



# “What is the point of being able to enter a building if the service or activity is not adapted?”: Leisure opportunities for people with severe disabilities’

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## ARTICLE INFO

### Keywords:

Youth  
Severe disability  
Social inclusion  
Reflexive thematic analysis  
Specialised social services

## ABSTRACT

Leisure and relationships are crucial for human development, especially in the youth stage, and are recognised rights. Notwithstanding, young people with disabilities encounter many barriers to access these activities, especially those with severe disabilities. We aim to analyse their experiences and those of their families in this area. We conducted a reflexive thematic analysis of 25 interviews held with young people with severe disabilities and/or their guardians from different areas of Aragón (Spain). We detected difficulties, such as access to resources, and the relevance of family support and its impact. Aggravating factors, such as being institutionalised, being a migrant or having multidisability were assessed. After discussing participants' proposals with current research, we proposed measures to improve social inclusion in the leisure of young people with severe disabilities, such as recognising the leisure assistant figure, the training for and more professionals, or the incorporation of the intersectional perspective into specialised social services.

## 1. Introduction

Leisure is a necessary area of personal and social development for the life cycle (Kristis, 2018). Some benefits that it brings include the enhancement of potential, the promotion of autonomy and self-determination, social inclusion and improved health (Pickett et al., 2022; Mary, 2014; King et al., 2014; Law et al., 2015). In addition to this is the importance of personal enjoyment and conceiving leisure as a right for all people, including those with disability (Lazcano Quintana and Madariaga Ortuzar, 2018; Gilor et al., 2017).

However, the scientific literature shows that this right is not always fulfilled in reality, and reveals how people with disabilities (PWD), especially those with severe disabilities (SD), participate less in leisure activities (Lazcano Quintana and Madariaga Ortuzar, 2018; Doistua et al., 2020; King et al., 2014). Furthermore, if such activities are carried out, they are not always done under the inclusion conditions stipulated by the International Convention on the Rights of Persons with Disabilities (CRPD) (accessibility, application of necessary adjustments, participation in equal opportunities and in the community, etc.). Some of the barriers encountered, beyond those that derive from the person's own situation, are lack of either accessibility or public resources (e.g. transport, sports activities, adapted youth centres, etc.), which tend to

generate a cost overrun (Gilor et al., 2017; King et al., 2014; Roult et al., 2019; Steinhardt et al., 2021). In addition to these issues, lack of recruited staff and volunteers trained and/or made aware of working with young people with disabilities in leisure appears, especially in rural areas (Roult et al., 2019).

This context is directly linked to the factors that Heister et al. (2023) point out as key elements to consider in the leisure participation of PWD, in their case intellectual disabilities. Specifically, they suggest 6 relevant factors: external support, especially in the case of people with SD and high support needs for carrying out basic activities of daily living; the environment in which they live, for example institutionalised people have fewer possibilities for participation; the availability of free time, outside of therapies and/or medical processes; the lack of opportunities to make autonomous decisions reduces their participation; barriers in terms of social and accessibility of leisure services; and, finally, the development of social skills and self-determination, which in turn is influenced by factors such as the support received and the environment.

As pointed out by Gilor et al. (2017), Steinhardt et al. (2021) and Mira-Aladrén et al. (2023), these difficulties are also closely related to lack of clear legislation for PWD's accessibility and leisure, which young people with high support needs suffer to a greater extent. This deficiency also has repercussions on PWD's social relationships who, as Tarvainen

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(2021) points out, often only relate to their family and other PWD, which implies encapsulation experiences. All this means that leisure often ends up being a luxury for young people with SD, especially those living in rural areas, and those who are migrants and/or women (Gilor et al., 2017; Roult et al., 2019; Steinhardt et al., 2021; King et al., 2014; Mira-Aladrén et al., 2023; Saldívar Reyes and Alvarado García, 2020; Thabethe, 2022; Huete García et al., 2016; Baird et al., 2021; Madariaga et al., 2021).

In response to these needs and attending to some of these factors, some governments have developed supportive policies. For example, the effort invested in the Norwegian welfare state has been defined to facilitate the participation in leisure of young people with disabilities. Some of its actions involve the inclusion of both personal assistants for leisure and families in the design, development and evaluation of policies (Steinhardt et al., 2021). In Israel, policies have been developed by the Ministries of Health, Welfare and Education, and at the municipal level. Thus, if someone responsible for policy development is willing, actions enhance participation. However, involving so many administrations tends to lead to lack of both coordination and budget (Gilor et al., 2017).

In Canada, policies have been designed and implemented at provincial and federal levels, such as the introduction of adapted transport services, which have led to improvements in participation and access to leisure. However, these measures tend to focus exclusively on medical issues, the organisation of adapted summer camps, financial support, adapted sports programmes or improvements in accessibility. This leaves shortcomings in transport for leisure, or they focus on issues based on an adult perspective that address formal issues like employment (Shikako-Thomas & Law, 2015). In this sense, Roult et al. (2019) voice the need for more efforts made in rural Canada by increasing its budget and the important role of work in the community.

