technicians, families, and users, aimed at the diversity of the offers and the concern of the user’s characteristics and needs.

Some technicians still refer to the large number of adults with IDD and the low financial resources as real barriers to the personalisation of the therapeutic and occupational services of the CACI:

We have 165 users in four CAOs, so there are inevitably different reactions. However, for example, based on one of the CAOs where more people are supported, we have three typically occupational rooms. Then we have two rooms for socially useful activities. The work tends to focus more on well-being or purely occupational activities in the typically occupational rooms. And then, in each room, some employees provide more occupational activities, and others provide more welfare-related activities. (Technician C)

Family Member B mentioned:

We were talking and seeing how they could work differently with my son....Because he likes football and cooking, they think he can [create] a blog as he enjoys doing recipes and all that; blogging about cooking, recipes, and sports, but for now, this is on standby.

An exchange with another participant resulted in the following:

Interviewer: Do they give you the freedom to do an activity that the centre does not plan?

Adult A: Yes....Swimming pool.

Adult C, when asked if they had a choice in planning activities, also said: “Yes. Yes, I do.”
3.3.2. Internal Communication, Conflict Management, and Collaboration

There were two lines of approach regarding the importance of communication within the centre for effective intervention, the organisation socially constructed norms and values, and the capacity to minimise conflict and absorb change. Regarding managing conflicts between users and between these and the technicians, management seems relatively peaceful, as mentioned by Family Member D: “It was good, I noticed great companionship between her and her colleagues”. However, occasional altercations were noted: “We know that there are conflicts between colleagues, between users and staff, and they dislike being called to account, they dislike certain things that they see and observe” (Technician B).

3.3.3. Professionals’ Training

Concerning the CACI’s focus on the valorisation and professional training of its assets (technicians, staff), we understand that few contributions in our sample allow us to establish a strong position. Only one of the technicians directly referred to this investment:

As team members, one thing that is also part of our practice is that we promote the training of our monitors….Since 2019, we have started training sessions about the importance of self-determination. We went around the different rooms and the different locations to be able to show them [staff] that it was possible to let the person be a participant, even if not self-determined in some issues, in some cases [major disabilities], but an active participant in their life. (Technician A)

3.4. The Characteristics of the Individuals

Person-centred care is based on the individual characteristics of users, their personal attributes, and the development of features aligned with life projects.

3.4.1. Adults’ Needs, Interpersonal Relationships, and Internal Resources

Regarding the personal needs of the CACI users, their resources and personal characteristics, and the way these translate into their interpersonal relationships, we have observed that families are susceptible to the work developed in the centres, as this promotes feelings of inclusion, a sense of belonging and perceived personal “usefulness,” and supports a continuous work on their autonomy and constant investment in their skills. The technicians’ perspectives fit into this search for personalized/personalisation and intensive work directed towards their users:

Our role here is to promote...skills, not only professional skills, such as writing, reading, [but] personal and social skills [as well]...Essentially, our objective and what we work towards is that the activities we develop...be aimed at promoting these skills and also their happiness. (Technician B)

3.4.2. Professional Training and Development

Regarding the development of professional skills and competencies in adults with IDD, the perspectives of the interviewees are aligned in the sense that, whenever possible, this can be implemented in articulation with the community:

Strategies such as meetings with people who have nothing to do with the centre [on behalf of] integration in society; for example, for years she has had a job for two days a week, in an office...and some activities are entrusted to her alone. I think this is also very important, what they [the centre] do. (Family Member D)

The adults interviewed were clear when they expressed the goal of finding a job:

My goal is to be a worker in a car wash workshop, which is what I am doing now....it is about they [technicians] being there for a while to see the work, if I am doing it well or not. Moreover, giving a helping hand, maybe, when necessary. (Adult C)

3.4.3. Psycho-Emotional and Functional Well-Being

In this subcategory, several issues arise as families’ concerns (or priorities) tend to differ from the ones expressed by the technicians. Aspects of behavioural nature, emotional stabilisation, self-esteem, integration, and autonomy were consistently pointed out by families.

Technicians, on the other hand, show a growing concern with the real personalisation of intervention towards a better quality of life, “to meet their preferences and what is useful and has a significant impact on their rehabilitation or simply on improving their quality of life” (Technician A).

3.4.4. Involvement of Family and Friends in an Individual’s Intervention

Reflecting on the articulation between families and technicians in the sense of promoting the continuity of intervention strategies, we verified that there are many gaps in the families’ knowledge about individual plans and (personal, structural, financial) resources, which could hinder the results outside of the centre: “They explain what is going to happen, what they are going to do about…and explain how he [adult] has been doing. Because that is the way it is, I often do not read” (Family Member A).
Most of the time, technicians are aware of these difficulties:

Parents also have difficulties; sometimes they do not have the active role that we would like them to have. We try our best not to institutionalise the client from the onset to promote the active role of the family. (Technician A)

3.4.5. Self-Determination

Regarding the capacity of choice of the activities that compose users’ days, we can find some discrepancies as interviewees present different discourses. Our results tend to show that users do not have the full power of choice, nor do they enjoy the personalisation of care that the technicians were talking about throughout the interviews, often being “fitted” into the available activities or where it is more practical (from the organisational point of view) for them to be: “Speaking on the issue of self-determination, I think we are very far, I think we are far away” (Technician C).

