Dependency care and promotion of personal autonomy: an analysis of young people with severe and serious disabilities in the Aragón context

Atención a la dependencia y promoción de la autonomía personal:
un análisis en jóvenes con discapacidad grave y severa en el contexto aragonés

Marta Mira Aladrén

CONSEJO ECONÓMICO
Y SOCIAL DE ARAGÓN

CONSEJO ECONÓMICO Y SOCIAL DE ARAGÓN
COLECCIÓN TESIS DOCTORALES

Premio a tesis doctorales 2024

Autora de la tesis doctoral:
Marta Mira Aladrén

Directores de la tesis:
Marta Gil Lacruz
Javier Martín Peña

Calificación obtenida:
Sobresaliente *cum laude*

2024

Imagen de portada: www.freepik.es
Esta publicación se edita únicamente en formato digital.

Consejo Económico y Social de Aragón
c/ Joaquín Costa, 18, 1º
50071 Zaragoza (España)
Teléfono: 976 71 38 38
cesa@aragon.es
www.aragon.es/cesa

Premio del Consejo Económico y Social de Aragón a tesis doctorales 2024

El Consejo Económico y Social de Aragón, con el fin de promover y divulgar la investigación, convoca anualmente Premios a tesis doctorales, en cuya convocatoria del año 2024, efectuada por Resolución de 28 de junio de 2024, de la Presidencia del Consejo Económico y Social de Aragón (*Boletín Oficial de Aragón* número 134, de 11 de julio de 2024), pudieron participar los autores de tesis doctorales presentadas para la colación del grado de doctor leídas y calificadas de sobresaliente *cum laude*, por unanimidad, entre el 16 de septiembre de 2023 y el 15 de septiembre de 2024.

Por Resolución de 3 de diciembre de 2024, de la Secretaría General de la Presidencia (*Boletín Oficial de Aragón* número 241, de 13 de diciembre de 2024), se otorgó el premio del Consejo Económico y Social de Aragón 2024 a tesis doctorales.

El premio, con una dotación económica de 3.000 euros, se otorgó a la tesis doctoral *Dependency care and promotion of personal autonomy: an analysis of young people with severe and serious disabilities in Aragón* (Atención a la dependencia y promoción de la autonomía personal: un análisis en jóvenes con discapacidad grave y severa en el contexto aragonés), realizada por doña Marta Mira Aladrén.

La Comisión de valoración, que propuso por unanimidad la concesión del Premio, estuvo compuesta por los siguientes miembros del Consejo:

Presidente:	D. Juan García Blasco
Secretaria:	D.ª Belén López Aldea
Vocales:	D. Ángel Luis de Val Tena
	D. Pablo Castillo Morales
	D. Daniel Forniés Andrés

Dependency care and promotion of personal autonomy: an analysis of young people with severe and serious disabilities in the Aragón context

Atención a la dependencia y promoción de la autonomía personal: Un análisis en jóvenes con discapacidad grave y severa en el contexto aragonés

by

Marta Mira Aladrén

Supervised by
Dr. Marta Gil Lacruz
Dr. Javier Martín Peña

Doctoral Programme in Sociology of Public and Social Policies
University of Zaragoza
Zaragoza, 2024

CESA
CONSEJO ECONÓMICO
Y SOCIAL DE ARAGÓN

DEPENDENCY CARE AND PROMOTION OF PERSONAL AUTONOMY: AN ANALYSIS OF YOUNG PEOPLE WITH SEVERE AND SERIOUS DISABILITIES IN THE ARAGÓN CONTEXT

MARTA MIRA ALADRÉN

All the work described in this thesis was carried out in the Department of Psychology and Sociology (University of Zaragoza), under the supervision of Dr. Marta Gil Lacruz and Dr. Javier Martín Peña and financially supported by the Government of Aragón (Spain) with a grant to recruit pre-doctoral research staff in training for the period 2020-2024.

Illustration by Santiago Álvarez.

A Paola

AGRADECIMIENTOS

Con este texto parece que termina una aventura que no ha sido fácil, pero sí muy enriquecedora. Una aventura en la que me han acompañado y guiado Javier y Marta, mis directores, que no me han dejado sola y gracias a eso ha sido un poquito más llevadera. Gracias por pensar que merecía la pena hacer conmigo este camino y acompañarme, incluso en la laberíntica burocracia y el sprint final.

Una aventura que me ha llevado muy lejos gracias a la colaboración de Ana e Isabel, del Grupo de Investigación Bienestar y Capital Social, gracias a ellas conecté con un lujar que me llegó al corazón, Ibagué (Colombia). Gracias a Juan José, a Mónica, a Daniel, a Marcelita, a Ricardo, a Edgar, a Claudia, a Bibiana, a Sandra, a Elsa, a Mauricio, a Brenda, a Daniel, a Nico, a Lina, a Argemiro, a Alejandro, a Rosita, y a todas las personas que me acogieron, me hicieron probar y amar el café, los tamales, la lechona, el arequipe, el sancocho y las frijoladas de los jueves. Incluso (casi) consiguieron que superará mi miedo al tráfico de allá. Pero, sobre todo, me ayudaron a hacer hogar muy lejos de casa, gracias.

Pero esta aventura no ha sido un sprint, sino una carrera de fondo, una larga expedición en la que siempre es necesario contar con un campo base, mi querida Facultad de Ciencias Sociales y del Trabajo. La que se convirtió en mi segunda casa y donde palabras como sororidad, apoyo mutuo, empatía y compañerismo cobran sentido, especialmente de la mano de Pilar, Diana, Mª José, Raquel, Sandra, Mª Esther, Paula, Ramón o Diego, entre otros, que seguro que me dejo de poner aquí pero que sabéis que os agradezco igual. Que me dio un lugar en el que conocer a grandes mujeres que, como yo, estaban en la aventura que supone iniciar la carrera académica, las ya doctoras, Raquel y Marta, que me acompañaron en mis inicios; Mar, que llegó para recordarme la ilusión con la que empecé y darme fuerza en el empujón final; y Sonia y Mercedes, con quien reír, llorar y celebrar en paralelo me hizo sentir arropada cuando más frío hacía. Una casa en la que entrar por la puerta y cruzarme un "buenos días" y

una sonrisa con mis compañeros de conserjería, hasta que, en muchas ocasiones, también, "me echaban" de mi despacho esperando que pudiera descansar antes de volver. Gracias por vuestras sonrisas y cariño. Un centro que, también, servía de punto de avituallamiento, tanto de alimento para el cuerpo como de cariño. Contar con unos compañeros de cafetería que me dieron de comer, casi más que mi madre en todos estos años, con Gerardo como cara visible, que desde el 2016 has sido capaz de hacerme reír, consolarme, acompañarme en mi luto por el gluten e, incluso, descifrar si necesitaba té, coca cola o cerveza, y lo que ello suponía sólo con verme la cara. Gracias por alegrarme los peores días y celebrar conmigo los mejores.

Y es que esta aventura comenzó mucho antes, cuando Angelica, el Zuli, José Miguel, Marisa, Olguica, y, sobre todo, Fer y toda la OUAD y estudiantes que han pasado por ella me descubrieron que esta aventura era posible. Que podía dedicarme a investigar y a disfrutar de la Universidad, más allá de venir a clase. Que la Universidad era una comunidad en la que crecer a muchos niveles y que debía aprovecharlo, porque, de verdad, pensabais que podía hacerlo. Gracias por confiar en mí (incluso cuando yo no lo hacía), por hacerme sentir compañera y amiga (cervezas y vínicos incluidos) y por enseñarme todo lo que podíamos hacer juntos. No siempre es fácil encontrarnos, pero siempre puedo contar con vosotros. Gracias.

Y si el inicio es importante, contar con un mapa y una brújula es indispensable, para eso estáis vosotras, Aza, Ceci, Angelical, Santi, Yorkie y Anyu. Gracias por hacerme cuestionarme y cuestionar el sistema, por ayudarme a ser mejor profesional y, sobre todo, por ayudarme a ser mejor persona. Gracias, también, por esas conversaciones en las que todas decimos estar bien, hasta que encontramos la tecla que tocar para romper nuestro caparazón. Porque sabemos que ese es nuestro lugar y momento seguro en el que no nos vamos a juzgar, vamos a hablarnos desde la empatía y a ayudarnos siempre que podamos, incluso cuando no nos gustan las decisiones que tomamos. Gracias por llegar a mi vida acompañadas de Andrés, de Sarita, de Irene, de Bea, de Concha y de un montón de tigretones maravillosos de los que no parar de aprender y querer. Gracias por las experiencias, la falta de sueño, los enfados, los abrazos, las risas, los lloros, los chistes malos, y, ante todo, por mucho amor.

Esta aventura no sólo ha sido un camino de amor y felicidad, también ha tenido muchos momentos duros, de repensar si merecía la pena, de frustración y de cansancio y es ahí donde descubres que no todo el mundo es capaz de estar a tu lado y que poca gente sabe hacerlo bien. Necesitas unos bastones fuertes que te sirvan de apoyo. Gracias Julio por ser uno de esos apoyos fundamentales, por estar conmigo en las celebraciones, pero, también, en mis momentos más vulnerables. Por hacer de psicólogo, de cocinero, de supervisor, de enfermero, de payaso de la tele, de compañero de viajes, y muchas otras cosas más, y por hacer todas ellas desde el amor y el respeto. Gracias por quererme y entenderme, porque sé que no siempre ha sido fácil. Y gracias, también, a Carmen, a Clara y a Sarica, porque sé que han compartido conmigo esta aventura como si fuera una más y que, en gran medida, eres así por ellas. Gracias.

Por último, para que una aventura salga bien, también, es importante llevar una buena mochila, que lleve lo necesario para superar los llanos y las praderas verdes, pero, también, los páramos, las subidas duras y los tramos de piedras. Todo eso es sin duda mérito de mis padres, José Miguel y Palmira, y de mi hermana, Pilar. Ellos me han dado la mejor herencia que puedes recibir, la que nunca nadie te va a poder arrebatar y la que recibes en vida: educación y amor. Gracias por ser el mejor ejemplo a seguir, por estar siempre a mi lado, por ayudarme a ser mejor persona, por enseñarme a ser autosuficiente, a quererme y a querer. Gracias por darme la vida y enseñarme a vivirla. Os quiero mucho.

Pese a todo esto no toda la aventura ha salido como esperaba. Empezó con un adiós a una de las mujeres más importantes de mi vida, quien me enseñó que hay muchas formas de cuidar y amar, que mientras algo me hiciera feliz, lo llevase a cabo, aunque el resto no lo entendiera, y que, como buen ángel, me dio alas. Gracias yaya. Y casi terminó con un adiós a mi compañero de aventuras y mimos, ese por el que entrar en casa tenía aún más emoción. Una despedida que dejó a mi familia un poco más cojita. Gracias Pipo, por echarme una pata siempre que lo necesité, nunca te olvidaré.

Y es que esta aventura parece que ya llega a su fin, pero también será el inicio de todas las aventuras que me queden por vivir con esa pequeña revolución que con una sonrisa consigue que se me pasen los males, Miguelinchi. Gracias por llegar cuando más te necesitábamos. Porque no puedo decir que sea el principio ni el fin de mi aventura en la investigación, ni mucho menos en el buscar la inclusión. Porque esta aventura comenzó el 28 de marzo de 1994 cuando llegó a nuestras vidas la mejor maestra que alguien puede tener. Esa persona que sin decir nada es capaz de decirlo todo, que sabe exactamente qué y cuándo lo necesitas y que es mil veces más capaz que muchas de nosotras para hacer lo que de verdad importa: vivir y amar. Gracias por enseñarme a ver la vida desde otras perspectivas, escuchar sin voz y hablar con los ojos. Gracias por ser cómo eres, simplemente Paola. Y gracias, también, por haberme empujado, junto a tus padres, a hacer este trabajo que me ha llevado a escuchar a personas (casi) tan geniales como tú. Personas generosas que, a través de la ayuda de CERMI, Valentia, Araprode, Fundación DFA, Fundación Lacus, etc., han compartido conmigo sus historias. Aunque no os puedo nombrar una a una, vuestros rostros aparecen cada vez que escribo o leo. Sólo espero poder devolveros un poquito de lo que me habéis dado, porque la aventura continuará mientras sea necesaria. Gracias de todo corazón.

RESUMEN

A los jóvenes con discapacidad grave y severa que requieren del apoyo de una tercera persona para la realización de las actividades básicas de la vida diaria se les atiende en España tanto desde los servicios sociales especializados en discapacidad, como desde el sistema de dependencia. Pese a ello, y a la apuesta desde las políticas públicas y sociales por un modelo social y de derechos de la discapacidad, el catálogo del sistema de dependencia no contempla diferencias en la oferta y adaptación de los servicios y prestaciones atendiendo a las necesidades y demandas de las personas, cambiantes a lo largo de su ciclo vital.

En virtud de ello, el objetivo central de esta tesis doctoral es analizar la intervención realizada desde el ámbito público y social aragonés para la atención a los jóvenes con discapacidad grave y severa y sus familias. Así se pretende inferir posibles mejoras a las mismas, desde la perspectiva de la inclusión y la aplicación de la Convención Internacional de los Derechos de las Personas con Discapacidad.

Consecuentemente, mediante diferentes técnicas de investigación cualitativa se trata de lograr la consecución de los objetivos planteados. Primero, un análisis de contenido de la legislación aragonesa; después, una revisión sistemática de bibliografía, centrada en la evaluación; y, por último, dos análisis temáticos (uno centrado en los recursos y otro en las relaciones sociales) de entrevistas realizadas a 25 jóvenes con gran discapacidad y/o sus tutores de Aragón.

Los principales resultados de esta tesis doctoral señalan que, pese a haber un compromiso con la inclusión de las personas con discapacidad, las regulaciones e intervenciones no contemplan la diversidad propia de este colectivo tanto en situaciones de discapacidad como en necesidades propias de su desarrollo humano o factores sociodemográficos. Además, pese a que la normativa internacional indica la necesidad de apostar por la perspectiva del modelo social y de derechos de la discapacidad, los datos recabados a lo largo de esta tesis nos muestran que el diseño y desarrollo de las políticas destinadas a este colectivo están focalizadas en aspectos específicos, como la salud, la rehabilitación, la educación obligatoria y el empleo, dejando a un lado aspectos como el ocio, las relaciones interpersonales, el deporte o la cultura. Se deberían considerar factores que incrementan las dificultades experimentadas, como son ser joven, tener grandes necesidades de apoyo, estar institucionalizado, ser migrante, tener pluridiscapacidad o vivir en el medio rural. Por último, los resultados de la tesis han evidenciado que en las políticas públicas planteadas se generan diversas brechas burocráticas e institucionales en el momento de la juventud, repercutiendo en la calidad de vida de los jóvenes y sus familias.

En conclusión, se plantea que para avanzar en la implementación de una perspectiva social y de derechos de la discapacidad en las políticas públicas y sociales aragonesas, resulta fundamental repensarlas desde el proyecto vital de la persona y con una perspectiva interseccional. Por ello se propone, simplificar la actual complejidad institucional y ofrecer unos servicios tanto para ellos como para sus familiares que se adapten a sus necesidades concretas de cuidados, pero, también, en la esfera de la inclusión social.

PALABRAS CLAVE

Gran discapacidad | Dependencia | Jóvenes | Servicios Sociales | Política Social

ABSTRACT

Young people with severe and serious disabilities who require the support of a third person to carry out basic activities of daily living are cared for in Spain both by social services specialising in disability and by the dependency system. Despite this, and the commitment of public and social policies to a social and rights-based model of disability, the catalogue of the dependency system does not provide for differences in the supply and adaptation of services and benefits in response to the needs and demands of people, which change throughout their life cycle.

By virtue of this, the main objective of this doctoral thesis is to analyse the intervention carried out in the Aragonese public and social sphere for the care of young people with severe and serious disabilities and their families. The aim is to infer possible improvements from the perspective of inclusion and the application of the International Convention on the Rights of Persons with Disabilities.

Consequently, different qualitative research techniques are used to achieve the stated objectives. First, a content analysis of the Aragonese legislation; then, a systematic literature review, focusing on assessment; and finally, two thematic analyses (one focusing on resources and the other on social relations) of interviews with 25 young people with severe disabilities and/or their guardians in Aragón.

The main results of this doctoral thesis show that, despite a commitment to the inclusion of people with disabilities, the regulations and interventions do not consider the diversity of this group, both in terms of disability situations and in terms of their own human development needs or socio-demographic factors. Furthermore, despite the fact that international regulations indicate the need to focus on the perspective of the social model and disability rights, the data collected throughout this thesis show that the design and development of policies aimed at this group are focused on specific aspects such as health, rehabilitation, compulsory education and employment, leaving aside aspects such as leisure, interpersonal relationships, sport and culture. Factors that increase the difficulties experienced should be considered, such as being young, having high support needs, being institutionalised, being a migrant, having multiple disabilities or living in rural areas. Finally, the results of the thesis have shown that the public policies proposed generate various bureaucratic and institutional gaps at the time of youth, affecting the quality of life of young people and their families.

In conclusion, it is proposed that in order to advance in the implementation of a social and disability rights perspective in Aragonese public and social policies, it is essential to rethink them from the life project of the person and with an intersectional perspective. Therefore, it is proposed to simplify the current institutional complexity and to offer services for them and their families that are adapted to their specific care needs, but also in the sphere of social inclusion.

KEYWORDS

Severe disability | Dependency | Young people | Social services | Social policy

MEASURABLE CONTRIBUTIONS

PUBLICATIONS

- 6 peer-reviewed articles (3 JCR indexed-journal publications, 2 JCI indexed-journal publications, 1 Scopus indexed-journal publication).
- 1peer-reviewed article at *Revista Educación Investigación, Innovación y Transferencia (REIIT).*
- 3 peer-reviewed articles in review process at JCR indexed-journals.
- 1 book review at *European Social Work Research.*
- 1 co-author book.
- 12 book chapters in peer-reviewed books.

CONFERENCES

- 21 oral papers in international conferences.
- 4 oral papers in European conferences.
- 3 oral papers in national conferences.
- 1 poster in the I International Scientific Meeting on Healthy Organisations (Healthyorg). Emerging Trends in Corporate Social Responsibility and Strategic Human Resources Management.

GRANTS

- Recipient of a predoctoral researcher 4-year contract from the Gobierno de Aragón, Spain.
- Recipient of a grant to promote the mobility of pre-doctoral research staff in training for the year 2023 from the Gobierno de Aragón, Spain.
- Recipient of a grant for a mobility stay in Colombian universities within the framework of the Erasmus+ Internship Programme from the Iberus Campus of International Excellence, Spain.
- Recipient of a grant for internships for short- and long-term doctoral students in the framework of the "Iberus+" project supported by the Erasmus+ ka 1 Programme from the Iberus Campus of International Excellence, Spain.

SERVICE AND OTHER CONTRIBUTIONS

- 1 research internship (three months) at University of Ibagué (Colombia).
- Participation in 3 research projects (2 European projects, 1 regional project).
- Reviewer for 6 journals (2 JCR indexed-journal, 2 JCI indexed-journal, 1 Scopus indexed-journal, 1 non-indexed-journal) and 1 international conference.
- Member of the program committee in 3 international conferences.
- Member of the local committee in 1 international conference.

CONTENTS

4 Young people with severe disabilities, families and social services: a relation of resources and gaps 81

5 "What is the point of being able to enter a building if the service or activity is not adapted?" 105

6 General conclusions (spanish version) 129

7 Appendixes 151

ILLUSTRATIONS

TABLES

ABBREVIATIONS

ASD: Autistic Spectrum Disorder

CEICA: Research Ethics Committee of the Aragón

CERMI: Committee of Entities Representing People with Disabilities

CJEU: Court of Justice of the European Union

CRPD: Convention on the Rights of Persons with Disabilities (CDPD in Spanish)

DC: Day centre

DD: Developmental Disorders

EU: European Union

EUSRPD: European Union's Strategy on the Rights of Persons with Disabilities (EUEDPD in Spanish)

FC: Family care

IASS: Aragonese Institute of Social Services

ICF: International Classification of Functioning, Disability and Health

ID: Intellectual Disability

OT: Occupational therapist

PCPI: Initial Vocational Qualification Programmes

PRISMA: Preferred Reporting Items of Systematic Reviews and Meta-Analyses

PWD: Persons with disabilities (PCD in Spanish)

QoL: Quality of Life

SCDPA: System of Care for Dependency and Personal Autonomy

SC: Spanish Constitution

SD: Severe disability

SDGs: Sustainable Development Goals

SI: Social Interventions

SW: Social Work

UN: United Nations (ONU in Spanish)

WHO: World Health Organization

INTRODUCTION (SPANISH VERSION)

1.1 LA JUVENTUD, UNA CRISIS EN EL CICLO VITAL

A lo largo del desarrollo humano las personas atraviesan diversas etapas en las que varían factores como su autonomía e independencia y su grupo de referencia en la esfera social, surgiendo, de este modo, diferentes necesidades y demandas. Por ejemplo, en la infancia nuestra autonomía es muy limitada y nuestro grupo principal es la familia, mientras que en la adultez nuestra autonomía e independencia alcanza su máximo y abrimos nuestro círculo social incluyendo a otros ámbitos, como es el caso del entorno laboral (Santrock, 2006; Delval, 2008).

En el caso concreto de la juventud, se trata de un concepto que ha evolucionado en las últimas décadas, y más especialmente tras las crisis económicas de 2008 y del Covid-19, variando también su definición en función de los diferentes contextos socioculturales. Por ejemplo, de acuerdo a la ONU (2023) este colectivo está compuesto por personas entre 15 y 24 años; y, según la Unión Europea (UE, 2018) se considera jóvenes a aquella población que tiene entre 15 y 29 años.