In Spain, legislation on the inclusion of PWD (Royal Legislative Decree, 2013) recognises the right to this group's inclusion in leisure, but refers to neither young people nor young people with SD. It neither defines a holistic concept of accessibility nor specific measures (De Asis Roig, 2020; Mira-Aladrén et al., 2023). What has been legislated is the recognition of assistance dogs (Royal Legislative Decree, 2013) and their access to spaces and activities, or the right to a sign language interpreter in formal settings, such as universities (Organic Law 2/2023). Similarly, to what happens in Israel (Gilor et al., 2017) and Canada (Shikako-Thomas & Law, 2015), the leisure of young people with SD involves different specialised social services (Decree 55/2017). Of them, we highlight, on the one hand, disability services and, on the other hand, youth services, as well as the Spanish System of Care for Dependency and Personal Autonomy (SCDPA). The SCDPA has been promoted from various fields, such as disability and the elderly, and includes resources like care homes, day centres or aid for care in the family environment (Law 39/2006). The personal assistant figure is also included, although it is barely recognised in practice (only 0.5 % of the total benefits granted in Spain) (Ramírez-Navarro et al., 2023). Municipal bodies also offer leisure options in youth centres. All of this, as Lazcano Quintana and Madariaga Ortuzar (2018) point out, has generated difficulties in both participation and equal opportunities similarly to the Israeli case (Gilor et al., 2017). To improve this necessary equalisation, Doistua et al. (2020) and Lazcano Quintana and Madariaga Ortuzar (2018) are committed to the generation of intersectional, community-based and person-centred services.

“Therefore, it would make sense to strengthen the provision of inclusive and person-centered public and private leisure as a substantial element in the development of the autonomy of people with disabilities, considering that it is not a sole group, but instead each person has different needs that must be taken into account in the design of leisure offerings” (Doistua et al., 2020, p. 7).

Consequently, we asked the following questions: What are the implications in leisure activities and relationships for a young person and

their family if they have an SD? How do society and specialised social services attend to their needs? Are the demands they have as young people being met? What do young people need to improve their inclusion? According to young people's opinion and recent research, what changes or improvements are necessary to improve their inclusion?

To answer these questions, our general objective is to study the experiences of young people with SD in leisure services and specialised youth resources in Aragón (Spain) and their effect on social relationships. This objective is specified as: 1) finding the main demands and needs of young people with SD linked with leisure and relationships; 2) finding out about experiences in the Aragonese specialised services and/or leisure resources of young people with SD and their families; 3) suggesting improvements to include young people with SD in leisure activities and specialised social services.

## 2. Method

### 2.1. Research design

The present research forms part of a larger study that explores youth PWD and their families' experiences in the Spanish SCDPA by attending to the PWD's diversity and their specific needs with a semistructured interview.

Due to the characteristics of the Spanish SCDPA, which includes all persons in a situation of dependency care in the same services, regardless of their age, the study was limited to the Spanish context, and due to the great Spanish administrative complexity in the regional development of the SCDPA (Mira-Aladrén et al., 2023), the study was limited to Aragón (Spain).

Regarding the design of the study, On the one hand, we used close questions linked with socio-demographic data, and the resources that the SCDPA provides them with. On the other hand, we employed open questions linked with young PWD and their families' experiences based on quality of life questionnaires and interviews (Huertas Angulo, 2010; Sullivan et al., 2008; Dyke et al., 2013; Verdugo Alonso et al., 2012), social services quality (Parasuraman et al., 1988; García et al., 2021; Ramírez-Navarro et al., 2021; EQUASS, 2021), and their satisfaction, perceptions, feelings and needs as Huertas Angulo (2010) or Dyke et al. (2013) did in their research. The collected data were analysed by a thematic reflexive analysis (Braun & Clarke, 2021a; 2021b, 2022).

### 2.2. Study participants

#### 2.2.1. Researcher description

The researcher leader is a social worker with 13 years' experience of working with people of all ages with multiple and SD (and their families and support networks), and also in the youth field. This experience is added to her collaboration with different public and private entities in the dependency care field and to promote personal autonomy and youth care from social services. She also has personal experiences, especially with people with very severe intellectual and multiple disabilities.

#### 2.2.2. Participants

In Aragón (Spain), according to the data provided by the Aragonese Institute of Social Services (IASS), on 28 February 2022, there were 1,574 youths with disabilities and a recognised degree of dependency aged between 13 and 30. According to our research aims, the research design and our participant recruitment results, we finally interviewed 12 youth people, 12 relatives and one professional legal career from rural and urban areas, and with different disabilities and socio-demographic characteristics (see the descriptive information in Table 1). All this represents more than 1.6 % of the target population if we consider their different contexts (rural/urban) in the various provinces.