Some technicians tend to acknowledge this more than others, and we can state that some centres are starting to create formal opportunities (e.g., periodic meetings) to listen to their users, but these seem to have no strategic mediation or any implementation in practice:

Interviewer: They help. And do you have, for example, youth meetings?

Adult B: No.

Interviewer: So, you do not do that kind of…you have nothing, you just share your problems, is that it?

Adult B: ‘Yes.

3.4.6. Individuals’ Life Projects

Concerning the co-construction of individual life projects, the results obtained highlight minimal and erroneous perspectives on what they are and their nature/objectives. Families seem to be attached to a merely occupational approach for their relatives: “I do not think he has any objectives other than those he is achieving there. He likes it there, he loves it, he likes his friends, he likes all the staff” (Family B).

A technician was not clear about the true meaning of the construct “life project,” it being tied to a subjective, almost philosophical approach: “We are focusing on dreams. We want to focus on what is meaningful to that service user and [to his dreams]” (Technician B).

4. Discussion

Implementing person-centred interventions comes with increased pressure on the day-to-day practice of organis-
it should be noted that technicians make more references to self-determination, individual plans, and establishing a relationship with the community than family members. Furthermore, as mentioned in previous studies (Emerson & McVilly, 2004; Fiori et al., 2006), adults with IDD lived isolated from the community, with the centre staff, family members, and other adults from centres as the main elements of their circle of relationships. Though this could be a limitation for their emotional and psychological well-being, centres are increasingly aware of the relevance of users’ well-being, promoting several therapeutic activities (e.g., physical activities, psychological support) recognised by family members and users as positive.

In inner settings, since each CACI has the necessary tools and equipment to promote intervention and multidisciplinary teams with increasing specialisation, interventions could be easily implemented but can be hindered by a lack of adequate internal communication or by conflicts. On the other hand, the need for more staff trained in this domain seems essential for adequate care (O’Brien & O’Brien, 2000). Promoting staff training in inner settings and expanding political and financial support for disability in outer settings, in line with previous studies (Hower et al., 2019), is still needed. This lack of financial support to centres (e.g., outer settings) impacts organisational issues (e.g., inner settings). One of the mentioned issues is the need for more technicians and educational/monitor staff that support adults daily. Person-centred intervention is particularly demanding in terms of personnel, as it requires technicians available to support adults in their lives in the community.

Regarding intervention characteristics, staff and family members recognised that the person-centred planning model aims to reduce segregation and social isolation, providing new opportunities and developing skills necessary for the social inclusion of adults with IDD. Interviewees reveal the importance of implementing this planning to build life projects, giving them a perspective of inclusion in a global society. The community’s support corroborates previous studies on the same topic (Becker & Pallin, 2001; M. Pereira, 2014). Families recognise the effort of staff members and in some situations refuse to undertake this monitoring, leaving this task to the technician. The lack of family support and involvement could compromise the quality of the intervention (McCasland et al., 2021), as family plays a crucial role in creating interpersonal relationships (Kozma et al., 2009).

5. Conclusions

This study is one of the first studies in Portugal to explore the factors that facilitate/hinder the process of person-centred planning implementation, presenting at the same time the opinions of technicians, family members, and adults with IDD. A deeper understanding of how four centres organise daily activities while promoting self-determination, interpersonal relationships, valued social roles, and community inclusion is critical, particularly given the increased interest in person-centred interventions in practical contexts.

The analysis of this data led us to conclude that there is still much work to be done in transitioning from traditional planning to person-centred planning, as factors related to intervention characteristics, outer settings, inner settings, and individual characteristics are seen as hindering the process rather than facilitating it. The process is slow and lengthy, developed in different stages for each centre. Future studies are needed to understand this phenomenon from a larger perspective, with more centres and other intervening parties such as community members, directors of companies, or technicians from entities such as Social Security. In that case, a specific study on terminology and best-practice methods could contribute to optimising person-centred implementation. Moreover, questions about how technicians and organisations are prepared to help adults build a larger network of relationships, including members who are not paid to be in their lives, could be discussed. Training in this area could be an asset, with the selection of centres where the person-centred approach is already being implemented as case studies for other centres. Sharing knowledge and experiences among professionals with international and national colleagues would be useful for the implementation of the person-centred approach.

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Conflict of Interests

The author declares no conflict of interests.

Supplementary Material

Supplementary material for this article is available online in the format provided by the author (unedited).

References


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