Estas diferencias nos muestran que su definición única y consensuada presenta cierta dificultad. Se trata de una etapa vital de transición entre la niñez y la vida adulta y la emancipación, una época de cambios que la persona debe gestionar y que presenta una entidad propia. Los jóvenes reclaman mayor independencia, aunque todavía no han alcanzado una autonomía plena, y, en este sentido, la relación con el grupo de iguales es determinante para la formación de la propia identidad y el desarrollo social (Santrock, 2006; Delval, 2008).

Estas características generan una situación de incertidumbre en la que se deben tomar decisiones que afectan al futuro de la persona, como por ejemplo ¿quiero seguir estudiando?, ¿el qué?, ¿dónde?, ¿quiero trabajar?, ¿en qué?, ¿cómo puedo lograrlo?, ¿quiero irme de casa?, ¿puedo independizarme?, etc.

En este contexto surgen dificultades socioeconómicas en el acceso a la vivienda, la escasez de recursos económicos, las crecientes exigencias de flexibilidad, la falta de oportunidades, de recursos y servicios que atiendan a sus demandas. Todo ello vinculado a una creciente precarización y una demanda de independencia que no se cubre, llegando a mínimos históricos. Algunas de estas cuestiones se reflejan en el Informe del segundo semestre del 2022 del Observatorio de Emancipación del Consejo de la Juventud de España (2023) que indica que sólo el 15,9% de los jóvenes (entre 16 y 34 años) residían de manera autónoma.

Esta tendencia preocupante se explica con datos como que el alquiler de la vivienda supone el 83,7% del salario neto de una persona, o que el 48,1% de la juventud que trabajan a tiempo parcial lo hacen porque no han encontrado un trabajo a tiempo completo, en 2022. Además, hay que considerar que esta precarización se da en una población con un 29,1% de personas con estudios superiores y el porcentaje de personas jóvenes estudiando es el mayor registrado desde 2017. Cifras que se agravan en el caso concreto de la Comunidad Autónoma de Aragón, una de las pocas comunidades en las que disminuyó intensamente el empleo entre esta población (pasando del 46,4 % en 2021 al 42,2 % a finales de 2022). Estos factores, entre otros, suponen que el 30,2 % de personas jóvenes se encuentra en 2023 en situación de vulnerabilidad (Observatorio de Emancipación, 2023).

Es decir, se puede considerar a la juventud como un grupo social que comparte una serie de problemáticas derivadas de una situación de crisis en un momento vital que requiere de especial atención. Pero esto no puede significar que se entienda a la juventud como un grupo homogéneo, ya que existen factores que pueden influir negativamente en su situación, incrementando su vulnerabilidad. Algunos ejemplos son ser mujer, vivir en el medio rural, ser migrante o refugiado o estar en situación de discapacidad (Observatorio de Emancipación, 2023; Saldívar & Alvarado, 2020; García-Fuentes & Martínez García, 2020; Domínguez, 2020).

1.2 DISCAPACIDAD, UN CONCEPTO HETEROGÉNEO Y COMPLEJO

En relación a la discapacidad, hay que considerar que se trata de un término muy heterogéneo y complejo. Presenta diferentes tipos según su origen (congénita o adquirida), su grado de afectación (leve, moderada, grave o severa), la función o funciones afectadas (visual, orgánica, motora, auditiva, comunicativa, social, intelectual, psíquica, o varias simultáneamente) o la necesidad de apoyo, entre otras. Así como desde la perspectiva desde la cual lo enfoquemos (modelos de prescindencia, médico-rehabilitador o social y de derechos).

Además, desde el marco legal, hay personas que pueden tener una capacidad de obrar modificada, necesitando apoyos para tomar decisiones a nivel económico, médico o social (Ley 8/2021). Esto conlleva importantes diferencias es sus posibilidades de actuación. También hay que considerar que en España el grado de discapacidad legalmente reconocido, debe ser superior al 33% para tener acceso a apoyos institucionales o sociales. Si es menor, no se considera a la persona en situación de discapacidad (RD 1971/1999).

Por último, las personas difieren en cuanto a los cuidados que reciben (profesionales o informales), la situación de su cuidador principal (estado de salud), o la relación entre el cuidador y la persona que recibe los cuidados (padres, hijos, amigos, pareja, persona contratada, etc.). Estas diferencias influyen en si se recibe apoyo institucional o profesional. Un ejemplo de ello es que la valoración de compartir los cuidados con profesionales varía en función de las características personales y situacionales de los cuidadores. El estudio de Wittenberg et al. (2019), por ejemplo, mostró que el cuidado informal y profesional es peor valorado por los cuidadores de un padre o hijo con discapacidad mental y los cuidadores que tenían entre 45 y 64 años o que tienen un trabajo remunerado cuidando a una persona con discapacidad mental.

La situación de discapacidad, además, ha sido abordada desde diferentes puntos de vista, evolucionando de un paradigma médico rehabilitador a un paradigma más social centrado en cuestiones como la accesibilidad, la disponibilidad de apoyos y ajustes necesarios, la promoción de la autonomía personal o la inclusión (Aparicio, 2016; Artiles, 2013; Mira-Aladrén & Lozano-Blasco, 2022; Hernández, 2018; Salmón & Bergaglio, 2015). Todo ello avalado por textos como la Convención de las Naciones Unidas sobre los Derechos de las Personas con Discapacidad (CDPD) o la Estrategia de la Unión Europea sobre los Derechos de las Personas con Discapacidad 2021-2030 (EUEDPD), que se han incorporado al ordenamiento jurídico español.

Debe destacarse que, pese a esta apuesta por el modelo social de la discapacidad, autores como Russell (Rosenthal, 2020), Shakespeare (2014) o Goodley et al. (2019; 2018) y Goodley (2016) refieren grandes dificultades para hacerlo efectivo en una sociedad capitalista como la actual, a la que vinculan con el capacitismo. Es decir, en una sociedad en la que se promueve que la población sea productiva para el sistema es difícil incluir a personas con discapacidad y, especialmente a aquellas con grandes necesidades de apoyo, como es el tema que nos ocupa. Al mismo tiempo, en caso de intentarlo se hace desde una perspectiva vinculada a la formación y el empleo, tratando de encajarlas en la lógica productiva.

1.3 TENER DISCAPACIDAD, AFRONTAR BARRERAS

A partir de lo anterior, se puede afirmar que la gran heterogeneidad del colectivo de personas con discapacidad requiere un estudio en profundidad de la interacción entre las diferentes variables o situaciones personales para poder analizar y entender su realidad. Para ello, en primer lugar, es necesario profundizar en las barreras que muchas veces encuentran. Éstas están interrelacionadas y pueden clasificarse en 4 grupos: barreras sociales, actitudinales y de comunicación; barreras arquitectónicas y espaciales; barreras técnicas; y, por último, barreras económicas (Milios, 2022; Rodríguez-Gómez et al., 2009; Salmón & Bergaglio, 2015).

También, pueden encontrarse desde distintos ámbitos (familiar, grupal, individual, institucional, etc.) sufridas por todo el colectivo o hacia un grupo o persona concreta, es decir, por asociación. Y, además, pueden producirse tanto en forma de discriminación directa como indirecta (Jiménez-Lara, 2017). Las primeras son conductas ejercidas directamente contra la persona (Jiménez-Lara, 2017; Milios, 2022), como una agresión física; por normas sociales, como los prejuicios, hacia las personas con discapacidad, como la invisibilización (Artiles, 2013; Aparicio, 2016; Mira-Aladrén & Lozano-Blasco, 2022; Hernández, 2018; Milios, 2022). O, incluso, pueden suceder por la falta de apoyos necesarios, como la falta de una rampa, que no prohíbe el acceso de forma directa, pero sin ella no se puede entrar (Liisberg, 2015; Milios, 2022). Estas últimas están estrechamente relacionadas con el concepto de accesibilidad (Liisberg, 2015; Milios, 2022) y de ajustes razonables, que se refieren a la eliminación de posibles barreras u obstáculos, es decir, a la creación de entornos accesibles, sin que ello suponga una carga desproporcionada (CDPD, art. 2).

Pese a esta regulación en relación con las barreras, discriminación y apoyos para las personas con discapacidad, los resultados del Informe Olivenza 2020-2021 sobre la discapacidad en España (Observatorio Estatal de la Discapacidad, 2022), muestra unos indicadores de inclusión social y discapacidad con grandes diferencias entre la población con y sin discapacidad, especialmente en el eje de ciudadanía (con una diferencia del -66%) y en el eje de integración social (con una diferencia del -54,3%). Por un lado, en el eje de ciudadanía, los principales déficits se refieren al acceso a la educación, principalmente secundaria y superior; al acceso a la vivienda; y al acceso a la medicación necesaria. Por otro lado, en el eje de integración social, constata la dificultad de acceso a las actividades en el tiempo libre, las dificultades para hacer amigos y la mayor tasa de personas que han sufrido malos tratos. Además, el 23,4% de las personas con discapacidad manifiesta no contar con los apoyos necesarios o tenerlos insuficientes. Por último, se observan porcentajes elevados en relación con las barreras estructurales, que dificultan la vida de las personas con discapacidad: para las actividades de ocio (90,9%), para salir de casa (80,6%), para acceder y moverse por los edificios (61,9%), para pagar cuestiones esenciales (59,9%), para acceder a un empleo adecuado (57,1%) o para utilizar el transporte (55,2%).

Estas barreras y la percepción de discapacidad, además, aumentan en colectivos específicos como las mujeres (Observatorio Estatal de la Discapacidad, 2022; INE, 2022b) y los jóvenes (Huete et al., 2016). El estudio de Jiménez Lara (2017) sobre discriminación múltiple señala que, según datos de 2013 en España, casi seis de cada diez personas que se han sentido discriminadas por su discapacidad han sufrido, también, discriminación por otros motivos. Entre las variables que incrementan esa discriminación, las que representan un mayor peso explicativo son la edad, la falta de recursos económicos y la apariencia física; otras variables que influyen, aunque en menor medida, son el género, la etnia, la nacionalidad, las enfermedades crónicas o infecciosas y las creencias políticas.

Jiménez-Lara (2017) también analiza la discriminación múltiple a partir de los datos obtenidos en la Encuesta de Calidad de Vida. El riesgo de pobreza y exclusión se asocia con el sexo, la edad, el nivel educativo, el hábitat y la nacionalidad. De manera que el perfil más desfavorecido a nivel socioeconómico sería hombre entre los 30 y 64 años con alto nivel educativo y gran discapacidad que vive en zonas de densidad de población media o muy poblada y con nacionalidad no comunitaria (Jiménez, 2017). La suma de estos riesgos de vulnerabilidad pone de manifiesto la necesidad de repensar acerca de la intervención de las políticas públicas y sociales con respecto a estas barreras, atendiendo, en profundidad, a la situación de especial vulnerabilidad que puede darse por la suma de diferentes variables vinculadas a características personales y situacionales.

1.4 LAS POLÍTICAS PÚBLICAS Y SOCIALES COMO HERRAMIENTA DE INCLUSIÓN SOCIAL

Discapacidad, diversidad funcional, accesibilidad, inclusión, etc. son conceptos dinámicos y complejos que, especialmente desde la ratificación de la CDPD, en 2008, han cobrado mayor fuerza en las políticas públicas y sociales españolas. A la importancia creciente de esta normativa, contribuyen también los Objetivos de Desarrollo Sostenible (ODS). Especialmente en sus metas 4.5 (garantizar la igualdad de acceso a todos los niveles educativos para las personas vulnerables), 8.5 (lograr el empleo pleno y productivo y el trabajo digno para todos), 10. 2 (potenciar y promover la inclusión social, económica y política), 11.2 (facilitar el acceso a los sistemas de transporte para todos), 11.7 (proporcionar acceso universal a los espacios verdes y públicos) y 17.18 (aumentar el apoyo a la creación de capacidades en los países en desarrollo) (IDDH, 2019). El impulso de estas nuevas prioridades en los últimos años propicia un cambio en el paradigma de las intervenciones vinculadas a la atención de las personas con discapacidad y en el modelo de atención a este colectivo. Se incluyen nuevas legislaciones y se fomenta el sistema de promoción de la autonomía personal y atención a la dependencia, vinculado a la atención de personas con discapacidad grave y severa.

Pese a estos avances, la situación derivada del Covid-19 puso de manifiesto algunas necesidades no cubiertas de las personas con discapacidad como son: ajustes en la hospitalización, problemas de comunicación y exclusión dentro de la intervención, así como la relevancia de las personas cuidadoras (Vivas-Tesón, 2020). Adicionalmente, la salud física del 34% de esta población declinó, llegando al 50% en términos de salud mental. Y, en el 58% de los casos se vieron paralizados procesos terapéuticos afectando a su situación (Silván & Quífez, 2020). Todo ello agravado en el caso de las mujeres (Vivas-Tesón, 2020; Silván & Quífez, 2020).

Tampoco debe olvidarse el marcado carácter familista del estado de bienestar español y los cambios sociodemográficos de los últimos tiempos que han generado nuevas necesidades a considerar. Es de destacar, por un lado, el progresivo envejecimiento de las personas con discapacidad gracias a los avances científicos y, por ende, el envejecimiento de cuidadores principales, que también precisan de ayuda. Y, por otro lado, la incorporación al trabajo de la mujer, que ha cambiado las dinámicas de cuidados (Tobio et al., 2011). Para dar respuesta a estas cuestiones, los sistemas de bienestar (sanitario, educativo, de servicios sociales, etc.) necesitan adaptarse (accesibilidad, atención psicosocial a cuidadores, reducción de desigualdades agravadas en el caso de la discapacidad, etc.).

En definitiva, se trata de abordar de manera operativa la importancia del entorno social y el acceso a recursos y posibilidades para las personas con discapacidad (Yeung & Breheny, 2019). En España, éstos dependen de la edad (atención temprana, atención educativa o social y sistema de dependencia) o de la zona geográfica en la que se encuentren (cada región o comunidad autónoma tiene sus propios recursos independientes y diferenciados), ya que se trata de un sistema autonómico en el que las comunidades autónomas tienen delegada la competencia en servicios sociales (CE, art.149). En relación con este último punto, los recursos disponibles dependen a su vez del tamaño del municipio o de la zona en la que se encuentre, disminuyendo el acceso a los mismos en las zonas rurales con población inferior a 20.000 habitantes (Ley 7/1985). Este hecho es especialmente relevante en España, ya que hay comunidades que experimentan un descenso de población en todas sus provincias y durante un periodo prolongado. Por ejemplo, la pérdida de población es especialmente acuciante en Aragón, Asturias y Extremadura con una disminución porcentual del -1,24%, -0,66% y -0,44% respectivamente, en el último año (INE, 2022a). Esto puede afectar al acceso a los diferentes recursos en estos territorios, especialmente en sus localidades con menor población.

En este sentido, puede afirmarse que existen 17 sistemas de servicios sociales en España. Además, aunque en enero de 2023 se aprobó un *Anteproyecto de Ley de condiciones básicas para la igualdad en el acceso y disfrute de los servicios sociales* (Ministerio de Derechos Sociales y Agenda 2030, 2023), todavía no se ha hecho efectiva una norma a nivel estatal que coordine y regule la relación y derechos mínimos a cubrir por este sistema, igualando el acceso a los mismos derechos en todo el Estado.

A esta complejidad se suma que en España y, concretamente, en Aragón, deben diferenciarse entre dos tipos de servicios sociales, según su organización: generales y específicos. Los primeros hacen referencia a las áreas básicas de servicios sociales, estableciendo un Centro Comarcal o Municipal de Servicios Sociales en cada área (Ley 5/2009). Estas áreas básicas, tal y como se ha comentado anteriormente tienen delimitación territorial y precisan de, al menos 20.000 habitantes para ser de obligada creación (Ley 7/1985). Se trata de "servicios públicos de carácter polivalente y comunitario, cuya organización y personal están al servicio de toda la población" (art. 13, Ley 5/2009).

Sin embargo, los servicios sociales especializados tienen un alcance supracomarcal, de acuerdo con las circunstancias que se determinen adecuadas para su creación, que pueden ser geográficas, demográficas y de comunicación. Además, no tienen carácter obligatorio ni precisan de una población diana determinada cuantitativamente para la creación de centros. Es más, pueden prestarse, también, a través de servicios, programas y recursos específicos. Particularmente, se dedican a un colectivo o necesidades concretas que precisan de una especialización técnica o cuya intervención requiere una intensidad o complejidad que es difícil cubrir desde los servicios sociales generales (Ley 5/2009).

Dentro de estos últimos podemos encontrar recursos delimitados a mujeres, como el Instituto Aragonés de la Mujer; a menores, como el Centro de Observación y Acogida de menores; a mayores, como los Centros Municipales de Mayores; a jóvenes, como las Casas de Juventud o los programas y recursos del Instituto Aragonés de la Juventud; y, a personas con discapacidad, como las residencias y los centros de atención temprana (Decreto 143/2011; Gobierno de Aragón, 2023).

Uno de los colectivos a los que se les dedican servicios sociales especializados que componen todo un sistema propio es el de las personas en situación de dependencia, que resulta crucial para nuestra investigación. Pese a que discapacidad y dependencia no son sinónimos, la relación entre ambas cuestiones se manifiesta en normas como la Ley 39/2006, conocida como Ley de Dependencia. En ella se admite esta condición para personas que ya tenían reconocida "una gran invalidez o la necesidad de asistencia de tercera persona según el Real Decreto 1971/1999" (Ley 39/2006, DA9ª).

Dentro del catálogo de la Ley 39/2006, se recogen servicios y prestaciones tanto de atención a personas con discapacidad como a personas mayores. Estos son: servicio de atención residencial, servicios de centro de día y de noche, servicio de teleasistencia, servicio de ayuda a domicilio, servicios de prevención de las situaciones de dependencia, los servicios de promoción de la autonomía personal, prestación económica para ser atendido por cuidadores no profesionales, prestación económica vinculada al servicio y prestación económica de asistencia personal (Ley 39/2006).

Esta última prestación resulta especialmente controvertida en su aplicación, ya que, si bien es demandada en términos de inclusión, sólo se concede en el 0,5% de los casos en España y, concretamente en Aragón no se presenta precedente de que se haya concedido. El acceso e implementación de los recursos y servicios de dependencia, también, cuenta con un largo historial de quejas a causa de las largas listas de esperas para la valoración, el reconocimiento del grado de dependencia, el reconocimiento del servicio o prestación y el disfrute del mismo (Ramírez-Navarro et al., 2023). Otras carencias detectadas se refieren a su falta de inclusión y promoción de la autonomía personal (Blanca, 2017; Aparicio, 2016; Argullo et al., 2011; Jollien, 2011, Romañach & Palacios, 2008).

Por último, para el tema que nos ocupa, debe destacarse que en este catálogo no se diferencia atendiendo a variables sociodemográficas y factores de riesgo, tal y como sí ocurre en otros servicios sociales especializados destinados a colectivos concretos, como los comentados anteriormente (Ley 39/2006; Decreto 55/2017). Es decir, no existen servicios sociales especializados para, por ejemplo, jóvenes con discapacidad, pese a que, como hemos comentado anteriormente, las necesidades varían en función del contexto y de la etapa del desarrollo en la que nos encontramos.

En la literatura científica tampoco se encuentra solución a este dilema ya que son múltiples las referencias en relación con personas en proceso de envejecimiento, atendidos en centros de cuidados, o con niños en centros de atención temprana (Llewellyn et al., 2014; 2017; Sousa et al., 2022; Whitehead et al., 2015). En cambio, no se encuentran tantas referencias en relación con jóvenes con gran discapacidad y/o en situación de dependencia, entrando en contradicción con la bibliografía de psicología del desarrollo, que plantea el cambio de necesidades a lo largo del ciclo vital. En este sentido, conviene profundizar en este campo, de tal modo que se mejoren las políticas destinadas a este colectivo, desde una perspectiva interdisciplinar y centrada en la persona.

1.5 ABORDAR LA HETEROGENEIDAD DESDE LA PERSPECTIVA INTERSECCIONAL

En los apartados anteriores comentamos la heterogeneidad y diversidad de situaciones en las que se encuentran las personas con discapacidad. En este sentido, resulta difícil abordar la realidad de las personas que pertenecen a uno o varios grupos especialmente vulnerables, y que han recibido menos atención en las políticas públicas (Hankivsky & Jordan-Zachery, 2019), desde una teoría generalista (Crenshaw, 1989; 1991; Cho et al., 2013; Rodó-Zarate, 2021). Se necesita un método, una disposición y unas herramientas que den respuesta a este cruce de variables y contextos que aumentan o disminuyen las barreras que encuentra una persona con discapacidad. De esta necesidad se hace eco la perspectiva de la interseccionalidad (Crenshaw, 1989; 1991; Carbado et al., 2013; Cho et al., 2013).

El término interseccionalidad fue acuñado por Crenshaw (1989; 1991) para explicar un sentimiento de sufrimiento por ser una persona que pertenece a más de un grupo social en riesgo de exclusión (en su caso ser una mujer negra en Estados Unidos). Según la metáfora de la encrucijada que utiliza, la persona se encontraría en el centro de un cruce de diferentes situaciones de opresión, sintiéndose afectada no sólo por el hecho de ser mujer o ser negra, sino por la conjunción de ambas condiciones, que generan una tercera condición, ser mujer negra (Crenshaw, 1989; 1991; Rodó-Zarate, 2021).