Concretely, the average age of the young participants was 24.6 years and the average age of the representatives was 56.58 years. Regarding the occupation of the young people, 9 were students, one was self-

**Table 1**  
Sample characteristics.

Case	Age	Gender	Residence	Studies	Type of Disability	Degree of disability	Behavioural problems	Dependency resource
1	20	Man	Urban	Special Education	Physical and Intellectual	97	No	Family care (FC)
2	24	Man	Urban	Special Education	Physical, intellectual and visual	97	No	Day centre (DC)
3	29	Woman	Urban	Master	Physical	69	No	FC
4	19	Man	Urban	Special Education	Physical and Intellectual	92	No	FC
5	28	Man	Urban	Special Education	Physical and Visual	92	No	DC
6	30	Woman	Rural	Do not know	Intellectual	0	No	DC
7	24	Man	Rural	Special Education	Physical and Intellectual	0	No	DC
8	27	Man	Rural	Special Education	Physical and Intellectual	0	No	DC
9*	Several	Several	Several	Several	Several	Several	–	Care home
10	29	Woman	Urban	Special Education	Physical and Intellectual	78	No	DC
11	28	Man	Urban	Special Education	Intellectual	78	No	DC
12	28	Man	Urban	Special Education	Physical, Intellectual and Autistic Spectrum Disorder (ASD)	79	Yes	Care home
13	22	Man	Urban	Special Education	Physical, Intellectual and ASD	88	No	DC
14	30	Man	Urban	Special Education	ASD	67	Yes	DC
15	30	Man	Rural	Special Education	Physical and Intellectual	72	Yes	Care home
16	24	Man	Rural	PCPI	Physical	79	No	DC
17	29	Man	Rural	Special Education	ASD and Attention Deficit Hyperactivity Disorder (ADHD)	86	Yes	Care home
18	18	Woman	Urban	PCPI	Physical and Intellectual	53	No	FC
19	19	Woman	Urban	PCPI	Physical and Intellectual	Do not know	No	Do not know
20	19	Man	Urban	PCPI	Physical and Intellectual	56	No	In hand
21	20	Woman	Rural	PCPI	Visual, Eating Disorder and Intellectual	89	No	FC
22	19	Man	Urban	PCPI	Physical	Do not know	No	Do not know
23	21	Man	Urban	PCPI	Physical and ASD	68	No	FC
24	25	Man	Urban	PCPI	Physical	82	No	FC
25	29	Woman	Urban	Year 2 Secondary	Physical	70	No	In hand (refugee status)

\* They are responsible for a guardianship service and, therefore, answer on behalf of people with different characteristics.

\*\* Initial Vocational Qualification Programmes.

employed and the rest were pensioners and their occupation focused on attending occupational workshops, day care and/or residential centres. The profile of the representatives was more varied, 26 % were workers with higher education (e.g. lawyers or architects), 23 % were retired, 20 % were unemployed, 17 % were workers and 14.3 % were care workers (e.g. residential assistant or cleaning staff). Regarding the marital status of the young people, all of them were single, except for one who was divorced. In the case of the parents, 50 % were married, 30.77 % were divorced, 3.85 % were widowed and the rest were in other types of unions or were under the guardianship of entities or administrations.

### 2.3. Researcher-participant relationship

All the interviews were conducted by the researcher leader. There was no relationship between the first author and any of the participants.

### 2.4. Participant recruitment

Most of youth PWD in Aragón (Spain) are cared for by different social entities in specialised care centres, such as rehabilitation programmes, schools, day centres (DCs) or residential centres. To gather all these views and to access the population under study and their families, contact was made with the headquarters of the Committee of Entities Representing People with Disabilities (CERMI) in Aragón (Spain), which brings together most of these entities. Through CERMI, families and young people with SD or very SD were contacted and offered the

possibility to participate in the study. To make up a heterogeneous sample, which would allow us to represent the reality of different contexts, and following a criterion of significance in an attempt to avoid biases in research, we offered and interviewed people from both rural and urban areas, and from all the provinces of Aragón (Spain).

Despite the fact that the target population of the study was formed by young PWD, a decision was made to include as informants the families of those people who, due to their SD or very SD, could not participate in the study with their own voice. In this way, they were included on the basis of their legal representatives, relatives or main carers, and on the understanding that these were fully aware of their situation and spoke on behalf of their interests. Half of all the interviews (13) were conducted in this way.

#### 2.4.1. Ethical clearance and considerations

The University of Zaragoza and the Research Ethics Committee of the Aragón (CEICA) approved the project and its instruments from an ethical point of view, in their resolution number C.I. PI22/198. No participants received financial compensation for their collaboration in the study.

### 2.5. Data collection

After contacting the young people and relatives, representatives or carers who showed an interest in participating in our study, we provided them with an informative document. We wished highlight that this document was written in their language and in an easy reading version

to facilitate access to information for people with cognitive impairments. After checking with the interviewer that they had understood all the information, they signed a written and verbal consent before being interviewed.

A one-on-one semi structured interview was conducted with all the 25 participants. The average length of interviews was 52.4 min, with the longest being 103 min and the shortest 24 min. It should be noted that the longest interviews were held with family relatives, and the shortest were with the people with intellectual disabilities and/or pervasive developmental disorders due to their characteristics. All the meetings took place in the space that interviewers decided to facilitate their participation in accessibility, conciliation and accommodation terms. Interviews were recorded and transcribed verbatim by the main interviewer.

## 2.6. Analysis

### 2.6.1. Analytic data strategies

The conducted interviews were analysed by the reflexive thematic analysis approach (Braun & Clarke, 2021a; 2021b; Braun & Clarke, 2022) which, in a simplified manner, involves a systematic process of data coding to identify any patterns in the data and/or to provide a theoretically informed interpretation of these patterns (Braun & Clarke, 2022). Following the aforementioned approach, experiential orientation to the data analysis was adopted. This meant that the analysis sought to acknowledge the social nature of the research topic when examining the participants' subjective 'personal states'. In the reflexive thematic analysis, the literature review firstly provided us with the initial lens to our analysis from a deductive approach, which was meaningful to the research questions. Hence a predominantly inductive approach was adopted using an 'open-coded' method to best represent the meaning as communicated by the participants. This was followed by an iterative process of refinement and a reflexive thematic analysis. The focus of the meaning was placed on the explicit or manifest level of data.

All this provided a thematic analytical framework agreed with by the research team, and involved several phases in this process (Braun and Clarke, 2022), such as familiarisation (deeply familiar immersion with dataset content); coding (identifying data segments by capturing specific meanings systematically and thoroughly that are relevant to the research question); generating initial themes (identifying shared patterned meaning across the dataset; describing broader meanings); reviewing and developing themes (assessing that candidate themes make sense in relation to coded extracts); refining, defining and naming themes (finely tuning themes by deciding names); writing up (integral completion and final inspection of the report). Each interview was (re) read and coded by the first author according to this framework using the MaxQda 2022 software.

### 2.6.2. Methodological integrity

First of all, our research followed elements of methodological integrity and reporting standards (Levitt et al., 2018; Levitt, 2020), as well as criteria for a good reflexive thematic analysis (Braun & Clarke, 2022). According to adequacy (Levitt et al., 2018), our initial research and the created semistructured instrument not only allowed us to analyse the experiences, opinions, feelings and beliefs of PWD and their families, but to also explore any concepts linked with more intersectional factors like living in rural areas, being women, having more than one disability or being a migrant. Hence qualitative research, such as a reflexive thematic analysis conducted with an intersectional framework, may contribute to address the diversity of PWD and their specific needs, while also providing participants a voice (Braun & Clarke, 2021a; 2021b; 2022).

Secondly, due to the characteristics of the qualitative method, we had to manage our researchers' perspectives (Levitt et al., 2018). Indeed we had to adapt our instrument to attend to people with cognitive disabilities, but with oral communication, by: easy reading methods or with

longer oral explanations; our questions being adapted to every specific situation by amplifying them with questions about the migrant condition; adapting the response form to a person with oral communication problems, but with cognitive ability to, thus, adapt the instrument to closed responses that could be answered by blinking when participants agreed.

Thirdly, we wish to point out some limitations in our method in fidelity and utility terms. Given the special data protection relating to health, disabilities or special educational needs, there are restrictions on access to the study population that could reduce access to part of the population or condition their participation. Furthermore, considering that quantitative correction factors cannot be applied to qualitative studies, the findings of this study can only be attributed to the studied subpopulation, without generalising all the young people with SD in Aragón (Spain) (Flick, 2018).

## 3. Findings

Throughout our analysis, several themes and subthemes emerged that cut across interviewees' experiences, which were expanded upon during the process of reading and iteration, namely: intersectionality and its subthemes (rural, multidisability, migration and women); the subtheme about changes in the concept of youths throughout history; the subtheme of autonomy and self-determination in relation to the leisure and personal relationships theme; the subthemes that helped to understand those initially raised (negative experiences, positive experiences, lack of awareness) and were incorporated into the initially raised themes and subthemes. Both the initially defined themes and the subsequently developed subthemes and themes (See Appendix 1) are analysed and related in depth throughout this section.

### 3.1. Youth

Firstly, some questions were posed: what is it to be young, what are its implications, what demands and needs does a young person have, and what about a young person with SD? In response to these questions, it should be noted that, in the definitions of youth, there are several cases which stress that it is not possible to define what a young person is at present given that the person interviewed or their relative is living a different kind of youth to that of a person without disability. Notwithstanding, youth was mostly defined as a time of transition that is exciting with learning and experimentation, and if highly relevant for the peer group, with a desire for independence, new activities and getting to know new places. Youth PWD talked this way about young adulthood:

"That vital stage in which we have to explore our limits and start connecting with adult life." (Reporter 3).