El desarrollo de este concepto debe entenderse como un trabajo en proceso, particularizado, provisional e incompleto internacional, interdisciplinar y con una dimensión de cambio social (Carbado et al., 2013; Cho et al., 2013). Por ello, aunque este concepto parte del campo del derecho, puede y debe aplicarse y analizarse desde otros campos, como la sociología, el trabajo social o la ciencia política. Esto favorecerá la eliminación de estereotipos al emplear conceptos como el de discriminación, que conducen a metodologías, operacionalizaciones e interpretaciones marginadoras (Goff & Khan, 2013); así como la oportunidad de pensar en nuevas soluciones para las personas con discapacidad (Artiles, 2013).

Diferentes autores han defendido la necesidad de utilizar una visión interseccional para estudiar la situación de las personas con discapacidad y realizar intervenciones centradas en la persona. Dado que, como decíamos anteriormente, el concepto de discapacidad es muy heterogéneo (por origen, situación legal o administrativa, necesidad de apoyo, función o funciones afectadas, etc.) y las experiencias de las personas varían según el tipo de discapacidad que tienen, pero, también, según el contexto en el que se encuentra la persona. Así, la investigación sobre estos temas evidencia la conveniencia de adoptar el modelo interseccional. La pertenencia a 2 o más colectivos de riesgo (etnicidad, sexualidad, obesidad y discapacidad) aumenta la posibilidad de discriminación (Armstrong et al., 2021). Del mismo modo la discriminación racial percibida en Estados Unidos se asociaba con un número significativamente mayor de discapacidades concurrentes, con dificultades que variaban entre las poblaciones latina y asiática (Waldman et al., 2020).

Por último, el estudio de Lindsay et al. (2022) explora más a fondo el concepto de interseccionalidad en el caso de los jóvenes con discapacidad, por un lado, con la raza, la etnia y el género; y, por otro, con la raza, la etnia y el estatus socioeconómico. Esta revisión sistemática de estudios cualitativos muestra que las mujeres con discapacidad tienden a estar más sobreprotegidas y a tener menos oportunidades de empleo y educación en comparación con los hombres en la misma situación. Aunque muestra que existen diferencias en la fuerza de la relación en la experiencia, mientras que algunos estudios destacan el género por encima de la raza y la etnia, otras investigaciones destacan tener una discapacidad por encima de otras.

Estos datos nos aportan información relevante no sólo sobre los colectivos que tienen mayor posibilidad de sufrir discriminación, sino que, también, contribuyen a conocer qué factores presentan un mayor peso específico. No obstante, es necesario seguir investigando sobre estos temas en relación con las políticas públicas y sociales porque, pese a mostrar una mayor tasa de discriminación, esta perspectiva no se está incluyendo en los estudios que evalúan las intervenciones destinadas a mejorar la inclusión (Llewellyn, 2014; 2017).

En definitiva, los estudios interseccionales refuerzan la definición de los conceptos de discapacidad y de juventud como heterogéneos y contextualizados en tiempo y lugar. Además, reflejan cómo ambos pueden entenderse como factores de riesgo social, siendo mayor la vulnerabilidad cuanto mayor es la discapacidad y el número de factores de riesgo que se sumen. En este sentido, resulta necesario explorar las políticas públicas y sociales destinadas a las personas con gran discapacidad, también, desde esta perspectiva, especialmente si se trata de personas que, además, son jóvenes.

1.6 OBJETIVOS

1.6.1 Objetivo general

Analizar la intervención realizada desde el ámbito público y social para la atención a los jóvenes con discapacidad grave y muy grave o severa y sus familias, desde la perspectiva de la inclusión y la aplicación de la CDPD, en Aragón.

1.6.2 Objetivos específicos

1. Conocer el impacto de la CDPD en el marco legislativo aragonés vinculado a los jóvenes con discapacidad grave y muy grave o severa y la atención a la dependencia y la promoción de la autonomía personal.
2. Revisar los instrumentos de evaluación y sus resultados para las intervenciones realizadas sobre jóvenes con discapacidad grave y muy grave o severa y en situación de dependencia, a nivel internacional.
3. Explorar las experiencias, la situación psicosocial y las necesidades de los jóvenes aragoneses con discapacidad grave y muy grave o severa y sus familias en relación con los servicios sociales especializados que les atienden.
4. Plantear propuestas de mejora en relación con la inclusión social, las relaciones sociales y el ocio de los jóvenes con discapacidad grave y muy grave o severa y en situación de dependencia en Aragón.

1.6.3 Estructura de la tesis

Los cuatro capítulos que conforman esta tesis son estudios independientes, pero vinculados al tema que nos ocupa, y que siguen la estructura propia de los artículos de investigación. Estas secciones se plantean, siguiendo los objetivos propuestos, comenzando por aspectos más macro y abstractos, con un análisis de contenido de la legislación, para llegar a lo más concreto y micro. Se continua con una revisión sistemática de las intervenciones realizadas a nivel internacional y sus evaluaciones, favoreciendo el conocimiento de herramientas y preguntas necesarias para profundizar en las experiencias de este colectivo. Y, culmina con los análisis temáticos de las experiencias de los jóvenes con gran discapacidad y sus familias. Así, la metodología cualitativa que se emplea supone una oportunidad para profundizar en los discursos y experiencias desde una perspectiva centrada en la persona. Recogiendo la voz de parte de los jóvenes con discapacidad grave y severa y sus familias, que a menudo es invisibilizada.

El primer capítulo estudia el impacto normativo y en la atención a la dependencia de la CDPD en Aragón, con respecto a los conceptos de inclusión y accesibilidad universal. Realiza un análisis de contenido de 36 normas relacionadas con la discapacidad y la dependencia en Aragón. Y muestra que, a pesar de ciertos avances, la adaptación de la normativa no se ha consolidado, afectando al reconocimiento de derechos de las personas con discapacidad, especialmente de las más jóvenes y con grandes necesidades de apoyo.

En segundo lugar, mediante una revisión sistemática de bibliografía, basada en el modelo PRISMA, se analizaron 19 intervenciones sociales a nivel internacional, desarrolladas con personas con discapacidad y sus evaluaciones. Los resultados ponen de manifiesto cuestiones como la escasez de publicaciones con evaluaciones, la falta de homogeneidad en los indicadores de evaluación utilizados, o el foco en aspectos formales (empleo, rehabilitación, etc.). Esta revisión ayuda a futuras investigaciones a plantearse diferentes cuestiones sobre los indicadores de evaluación y la implementación del modelo social, entre otras.

En el tercer capítulo se analizan las experiencias de los jóvenes con discapacidad severa y sus familias en el sistema de atención a la dependencia. Para ello, analizamos temáticamente 25 entrevistas realizadas a jóvenes con discapacidad severa y/o a sus tutores de diferentes zonas de Aragón (España). De este modo, detectamos cómo la relación con los servicios sociales es compleja y genera cuatro grandes brechas a lo largo del desarrollo, que afectan directamente a la calidad de vida (18 años, 21 años, envejecimiento o enfermedad de los progenitores y, en el caso de migrantes, el momento de la llegada al lugar de destino). Además, la interseccionalidad emergió de forma transversal demandando una mayor atención al respecto. En definitiva, se detectó la necesidad de repensar los recursos y el diseño del sistema de atención a la dependencia en función del proyecto de vida de sus usuarios, de sus necesidades y demandas.

Y, por último, en el capítulo cuatro, se analiza la relevancia de las relaciones personales, el ocio y la inclusión social en la juventud en relación con la intervención de los servicios sociales en la cobertura de este derecho. Así, continuamos con el análisis temático iniciado en el capítulo anterior, pero focalizado esta vez en los temas relativos al ocio y las relaciones sociales. Detectamos dificultades como el acceso a recursos, la relevancia del apoyo familiar y su impacto. Además, surgieron factores agravantes como estar institucionalizado, ser inmigrante o tener pluridiscapacidad. Finalmente, se proponen medidas de mejora, como el reconocimiento de la figura del asistente de ocio, la formación e incremento de profesionales en los recursos para jóvenes, o la incorporación de la perspectiva interseccional en los servicios sociales especializados.

1.7 REFERENCIAS

Aparicio, M. (2016). Estigmatización, invisibilización y cosificación de las personas con diversidad funcional. Una aproximación desde la justicia como reconocimiento de Axel Honneth. *Revista Española de Discapacidad*, 4(1), 177-190. https://www.cedd.net/redis/index.php/redis/article/view/245.

Argullo, C., Arroyo, J., Ema, J.E., Gámez, C., Gómez, E., Jiménez, P., Rodríguez, E., Salvador, M., Orfi, M. & Colina, M.P. (2011). *Cojos y precarias: haciendo vidas que importan. Cuaderno sobre una alianza imprescindible*. Traficantes de Sueños.

Armstrong G., Haregu T., Young J. & Paradies, Y. (2022). What are the effects of ethnicity, sexuality, disability and obesity on the odds of experiencing discrimination among Australian males? A nationwide cross-sectional survey. *BMJ Open* 2022*, 12*, e053355. DOI: 10.1136/bmjopen-2021-053355

Artiles, A.J. (2013). Untangling the racialization of disabilities: An intersectionality critique across disability models. *Du Bois Review: Social Science Research on Race*, 10(2), 329-347. DOI: 10.1017/S1742058X13000271

Blanca Gutiérrez, J.J. (2017) *Metaestudio sobre la experiencia vital de las personas mayores que viven en residencias como fundamento de los cuidados enfermeros geriátricos*. Biblioteca Lascasas, V13. http://www.indexf.com/lascasas/documentos/e11575.php

Carbado, D., Crenshaw, K., Mays, V., & Tomlinson, B. (2013). Intersectionality: Mapping the Movements of a Theory. *Du Bois Review: Social Science Research on Race,* 10(2), 303-312. DOI: 10.1017/S1742058X13000349

Cho, S., Crenshaw, K. W., & McCall, L. (2013). Toward a field of intersectionality studies: Theory, applications, and praxis. *Signs: Journal of women in culture and society*, 38(4), 785-810. https://doi.org/10.1086/669608

Constitución Española (CE).

Convención sobre los Derechos de las Personas con Discapacidad. (CDPD).

Crenshaw, K. (1989). Demarginalizing the intersection of race and sex: a black feminist critique of antidiscrimination doctrine, feminist theory, and antiracist politics. *University of Chicago Legal Forum*, 1(8), 139-167. http://chicagounbound.uchicago.edu/uclf/vol1989/iss1/8

Crenshaw, K. (1991). Mapping the margins: intersectionality, identity politics, and violence against women of colour. *Standford Law Review*, 43(6), 1241-1299. DOI: 10.2307/1229039

Decreto 143/2011, de 14 de junio, del Gobierno de Aragón, por el que se aprueba el Catálogo de Servicios Sociales de la Comunidad Autónoma de Aragón.

Decreto 55/2017, de 11 de abril, del Gobierno de Aragón, por el que se aprueba el Mapa de Servicios Sociales de Aragón.

Delval, J. (2008). *El desarrollo humano*. Siglo Veintiuno de España.

Domínguez Álvarez, J.L. (2020). El desigual acceso de la juventud rural a los servicios públicos: la necesidad de impulsar la educación en la España vaciada. *Cuadernos de Investigación en Juventud*, (8), 60-78. DOI: 10.22400/cij.8.e047

Estrategia de la Unión Europea por la Igualdad para los Derechos de las Personas con Discapacidad 2021-2030.

García-Fuentes, J., & Martínez García, J.S. (2020). Los jóvenes “Ni-Ni”: Un estigma que invisibiliza los problemas sociales de la juventud. *Archivos Analíticos de Políticas Educativas*, 28(20). DOI: 10.14507/epaa.28.4652

Gobierno de Aragón (2023). Instituto Aragonés de Servicios Sociales (IASS). *Gobierno de Aragón*. https://www.aragon.es/-/instituto-aragones-de-servicios-sociales-14

Goff, P., & Kahn, K. (2013). How psychological science impedes intersectional thinking. *Du Bois Review: Social Science Research on Race, 10*(2), 365-384. DOI: 10.1017/S1742058X13000313

Goodley, D. (2016). *Disability Studies: An Interdisciplinary Introduction*. SAGE.

Goodley, D., Lawthom, R., Liddiard, K & Runswick-Cole, K. (2019). Provocations for Critical Disability Studies. *Disability & Society*, 34(6), 972-997. DOI: 10.1080/09687599.2019.1566889

Goodley, D., Liddiard, K. & Runswick-Cole, K (2018). Feeling disability: theories of affect and critical disability studies. *Disability & Society*, 33(2), 197-217. DOI: 10.1080/09687599.2017.1402752

Hankivsky, O. & Jordan-Zachery, J. S. (2019). *The Palgrave handbook of intersectionality in public policy*. Palgrave Macmillan.

Hernández Artigas, A. (2018). Opresión e interseccionalidad. *Dilemata*, 10(26), 275-284. https://dialnet.unirioja.es/descarga/articulo/6278551.pdf

Huete García, A., Quezada García, M.Y. & Caballero Juliá, D. (2016). *Jóvenes con discapacidad en España 2016*. INJUVE-CERMI.

Instituto Danés de Derechos Humanos (IDDH) (2019). La guía de los derechos humanos a los ODS. *Instituto Danés de Derechos Humanos.* https://sdg.humanrights.dk/es/goals-and-targets

Instituto Nacional de Estadística (INE) (2022a). *Demografía y población*. Instituto Nacional de Estadística. https://www.ine.es/dyngs/INEbase/es/operacion.htm?c=Estadistica_C&cid=1254736176951&menu=ultiDatos&idp=1254735572981

Instituto Nacional de Estadística (INE) (2022b). *Encuesta sobre Discapacidad, Autonomía Personal y situaciones de Dependencia (EDAD)*. Instituto Nacional de Estadística. https://www.ine.es/dyngs/INEbase/es/operacion.htm?c=Estadistica_C&cid=1254736176782&menu=resultados&idp=1254735573175

Jiménez-Lara, A. (2017). *Personas con discapacidad y discriminación múltiple en España: situación y propuestas*. Observatorio Estatal de la Discapacidad.

Jollien, A. (2011). *El oficio de ser hombre*. Octaedro.

Ley 39/2006, de 14 de diciembre, de Promoción de la Autonomía Personal y Atención a las personas en situación de dependencia.

Ley 5/2009, de 30 de junio, de Servicios Sociales de Aragón.

Ley 7/1985, de 2 de abril, Reguladora de las Bases del Régimen Local.

Ley 8/2021, de 2 de junio, por la que se reforma la legislación civil y procesal para el apoyo a las personas con discapacidad en el ejercicio de su capacidad jurídica

Liisberg, M.V. (2015). Accessibility of services and discrimination: Concentricity, consequence, and the concept of anticipatory reasonable adjustment. *International Journal of Discrimination and the Law, 15(1-2)*, 123-144. DOI: 10.1177%2F1358229114558545

Lindsay, S., Ahmed, H., Tomas, V. & Vijayakumar, A. (2022). Exploring the lived experiences of ethnic minority youth with disabilities: a systematic review and meta synthesis of qualitative data. *Disability and Rehabilitation*, DOI: 10.1080/09638288.2022.2040614

Llewellyn, G. & National Disability Research and Deveopment Agenda, sponsoring body & University of Sydney. Centre for Disability Research and Policy, issuing body. (2014). *Report of audit of disability research in Australia*.

Llewellyn, G. & National Disability Research and Deveopment Agenda, sponsoring body & University of Sydney. Centre for Disability Research and Policy, issuing body. (2017). *Audit of disability research in Australia update report 2017*.

Milios, G. (2022). El derecho a la no discriminación por motivo de discapacidad: la compleja coexistencia de la normativa y jurisprudencia nacional y supranacional.

Derechos y Libertades: Revista De Filosofía Del Derecho Y Derechos Humanos, 47, Época II, junio 2022, 241-271. DOI: 10.20318/dyl.2022.6882

Ministerio de Derechos Sociales y Agenda 2030 (2023). *Anteproyecto de Ley de condiciones básicas para la igualdad en el acceso y disfrute de los servicios sociales.* *https://www.mdsocialesa2030.gob.es/servicio-a-la-ciudadania/proyectos-normativos/documentos/AP-SERVICIOS-SOCIALES.pdf*

Mira-Aladrén, M. & Lozano-Blasco, R. (2022). Vulnerabilidad, opresión e injusticia social: el caso de la diversidad funcional desde la perspectiva de Iris Marion Young. *EN-CLAVES del pensamiento, 0(31)*, e499. DOI: 10.46530/ecdp.v0i31.499

Observatorio de Emancipación (2023). *Informe estatal segundo semestre 2022*. Consejo de la Juventud España. https://www.cje.org/observatorio-de-emancipacion/#258-186-segundo-semestre-2022-1691745583

Observatorio Estatal de la Discapacidad (2022). *Informe Olivenza 2020-2021 sobre la situación de la discapacidad en España*. Observatorio Estatal de la Discapacidad. https://www.observatoriodeladiscapacidad.info/wp-content/uploads/Informe-Olivenza-2020-2021-v2.2.pdf

ONU (2023). Juventud. *Organización de las Naciones Unidas*. https://www.un.org/es/global-issues/youth

Ramírez-Navarro, J.M., Revilla Castro, A., Fuentes Jiménez, M., Sanz Yagüez, D. & Cavero Cano, G. (2023). *XXIII Dictamen del Observatorio Estatal de la Dependencia*. Ed. Asociación de Directoras y Gerentes de Servicios Sociales de España.

Real Decreto 1971/1999, de 23 de diciembre, de procedimiento para el reconocimiento, declaración y calificación del grado de minusvalía.

Rodó-Zarate, M. (2021). *Interseccionalidad. Desigualdades, lugares y emociones*. Bellaterra Edicions.

Rodríguez Gómez, P., Suso Araico, A., Vázquez Rolland, D. & Velasco Gisbert, M.L. (2009). *Discapacidad, estudios superiores y mercado de trabajo. Barreras de acceso y repercusión en la inserción laboral. Programa Operativo de Lucha contra la Discriminación*. Fundación ONCE.

Romañach Cabrero, J. & Palacios Rizzo, A. (2008). El modelo de la diversidad: una nueva visión de la bioética desde la perspectiva de las personas con diversidad funcional (discapacidad). *Intersticios. Revista sociológica de pensamiento crítico*, 2(2). http://www.intersticios.es/article/view/2712

Rosenthal, K. (2020). *Capitalism & Disability. Selected writtings by Marta Russell.* Haymarketbooks.

Saldívar Reyes, A., & Alvarado García, F. (2020). Aproximación a las experiencias de vida de jóvenes con discapacidad motriz. *RPP*, (30). DOI: 10.21555/rpp.v0i30.2028

Salmón, E. & Bregaglio, R. (2015). *Nueve conceptos clave para entender la Convención sobre los Derechos de las Personas con Discapacidad.* Pontificia Universidad Católica del Perú.

Santrock, J.W. (2006). *Psicología del desarrollo: El ciclo vital* (10ª ed.). McGraw-Hill.

Shakespeare, T. (2014). *Disability Rights and Wrongs Revisited.* Routledge.

Silván, C. & Quífez, L.E. (2020). *Efectos y consecuencias de la crisis de la COVID-19 entre las personas con discapacidad.* Odismet. Fundación ONCE. https://www.odismet.es/sites/default/files/2020-07/Informe_EstudioCOVID_19_v3_0.pdf

Sousa, L., Gemito, L., Ferreira, R., Pinho, L., Fonseca, C., Lopes, M. (2022). Programs Addressed to Family Caregivers/Informal Caregivers Needs: Systematic Review Protocol. *J. Pers. Med.*,12, 145. DOI: 10.3390/jpm12020145

Tobio, C., Agulló Tomás, M.S., Gómez, V. & Martín Palomo, M.T. (2011). *El cuidado de las personas.* La Caixa. http://www.abc.es/gestordocumental/uploads/Otras/volumen-completolacaixa.pdf

Unión Europea (2018). *Situation of young people in the European Union*. Publications Office of the European Union. https://op.europa.eu/en/publication-detail/-/publication/b6985c0c-743f-11e8-9483-01aa75ed71a1

Vivas-Tesón, I. (2020). Las personas con discapacidad y sus familias antes las crisis sanitarias. En Atienza, E. & Rodríguez, J. F. (2020). *Las respuestas del derecho a las crisis de salud pública.* Dykinson.