"It's a fun time when new things happen. Things change in your life, when you'd like to have friends and go out. You want to be independent and live with friends. And you have lots of friends" (Reporter 2).

However, in addition to these issues that emerge in youth, difficulties also came over that did not exist in previous stages, such as adults not listening, lack of financial resources, problems in accessing housing, employment, or specialised social services for youths, leisure and free time, as well as the effect of the environment on the creation of one's own identity, also emerged in both the PWD and proxy groups. In addition, most of the participants have a few or no friends without disability.

"For example, youth centres have all these types of resources, but I don't think that nowadays they take into account the disability perspective at all (the resources). So on the one hand, yes, but on the other hand no. (...) I think that, to a certain extent, they are not taken into account enough to really enhance young people's capacities because I think that they are also somewhat in no man's land. We're

not kids, but we're not adults yet. So you find yourself in a bit of a limbo" (Reporter 3).

"Now we don't have enough money to live in flats" (Informant 6).

"Well, you have to have a job, finish your studies, which isn't easy for young people" (Reporter 21).

In addition to the general difficulties, some difficulties inherent to certain diseases that generated their disability came over, along with physical and communication barriers. For young PWD and their representatives, there were also attitudinal barriers that complicated their situation, as well as the need for a support person, who was often a family relative and, therefore, as PWD told, interfered in their relationships with their peers.

"Associated with disability, from difficult access to leisure resources due to architectural barriers, or even because your condition means you can't access these social barriers. I'm sorry, but people without the disability condition don't have to get over, for example, people looking or people's direct judgements, or people's comments or verbal aggression (...) When it comes to participating in activities, I'm allowed to go as a user, but no-one understands that I can also offer to be a volunteer or organiser because I have a disability" (Reporter 3).

"That's OK, but now they tell me that I have to find a room, but I can't find one with the money they've given me, which isn't much at all. It's impossible to find an adapted room, it really is. Sometimes I find a room with a lift to it, but its shower is very narrow, so I can't even get in it" (Reporter 25).

"She has always wanted to, she has fought for herself, because she wanted to do a course, like the laundry course. It was difficult for her because she was picked up at 7 in the morning for the laundry course, but I got her up at 6 in the morning because she had a problem with urine and nappies, she had to take a shower. At 6 in the morning in winter she'd take a shower before going to the course, and instead she went (...) perhaps she'd have liked it better, maybe, like you have done, to go out with other young people and get around, which she could not do. Now that she's a bit older, you can leave her alone for a bit, but she normally always to be with her mother or father, with one of us, always with her parents. So maybe she would have been happier if she could have gone out with other friends, with other friends. So, she hasn't been able to do what normal young people do" (Reporter 10).

"He's not even like other colleagues with less severe disabilities, who can express themselves and say I want to go to a bar or I want to go on an outing or see the football. He doesn't know if he wants to, or even knows what it is; he likes going out a lot, and likes to go for walks, but not other things, and it depends on what things. Being in places with lots of people is very stressful for him. He gets very nervous, so things have to be quieter, less stressful. Other kids of his age may like going to a party, going out, as you say, but he can't stand that. (...) It's what the others did, but not him. They did cook workshops and he did well with that because he loves eating. He has circulation and vascular problems, but now he's lost weight, but if it isn't a cooking workshop, he looks like a statue, I speak for him, but it's what I perceive (Reporter 12).

### 3.2. Leisure and personal relationships

When facing these difficulties, demands and needs to be emerged by focusing mainly, for both families and young PWD, on inclusive leisure, education to address the issues of transition to adult life, the option of adapted housing and jobs, and also volunteering.

"I think that you need educational foundations to really work on those pillars that will later enable us to perform in adult life. I think that there are still some pillars today that are not as basic as they should be. For example, in sex education terms for young people or

other leisure activities. I believe that specific resources are needed, not only to take into account the adaptation factors that you will need to be able to enjoy them, but also to train professionals in the field to carry out inclusive leisure activities from a basic level. And I also think they should be accessible in terms of both architectural accessibility and economic accessibility because we also have to be aware of this factor and, in the end, be able to pay for all the services we need often makes it difficult for us to have money to access other types of resources, and perhaps this applies even more for young people. If I have to choose between going to for physio or to a dance class, I have to prioritise my direct physical health and not my social health. But I think they should be subsidised as well" (Reporter 3).

"More supervised flats (...). I think that encouraging deinstitutionalisation, eh, support, which is already underway, isn't it? But the power that the administration can favour this, well, in terms of young people is fundamental because that's what everyone is asking for" (Reporter 9).

"To be in a place where he can be adapted to for those 4 h during which he could do a job without it being a martyrdom for him because I don't think he could work 8 h. So, he can continue with what he now has at the centre; his usual friends, the people he loves, the people he shares with, whom he wants to be with" (Reporter 16).

"Well, a volunteer could also come and go with children or take three children out for a walk somewhere. It's a job that monitors (at the care home) can be more organised and then they, these volunteers, see that they can look after them and take them to the places, place themselves at their level as well" (Reporter 17).