Waldman, K., Stickley, A., Araujo Dawson, B., & Oh, H. (2022). Racial discrimination and disability among Asian and Latinx populations in the United States. *Disability and rehabilitation*, *44*(1), 96–105. DOI: 10.1080/09638288.2020.1760363

Whitehead, P. J., Worthington, E. J., Parry, R. H., Walker, M. F., & Drummond, A. E. (2015). Interventions to reduce dependency in personal activities of daily living in community dwelling adults who use homecare services: a systematic review. *Clinical Rehabilitation*, 29(11), 1064-1076. DOI: 10.1177/0269215514564894

Wittenberg, Y., de Boer, A., Plaisier, I., Verhoeff, A., & Kwekkeboom, R. (2019). Informal caregivers' judgements on sharing care with home care professionals from an intersectional perspective: the influence of personal and situational characteristics. *Scandinavian Journal of Caring Sciences*, 33(4), 1006-1016. DOI: 10.1111/scs.12699

Yeung, P. & Breheny, M. (2019). Quality of life among older people with a disability: the role of purpose in life and capabilities. *Disability and Rehabilitation*. DOI: 10.1080/09638288.2019.1620875

2 DISABILITY AND SOCIAL SERVICES: TALKING ABOUT ACCESSIBILITY IN INSTITUTIONAL COMPLEXITY

Partial results of this work were presented at the VIII Workshop of Young Researchers in Economics and Business of the University of Zaragoza, held on 1 and 2 September 2021 in Teruel (Spain); and at the XI Jornadas Científicas de Investigación sobre Personas con Discapacidad, organised by the University of Salamanca, held from 16 to 18 March 2022 in Salamanca (Spain). In addition, it was published in full in its Spanish version in the journal *Derechos y Libertades*, with the following reference:

Mira-Aladrén, M., Martín-Peña, J., & Gil-Lacruz, M. (2023). Discapacidad y servicios sociales: analizar la accesibilidad en la complejidad institucional. *Derechos y libertades: Revista De Filosofía Del Derecho Y Derechos Humanos*, (49), 259-290. DOI: 10.20318/dyl.2023.7725

2.1 INTRODUCTION

Public administration is a complex system. It is not always easy to carry out different procedures, understand the regulations or know which body to contact. This becomes more complex if we add variables such as cognitive impairment or visual impairment. In this sense, the international regulations contemplate these circumstances and raise the institutional need to adapt to them, especially since the International Convention on the Rights of Persons with Disabilities (CRPD). Furthermore, these adaptations must be made on the basis of inclusion and universal accessibility criteria.

All of this requires a homogenisation of criteria between professionals, disciplines and institutions, guaranteeing the coverage of the social rights of people with disabilities under equal conditions, regardless of the territory, the institution or the system responsible for guaranteeing them.

In this sense, to our knowledge, no studies have been found that analyse the relationship between regulatory law, institutional complexity, accessibility and inclusion. However, there is scientific literature that has addressed these issues in isolation. For this reason, our research focuses on creating a database that compiles the regulations related to the attention to diversity in youth in Aragon, with indicators and variables, which can be applied in future analyses of regulations outside the Aragonese territory. Through the definition of qualitative units of analysis of laws related to inclusion, accessibility and institutional complexity, it contributes to the development of some necessary proposals in the institutional reality of Aragon and, in general, of Spain. It brings to regulatory law institutional evidence aimed at eliminating barriers to access to the social rights of people with disabilities in Aragon, serving as a starting point for its application in other areas and territories.

In this context, the following research questions are posed: Can universal accessibility be made compatible with a complex system such as that of public administration, are the needs of people with severe and very severe or severe disabilities taken into account in the regulation of their rights, are the systems of care for dependency and social services adapted to the CRPD, are the systems of care for dependency and social services adapted to the CRPD, and are they adapted to the CRPD, are they adapted to the CRPD and are they adapted to the CRPD?

Taking the above into account, our general objective is: To analyse the institutional complexity around accessibility and inclusion criteria so that regulatory law does not end up being an impediment to access to the rights of persons with disabilities. To achieve this, we set out the following research objectives:

1. To understand the regulatory reality of young people with serious and very serious or severe disabilities included in the Aragonese dependency system, since the ratification of the CRPD.
2. To find out how laws define and recognise the concepts of disability, youth and accessibility, their regulation and recognition of rights.
3. To compare the right to accessibility enshrined in the CRPD with the structure of the public administration for the care of young people with disabilities.

This article focuses on the impact of institutional complexity on the right to accessibility and is divided into three parts. The first part analyses accessibility as a right, especially for persons with disabilities, and its scope on a theoretical level. The second part deals with the concept of regulatory law, institutional complexity and its application in the field of disability in Aragon. Finally, based on a qualitative study of the legislation relating to young people with severe and very severe disabilities and dependence in Aragon, it analyses the deficits, contradictions and needs regarding the right to accessibility within the institutional complexity of Aragon.

2.2 ACCESSIBILITY AS A RIGHT

Defining disability is more difficult than it seems (Shakespeare, 2014; Milios, 2022; Asis Roig, 2020). Firstly, it could be thinking like a physical, rehabilitation or medical issue, but if you dig deeper, it becomes more complex. For example, World Health Organization (WHO) (2020) recognises the environmental importance, promoting a bio-psychosocial model. In essence, this meaning focuses the social injustices that persons with some health problem suffer, according to a new model, the social model of disability (Aparicio, 2016; Mira-Aladrén & Lozano-Blasco, 2022). It was materialized in the International Classification of Functioning, Disability and Health (ICF), which, as some authors refer (Mitra & Shakespeare, 2019; Cerniauskaite et al., 2011; Alford et al., 2014), still has some shortcomings. Some examples are the requirement to incorporate socioeconomic determinants of health conditions to understand disability situation; and, improve the emphasis in some characters linked with activities and participation, that seem insufficient, moreover if we understand that as an important thing in the social model (Shakespeare, 2014). Finally, they propose to attend to "personal factors" with more range, using for example subjects about life quality (Verdugo et al., 2012).

The theoretical and normative context of disability has been improved with the CRPD, adopting this social and contextual model (Mitra & Shakespeare, 2019; Milios, 2022), but not without contradictions in its adaptation by the European Union and Spain (Milios, 2022). Some of these contradictions have been detected both in the regulations themselves and in national and international case law. In this sense, the CRPD understands disability as a situation of interaction with the environment that limits people's participation in different social spheres; on the other hand, the Court of Justice of the European Union (CJEU) approaches it only from an employment perspective and Spanish legislation requires administrative recognition of 33% (Royal Legislative Decree 1/2013, art. 4). Furthermore, in the international legal debate, there are discrepancies in the consideration of illness as a disability, requiring long-term illnesses in the case of the CRPD and, foreseeably, permanent illnesses in Spanish legislation (Milios, 2022).

This Treaty also includes different rights, including accessibility as a necessary condition for achieving independent living, in paragraph 9. This implies the identification and elimination of obstacles and barriers to access in areas such as communication, transport, electronic services, etc. Thus, the signatory states undertake to promote public and social policies to ensure that all people can have equal access to the different areas, making the appropriate reasonable adjustments (Asis & Barranco, 2010; Pindado, 2015). Only with a firm commitment to the implementation of these measures can we speak of an inclusive society and personal autonomy.

In this sense, we cannot speak of accessibility only as the existence of a ramp, a Braille sign or a signpost, known as accessibility in a restricted sense. Rather, it refers to the elimination of many other barriers (Pindado, 2015), associated with different forms of oppression experienced by this group (Shakespeare, 2014; Aparicio, 2016; Mira-Aladrén & Lozano-Blasco, 2022), among which are those of difficult access to information or difficulties in achieving full psychosocial interaction, something closely linked to the relationship with institutions, related to accessibility in a broad sense. Some of the issues regulated by the existing directives are signposting, or the easy-to-read wording of administrative and legal documents or their availability. Different types of accessibility can be defined: physical, cognitive and symbolic (Sampedro-Palacios & Pérez-Villar, 2019), and different senses of accessibility: restricted (focused on products) and broad (linked to goods and rights) (Asis, 2020).

In addition to this diversity and the complexity of the term accessibility itself, there is the difficulty of making this right effective. On the one hand, it can be done by implementing universal design (CRPD, art. 2), i.e. designing products, environments, goods and services that can be used by the majority of people without the need for adaptations. And, on the other hand, through the so-called reasonable adjustments (CRPD, art. 2), which are specific adaptations necessary for people to be able to exercise their rights with equal opportunities, as long as they are proportional.

The difficulty of this implementation lies in the adjective "reasonable" and the need for proportionality. Thus, there are discrepancies in the limits (of knowledge, structures and attitudes, and reasonableness) of accessibility, for example, in the strength of economic criteria when it comes to delimiting this reasonableness (Asis, 2020). While in the rights discourse these criteria have no place, national and international legislation and jurisprudence in this field do not seem to coincide. While European and national legislation maintains that economic criteria must be considered in order to make or not make such adjustments, the CRPD does not consider these as an excuse for not making "reasonable adjustments", considering this as a cause of discrimination (Milios, 2022; Asis, 2020).

2.3 REGULATORY RIGHT AND INSTITUTIONAL INCREASING COMPLEXITY IN SPAIN

CRPD supposed a new paradigm in disability studies, research, and regulations around the world. Focusing in Spain case, since 1978, with the Spanish Constitution (SC), the country has undergone a great deal of legislative change, augmented by issues related to regulatory law, increasing soft law instruments and flexible judicial (Saura, 2010).

First of all, we must deep in the concept of regulatory law to know the problems and advantage of this changes to people in disability situation. After the socioeconomic crack in 1929, there was a shift from a liberal legal tradition focused on guiding behaviour, surveillance and control to a social conception through positive regulation (Weber, 1979). Through this intervention of law in civil society, a new bureaucratic and political rationality is generated. Including technical, economic, social, politic, etc. determinants and criteria, increasing the arbitrariness in the law application (Arlotti et al., 2021; Calvo & Picontó, 2017; Calvo, 2005; Brodkin, 2006).

Probably, the best example of this new paradigm, related to the issue at hand, is the system of care for dependency and promotion of personal autonomy created in Spain in 2006, with the Law 39/2006, of 14 December, on the Promotion of Personal Autonomy and Care for Persons in a Situation of Dependency, which refer disability people and old people care, creating the dependency care system. This is a two phases process. In this case, for example, in accordance with Law 39/2006 the first step is the recognition of dependency. It´s initiated by the person concerned, his or her guardian, in the event that he or she doesn’t have sufficient capacity to carry out the process.

On the basis of this request, an assessor will contact the person concerned or their representative to draw up a report on the environment, in accordance with the scale established by Royal Decree 174/2011, of 11 February, approving the scale of assessment of the situation of dependency established in Act 39/2006, of 14 December, on the Promotion of Personal Autonomy and Care for Persons in a Situation of Dependency. Its application is carried out by trained technical staff with one of the following degrees: Occupational Therapy, Physiotherapy, Nursing or Social Work. An issue closely linked to the characteristics of the regulatory law raised by Calvo (2005) and Brodkin (2006). After this assessment, a decision is issued in which, depending on the score obtained, a degree (between 1 and 3) of dependency is recognised and which gives rise to the different benefits in the preparation of the Individualised Care Plan, which will be drawn up by a social worker in collaboration with the family and, where appropriate, the dependent person.

According to this example, reference can be made to the characteristics of regulatory law such as the economic criteria which, once the assessment has been carried out, may or may not provide access to resources, as well as the need to anticipate the risks (Brodkin, 2006) of an ageing society or the "avalanche of regulations" (Calvo, 2005, p. 10), as is the case of Royal Decree 17/2014 and Order CDS/456/2019, of 17 April, which regulates the procedure for the recognition of the situation of dependency of persons and access to the benefits of the system for autonomy and care for dependency in the Autonomous Community of Aragon, necessaries for the correct development of Law 39/2006. Another of the issues of relevance in this process is the question of the incorporation of "scientific-technical" knowledge in the process, not directly related to the legal field as Physiotherapy, Nursing or Social Work (Brodkin, 2006; Calvo, 2005).

Some theories (Calvo, 2019; Oliver-Lalana, 2019; Del Pino & Catalá, 2016) affirm that this revolution has increased and accelerated with 2008 economic crisis based in economic, technical and politic arguments. Authors such as Asís and Barranco (2010) and Pindado (2015) point out that the approval of the CRPD has repercussions on laws such as 39/2006 or the Organic Law 4/2007, of 12 April, which amends Organic

Law 6/2001, of 21 December, on Universities, among others, which can directly affect accessibility and the recognition of rights.

An example of this complexity and its impact on the rights of people with disabilities is the obstacle to access to public employment for groups such as those with intellectual disabilities. Some of the difficulties detected in this sense were: an insufficient number of calls for applications; the texts of the calls for proposals are difficult to find; are unadapted and difficult to understand or the complexity of the registration process is, which requires the submission of a lot of documents and paperwork with forms that are not adapted for easy forms that are not easy to read; or, long delays from the time the exam is called until the exam arrives, which prevents the person from planning their preparation and increases their sense of insecurity (Muñoz, 2018).

Continuing with the example of the dependency system, it can be affirmed that the difficulties for the effectiveness of rights such as those included in Law 39/2006 have repercussions on the quality of life of people with disabilities and their families. In other words, it affects the Welfare State itself. Therefore, given the characteristics of this group, when talking about the rights of people with disabilities and their families, it is worth analysing the relationship between institutional complexity and the Welfare State.

2.3.1 The Welfare State in Aragon and institutional complexity

The Spanish Welfare State is typically family-oriented. But, it has been modified in recent years, requiring a greater presence of other agents. For example, the Law 39/2006 created resources to meet these needs, such as residences or day and night centres (Law 39/2006, art. 15). Although these resources have been questioned in terms of inclusion, sustainability or personal autonomy in recent years (Leenknecht, 2020; Huete & Quezada, 2016; Iáñez-Domínguez, 2018; Guillem et al., 2010).

Some of the main changes are the migration from rural to urban areas, which leads to the division of families; the incorporation of women, traditionally carers, into the labour market and the need to reconcile care with work; or the increase in the age and, therefore, the need for support, of the main carers. In addition, medical advances have increased the life expectancy and quality of life of people with severe disabilities and long-term degenerative diseases, which have a major impact on family dynamics and the life trajectory of caregivers. Despite this change, one or more family members, usually women, still have to give up their professional careers to carry out care work (Martínez, 2013; Del Pino & Catalá, 2016; Tobio et al., 2011), understood as discrimination by association (Milios, 2022).

It should not be forgotten that this issue is compounded by the effects of the latest economic crisis, where one of the groups that has been strongly affected by the recent economic crises is that of young people. This is a decisive stage of transition to adulthood where different interventions linked to all the different welfare systems come together. On the other hand, previous studies show this stage as one of the most complex, which does not always cover needs such as social relations between peers, the transition to higher educational stages or incorporation into the labour market (Fundación Adecco, 2021; 2020). Furthermore, it's worth bearing in mind the relevance of issues such as the importance of relationships with peers, the need for privacy or the demand for independence at this stage of development (Morán et al., 2019; Delgado, 2008; Castells & De Dou, 1999), which are addressed for the general population by specific resources such as the Specialised information and counselling services for young people (Decree 55/2017).

Added to this situation is the complexity of an autonomous state model, with seventeen regions and two autonomous cities. That can assume competences related to the management of social services and, therefore, linked to disability and the promotion of personal autonomy (as accepted by the SC). Thus, it could be argued that there are at least seventeen social service systems linked together by a set of framework guidelines defined in state legislation. This situation is similar to that of other countries such as Italy or Netherlands, where authors such as Arlotti et al. (2021)

or Jansen et al. (2021) point to the existence of tensions and bureaucratic complexity in social services.

Deeping in state social protection, we must study social services, which are link with some systems like pensions system or dependency system, as the main provider of the resources, services and benefits needed to realise these social rights (SC, arts. 49, 50 & 148). It should be noted that competence in matters of social assistance may fall, according to Article 148.1.20 of the SC, to the Autonomous Communities. In the case at hand, the Organic Law 5/2007, of 20 April 2007, on the reform of the Statute of Autonomy of Aragon assumed this capacity in Article 71.34, developing it as an exclusive competence (Statute of Autonomy of Aragon, 2007, art. 27).

Regarding the management of this competence, on the one hand, it is differentiated at a functional level, with general social services centres; and specialised centres, in relation to specific groups or resources. On the other hand, at a territorial level, there is an obligation to design and approve a Social Services Map. There are basic areas of intervention are defined, each with a Social Services Centre (with at least one general centre) (Law 5/2009). These correspond to the regional boundaries, and may in turn constitute one or more basic areas in municipalities with more than 20,000 inhabitants, such as the 15 areas of the city of Zaragoza. As for specialized social services, their territorial organization is more flexible and can be carried out according to the characteristics of the territory or directly from the central services (Decree 55/2017).

2.4 INSTITUTIONAL COMPLEXITY AND DISABILITY IN ARAGONESE, NATIONAL AND SUPRANATIONAL LEGISLATION

This section focuses on a deductive content analysis (Krippendorff, 2004; Mayring, 2015; Elo et al., 2014) to analyse regulations, in accordance with the previous categories elaborated on the basis of the research objectives of this study. Legislation relating to young people with severe and very severe disabilities and dependency in Aragon was included, at international, national and Aragonese level that affects the care of these people in Aragon. Legislation that does not directly affect the regulation of persons with disabilities and in a situation of dependency or the promotion of personal autonomy was excluded; and regulations that include agreements, collaboration agreements, appointments, calls for subsidies, setting annual amounts, prizes and private calls for applications.

The period of the regulations analysed covers the period between the ratification of the CRPD in Spain (2008) and March 2020. This time limit was set given that after the declaration of the state of health alarm resulting from Covid-19, a regulatory explosion was generated that requires an exclusive analysis in the future. The total number of regulations analysed was 36 (see Appendix 1).

A codebook with a system of categories (see Appendix 2) was used to systematise the analysis of the materials, defining the unit of analysis as specific segments of the text that are characterised by being ascribed to a specific category (Krippendorff, 2004; Holsti, 1969). This book is composed of 31 variables, of which 12 are formal, aiming to define the generalities of the laws, such as name, year, territorial level, accessible format, etc.; and, 19 are content variables, aiming to define the presence or absence of some concepts such as accessibility, disability, youth, high support needs, etc. The results obtained were coded in a quantitative database in *SPSS-20*.

2.4.1 Manifestation of institutional complexity

In first place, we show the distribution of the 36 regulations collected according a classification based in normative hierarchy and normative regulation. Second one is relative at general regulations and specific disability normative. According to our theoretical framework, we could define four principal types of regulations according to disability and territorial organisation: 1) national laws about disability rights and dependency system; 2) national laws with some specific articles linked with disability rights and dependency system; 3) specific regional laws about disability rights and dependency system; and, 4) regional laws with some specific articles linked with disability rights and dependency system. To all of them must be added those of lower territorial levels such as provinces, counties and municipalities; and, international regulations. With this ranking the results were:

Table 1. *Normative hierarchy and specify.*

Normative hierarchy	General rules	Specific disability rules	Total
National rules	8	7	15
International laws	4	6	10
National laws	2	4	6
Regional laws	1	1	2
Regional rules	2	-	2
National laws corrections	-	1	1
Total	**17**	**19**	**36**

As we can see in Table 1, most of the rules collected are national's laws or rules followed by international laws. This fact demonstrates the relevance of having a legislative framework on which to base lower institutions and territories, such as autonomous communities, provinces or municipalities. Including in this sense the international regulations that mark the directives to be followed by the member countries of the European Union (EU) or the United Nations (UN) with regard to the recognition of the rights of people with disabilities. This is in line with the characteristics of regulatory right. Continuing with the analysis of institutional complexity, it seems necessary to analyse the welfare systems to which the collected laws are directly related, as well as their relationship or not with other systems. In this sense, we added a category called "Legal" to refer *hard laws* and rules.

Table 2. *Rules in terms of the welfare system*

Principal Welfare System	Total	Rules linked with other systems
Legal	16	14
Dependency	7	7
Social Services	6	5
Pensions/Labour	3	3
Other/ Not Specified	3	3
Health	1	1
Education	0	0
Total	**36**	**33**

In Table 2 it can be seen how the rights of persons with disabilities are mostly regulated in texts considered as soft laws, despite the large number of texts of the so-called hard laws that exist in this field. At the same time, it should be noted that 91.6% of the regulations collected affect other welfare systems, mainly Social Services, Pensions/Labour and Dependency. In the case of hard laws, it is worth highlighting the fact that 85.7% of the regulations analysed affect all other systems. Therefore, it can be stated that there is a strong interrelation between welfare systems and their regulation with regard to the social rights of persons with disabilities. In turn, this relationship affects both the so-called hard laws (87.5%) and the soft laws (95%), being greater in the latter.

2.4.2 Complexity in the definition of disability and accessibility

In view of this complexity, the definitions and criteria of disability and accessibility used were analysed in such a way as to facilitate the homogenization of criteria between professionals, disciplines and institutions, guaranteeing the coverage of the social rights of people with disabilities under equal conditions, regardless of the territory, the institution or the system responsible for guaranteeing them.

Table 3. *Number of rules with definition of disability and/or accessibility*

	Nº rules with definition of disability	**Nº rules with definition of accessibility**
No	24	23
Yes	8	5
No, but defines assailable concepts	2	7
Yes, in different ways	1	1
Other/ Not Specified	1	-
Total	**36**	**36**

It's important to highlight that more than 60% of the analysed rules don´t define what do they considered disability or accessibility. As we will see below, this lack of specificity can lead to a certain arbitrariness in the subsequent development of the rule, thus affecting the rights of persons with disabilities. Within the definitions of disability, there are differences between them, especially between regulations that recognize social rights linked to benefits or services for this group, as opposed to other regulations that only recognize more general rights. Some examples are:

> *"(…) Nevertheless, for the purposes of this Act, persons with disabilities shall be considered to be those who have been recognized as having a degree of disability equal to or greater than 33%. In any case, those Social Security pensioners who have been recognized as having a permanent incapacity pension in the degree of total, absolute or great disability, (…) shall be considered to have a degree of disability equal to or greater than 33%." (Law 26/2011, Art. 1.2).*

> *"People with disability: those persons who have long-term physical, mental, intellectual or sensory impairments which, in interaction with various barriers, may hinder their full and effective participation in society, on an equal basis with others" (EU Directive 2019/882, Art. 3.1).*

In the other hand, we must highlight that definition of accessibility is more homogenous than disability one. But, it´s more generalist, considering in turn that universal accessibility considers a multitude of elements and criteria to be considered. In this sense, some of the assailable concepts, that complement accessibility detected in the analysed laws are: effective access, reasonable accommodation, discrimination, design for all people, universal design. One of the most concrete definitions is included in the Law 5/2019 on the rights and guarantees of persons with disabilities in Aragon, which includes different types of accessibility and the concepts mentioned before. It is worth noting that this is a regional regulation and not a national or international one that defines a common framework throughout the territory:

> *"Universal accessibility: is the condition that environments, processes, goods, products and services, as well as objects, instruments, tools and devices, must meet in order to be understandable, usable and practicable by all people in conditions of safety and comfort and in the most autonomous and natural way possible. It presupposes the strategy of "universal design or design for all people", and is without prejudice to reasonable adjustments to be adopted. Cognitive accessibility: Designates the property of environments, processes, goods, products, services, objects, instruments, tools and devices that are easily understood or easily comprehended by people with intellectual disabilities." (Law 5/2019, Art. 3).*

Continuing with the concept of accessibility, 69.4% of the standards analysed include measures for accessibility. In order to access these measures, 17 of the regulations don't set any requirements, five require a recognized disability, two require an application by the person concerned, three require a recognized disability and an application, two set other requirements and three don't specify. In turn, it should be noted that 24 standards cover different types of accessibility and only one deals only with physical accessibility. Therefore, it can be stated that accessibility at a formal level is present and covers a large part of the entire group of people with disabilities. Despite the above, in terms of the accessibility of the laws studied, it should be noted that only 4 (11.1%) are in easy-to-read format. Furthermore, to find them, it was necessary to resort to web resources outside the official gazette (https://www.plenainclusion.org/coleccion/legislacion/ and https://transparencia.aragon.es/GobiernoFacil).