Moreover, these situations were experienced differently depending on the resource granted in the SCDPA. For example, it was detected that PWD in care homes mentioned fewer problems in the subthemes linked with accessibility, social rejection and awareness, with general difficulties for young people. All of this is linked with the fact that care homes are accessible environments and leisure activities are carried out in the same resource. However, this does not mean that they are any less isolated because they are places where there is only PWD, with 24-hour care every day of the year, and with leisure activities that are planned and defined by the service itself, within its possibilities. This last issue had an impact on the subtheme self-determination and affected their social relationships and experiences for both families and young PWD:

"In quality of life terms, well, I don't know. They form their groups, but then institutionalised people also move a lot be's complicated in centres, a bit like being in prison. Here, well... Yes, there are people who have been institutionalised all their lives. That's why they move around, they grow closer to one another because it suits them. And they are afraid of one another. I mean there are roles, positions, right?" (Reporter 9).

Of the analysed issues, day centre users and people with care resources in the family environment coincide about the importance of the timetable in which an activity is carried out. As commented by the representatives, it is sometimes an added cost because it is not included in the services offered by the resource. Nor is not offered during the hours when professional careers are available. In these cases, family relatives must resort to complementary private resources or even to their own overload.

"We are lucky to be able to count on Y, who is their support person (hired by the family), but when Y can't come because it's not from Monday to Friday, it's the weekend, because it's outside the usual hours, because, for example, tomorrow there is a cinema session from 19.30 h to 21.30 h, Y has a schedule. If we want X to go or if he wants to go, Y will start and then I will follow. (...) Another thing that I have also mentioned is that there are many articles in accessibility issues; in the Law I think that it's about people with disabilities, I think that (Article) 50 is about support dogs and (Article) 35 is about support people. The issue of support dogs has been



regulated, but the issue of support people has not. I say let's see if support people are given the same rights as support dogs. It costs twice as much for a ticket" (Reporter 2).

Based on the above, the family was, therefore, seen as a key support in enabling young people with SD to access leisure activities. It was even recognised by the families themselves that their status in the community could directly influence their ability to access these activities.

"Because I also believe that he's been in a family that has received resources, we are recognised in the society around us and our son is also recognised because this depends on the circle in which parents move. He has a very good relationship, very good vocabulary, and he can relate very easily. He has his friends wherever he goes, he can talk to people. I go to concerts with him, (...) with the people we surround ourselves with or with whom we've always felt supported, loved and valued; always" (Reporter 16).

### 3.3. Intersectionality

#### 3.3.1. Multidisabilities

Considering the intersectional issue, these barriers increase; for example, for people with multiple disabilities because one of the disabilities is addressed, but not the sum of several, which breaks down only some of the barriers that may be encountered.

#### 3.3.2. Migration

With migrants, especially those without a family network in a city, this situation sometimes means that these people have an informal support network and more limited social relationships because they lack opportunities to meet people. This also means that, as PWD said, they do not leave their homes at weekends or, if they do, they do so alone or, if they are accompanied, they do so with their immediate family. These experiences are perceived as not only a negative experience, but also as lack of opportunities to meet resources or to learn the language. For example:

"There should be activities designed for people with severe disabilities, not for people with disabilities. Because we always try and look for normal activities, we adapt to them as best we can (...) For example, we go to the theatre, but we can't go on stage because there is no ramp. They should think about adapting all cultural sites, at least are important ones. And also activities because, what's the point of being able to enter a building if the service or activity isn't adapted? For example, campsites with an adapted bus, but you can't go, so why do I want an adapted bus?, Do you understand? And why do I want an adapted building? And why do I want to be asked if I'm allergic to food or they tell you that you can't come? Because we don't have support people, because we can't communicate with you, because we don't... access doesn't only involve kerbs" (Reporter 2).  
 "I'd like to go out, but I still don't have Spanish friends. I have friends from my country, but they all have their own problems or are far away or...you know? At weekends, I sometimes don't go out and, if I do, I go for a walk and come back home" (Reporter 25).  
 "I don't have friends. I only have friends here, only in class and I talk to them, but I don't go out much with them. I do go out is with my mother and my family. I like going out with friends a lot, and I can also learn more Spanish" (Informant 22).

#### 3.3.3. Rural environment

With regard to rural areas, it was observed that representatives and PWD on the one hand stated that their experiences were more influenced by issues, such as climate, distance or the existence of fewer resources. But, on the other hand, the experience in rural areas was more inclusive in those cases where it was possible to participate. Smaller communities extended the informal support network of friends, although more

volunteers were needed for care and support tasks, which was particularly relevant for families of people with behavioural problems and multiple disabilities.

"With snow, it was very difficult. The road has been bad these days and has been closed several times. A colleague had to turn around because it was impossible to come up here and he had to turn back. Tomorrow it will snow again. Weather makes it easy or difficult" (Reporter 8).

"It's not that we don't have anything, what we don't have anything is leisure. He goes to football and with another friend to mass on Sundays because he sings there with the man who plays in the choir, things like that. But always in public things and like any other person, but also because he has that ability. Another child who wanted to do with another type of disability or less cognitive ability couldn't, and couldn't be so integrated" (Reporter 16).

"Here there is the volunteers' issue. There are always very few of them and if you look for someone, as I was saying, you usually pay and, of course, it doesn't matter because the people who can afford to with to see their child happy, you do whatever, of course, but the problem is that there are no people (...), there's nothing, it's true. In the care home, the only thing I know is that there's a girl who goes up there one day a week to paint with residents. There's nothing else. That's all (...) In this town, lack of people is marked, I just stood still when I saw so many volunteers in the capital, but where did they come from? Of course, I imagine that there must be volunteers in cities, but here I don't know. It's very difficult" (Reporter 17).

### 3.4. Proposals

Finally, regarding the issue of proposals, it should be clarified that all the proposals made by the interviewed people were linked with the issues discussed above. For example, recognising the support person with access to leisure spaces and activities, the promotion of specialised social services from an intersectional perspective, training and awareness-raising, or improving accessibility.

## 4. Discussion

Social relationships, leisure, the possibility of experiencing and getting to know new places are fundamental aspects of the youth stage of the life cycle, including PWD (Pickett et al., 2022; Mary, 2014; Law et al., 2015). We, therefore, set out to learn about the experiences of young people with SD, who are often discriminated in this field, and in relation to the proposed themes of youth, leisure and social relationships and intersectionality. As our results show, youths are perceived by the reporters as a time of change and personality formation during which these experiences favour the development of one's own identity as a recognised right for PWD (Royal Legislative Decree, 2013).

Nevertheless, according to our results, and in line with previous studies (Gilor et al., 2017; Steinhardt et al., 2021; Roullet et al., 2019; Shikako-Thomas & Law, 2015), it is not always easy to be young, especially if you have SD. The main barriers to enjoy leisure are related to: lack of accessibility; high cost of services; lack of an adequate offer of activities by both specialised youth services, which do not meet the needs of young people with SD, and disability and dependency services, which focus more on traditional care or carrying out activities in the centre itself than in the community. Furthermore, in DCs and for school resources, daily activities are demanding in effort and time terms, which implies lack of participation in leisure activities, as suggested by other studies like that by Steinhardt et al. (2021) or Heister et al. (2023). Consistently with previous results, our study has shown that during activities, PWD are conceived as users, and not as leaders, which implies discrimination (Aparicio, 2016).

Of these difficulties, we detected factors that may be facilitators or barriers for young people with SD to participate. Firstly, family support

is presented as a key variable in its promotion, which coincides with previous studies (Madariaga et al., 2021; Steinhardt et al., 2021; King et al., 2014; Shikako-Thomas & Law, 2015). In addition, the social position of the family in the community was also suggested to influence available leisure and relationship opportunities. This support also entailed, on the other hand, time constraints for family relatives and caregivers and, on the other hand, the obligation to pay double to perform an activity to pay the support person's assistance. These difficulties have been highlighted in many studies, such as Gilor et al. (2017), King et al. (2014) and Roult et al. (2019) and Steinhardt et al. (2021), who refer to the support staff implemented by Norway to improve this situation.

In accessibility terms, design from adult perspectives, high costs, travel or the complication of growing older have already been mentioned in previous studies (Gilor et al., 2017; Heister et al., 2023; Roult et al., 2019; Steinhardt et al., 2021; Doistua et al., 2020; Lazcano Quintana and Madariaga Ortuzar, 2018; Shikako-Thomas & Law, 2015). In our case, other issues were addressed, such as being institutionalised that facilitated accessibility, but not inclusion, as pointed out by Heister et al. (2023), or having multidisabilities, which meant that not all accessibility needs were met (people can enter, but cannot participate), this factor is linked to what Heister et al. (2023) refer to as Body and Mental Functioning. Finally, the rural environment is perceived as a barrier because resources and volunteers are scarce, and transport is difficult, which coincide with Roult et al. (2019), but there is the capacity to more easily generate informal support networks. All these generated situations in which participants only related to their family and other PWD, as Tarvainen (2021) previously indicated by defining it as an encapsulation experience.

Faced with these situations, reporters also proposed policies to be developed to improve access to inclusive leisure for young people with SD, among which the most important are firstly, regulating access, availability and recognition of the support person to leisure, as in Norway (Steinhardt et al., 2021). In this way, PWD would be able to attend activities without their family members, improving a better relationship with peers and favouring their autonomy and self-determination. It is particularly striking that in Spain these support persons have to pay the participation fees, when they are a necessary condition for the person with a disability to participate, thus adding another economic barrier for young people with SD.