All of this, added to the approaches to discrimination and accessibility developed in legal theory (Milios, 2022; Asis Roig, 2020; Asis & Barranco, 2010; Pindado, 2015), suggests the need to analyse the possibility of arbitrariness in the application of regulations, whether for economic reasons or due to the lack of specific criteria or the existence of different interpretations by the States or regions and the technicians who apply these laws. In relation to this aspect, it is worth noting that 20 regulations have been found that in one way or another leave a certain margin for discretionally, some examples being:

> *"Have sufficient aptitude for the performance of the function of jury" (Organic Law 1/2017, art. 1.1).*
>
> *"When they do not exceed certain dimensions and whenever technically possible" (Royal Decree 537/2019, general provisions). "In these cases, the wheelchair or powered electric scooter must be able to be folded or disassembled" (Royal Decree 537/2019, art. 1.2).*
>
> *"The compatibility of the physical, mental and sensory conditions of the applicant selected for the disability category with the performance of the duties corresponding to the post in training in the speciality for which he/she has opted shall be accredited by passing the medical examination at the Occupational Risk Prevention Service that corresponds in each case" (Royal Decree 578/2013, art. 6.1).*

> *"When more than one year has elapsed between the date of effectiveness of the service or financial benefit and the date of the resolution establishing the Individual Care Programme and determining the corresponding benefit, (...) it may be conditional on the availability of the budget for the financial year" (Royal Decree 99/2009, art. 1.2.5).*

2.4.3 Multiple disability and youth situations

In this sense, it was considered necessary to analyse the reality of people with high support needs and the reference made to them in the regulations studied. Of the 36 regulations studied, only nine refer to people with high support needs and one does not make direct reference, but mentions resources for this group and their caregivers, the Law 5/2009 on Social Services of Aragon. From these rules, four are linked with dependency system, two with social services system, two with legal category and one is linked with labour system. According to these results, we could say that in formal sense people with serious, very serious and severe disabilities are included in the group of people with disabilities, despite the fact that they require greater support in terms of accessibility or personal autonomy. Furthermore, despite the fact that disability is not synonymous with dependency, in the case of these people, it can be observed that their care at the formal level is mainly delegated to this system.

Following the Opinion of the European Economic and Social Committee on 'Young people with disabilities: employment, integration and participation in society' (2012/C 181/02), the need to consider whether the needs of young people with disabilities are addressed in the standards collected, as a group requiring special attention, was raised. It was noted that only seven pieces of legislation showed some kind of reference to young people with disabilities in their articles. These references were mainly in the field of education and work-related training. It was striking that in five of the standards that did not refer to youth, reference was made to children with disabilities and their rights under the Convention on the Rights of the Child.

All this is aggravated if the variables youth and high support needs are grouped together, as only two laws refer to these young people, as follows:

> *"In said Law, in addition to the general amount, another specific amount shall be established in the case of a dependent child over the age of eighteen, with a degree of disability equal to or greater than 75 percent and who, as a result of anatomical or functional losses, needs the assistance of another person to carry out the most essential acts of life, such as dressing, moving around, eating or similar." (Royal Legislative Decree 8/2015, art. 353.2).*

> *"The schooling of these pupils in special education centres or substitute units will only be carried out when, exceptionally, their needs cannot be met within the framework of the measures for attention to diversity in ordinary centres and taking into consideration the opinion of the parents or legal guardians" (Royal Legislative Decree 1/2013, art. 18.3).*

All in all, an under-representation of young people, of people with high support needs, and specifically of young people with high support needs, is detected at the formal level. As well as a linking of young people with formal spaces and not so much with other areas of their vital development, such as leisure and contact with peers. All this makes us think about the coverage of their needs and rights.

2.5 DISCUSSION

The CRPD, as has occurred with other similar documents, such as the Convention on the Rights of the Child, has affected the legislation of signatory countries, such as Spain. In this sense, it is worth highlighting the relevance of this type of international standards for the recognition of the rights of vulnerable groups, such as children and women. Despite this importance and the vulnerable situation of young people with disabilities, on which the European Union has focused its attention, it is striking that there are no similar international declarations, affecting, as we have seen, the regulation and recognition of their rights.

As Shakespeare (2014) points out, disability definition is complex. In our study, we were able to see how the CRPD gives a broad definition of disability. However, in its application the conceptualisation of disability takes on different meanings (Mitra & Shakespeare, 2018; Cerniauskaite et al., 2011; Alford et al., 2014). Something similar occurs with the right to accessibility (CRPD, art. 9), despite its relevance for the social inclusion of this group. This right has been included in the legislation analysed, but leaving a wide margin for its further development. In this sense, accessibility involves many variables and different situations and needs (Asís & Barranco, 2010; Pindado, 2015; Shakespeare, 2014; Bisht et al., 2010; Pound & Hewitt, 2004), as well as being considered in different types (Sampedro-Palacios & Pérez-Villar, 2019). In our study we detected a low number of standards with a definition of accessibility, with only one being specific and varied enough to cater for different types of accessibility. On the other hand, we should point out that 24 standards include different types of accessibility, so we can affirm that most types of accessibility at a formal level are included and cater to a large part of the entire group of people with disabilities.

Furthermore, the absence of a clear definition of accessibility or of criteria established in the law may increase arbitrariness in the application of the law (Arlotti et al., 2021; Calvo & Picontó, 2017; Calvo, 2005; Jansen et al., 2021), affecting the rights of persons with disabilities. To this can be added the complex and lengthy bureaucratic processes for applying social policies (Arlotti et al., 2021; Jansen et al., 2021; Weber, 1979) that are adapted to "personal factors" (Verdugo et al., 2012). It is worth highlighting the interrelation of complex systems detected in these bureaucratic processes that can hinder access for people with certain disabilities. In addition, the scarce number of laws in easy-to-read format and official websites that are not accessible to all disabilities could complicate access to services, communication with the administration or access to public employment, thus violating the rights of some people with disabilities, especially intellectual or developmental disabilities (Muñoz, 2018).

In reference to the need to address "personal factors" (Verdugo et al., 2012) and the development of people with disabilities, we detected an under-representation of young people in the standards studied. They refer to the recognition of rights, services or benefits linked to relevant issues in the intervention with young people, such as the labour market or the educational sphere (Fundación Adecco, 2021; 2020). Despite this, a deficit has been revealed in areas linked to leisure and free time (focusing only on formal education), emancipation, culture or sport, among others. This fact clashes with the characteristics of youth (Delgado, 2008; Castells & De Dou, 1999) and the social model of intervention (Shakespeare, 2014; Morán et al., 2019).

Taking this into account, we can say that accessibility is present in a large number of regulations, but it is not sufficiently concrete for its subsequent application and is subject to conditioning factors such as the so-called reasonable adjustments or economic conditioning factors. This reality would be closely related to the paradigm of regulatory law (Calvo, 2005; 2019; Del Pino & Catalá, 2016). This issue also slows down the process of adaptation to the social model of disability, for example, with a scale for the recognition of disability in Spain from 1999 or a law on care for dependency and promotion of personal autonomy from 2006. A fact that, after the analysis carried out, affects the rights of people with disabilities, especially those with high support needs

Related to the above and linked to the new reality of the Spanish welfare state, deficits have been detected in the references made to intervention or care for people with high support needs. This is in line with some criticisms in terms of inclusion, accessibility and personal autonomy made of these services, benefits and resources (Leenknecht, 2020; Huete & Quezada, 2016; Iáñez-Domínguez et al., 2018 , 2018; Guillem et al., 2010). Furthermore, in the legislation studied, references to the maintenance of the familist model of welfare have been detected (Martínez, 2013; Del Pino & Catalá, 2016), with references to the reduction of the working day to care for children, even non-minors. This would conflict with the progressive change in the dynamics of care and population ageing described by Tobio et al. (2011) and Martínez (2013).

In conclusion, Spain's ratification of the CRPD generated a normative explosion, which attempted to reflect at a formal level the paradigm shifts in disability towards a social model. On the contrary, it cannot be said that the adaptation to this new situation promoted by the CRPD is consolidated in Spain, with outdated legislation (such as the scale for the recognition of disability) and a conditioned effectiveness of rights.

This work has not been free of limitations, such as the difficulty in finding laws related to the field of disability and dependence, as there is no official thematic search engine. For this reason, we turned to the Fundación Once's Discapnet website. Initially, 1056 laws from different regions and with a wide variety of topics were collected. Both their dispersion and the substantial differences in the institutional organisation of reference made it necessary to apply a large number of exclusion and inclusion criteria in order to work with a more limited sample, but this did not facilitate comparison between territories or the possibility of carrying out a study at national level. Furthermore, it should be noted that the lack of accessibility indicators from public administrations, as well as the absence of clear criteria, only specified in the certification of websites, made the task of assessing accessibility difficult.

All this makes it necessary to check in the future how the social model develops in practice in Aragon. Likewise, in view of the deficit detected in relation to references to young people and people with high support needs, the feasibility and positivity or otherwise of designing and implementing specific policies for specific groups is raised. Furthermore, the study and creation of indicators to evaluate the accessibility of public administrations is suggested. Finally, the database generated for this pilot case will be used for the analysis of legislation in other territories, according to common criteria.

2.6 REFERENCES

Alford V.M, Ewen S., Webb G.R., McGinley J., Brookes A., & Remedios L.J. (2014). The use of the International Classification of Functioning, Disability and Health to understand the health and functioning experiences of people with chronic conditions from the person perspective: a systematic review. *Disability and Rehabilitation,* 37(8), 655-666.

Aparicio M. (2016). Estigmatización, invisibilización y cosificación de las personas con diversidad funcional. Una aproximación desde la justicia como reconocimiento de Axel Honneth. *Revista Española de Discapacidad* 4 (I), 177-190.

Arlotti M., Parma A. & Ranci C. (2021). Multi-level governance and central-local tensions: The issue of local discretion in long-term care policy in Italy. *Social Policy Administration* 55(7): 1129-1144.

Asis, R. & Barranco M.C. (2010). El impacto de la Convención Internacional sobre los derechos de las personas con discapacidad en la ley 39/2006, de 14 de diciembre. Ediciones Cinca.

Bisht S.S., Mishra, V. & Fuloria S. (2010). Measuring accessibility for inclusive development: a census-based index. *Social indicators research,* 98(1), 167-181.

Brodkin, E.Z. (2006). Bureaucracy redux: Management reformism and the welfare state. *Journal of Public Administration Research and Theory,* 17 (1), 1-17.

Calvo García, M (2019) Retorno al derecho regulativo. Implementación y evaluaciones de impacto. In Oliver-Lalana, A.D. *La legislación en serio. Estudios sobre derecho y jurisprudencia.* Tirant Lo Blanch, 587-627.

Calvo García, M. & Picontó Novales, T. (2017). *Introducción y perspectivas actuales de la sociología jurídica.* Editorial UOC.

Calvo García, M. (2005). *Transformaciones del Estado y del Derecho.* Universidad Externado de Colombia.

Castells Cuixart, P. & de Dou Playá, J. (1999). Aspectos psicológicos de la adolescencia. Características normales de esta etapa de la vida. Indicaciones clínicas de desarrollo de patología. *Medicine: Programa de Formación Médica Continuada Acreditado,* 7 (132), 6225-6233.

Cerniauskaite, M., Quintas, R., Boldt, C., Raggi, A., Cieza, A., Bickenbach, J.E. & Leonardi, M. (2011). Systematic literature review on ICF from 2001 to 2009: its use, implementation and operationalization. *Disability and Rehabilitation,* 33 (4), 281-309.

Convention on the Rights of Persons with Disabilities (CRPD).

Convention on the Rights of the Child.

de Asis Roig, R. (2020). Sobre el sentido, contenido y configuración jurídica de la accesibilidad. *Universitas. Revista de Filosofía, Derecho y Política*, 32, 2-21.

DECREE 55/2017, de 11 de abril, del Gobierno de Aragón, por el que se aprueba el Mapa de Servicios Sociales de Aragón. Spain.

Del Pino, E. & Catalá Pérez, D. (2016). El welfare-mix español durante la crisis y la privatización del riesgo social: los casos de la sanidad, los servicios sociales y la atención a la dependencia. *Revista del CLAD Reforma y Democracia*, 66 (Oct.), 163-194.

Delgado Egido, B. (coord.) (2008). *Psicología del desarrollo: desde la infancia a la vejez*. McGraw-Hill.

Directive (EU) 2019/882 of the European parliament and of the council of 17 April 2019 on accessibility requirements for products and services.

Elo, S., Kääriäinen, M., Kanste, O., Pölkki, T., Utriainen, K. & Kyngäs, H. (2014). Qualitative content analysis: A focus on trustworthiness. *SAGE Open*, 4(1), 215824401452263.

Fundación Adecco (2020). *Informes Fundación Adecco. Jóvenes con discapacidad: motor de futuro*. Fundación Adecco y JYSK.

Fundación Adecco (2021). *Informes Fundación Adecco. Discapacidad y Familia*. Fundación Adecco y Gedia.

Guillem, R.B., Barberà i Guillem, R., Poveda Puente, R., Ródenas Rigla, F., Carretero Gómez, S., Bollaín Pastor, C., Cordero Roma, L., Castelló Mercé, P. & Gómez Herrero, J.A. (2010). Análisis coste-beneficio de la incorporación de productos de apoyo como extensión de los servicios de atención a domicilio para personas mayores dependientes. *Revista de biomecánica,* 54, 49-51.

Holsti, O. (1969). *Content analysis for the social sciences and humanities*. Addison-Wesley.

Huete García, A. & Quezada García, M.Y. (2016). Análisis de Retorno Social de la Inversión en dos sistemas de apoyo a personas con gran discapacidad: asistencia personal y servicio residencial. Un estudio de caso. *Revista Española de Discapacidad,* 2(1), 51-69.

Iáñez-Domínguez, A., Chaves, J.L.A. & Romero, J.G. (2018). Impacto económico y social de la asistencia personal a través de la metodología del Retorno Social de la Inversión. *Revista Española de Discapacidad* (REDIS), 6(2), 81-102.

Jansen, E., Javornik, J., Brummel, A. & Yerkes, M.A. (2021). Central-local tensions in the decentralization of social policies: Street-level bureaucrats and social practices in the Netherlands. *Social & Policy Administration,* 55 (2), 1–14.

Krippendorff, K. (2004). *Content analysis. An introduction to its methodology*. SAGE.

Law 26/2011 of 1 August 2011 on the adaptation of legislation to the International Convention on the Rights of Persons with Disabilities. Spain.

Law 39/2006, of 14 December, on the Promotion of Personal Autonomy and Care for Dependent Persons. Spain.

Law 5/2009 on Social Services of Aragon. Spain.

Law 5/2019 on the rights and guarantees of persons with disabilities in Aragon. Spain.

Law 51/2003, of 2 December, on Equal Opportunities, Non-Discrimination and Universal Accessibility for Persons with Disabilities. Spain.

Leenknecht, A.S. (June 2020). *EDF input to the European Disability Rights Agenda*. European Disability Forum.

Martínez García, J.S. (2013). La tensión entre vida personal, familiar y laboral. In: Martínez Garcia, J.S., *Estructura social y Desigualdad en España*. Catarata, 115-120.

Mayring, P. (2015). Qualitative content analysis: Theoretical background and procedures. In: Bikner-Ahsbahs, A., Knipping, C. & Presmeg, N. (eds.) *Approaches to Qualitative Research in Mathematics Education: Examples of Methodology and Methods*. Springer Netherlands, 365-380.

Milios, G. (2022). El derecho a la no discriminación por motivo de discapacidad: la compleja coexistencia de la normativa y jurisprudencia nacional y supranacional. *Derechos y Libertades: Revista De Filosofía Del Derecho Y Derechos Humanos*, 47, Época II, 241-271. DOI: 10.20318/dyl.2022.6882

Mira-Aladrén, M. & Lozano-Blasco, R. (2022). Vulnerabilidad, opresión e injusticia social: el caso de la diversidad funcional desde la perspectiva de Iris Marion Young. *EN-CLAVES del pensamiento, 0(31)*, e499. DOI: 10.46530/ecdp.v0i31.499

Mitra, S. & Shakespeare, T. (2019). Remodeling the ICF. *Disability and health journal* 12(3), 337-339.

Morán Suárez, M.L., Gómez Sánchez, L.E. & Alcedo Rodríguez, M.A. (2019). Inclusión social y autodeterminación: los retos en la calidad de vida de los jóvenes con autismo y discapacidad intelectual. *Siglo Cero Revista Española Sobre Discapacidad Intelectual* 50(3), 29-46.

Muñoz, S. (coord.) (2018). *Cuadernos de Buenas Prácticas. Las personas con discapacidad intelectual en la función pública: Informe sobre situación, recomendaciones y apoyos tecnológicos*. Plena Inclusión.

Oliver-Lalana, A.D. (2019). *La legislación en serio. Estudios sobre derecho y jurisprudencia*. Tirant Lo Blanch.

Opinion of the European Economic and Social Committee on 'Young people with disabilities: employment, integration and participation in society' (2012/C 181/02). Brussels.

ORDER CDS/456/2019, of 17 April, regulating the procedure for the recognition of the situation of dependency of persons and access to the benefits of the system for autonomy and care for dependency of the Autonomous Community of Aragon. Spain.

Organic Law 1/2017, of 13 December, amending Organic Law 5/1995, of 22 May, on the Jury Court, to guarantee the participation of persons with disabilities without exclusions. Spain.

Pindado García, F. (2015). *Hacia una única catalogación de los derechos fundamentales –los derechos económicos, sociales y culturales de las personas con discapacidad como derechos fundamentales–*.Ediciones Cinca.

Pound, C. & Hewitt, A. (2004) Communication barriers: building access and identity. In: Swain, J., French, S., Barnes, C. & Thomas, C. (eds.) *Disabling Barriers – Enabling Environments*. SAGE Publications, 161-169.

Royal Decree 174/2011, of 11 February, approving the scale of assessment of the situation of dependency established by Law 39/2006, of 14 December, on the Promotion of Personal Autonomy and Care for Dependent Persons. Spain.

Royal Decree 537/2019, of 20 September, amending Royal Decree 1544/2007, of 23 November, which regulates the basic conditions of accessibility and non-discrimination for access to and use of modes of transport for people with disabilities. Spain.

Royal Decree 578/2013, of 26 July, establishing positive action measures applicable to persons with disabilities who participate in the annual calls for selective tests for access to specialised health training places, in development of article 22.3 of Law 44/2003, of 21 November, on the organisation of health professions. Spain.

Royal Decree 99/2009, of 6 February, amending Royal Decree 614/2007, of 11 May, on the minimum level of protection of the system for autonomy and care for dependency guaranteed by the General State Administration. Spain.

Royal Legislative Decree 1/2013, of 29 November, approving the Consolidated Text of the General Law on the Rights of Persons with Disabilities and their Social Inclusion. Spain.

Royal Legislative Decree 8/2015, of 30 October, approving the revised text of the General Social Security Act. Spain.

Sampedro-Palacios, C.B. & Pérez-Villar, J. (2019). Innovación Social como herramienta en la transformación de una sociedad inclusiva. Accesibilidad e Innovación Social. *Prospectiva. Revista de Trabajo Social e intervención social,* 28 (julio-diciembre), 93-119.

Saura, Á.G. (2010). Crisis de la capacidad regulativa y flexibilidad del Derecho. *Cuadernos electrónicos de filosofía del derecho* (21), 39-61.

Shakespeare, T. (2014). *Disability Rights and Wrongs Revisited.* Routledge.

Spanish Constitution (SC)

Tobio, C., Agulló Tomás, M.S., Gómez, V. & Martín Palomo, M.T. (2011). *El cuidado de las personas.* La Caixa. http://www.abc.es/gestordocumental/uploads/Otras/volumen-completolacaixa.pdf

Verdugo Alonso, M.A., Rodríguez Aguilella, A. & Sainz Modinos, F. (2012) *Escala de vida familiar. Manual de aplicación*. INICO.

Weber, M. (1979). *Economía y sociedad. Esbozo de sociología comprensiva*. FCE.