Secondly, with regard to specialised social services, they propose that they should be intersectional and person-centred and also improve their coordination, in agreement with Doistua et al. (2020), Lazcano Quintana and Madariaga Ortuzar (2018), Roult et al. (2019) or Gilor et al. (2017) and Shikako-Thomas and Law (2015). That is, that services for young people, for PWD, for people in a situation of dependency, consider that, in addition to being young people, they have a disability or that they may have more than one disability and that they not only have needs due to a situation of dependency but that, in addition, they have needs as young people. They demand that these services be prepared to be able to attend to them by promoting networking and taking advantage of the resources already available in each of the welfare systems. Although in the Spanish case this is complicated by the rigidity of these systems and the territorial and administrative organisation of the country (Mira-Aladrén et al., 2023).

Linked to the above, informants also proposed improving accessibility in spaces and access, which is also economic, and the design of the

activities themselves, as suggested by Gilor et al. (2017), King et al. (2014) and Steinhardt et al. (2021). Thus, it is not enough to provide a ramp to access the Community Centre, it is also necessary that the activity is adapted to the person who will attend (e.g. giving more time, facilitating access to the front row or speakers to notice the vibrations, explaining things in easy language, being able to mobilise, having augmentative and alternative communication tools or understanding the specific stereotypes and needs of the people who attend). But this requires an increase in budgets and trained staff, as suggested by Doistua et al. (2020), Lazcano Quintana and Madariaga Ortuzar (2018), Gilor et al. (2017), Shikako-Thomas and Law (2015) and Roult et al. (2019).

Finally, informants, especially families, stressed the need to promote volunteering and community awareness to facilitate knowledge of the reality of PWD and their demands and needs, in line with Gilor et al. (2017), Steinhardt et al. (2021) or Pickett et al. (2022). All this considering that young people with SD are users, but they should also be able to be protagonists, and even volunteers, as part of an activity.

Thus, in order young people with functional diversity to enjoy leisure as a right and social conquest, it should be taken into account that there are many barriers and the role of the family and specialised social services is fundamental. Both require improvements and support from a holistic, coordinated and intersectional perspective. In short, care for young people with SD must go beyond traditional care, and must include the perspective of the CRPD social model.

A series of implications for practice and social policies are derived from these conclusions. These include the need to promote a social model and person-centred care, in which the person can participate in the design of their life project. In this sense, the offer of leisure services for young people with SD should be increased, training professionals in youth services, providing them with resources to make the necessary adaptations and considering the inclusion of the proposals put forward in this research. Furthermore, in the field of social work, professionals should consider the factors mentioned in this article when recommending a SCDPA service, in such a way as to achieve the greatest possible inclusion and participation, but also to support the family, avoiding overloading them and facilitating their work-life balance.

This work raises future research lines into the needs of specialised social services to be able to: support these young people: study the possibilities for leisure and personal relationships offered by new technologies and their accessibility, especially for those who cannot leave their homes; investigate the improvement of the participation of young people with SD in the design, evaluation and planning of services.

## Funding

We acknowledge financial support from the Government of Aragón (Spain) with a grant to recruit pre-doctoral research staff in training for the period 2020–2024. The edition of this article was funded by the Department of Science, University, and Knowledge Society of the Government of Aragón (Spain), in charge of the reference research group Wellbeing and Social Capital (project number: S16-23R).

## Declaration of competing interest

The authors declare that they have no known competing financial interests or personal relationships that could have appeared to influence the work reported in this paper.

## Appendix 1. . Themes and related subthemes from the thematic analysis

Theme/subtheme	
1. Proposals	Proposals expressed
2. Youth	Youth experiences
2.1 Changes	Changes experienced in youth
2.2 Concept	Definition of youth
2.2.1 Changing	Changes in the concept of youth until the present-day
2.3 Demands And Needs	Demands and needs detected
2.4 Specific Difficulties	Difficulties specific to the stage of youth with disabilities
2.5 General Difficulties	Difficulties experienced by youth
3. Leisure and personal relations.	Experience in the field of leisure and personal relationships
3.1 Social Rejection And Awareness-Raising	Experiences of rejection
3.1.1 Negative Experiences	Experiences of social rejection.
3.1.2 Positive Experiences	Experiences with no rejection or third-party advocacy.
3.1.3 Lack Of Awareness	Experiences and claims of lack of awareness and empathy from the rest of society.
3.2 Accessibility	Accessibility of leisure resources (cinema, amusement parks, bars, youth centres, etc.)
3.3 Autonomy And Self-Determination	Ability to develop leisure plans and/or plans with friends
3.4 Support	Support for leisure services and resources
3.5 Friendships	Experiences with friends
3.6 Resources	Possibility of accessing leisure resources
4. Intersectionality	Comments on the cross-checking of socio-demographic variables
4.1 Rural Environment	Experiences from small towns or villages
4.2 Multidisabilities	Having more than one type of disability
4.3 Women	Being a woman with a disability
4.4 Migration	Being a migrant with a disability

## Data availability

The authors do not have permission to share data.

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