World Health Organization (WHO) (2020). *Disability and health*. World Health Organization, https://www.who.int/news-room/fact-sheets/detail/disability-and-health

3 EVALUATION OF SOCIAL INTERVENTIONS WITH PEOPLE WITH DISABILITIES: A SYSTEMATIC LITERATURE REVIEW

Partial results of this work were presented at the XXXI International Congress of the Réseau Européen de Formation Universitaire en Travail Social (REFUTS), held on 27-29 June 2022, in Zaragoza; and at the 12nd European Conference for Social Work Research (ECSWR 2023), held on 12-14 April 2023, in Milan. In addition, it was accepted for publication in full in the journal *Social Work Research.*

3.1 INTRODUCTION

The International Convention on the Rights of Persons with Disabilities (CRPD) recognised the needs and rights of persons with disabilities (PWD), modifying their care. It speaks of a new social model of disability, as opposed to a model focused on medical-rehabilitative issues (Pindado, 2015; Shakespeare, 2014). It also highlights the commitment of the signatory countries to this vision in their social policies and the promotion of interventions along these lines. All of this was reinforced in the Sustainable Development Goals (SDGs), especially in their targets 4.5 (ensure equal access to all levels of education for vulnerable people), 8.5 (achieve full and productive employment and decent work for all), 10. 2 (empower and promote social, economic and political inclusion), 11.2 (provide access to transport systems for all), 11.7 (provide universal access to green and public spaces) and 17.18 (increase support for capacity building in developing countries) (DIHR, 2019; UN, 2015).

Furthermore, the CRPD and the European Union's Strategy on the Rights of Persons with Disabilities 2021-2030 (EUSRPD) propose the need for an evaluation of social services for PWD in order to improve their quality (art. 25, CRPD; EUSRPD, point 7; Høydal & Tøge, 2021). This evaluation, in turn, is part of the theory of social interventions (SI) from the field of social work (SW) (De Smidt & Goreydt, 1997). This SI phase facilitates the analysis of the objectives set and their achievement or non-achievement in terms of activity, effectiveness, efficiency and satisfaction, to their improvement. For this, it is not only necessary to adapt this phase to the characteristics of each SI, but also to use a validated method of evaluation (Izuzquiza & Rodríguez, 2016; De Smidt & Goreydt, 1997; Stufflebeam, 2003). Therefore, it is necessary to generate mechanisms and indicators that allow for a systematic evaluation, based on those promoted by policies developed at the international level (e.g. SDGs or EUSRPD).

Despite this need, studies, such as Llewellyn (2014; 2017), show that there are certain deficits. Some of them are: the lack of research; the absence of an intersectional approach that addresses specific groups such as women or young people; the lack of involvement of PWD in the co-production of the studies as researchers using participatory methodologies; or the few longitudinal studies that address the long-term impact of the SIs developed.

Moreover, some difficulties, given the characteristics of the population under study, have been encountered. PWD are sometimes institutionalised and/or with a modified capacity to act, potentially making direct access to them difficult. Increasing the possibility of research bias. Moreover, there are people who need adaptations to express themselves or respond to studies, due to their disability. These and other challenges and risks (Gavidia-Payne & Jackson, 2019), raise further concerns regarding the evaluation of interventions with PWD. Therefore, the inclusion of PWD in the scientific production is advocated.

In order to achieve an evaluation methodology in SI with PWD, it is first necessary to: a) know the interventions implemented so far; b) review the literature on these, their characteristics, outcomes and evaluations, accommodated to these characteristics; and, c) know the evaluation methods used and their effectiveness for the different interventions. Based on this research problem, our objective was to review research articles on the evaluation of SI with PWD. This objective was further elaborated into the following specific objectives:

1. To provide an overview of scientific publications on SIs with PWD at international level in the last five years.
2. To study existing data on the evaluation of SIs in the field of PWD.
3. To describe the evaluation measures used in SIs with PWD.

As a result of this research, it will be possible to discover: a) what SIs are being developed; b) how they are evaluated, in terms of their characteristics and those of their target population; c) their results and deficits; and, d) good practices.

3.2 METHOD

In order to achieve our objectives and given the exploratory nature of our study, following examples like Sabbe et al. (2020), a systematic review of the literature was conducted, using the Preferred Reporting Items of Systematic Reviews and Meta-Analyses (PRISMA) (Moher et al., 2015) procedure. This method is widely used and validated in the scientific literature. It allows to obtain a holistic view of the research problem that favours its understanding and subsequent deepening (Corbetta, 2010; Higgins et al., 2020).

The protocol used for the implementation of this method was based on various manuals and studies on meta-analysis as a research technique (Botella & Sánchez, 2015; Higgins et al., 2020; Moher et al., 2015; Sabbe et al., 2020). Particularly useful was the documentation produced by PRISMA (Page et al., 2021a; 2021b), which allowed for a graphical representation of the process and tools for its validation. It also provides a systematisation that allows for the replicability of the review both internationally and in subsequent years.

Within this protocol, the first step was to define the research problem, presented above. Based on these, and in accordance with the methodology employed, criteria were generated for selecting the sources to be worked with (Botella & Sánchez, 2015). These were:

- Area of study. The selected studies focused on the area of social sciences, specifically SW, social education and social policy.
- Date of publication. The selected articles were published between 2017 and 2021, based on the SDG impact discussed above.
- Type of papers. Only indexed journal articles were selected.
- Access Type. All types of articles were selected.
- Language. Given the language skills of the research team, priority was given to articles published in English and Spanish.
- Exclusion criteria:
    - Studies that do not focus on PWD.
    - Studies dealing with therapeutic, clinical or other types of social science interventions, such as pedagogy or clinical psychology.

- Non-empirical studies, which lack primary data or which do not refer to the evaluation of the interventions presented.

We studied researches published on SI with PWD between 2017 and 2021, because of the international political impact of the SDGs. This document, approved in 2015, represents a commitment to be fulfilled between 2016 and 2030. Therefore, it was understood that the period between 2017 and 2021 should reflect its spirit, also in SIs with PWDs. Furthermore, the SDGs provide indicators whose implementation could reinforce the evaluation of the different actions developed (DIHR, 2019; UN, 2015).

The databases selected for the search of studies were Scopus and Web of Science, given the large number of articles with international impact and linked to public and social policies that they contain. In addition, these databases allow us to use so many search filters. The databases selected for the search of studies were Scopus and Web of Science, given the large number of articles of international impact and linked to public and social policies that they contain. In addition, these databases allow us to use numerous search filters. "Search filters are predefined strategies that are designed to retrieve specific types of records, such as those of a particular methodological design" (Kugley et al., 2016, p.32). Search filters provide a useful way of describing specific characteristics that are of interest to our research, facilitating screening. However, as Kugley et al. (2016) suggests, they should be used with caution in the social sciences, given the less comprehensive indexing in this field. Therefore, both the filters that can be applied, as well as the quality of the indexing of these databases and the large number of articles in English available, were sufficient reasons to use these databases.

The search for studies was conducted in August 2021. Keywords and their synonyms were selected based on those used by previous studies, such as De Schmidt (1997), Llewellyn (2014; 2017) and Fleming et al. (2019). Furthermore, we incorporate words linked to European and Spanish social policies, such as dependency. The keywords, that finally we used, were: disability, dependency, inclusion and social intervention. These words were used in combination, thus making the search more concrete. It should be noted that these words were combined with some synonyms frequently used in this type of research in this way:

- Disability: functional diversity, special needs, impairment, handicap and deterioration.
- SI: social practice, social services, public policies and social policies.

These synonyms were used using the Boolean term OR. Moreover, soci* was used for the word social intervention, favouring the search for studies also related to the social, care and health fields and linked to public and social policies. The Boolean term AND was also used to limit the search to documents that contained more than one of the mentioned concepts.

3.3 RESULTS

According to the procedure discussed above, we worked with the 19 studies collected. It should be noted that most of the articles were discarded under the last intra-observer exclusion criterion, i.e. lack of empirical or evaluation data. Considering our objectives, in this section we will show the interventions implemented so far, dividing them according to their characteristics. After their presentation in a summarize table, we compare their peculiarities, the evaluation methods they used and their effectiveness, according to their specific characteristics. To conclude, we present a general summary of the results, which helps to answer our research problem, to advance in the improvement of the evaluation of social interventions with and for PWD.

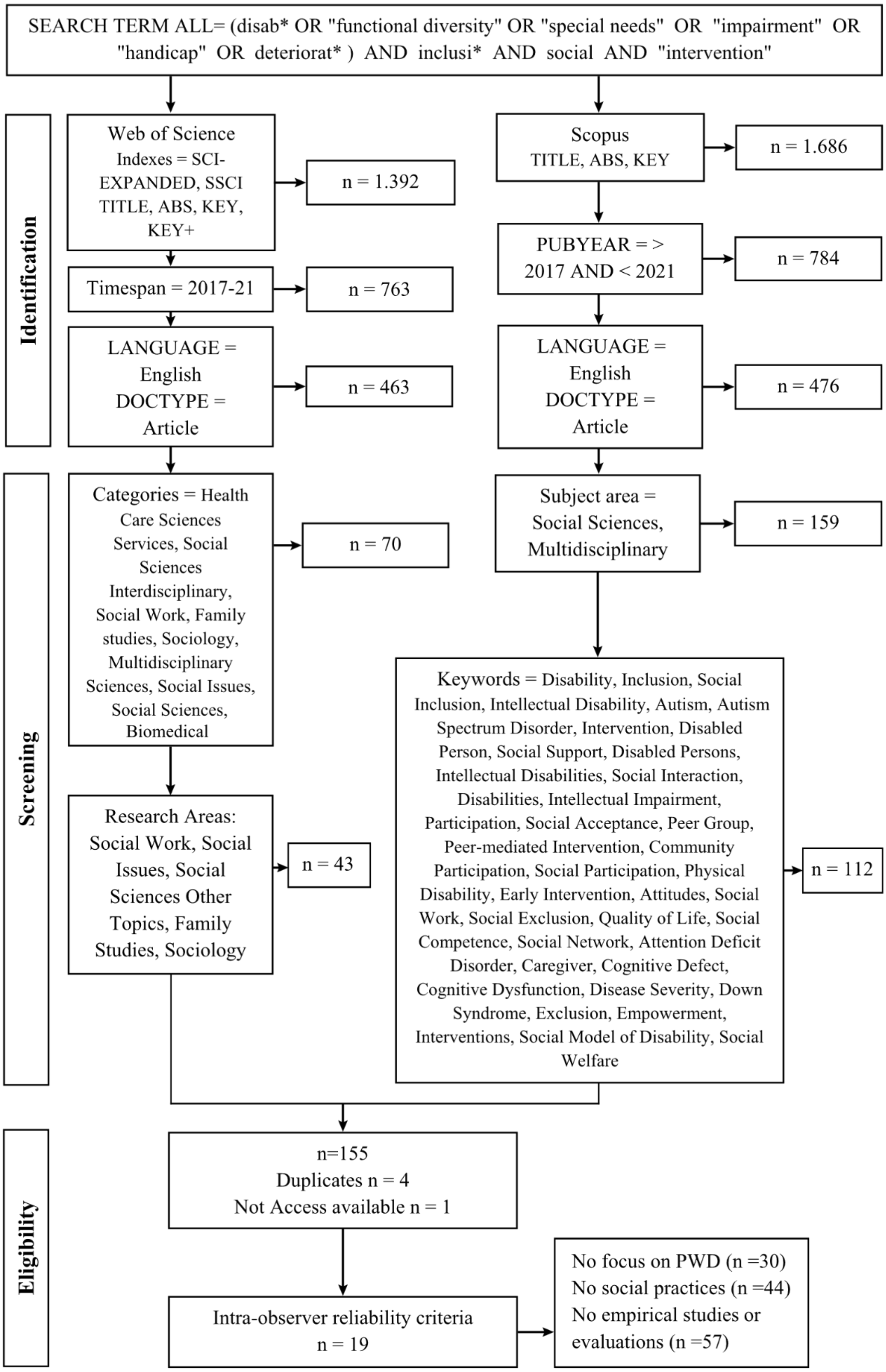

Figure 1. PRISMA Flow Diagram of the search strategy

In order to fulfil our objective of finding out about the interventions carried out and their characteristics, a summarize table (Table 4) was drawn up to meet these characteristics. Particularly noteworthy are the characteristics in relation to the type of intervention: individual (5), group (4) or community (10), where the latter clearly stand out. Furthermore, considering the international context, it can be stated that individual interventions are preferred by Anglo-Saxon countries, group interventions by European countries, and that there is more variety in community interventions, with the type of intervention most frequently carried out in Asian countries.

Table 4. *Systematic review sample characteristics*

Reference	Country	Area	Disability	System	Intervention	Sample (N)	Age	Professionals
Garrels, (2018)	Norway	NS	ASD and Mild ID	Education	Individual	1	14	Educator
Walsh (2019)	Ireland	NS	ASD and ID	Social Services	Individual	6	21-27	Teachers
Watchman (2020)	Scotland and United Kingdom	NS	ID	Health and Social Services	Individual	16	38-77	NS
Wilson (2019)	Australia	Mixed	ID	Social Services	Individual	5 Mentees 12 Mentors	Mentees 15-17 Mentors 53-81	Occupational therapist (OT) and mentors
Wilson (2017)	Australia	Mixed	ID	Social Services	Individual	18	17-24	OT and mentors
Adolfsson (2019)	Sweden	Urban	ID	Social Services	Groups	9	24-51	NS
Kalgotra (2019)	India	Mixed	ID	Education	Groups	70	6-17	Special educators, psychologists and parents
Mercado (2021)	Spain	Urban	ID	Art	Groups	9	22-58	Dancers and coaches
Vasileiadis (2018)	Greece	Mixed	Mild ID	Education	Groups	20	6-7	Speech therapist, psychologist and special education teacher
Kafaa (2021)	Indonesia	NS	NS	Health	Community/ Public Policy	28	NS	PWDs, community, government and selected informants
Bigby (2021)	Australia	Mixed	ID	Social Services	Community	10 PwDs 18 staff	19-48 PWDs	CEO, managers, team leaders and front-line support workers
González (2020)	Spain	NS	ID	Social Services	Community	125	Average 56,7	NS
Jeanes (2018)	Australia	NS	NS	Sport	Community	3 clubs	Young	Sport development workers and volunteers

Reference	Country	Area	Disability	System	Intervention	Sample (N)	Age	Professionals
Kruithof (2021)	Netherlands	Urban	ID and Mental Health	Social Services	Community	13	33-76	Social workers (SW)
MacRae (2020)	Scotland	Urban	ID	Sport	Community	10 participants 10 carers 3 staff	>70	NS & Volunteers
Mathias (2018)	India	Urban	Psycho-social	Health	Community	437	NS	Community leaders, functionaries, pre-school workers, auxiliary nurse midwives
Trani (2021)	Afghanistan	Urban	All	Health & Social Services	Community	1184 CBR 927 Control	Mean 16,13 (CBR) Mean 35,6 (Control)	NS
Webber (2019)	England	Mixed	Learning and/or Mental Health	Mental Health & Learning Services	Community	117	16-87	Social care workers, SW, OT, nurses, psychologists, psychiatrists and team managers
Yoon (2020)	Australia and South Korea	NS	Cognitive	Art	Community	4 organisations	NS	Art Director, Studio Manager and Graphic Designer

First of all, the five individual interventions are related with some cognitive or developmental disorders (DD) (see Table 4). Moreover, their interventions were linked to the field of training for employment or the improvement of social skills, using mentoring programs. For the evaluation of the interventions, they used a variety of methods, mainly focused on the achievement of objectives, with different psychometric instruments linked to DD and interviews.

Individual SIs focus on mentoring actions in individual sessions. In four of the cases, social and communication skills are worked on (Garrels, 2018; Walsh et al., 2019; Wilson et al. 2017; 2019). In two of the cases (Wilson et al. 2017; 2019) the focus was on employment and vocational skills and activities. Finally, Watchman et al. (2020) discusses different ISs to improve the situation of people with dementia, including games, sports, music, cooking, etc. These interventions are complemented in different ways. In the case of Garrels (2018), putting skills into practice with peers, during lunchtime. And at Walsh et al. (2019), with videos and group sessions.

Table 5. *Evaluation of individual interventions*

Reference	Measures	Method	Results
Garrels (2018)	Achievement of goals Conversational skills Satisfaction	Qualitative: Interview schedule and observation checklist	Improving conversational skills Improving self-determination
Walsh (2019)	Social skills Social Behaviours	Quantitative: Observations, Validated Surveys.	Improvement in social skills Generalised improvement in natural environments
Watchman (2020)	QoL Neuropsychiatric factors Personal characteristics Changes in the PWD Impact perception Facilitators and challenges	Mixed: Validated questionnaires, staff intervention diary and the behaviour change tool, semi-structured interviews, photo voice	Reduction of medication, distress and/or agitation Meeting and improving individual targets Existence of fears about dementia
Wilson (2017)	Psychiatric and psychologic factors Adaptive behaviours Independent Living Decision-making Skills Community Integration Self-Determination Work Skills/Adjustment QoL	Mixed: Pre- and post- intervention outcomes measures. Individual Interviews.	Better self-assessment Pride in achievements and enjoyment of the activity Perception of learning for mentors and mentees Benefit of sense of ownership Need to lengthen the programme Need for improvement in planning, support and training for mentors Problems of young people with ID in completing self-reporting
Wilson (2019)	QoL Personal Wellbeing Work adjustment Loneliness	Quantitative: Quasi-experimental pre-test post-test with validated questionnaires.	Improving QoL at the community level No significant differences in loneliness, well-being or workplace adjustment. Low drop-out rates Improved sense of community and work skills

In group interventions we found four interventions, all linked with ID (see Table 4). Their interventions were linked to the management of coexistence, interactions and self-regulation. For their evaluation, mostly used qualitative method, but with different measures.

In education system we found a coexistence programme between a general and a special primary school to promote their interaction (Vasileiadis & Doikou-Avlidou, 2018). They worked on communication and personal relationships; and secondly, twice a week, a teacher accompanied a pupil to activities in the neighbourhood. Kalgotra et al. (2019), used role-play, rewards, verbal instruction and feedback to work on different social and behavioural skills (aggression control, interaction skills, cleanliness, etc).

Adolfsson et al. (2019), in social services, worked with a group of mothers with cognitive limitations who have children in residential care. Their aim was to help them understand and cope with their situation and to receive support from other mothers, e.g. in parental rights, cognitive difficulties or court proceedings.

Finally, although it was not a specific programme, we included Mercado et al. (2021) in our results, as a form of SI with PWD from the field of dance. She asked parents, people with ID and coaches about the intervention in which they participate and its impact.

Table 6. *Evaluation of group interventions*

Reference	Measures	Method	Results
Adolfsson (2019)	Acceptation Relation with the system Mother role Mother experience Maturing Challenge and changes	Qualitative: Interviews	Improved mother's maturation Expansion of life expectancy Need of more research Require supports beyond maternal role
Kalgotra (2019)	Social Skills Social Madurity Intellectual quotient Socio-economic factors	Quantitative: Quasi-experimental pre-test post-test	Strong effect on children with mild ID Moderate effect in children with moderate ID
Mercado (2021)	QoL Wellbeing Social Relationships Self-Determination Social Inclusion Rights	Qualitative: Review of literature and Semi-structured interviews	Improve the QoL for people with ID Improve self-esteem, confidence and the development of soft skills Supports the visibility of the group Limitations of sample and methodology
Vasileiadis (2018)	Behaviours Interaction Solitary activity	Qualitative: Systematic observation, semi-structured interviews and teacher's journal	Significant increase in positive interactions inside and outside the classroom and participation. Decrease in negative interactions Positive changes in attitudes of regular children Positive changes persist after the programme Relevance nature of play activities, with clear boundaries and structure; the systematisation of the programme; and, the individualised plan. Need for teacher support and collaboration between teachers.

Finally, we analysed the 10 community interventions found. These actions were more diverse in terms of the type of disability and the system from which they were implemented (see Table 4). They were mainly linked to promoting social inclusion, raising awareness and improving social networks and community resources. For the evaluation of the interventions, mostly semi-structured interviews were used, mixed in some cases with different psychometric instruments, as Adaptative Behaviour Scale, Social Participation Index, Emotional well-being Index or GENCAT Scale (questionnaire measuring quality of life), all of them with different indicators.

All interventions linked to the social services system focus on social inclusion, community participation and improving the quality of life (QoL) of PWD, varying the method of intervention for the same objective. Kruithof et al. (2021) proposes inclusion through volunteering actions of PWD; Bigby & Anderson (2021) worked with two organisations, generating controlled convivial encounters, regular and brief social interactions around an activity, respecting the interests of PWD; and, González et al. (2020) analysed the social inclusion of people living in residential settings and the interventions that do or do not promote it.

Interventions made between the health and social services system consider the training and awareness-raising of professionals. On the one hand, Trani et al. (2021) with an interdisciplinary and local intervention, which reduces inequalities and favours the empowerment of PWD. On the other hand, Webber et al.'s (2019) model is based on a co-productive process in which objectives are jointly established and opportunities are identified. Along these lines, but from within the health system, is the SI by Mathias et al. (2017), which aimed to create community knowledge, safe social spaces and partnerships for action to change attitudes towards PWDs Yoon et al. (2020) proposes this change in the social perception of disability through art, promoting the careers of artists with disabilities. Also, from health sector, Kafaa (2021) presented a Social Protection Programme for PWD to reduce the socio-economic risk factor of disability in Indonesia.

There are two experiences of interventions through sport. On the one hand, one based on a modified form of sport, the walking football programme for people with dementia (MacRae et al., 2020). And, on the other hand, the case of three youth clubs for PWD that raise the need to include PWD, although some critics argued that this sacrificed part of the competitive essence (Jeanes et al., 2018).

Table 7. Evaluation of community interventions

Reference	Measures	Method	Results
Bigby (2021)	Behaviour Social interactions Social skills	Mixed: Semi-structured interviews and validated questionnaire	Improve lexicon Great work of the staff for the organization and supervision of the meetings. Improve choice and accountability results in the offer with clarity in individualized funding.
González (2020)	QoL	Quantitative: Validated questionnaire	Deficits in levels of psychosocial well-being that correlate significantly with QoL. Need to strengthen relationships with their environments. No relationship with sex or degree of dependence, in general. Importance of centre specialization.
Jeanes (2018)	Inclusion understood Inclusion policies Strategies Benefits Challenges	Qualitative: Semi-structured interviews	Resistance to inclusion policies in sport. Provision is seen as too difficult to implement, unethical to competition or outside the core business. Need to combat ableism, training and inclusion in clubs.
Kafaa (2021)	Social Protection Programmes	Qualitative: Review of literature, interviews and directly observed	Increase of inclusive social protection for PWD in Indonesia. Difficulties in ensuring participation of PWDs in the insurance scheme. Lack of coverage such as transportation or some of the necessities. Limited participation in community health program, only covers the poor.
Kruithof (2021)	Wellbeing Relationships Mental health Experiences	Qualitative: Semi-structured Interviews	Improvements in inclusion, mental health and well-being. Provided superficial but meaningful contacts in the community. Countered feelings of stigmatization.
MacRae (2020)	Memories Social Impact Carer respite	Qualitative: Semi-structured Interviews	Counteracts cultural, social and stigma barriers Can help maintain or improve functioning, interpersonal relationships and QoL. Need to provide information and necessary means (time, transport, etc.) Improve mood Need for methodological flexibility Positivity of playing in environments with emotional reminders, incorporating social interactions, "being one of the boys", separating caregivers and offering flexible respite.

Reference	Measures	Method	Results
Mathias (2018)	Knowledge outcomes Knowledge mechanisms Safe social spaces Social inclusion Safe spaces mechanisms Partnerships outcomes Partnerships mechanisms Social capital	Mixed: Focus Groups Discussion, participant observation, document review and monitoring matrix of outputs/outcomes	Improved community awareness, social support and inclusion. It created safer social spaces. Non-hierarchical system and informal conversations allowed for "organic" integration of biomedical knowledge. Better communication skills with PWD. Facilitating social networks enhances women's collective capacity. Actions at local level contribute most to learning, stigma reduction and help-seeking. Progress is uneven and slow.
Trani (2021)	Social Participation Wellbeing Daily activities Communication Employment skills and activities	Quantitative: Validated questionnaires and employment and sociodemographic covariates	Improve daily mobility and communication Improve emotional well-being, social participation and access to employment. Effectiveness in advocating for the rights of PWD and promoting social awareness. Lack of standardisation in the CBR programme. The most successful specific processes could not be identified.
Webber (2019)	Wellbeing Relationships QoL Social adjustment Social opportunities and resources	Mixed: Prospective one group pretest-posttest pre-experimental study. Semi-structured Interviews, Resource-Generator UK, Social and Community Opportunities Profile and validated questionnaires	No statistically significant differences between participants who experienced high and low fidelity IPC. Improvements in high fidelity participants: significantly greater access to social capital; greater perceived social inclusion; and, lower costs of services. Higher mental wellbeing. Positive life events and medication as variables to be studied in fidelity and improved outcomes.
Yoon (2020)	Social opportunities Artistic quality and capability Support Barriers Individual experiences	Qualitative: Observation and Semi-structured interviews	Growing demand for the development of professional artistic careers for PWD. Greater willingness in Australia than in Korea. Institutional focus on therapeutic and recreational, leading to funding problems. Need for social support and opportunities to show their art. The change of perspective creates a more diverse artistic space.

In general, in terms of the evaluations developed, 53% opted for qualitative research, mainly using interview and observation techniques. All of them were justified in order to broadly analyse the perspectives of the participants, or the need to clarify concepts and questions given the characteristics of their disabilities. The 26% opted for a quantitative assessment focused on the use of different already validated questionnaires (González et al., 2020; Trani et al., 2020; Walsh et al., 2019; Wilson et al., 2019). These tools coincided in terms of objectives with those used in mixed methods (Bigby & Anderson, 2021; Watchman et al., 2020). In relation to the measures, six of the articles (González et al., 2020; Mercado et al., 2021; Watchman et al., 2020; Webber et al., 2019; Wilson et al., 2017; 2019) chose QoL as one of them, due to different existing questionnaires and the multitude of aspects it covered. From an international perspective, we should consider that there are no considerable differences between the tools used and the country of research. Except in the case of group interventions, where only the Asian research used quantitative methodology as opposed to the qualitative methodology chosen by the rest of the studies. Therefore, answering to our research problem, these indicators can be understood as the basis for the creation of generalised indicators for the evaluation of SI with PWD.

3.4 DISCUSSION

The evaluation of SI with PWD is a growing demand both from theory (Høydal & Tøge, 2021; De Smidt & Goreydt, 1997) and from institutions. For this reason, and considering the challenges and research gaps in this field (Gavidia-Payne & Jackson, 2019; Llewellyn, 2014; 2017), a systematic review of nineteen relevant articles of the literature on SI with PWD and its evaluations was proposed.

Firstly, a scarcity of results was revealed, which would have to be explored if it is due to a lack of SIs or a lack of publications on their evaluation. The latter hypothesis is the most likely given the multitude of social entities and projects focused on PWD that obtain external funding for their development, although not for their evaluation and publication through longitudinal studies (Llewellyn, 2014; 2017).

In addition, most SIs are community-based and linked to people with ID or DD, being more diverse or general in community interventions. Furthermore, it is also noted that most of them focus on social inclusion or on improving social and communication skills, in line with the objectives of the CRPD and the EUSRPD, as opposed to group interventions, which are more focused on emotional self-regulation, and individual interventions, which are more focused on employment skills work and formal education.

Attending to international context, Europe and Australia have the largest number of publications. There were specific cases in Indonesia, India and Afghanistan. Specifically, interventions in developing countries have a more medical focus (Kafaa, 2021; Mathias et al., 2018; Trani et al., 2021). There is scarcity of studies focusing on rural areas. Moreover, they present age ranges that are either very broad or focused on childhood. Consequently, it follows that there is only a specialisation in addressing disability in childhood, leaving aside other moments such as youth, only addressed by Walsh et al. (2019) and Jeanes et al. (2018). In this sense, it should be studied whether a specialisation of resources for PWD (young, ageing or adult) is necessary or desirable (González et al., 2020; Wilson et al., 2017) or the effects that this joint attention has on the entire population, with age ranges up to 71 years (Webber et al., 2019).

Furthermore, it is worth noting the lack of intersectional studies that cross-analyze variables such as age, gender or sexual orientation with the disability variable, helping to detect interventions for particularly vulnerable PWD, in line with Fleming et al. (2019), Llewellyn (2014;2017) and Gavidia-Payne & Jackson (2019). Additionally, although this may depend on the tradition of each country, it is curious to note that, despite being fundamental for SI, the figure of the SW only appears explicitly in two studies (Kruithof et al., 2021; Webber et al., 2019).

Related with evaluation, there is a deficit of participation of PWDs. Only one article (Garrels, 2018) evaluated participants' satisfaction with the activity, and only three papers address the experience of participants with and without disabilities (Adolfsson et al., 2019; Kruithof et al., 2021; Yoon et al., 2020). Also, it is worth noting that only one paper mentions the co-production of studies and interventions (Webber et al., 2019), in line with Fleming et al. (2019), Llewellyn (2014;2017) and contrary to what is proposed by textbooks such as Gavidia-Payne & Jackson (2019).

Finally, in relation to the results obtained, all the SIs analysed showed improvements in the recipients (e.g. in perceived QoL or social inclusion). Despite this, there was agreement on different deficits, such as the existence of fears; the need for more training and support of professionals (Mathias et al., 2018; Vasileiadis & Doikou-Avlidou, 2018) and funding (Yoon et al., 2020); and, mainly, a need to change the social perception (Adolfsson et al., 2019; Jeanes et al., 2018; MacRae et al., 2020; Mathias et al., 2018; Mercado et al., 2021; Yoon et al., 2020). Furthermore, only Kafaa (2021), Gonzalez (2020) and Trani et al. (2021) refer to the CRPD (2006) and only Kafaa (2021) justifies his study in relation to the SDGs (UN, 2015). Therefore, it is not yet possible to speak of consolidated, homogeneous and structured indicators or assessment methods for SI with PWD, despite the calls of the CRPD and the EUSRPD.

An example of this is the discussion of Jeanes et al. (2018) and MacRae et al. (2020) who raise issues such as inclusion versus competitiveness and the essence of sport. The CRPD talks about reasonable accommodation in these activities, i.e. making adaptations without losing the essence of the activity or at great cost. However, this debate raises questions such as: is it compatible to talk about inclusion and make it conditional on reasonable accommodation? How do we assess what is the essence of the activity?

In this sense, different questions arise: Are we really carrying out the activity with these people in mind? If there is no co-production of the activity and its evaluation, are we including them? Has the medical model been overcome if we focus on the evaluation of psychometric variables without considering the preferences of the PWD who participate in the activities? Some of these questions are raised by Yoon et al. (2020) or Jeanes et al. (2018), although without elaborating on their answers or the necessary modifications. Therefore, it can be raised as a future line of research.

In conclusion, despite the limited number of samples studied and the needs to deepen the connection between the SDGs and the SIs, it can be affirmed that the implementation of SI assessments, promoted by institutions, is not yet a reality. Furthermore, agreeing with Fleming et al. (2019) and Llewellyn (2014; 2017), there is a deficit of scientific publications in this field, especially in developing countries. Nevertheless, the studies analysed show progress in the systematic evaluation of SIs, although they lack homogeneity in their indicators, measures and methods.

A future line of research would be to analyse the convenience or otherwise of developing SIs focused on certain moments of development, such as youth or ageing, meeting the specific needs of each stage of life. And, to implement intersectional studies in order to address vulnerable groups within PWDs.

3.5 REFERENCES

A/RES/70/1 Resolution adopted by the General Assembly on 25 September 2015. Transforming our world: the 2030 Agenda for Sustainable Development.

Adolfsson, P., Janeslätt, G., Lindstedt, H. & Jöreskog, K. (2019). Mothers with cognitive limitations who have children in placement benefit from intervention. *Child & Family Social Work*, 26, 79–88. DOI: 10.1111/cfs.12791

Bigby, C. & Anderson, S. (2021). Creating opportunities for convivial encounters for people with intellectual disabilities: “It looks like an accident. *Journal of Intellectual & Developmental Disability*, 46 (1): 45-57, DOI: 10.3109/13668250.2020.1812178

Botella Ausina, J., & Sánchez Meca, J. (2015). *Meta-análisis en ciencias sociales y de la salud.* Síntesis.

Convention on the Rights of Persons with Disabilities (CRPD).

Corbetta, P. (2010). *Metodología y técnicas de investigación social* (ed. rev.). McGraw-Hill.

de Smidt, G. A. & Gorey, K. M. (1997). Unpublished social work research: Systematic replication of a recent meta-analysis of published intervention effectiveness research. *Social Work Research*, 21 (1), 58-62.

Fleming, P., McGilloway, S., Hernon, M., Furlong, M., O'Doherty, S., Keogh, F., & Stainton, T. (2019). Individualised funding interventions to improve health and social care outcomes for people with a disability: a mixed-methods systematic review. *Campbell Systematic Reviews*, 3.

Garrels, V. (2018). Getting good at small talk: student-directed learning of social conversation skills. *European Journal of Special Needs Education*. DOI: 10.1080/08856257.2018.1458472

Gavidia-Payne, S., & Jackson, M. (2019). Research Priorities and Protections. In Matson, J.L. (ed.). *Handbook of Intellectual Disabilities*, 247-261.

González Casas, D., Ducca Cisneros, L.V. & García Román, C. (2020). The Influence of Community Social Support in the Life Quality of People with Disabilities. *Siglo Cero*, 51 (3), 83-103. DOI: 10.14201/scero202051383103

Higgins, J. P., Thomas, J., Chandler, J., Cumpston, M., Li, T., Page, M. J., & Welch, V. A. (eds.) (2020). *Cochrane handbook for systematic reviews of interventions*. John Wiley & Sons.

Høydal, Ø. S., & Tøge, A. G. (2021). Evaluating social policies: Do methodological approaches determine the policy impact?. *Social Policy & Administration*, 55(5), 954–967. DOI:10.1111/spol.12682

Izuzquiza, D. & Rodríguez, P. (2016). Evaluación de la metodología Empleo con Apoyo (ECA) en el Programa Promentor (UAM-PRODIS). El ajuste competencial. *Siglo Cero*, 47(1), 37-54. DOI:10.14201/scero201613754

Jeanes, R., Spaaij, R., Magee, J., Farquharson, K., Gorman, S. & Lusher, D. (2018). Developing participation opportunities for young people with disabilities? Policy enactment and social inclusion in Australian junior sport. *Sport in Society*, DOI: 10.1080/17430437.2018.1515202

Kafaa, K. (2021). Special Health Insurance as an Inclusive Social Protection Program for People with Disabilities. *Jurnal Ilmiah Peuradeun. The International Journal of Social Sciences*, 9(1), 71-86. DOI:10.26811/peuradeun.v9i1.462

Kalgotra, R., Warwall, J.S. & Teji, V. (2019). Social development of children with mild and moderate Intellectual Disabilities at special schools in India. *Life Span and Disability*, XXII (1), 29-53.

Kruithof, K., Suurmond, J., Kal, D. & Harting, J. (2021). Volunteer work with vulnerable persons in the community: A qualitative study of social inclusion. *Journal of Social Work*, 21(4), 696–712. DOI: 10.1177/1468017320919874

Kugley, S., Wade, A., Thomas, J., Mahood, Q., Jørgensen, A.M.K., Hammerstrøm, K., Sathe, N. (2016). Searching for studies: A guide to information retrieval for Campbell Systematic Reviews. *Campbell Methods Guides 2016*,1. DOI: 10.4073/cmg.2016.1

Llewellyn, G. & National Disability Research and Deveopment Agenda, sponsoring body & University of Sydney. Centre for Disability Research and Policy, issuing body. (2014). *Report of audit of disability research in Australia.*

Llewellyn, G. & National Disability Research and Deveopment Agenda, sponsoring body & University of Sydney. Centre for Disability Research and Policy, issuing body. (2017). *Audit of disability research in Australia update report 2017.*

MacRae, R. Macrae, E. & Carlin, L. (2020). Modifying walking football for people living with dementia: lessons for best practice. *Sport in Society*, DOI: 10.1080/17430437.2020.1825383

Mathias, K., Mathias, J., Goicolea, I. & Kermode, M. (2018). Strengthening community mental health competence—A realist informed case study from Dehradun, North India. *Health Social Care Community*, 26, e179–e190. DOI: 10.1111/hsc.12498

Mercado García, E., Merino Gallego, C. & González Casas, D. (2021). Los beneficios de la danza en la mejora de la calidad de vida (CdV) de personas con discapacidad intelectual (PcDI). *Alternativas. Cuadernos de Trabajo Social*, 28(2), 215-246. DOI: 10.14198/ALTERN2021.28.2.04

Moher, D., Shamseer, L., Clarke, M., Ghersi, D., Liberati, A., Petticrew, M., Shekelle, P., Stewart, L.A. & PRISMA-P Group (2015). Preferred reporting items for systematic review and meta-analysis protocols (PRISMA-P) 2015 statement. *Systematic Reviews Journal*, 4, 1.

Page M.J., Moher, D., Bossuyt, P.M., Boutron, I., Hoffmann, T.C., Mulrow, C.D., et al. (2021a). PRISMA 2020 explanation and elaboration: updated guidance and exemplars for reporting systematic reviews. *British Medical Journal (BMJ)*, 372 (160). DOI: 10.1136/bmj.n160

Page, M.J., McKenzie, J.E., Bossuyt, P.M., Boutron, I., Hoffmann, T.C., Mulrow. C.D., et al. (2021b). The PRISMA 2020 statement: an updated guideline for reporting systematic reviews. *British Medical Journal (BMJ)*, 372 (71). DOI: 10.1136/bmj.n71

Pindado García, F. (2015). *Hacia una única catalogación de los derechos fundamentales –los derechos económicos, sociales y culturales de las personas con discapacidad como derechos fundamentales–*. Ediciones Cinca.

Sabbe, M., Moyson, S. & Schiffino, N. (2020). Citizen-agency versus state-agency at the frontline in prisons and probation services: A systematic literature review. *Social Policy & Administration*, 55, 206-225. DOI: 10.1111/spol.12633206

Shakespeare, T. (2014). *Disability Rights and Wrongs Revisited.* Routledge, Taylor & Francis Group.

Stufflebeam, D.L. (2003). The CIPP model for evaluation. *New Directions for Program Evaluation*, 19, 7-98.

The Danish Institute for Human Rights (DIHR) (2019). The Human Rights Guide to the Sustainable Development Goals. *The Danish Institute for Human Rights.* https://sdg.humanrights.dk/en

Trani, J.F., Vasquez-Escallon, J. & Bakshi, P. (2021). The impact of a community-based rehabilitation program in Afghanistan: a longitudinal analysis using propensity score matching and difference in difference analysis. *Conflict and Health*, 15, 63. DOI: 10.1186/s13031-021-00397-y

Union of Equality Strategy for the Rights of Persons with Disabilities 2021-2030. European Union.

Vasileiadis, I. & Doikou-Avlidou, M. (2018). Enhancing social interaction of pupils with intellectual disabilities with their general education peers: the outcomes of an intervention programme. *Journal of Research in Special Educational Needs*, 18 (4): 267–277. DOI: 10.1111/1471-3802.12410

Walsh, E., Holloway, J., Lydon, H., McGrath, A. & Cunnigham, T. (2019). An Exploration of the Performance and Generalization Outcomes of a Social Skills Intervention for Adults with Autism and Intellectual Disabilities. *Advances in Neurodevelopmental Disorders*, 3: 372–385. DOI: 10.1007/s41252-019-00125-x

Watchman, K., Mattheys, K., McKeron, M., Strachan, H., Andreis, F. & Murdoch, J. (2020). A person-centred approach to implementation of psychosocial interventions with people who have an intellectual disability and dementia—A participatory action study. *Journal of Applied Research in Intellectual Disabilities*, 34, 164–177. DOI: 10.1111/jar.12795

Webber, M., Morris, D., Howarth, S., Fendt-Newlin, M., Treacy, S. & McCrone, P. (2019). Effect of the Connecting People Intervention on Social Capital: A Pilot Study. *Research on Social Work Practice*, 29(5): 483-494. DOI: 10.1177/1049731517753685

Wilson, N.J., Cordier, R., Ciccarelli, M., MacCallum, J., Milbourn, B., Vaz, S., Joosten, A., Buchanan, A., McAuliffe, T. & Stancliffe, R.J. (2018). Intergenerational mentoring at Men's Sheds: A feasibility study. *Journal of Applied Research in Intellectual Disabilities*, 31, e105–e117. DOI: 10.1111/jar.12338

Wilson, N.J., Cordier, R., Milbourn, B., Mahoney, N., Hoey, C. & Buchanan, A. (2019). Intergenerational mentoring for young adult males with intellectual disability: Intervention description and outcomes. *Journal of Intellectual & Developmental Disability*. DOI: 10.3109/13668250.2019.1582758

Yoon, J. H., Ellison, C. & Essl, P. (2020). Shifting the perspective from 'incapable' to 'capable' for artists with cognitive disability; case studies in Australia and South Korea. *Disability & Society*. DOI: 10.1080/09687599.2020.1751079.

4

YOUNG PEOPLE WITH SEVERE DISABILITIES, FAMILIES AND SOCIAL SERVICES: A RELATION OF RESOURCES AND GAPS

4.1 INTRODUCTION

To talk about youth and disability is to talk about heterogenous concepts. Not only one youth or only one disability exists, let alone only one type of young people with disabilities (PWD) or severe disability (SD), which is our case (Saldivar & Alvarado, 2020). The transition from infancy to adulthood directly affects how someone conceives the world, their need, and their quality of life and that of their family. It is here where social services play a fundamental role (Saldívar & Alvarado, 2020; Banati & Bacalso, 2021). Thus, it is worth firstly dealing with these concepts, the impact that disability has on youths and their families, and the cover that socials services offer to meet their needs on order to look in-depth at this very vulnerable group's experiences.

Delimitation of disability varies according to the affected function, its time of origin, its degree of severity or the approach taken to understand it (Shakespeare, 2014). Unlike a medical approach, which is questioned by many authors (Goodley et al., 2019; 2018; Alford et al., 2014; Shakespeare, 2014), different models emerged in the 2000 decade, including the biopsycho-social model, which centred on the context and the social barriers that limit these people's development (Abellán & Hidalgo, 2011), as well as the model of rights, which was reinforced by the ratification of the *International Convention on the Rights of Persons with Disability* (CRPD).

From this perspective, the needs of PWD and their families vary throughout the life cycle. Thus, the traditional healthcare domain must be dealt with, but the processes that involve their characteristics deteriorating due to ageing must also be intervened by attending to access to education, leisure, housing, work, etc. This context becomes more important when it is understood as a facilitator, or not, of social inclusion, and even more so if it deals with people with SD or considerable support needs, where families play a relevant role in their care and them accessing inclusion possibilities. So, it is worth taking a cross-sectional perspective that covers the life cycle of these people and their families in the interest of intervention from the public and social domain (Verdugo et al., 2012; Pérez & Moral , 2008; Tint & Weiss, 2016; Madariaga et al., 2021).

The family is particularly relevant in countries like Spain, where it plays a key role as an agent who supplies well-being (Foubert et al., 2014). This creates the need to interconnect official support services (i.e.: social services) and non-official support networks (family or friends). This is further emphasised when combined with PWD's gradual ageing, plus that of their main carers, or women who work, which is changing care dynamics (Tobio et al., 2011).

To attend to these realities, policies have been developed, such as the creation of the System of Care for Dependency and Personal Autonomy (SCDPA). It has been promoted from the disability area, and from other areas like the elderly. The catalogue of Spanish Law 39/2006 on Promoting Personal Autonomy includes resources to attend PWD and the elderly (e.g., care homes, day centres, telecare or services to promote personal autonomy).

This catalogue makes no clear differentiation among services, which occurs with other specific social services intended for groups; e.g. youths, infants or the elderly (Law 39/2006; Decree 55/2017). In turn, there is the complexity of the social services system and attending to dependency, plus the characteristics of the 17 Spanish Autonomous Communities with the creation of 17 different complex systems that intervene in the material acknowledgement of these persons' rights. The resources and services included in this catalogue include many complaints about the inclusion and promotion of the personal autonomy they offer (Blanca, 2017; Aparicio, 2016; Argullo et al., 2011; Jollien, 2011, Romañach & Palacios, 2008; Mira-Aladrén et al., 2023).

To all this, we need to add some detected risk factors, such as living in a rural setting, especially in such a disperse territory as Aragón, being a migrant, a woman or, as in our case, a youth with considerable support needs (Mira-Aladrén et al., 2023; Saldívar & Alvarado, 2020; Thabethe, 2021; Huete et al., 2016; Baird et al., 2021). In other words, an intersectional perspective must be maintained that combines several factors to increase discrimination and/or already existing difficulties (Crenshaw, 1991).

Therefore, the following questions arise: What are the implications for young people and their family if they have SD? How do social services address their needs? Are the demands they have as young people met? What changes or improvements are necessary to improve their attention and inclusion?

Attending to these questions, our general objective is to explore the experiences of young people with SD in social services in Aragón (Spain). This objective is specified to:

1. To identify the main demands and needs of young people with SD and their families
2. To learn about experiences in the aragonese social services of young people with SD and their families
3. To propose improvements in the social services intervention.

4.2 METHOD

4.2.1 Research design

This study forms part of a larger research project on the needs of young people with SD in the social services in Aragón (Spain). According to our aims and from an intersectional perspective, a semi-structured interview was conducted to investigate youth PWD and their families' experiences in SCDPA by attending to the diversity of PWD and their specific needs. Closed questions were linked with: 1) socio-demographic data and the resources that SCDPA provides; 2) youth PWD and their family's experiences based on quality of life questionnaires and interviews (Huertas, 2010; Sullivan et al., 2008; Dyke et al., 2013; Verdugo et al., 2012), social services quality (Parasuraman et al., 1988; Álvarez, 2021; Ramírez-Navarro et al., 2021; EQUASS, 2021), and their satisfaction, perceptions, feelings and needs, as Huertas (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).

4.2.2 Study participants

4.2.2.1 Researcher description

The first author, a social worker with 13 years' experience, has a background in working with individuals with SDs and their families, including collaborations in the dependency care field and youth services.

4.2.2.2 Participants

In Aragón (Spain) according to the data provided by Aragonese Institute of Social Services (IASS), in 28 February 2022 there were 1,574 youths with disabilities and a recognised degree of dependency aged 13-30 years. Our research included 12 youths, 12 relatives and one legal career professional from diverse backgrounds representing over 1.6% of the target population in rural and urban areas (see Table 8).

Table 8. *Characteristics of the sample interviewed on social resources and services*

Case	Age	Gender	Residence	Studies	Parents' marital status	Disability Degree	Behavioural problems	Dependency resource
1	20	Man	Zaragoza	Special Education	Married	97	No	Family care (FC)
2	24	Man	Zaragoza	Special Education	Married	97	No	Day centre (DC)
3	29	Woman	Zaragoza	Master	Married	69	No	FC
4	19	Man	Zaragoza	Special Education	Married	92	No	FC
5	28	Man	Zaragoza	Special Education	Divorced	92	No	DC
6	30	Woman	Sabiñánigo	Do not know	Supervised	0	No	DC
7	24	Man	Jaca	Special Education	Married	0	No	DC
8	27	Man	Sabiñánigo	Special Education	Married	0	No	DC
*9**	Several	Woman	Several	Professional tutors	Supervised	Several	Several	Care home
10	29	Woman	Huesca	Special Education	Married	78	No	DC
11	28	Man	Huesca	Special Education	Married	78	No	DC
12	28	Man	Huesca	Special Education	Married	79	Yes	Care home
13	22	Man	Huesca	Special Education	Married	88	No	DC
14	30	Man	Huesca	Special Education	Married	67	Yes	DC
15	30	Man	Monzón	Special Education	Cohabit	72	Yes	Care home
16	24	Man	Monzón	**PCPI	Divorced	79	No	DC
17	29	Man	Barbastro	Special Education	Divorced	86	Yes	Care home
18	18	Woman	Zaragoza	PCPI	Divorced	53	No	FC
19	19	Woman	Zaragoza	PCPI	Married	Do not know	No	Do not know
20	19	Man	Zaragoza	PCPI	Married	56	No	In hand
21	20	Woman	Utebo	PCPI	Supervised	89	No	FC
22	19	Man	Zaragoza	PCPI	Widowed	Do not know	No	Do not know
23	21	Man	Zaragoza	PCPI	Divorced	68	No	FC
24	25	Man	Zaragoza	PCPI	Divorced	82	No	FC
25	29	Woman	Zaragoza	Year 2 Sec. Education	Divorced	70	No	In hand due to refugee status

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

**Initial Vocational Qualification Programmes

4.2.2.3 Researcher-participant relationship

The first author conducted all the interviews and had no relationship with any of the participants.

4.2.3 Participant recruitment

In Aragón, youths with SDs receive care through various social entities: rehabilitation programmes, schools, day centres or residential centres. We connected with the main hub in Aragón and Spain, which unites most of these entities. Through the Committee of Entities Representing People with Disabilities (CERMI) in Aragón, we reached out to families and youths with SDs, and ensured representation from rural and urban areas across all the provinces in Aragón. We included families as informants for the young people unable to participate due to their SDs. These family relatives, who act as legal representatives, relatives or primary caregivers, possess in-depth knowledge of youths' circumstances and can advocate their interests.

4.2.3.1 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.

4.2.4 Data collection

After contacting interested youths, relatives, representatives or caregivers, we provided an accessible information document in their language and an easy-to-read version. After the interviewer had verified their understanding, participants gave written and verbal consent before the one-on-one semi-structured interviews. On average, the resulting 25 interviews lasted 52.4 minutes (from 24 to 103 minutes). The longest interviews were with family relatives, and the shortest were with the individuals with intellectual disabilities or developmental disorders due to their specific needs. Meetings took place in locations chosen for accessibility reasons. The first author recorded and transcribed the interviews verbatim.

4.2.5 Analysis

4.2.5.1 Data analysis strategies

Interviews were analysed by a reflexive thematic analysis, following the process of familiarisation, coding, generating initial themes, reviewing and developing themes, refining, defining, naming themes, and writing up (Braun & Clarke, 2021a; 2021b; 2022). The literature review provided the initial lens through which we approached our analysis by offering a deductive approach, which was meaningful to the research questions. An inductive, 'open-coded' method was adopted to represent participants' meanings. Each interview was (re)read and coded by the first author using the MaxQda 2022 software. This process involved assigning a phrase or paragraph to a unit of meaning. It focused on the explicit data level. As broad patterns were identified (within and across data), themes were developed from these codes. During an iterative and refinement process, the research team met to discuss themes and subthemes to capture data richness and to preserve valuable nuances, rather than seeking a single 'correct' set of themes.

4.2.5.2 Methodological integrity

Our research adheres to methodological integrity, reporting standards (Levitt et al., 2018; Levitt, 2020) and Reflexive Thematic Analysis the Criteria (Braun & Clarke, 2022). It offered a flexible approach to distill the data that were underpinned and unified by a central idea (Braun & Clarke, 2022). It also placed an emphasis on researchers' interpretive lens by allowing us to capture the intricate and diverse interactions between young PWD's experiences and needs (e.g., including those in rural settings, women, with multiple disabilities or migrants) and the interventions of social services. All this aimed to improve their care and inclusion.

Due to the qualitative method's characteristics, we managed our researchers' perspectives (Levitt et al., 2018). The first author's experience with young PWD, particularly those with intellectual or multiple disabilities and communication challenges, led us to adapt our approach to people with cognitive disabilities, but who can orally communicate. We tailored questions for diverse scenarios (e.g., migration), and adjusted response formats for individuals with communication challenges, but intact cognitive abilities, using closed responses like blinking for agreement.

We recognise some limitations due to the data protection regulations that govern health, disabilities and special educational needs, which restrict access to the study population. Given our qualitative approach and the focus on understanding this population, our findings are specific to the studied subpopulation and are not generalisable to all young people with multiple disabilities in Aragon's settings (Flick, 2018).

4.3 FINDINGS

From our findings, several themes and subthemes were identified in relation to the experiences of those interviewed, and were extended during the analysis and iteration process. For instance, on the three initially reported themes (quality of life, family quality of life, social services), the intersectionality question and its subthemes (rural setting, pluridicability, migration, etc.) were incorporated. About these themes, subthemes were indentified, which helped to understand them (e.g.: quality of life aspects, intra-/extra-family relationships, positive/negatives experiencies, proceedings/ bureaucracy, gaps, etc.). All the themes and subthemes are summarised in a table (see Appendix 3), and were analysed and related in-depth throughout this section by also using relevant data extracts.

As caregivers' circumstances (marital status, health, geographical proximity, etc.) can impact quality of life and needs, we considered it necessary to examine their experience in relation to the subthemes (the family quality of life theme) of: conciliation; caregivers' status; family relationships; attending to these specific matters. Those cases whose parents had divorced referred less to caregivers' negative status, negative extrafamily relationships or better conciliation because the cares distribution was equitable due to a legal order. This was why they shared more time with them:

> *"You know?, in the end a divorce is a blessing because the lad is with his father for half a month and half with me. We have the other half month for our own free time, and this relief comes from the family itself" (Reporter 16).*

On this matter, it is also important to stress the references made by supervised people because, in their case, social services perform support tasks for vital decision making about their development. The administration assumes more responsibility for the offered service. So, it was striking that when the subthemes of the social services theme were analysed, some like these people's involvement, participation or access to supplementary resources appeared to a lesser extent. The difference between being supervised by a private social entity or social services, and relying on a foster family or not, was specifically referred to, and they all came over as being close. However, the former had a lower professionals/persons ratio to care for and can, therefore, pay more personalised attention:

> *"They have been good with us. We have thanked them a lot (…), when they come they tell you what you can do, what you cannot do, with the money they have, with your rights. It might be due to the money I have. I don't look at that at all; let them administer my payment…" (Reporter 6).*
>
> *"Well, yes, I´m pleased with family. It seemed a bit odd at first. I took a long time getting used to it, talking to them and always took the same position (head down) while they encouraged me. But now it's as though I trust them more, I tell them things…Sometimes we clash (…) because they don't let me spend much time alone, I lock myself inside the bathroom, in my bedroom…which I don't like. I try doing*

> *things properly because I know that if I don't, there'll be consequences, which I don't want…So they help me a lot"* (Reporter 21).

Regarding the resources offered by social services, for those cases with the FC resource, the importance of family support is stressed, as is having a stronger effect on family quality of life and caregivers' status. They refer, on the one hand, to the need to supplement help for those cases of outbreaks, agravation and unexpected situations for the main caregivers and, on the other hand, to insufficient quantity. The impact of COVID-19 was highlighted as being less because PWD in their resource entity did seem affected by confinement. Frequently, issues linked with interadministration subthemes and gaps created by changes in resources were minimised because they did not have to change the resources that occurs when reaching the age of 21. For instance, they mentioned:

> *"because we work as a team, we all coordinate to move forward. However, it's possible that I can't actively participate with outbreaks … my dependency increases and receiving home service could also help you, or some other type of support resource, depending on the type of activities"* (Reporter 3).

On the "quality of life" theme, the responses given by people living in a care home reflect a reduction in its emotional, material and self-determination aspects. Working with social skills, adapting to the population and being in contact with family relatives are challenges associated with a higher deinstitutionalisation demand. One point stressed by the families of these youths referred more to experiencing blame and fear about this decision, which affects caregivers' status. All this is linked with care homes being places where there are only PWD and, therefore, less inclusion, which affects their family relationships. There is also the profile of the sample in care homes, who mostly have behavioral and oral communication problems. They mentioned:

> *"I´m not sure about quality of life. They form their groups, but institutionalised people are also motivated by interests, a link, and the emotional/relational side of PWD. Well, I think this is complicated in centres, as it is in prisons. Here, well…Yes, some people have been institutionalised all their lives. So, they mix with just one person because it's more convenient for them. They feel afraid, so there are roles, positions, aren't there? (…) I think that promoting desinstitutionalisation, and support, well, they are already doing that, aren't they? But the power, which the*

> *administration can favour this with an eye on youths, is fundamental because it's what we all ask for. Yes, more resources for flats in the community" (Reporter 9).*

> *"It affects me considerably. I keep thinking if he's all right, or if he isn't. If what I would do for him is all right, or if I do more that I should, and how they treat him; here better communication with families is necessary. I don't need to be told what he's eaten, if he slept well or not; we´ve been to this place or he's behaved like this, although I´d like to know all this too. We need something more personalised, as if I could talk to my son everyday and ask him about his day, but he'd answer me; he can't. So, I´d like them to do that (Reporter 12).*

All those interviewed questions the integration of individuals of different ages and with varying degrees of dependency in both care homes and DCs (resource subtheme).

> *"Nowadays, I don't know if there's a centre, or not, that meets the characteristics needed to attend young people like X. There are two extremes: attending children or attending the elderly. The other would be, for example, *anonymised*, which would treat them as if they were in an old people's home together with the elderly. This means that there are no leisure activities; they only bath people and prepare food. They leave you sitting in a circle looking at the ceiling" (Reporter 1).*

Despite being a more inclusive alternative to institutionalisation in care homes compatible with caregivers' conciliation, the DC resource poses several problems with this subtheme. It increases costs (bus, dining room, physiotherapy, etc.) and makes conciliation difficult because of its limited timetable (not including evenings, holidays, weekends) and medical visits. This, along with the main caregivers being family relatives and no longer making social security payments because they cannot occupy job posts, is not good for them because they can neither conciliate nor make social security payments for their work as caregivers.

> *"They pass the Law of Dependency, but that's not for me; it's for day centres. I don't mention it. But my son has many needs at weekends, during holidays, when on holiday, in August, etc., I´m not sure if you understand, but I have many physical problems with my son. (…) When he's with me for 2 weeks, I´m worn out because I also go to work. I think they should offer a service to help these people, to help them when they're at home" (Reporter 5).*

> *"I don't think the change was at all brusque for her. She's always content. The same goes for us. It was actually better for us. Something that went well, us relaxing, and not them taking her away, which shouldn't be mentioned. Especially for her mum, for the problems she had with the children and, because of that, she was somewhat depressed, and I was working then. It was her mother who looked after her. So it was*

> *relaxing for her to say, well she can go to the day centre. They bring her home in the evening because they take her in the morning. They bring her home at 6 pm, which is very good" (Reporter10).*

Finally, in relation to the interadministration subtheme and its relevance for disability renewals, recognising rights/resources/services, changes linked with dropping out of the education system, etc., the bureaucracy and the institutional and organisational complexity of the Spanish system were reflected as problematic.

> *"the first resource we need is that the things (data) they have, they being society, the administration, the police, the Aragonese Regional Government, the City Council, the healthcare service, they should get them off one another. They ask us "do you authorise access to the database?" When they have shown interest in whether we have paid or not, medicines in chemists, they have contacted those from Inland Revenue to know what we all earn, and also with those from chemists. Then they tell us "you must pay such a percentage"; right? As they showed interest in that, they should do the same for everything else and shouldn't ask us for all this" (Reporter 2).*

> *"For example, having a blue card and parking in the blue zone depend on cities. When I'm on holiday, they call out "hey, don't park there". I mean the same rule changes depending on the region you are in. So, of course, dependency, social services, mobility and all that is referred. So, you must ask if you're still entitled in the city you visit" (Reporter 4).*

When looking at this matter in more depth, we initially considered the change that quite often occurs when shifting from an FC resource and a school to a dependency resource at the age of 21, which we call the 21 years gap. Throughout this research work, several families mention that they consider this time to be a gap:

> *"We had to wait a long time before they gave us a place in the centre. We took it as soon as they did. (…) It took just over a year (…) I left Huesca at the age of 21 because I couldn't stay on. I was bored at home. Then we started going and doing activities, we felt better. I felt bad that year. Thank goodness it didn't snow this year. We were always outdoors" (Reporter 4).*

> *"Moreover, you apply for a place when you want to change from dependency to a DC. Some request a place in April or May, but get a place in February the next year, or in December. They have behavioural problems, and if they have no routine… We´ve seen this with some at school; for example: a father was a hospital nurse. He and his wife separated. He had to change job. He had to ask for a place in a health centre to adapt to timetables…alternate days and times with his wife. He did the best he could. (…) Now his life has changed and he can't go back. Perhaps one day it'll happen*

> *and then…but it's not easy to arrange. It's not like "now I have a place at a DC; right, I can go back to do what I did before". It's not like that" (Reporter 1).*

However, they indicated another gap at the age of 18, when the disability certificate must be renewed and the disabled come of legal age, which they cannot fully exercise at times due to their disability. The families pointed out that, at this time, decisions must be made and proceedings must be done, which they do not know anything about or they might entail difficulties because they take too long.

> *"There's another gap at the age of 18, which we faced. We depend on certain documents like the disabled or dependency certificate, which some organisations request to do other proceedings. When he reached the age of 18, his disabled certificate expired, and so did the parking card. We could no longer park. The allowance paid for having a dependent child also stopped, even though it had been recently granted, and if we couldn't prove he was still disabled, we lose it. This allowance isn't paid for 3 months. If you lose it, you have to present documents again. When it's granted, you're not paid it for 3 months. It's not a matter of not being paid for 3 months and then being paid. So, it's never paid. Then there are medicines. He's no longer entitled to those he gets free because his disabled certificate has expired. Once I got a letter saying they wouldn't pay his medicines. Either I pay for them or nothing. They cost around €250-300 a month. Then there's the physiotherapist. The Social Security says that's fine, but only when you present the document. Keep any invoices you've paid (…). When we had to declare him invalid, which was another of the brilliant times when he reached the age of 18, we had no access to his money in the bank for more than 1 year …which we needed to pay for medications and such. I was so worn out. I honestly couldn't bear applying for more documents" (Reporter 1).*

They also point out other critical times, such as ageing parents or *post facto* invalidity, which involves restructuring received care, adapting to the new situation, fear for the future and worrying about who will look after their children when they die. When this occurs, you make a will to appoint a family relative or a responsible tutor if parents die. All such matters particularly affect caregivers' quality of life and, therefore, that of youths.

Some other variables that affect this situation are being migrants and refugees, which is a fourth gap; on the one hand, when they arrive in the country, they are unaware of resources, proceedings and opportunities. They do not have the expected requirements, such as nationality or residency; on the other hand, refugees have a limited period to leave the resource where there they are:

> *"I´m at an association in one of it's flats. At the moment I haven't got, I can't rent because I´m out of work. They help me with everything for the time being, but when my time with them ends, I have to seek solutions (…) The date is…next September, but only in my situation" (Reporter 25).*

It is also worth stressing that many discourses refer to the over-homogeneisation of the dependency system and resources, according to law, which leaves aside people's unexpected situations, multiple disabilities, age or interests. The situations of several children with disability, health problems or conciliation with caregivers are also excluded:

> *"What do we find? Not only X, but also other kids with multiple disabilities who very much depend on others. When the blind association or the association specialised in physical disability, or whatever, organises these activities, they take the standard disabled person because they can answer for this type. So, when X arrives, they say "no, we can't", "it's not thought for you", "we don't have the support resources". When this occurs, the next paradox appears: PWD associations ask society for integration, but members below do not integrate them. So, you wonder how can you ask something of society that you don't apply to members? So, the first difficulty faced when doing activities lies in the cases of those with multiple disabilities, and associations are willing to raise the level of their supply, help, or even collaboration among associations" (Reporter 2).*

> *"when you're to be assigned a degree of dependency, they value the problems you have and the help you need, but not when you pay social security payments. Not because they assign more, but because when you go to a day centre, you don't have to pay social security payments, but you cannot work because no boss is willing to put up with you not coming 5 times this month, or 6 times another month, to go to the doctor. Before I go to a neurologist, I must do an electro. If I go to an endocrine, I must first have densitometry and blood test results. Every visit to the doctor involves one test or two. This isn't because I am ill, but because they are needed for normal check-ups. Even though my health status is all right, I can still miss work 5, 6 or 7 times a month, which is a complete week. You'd have to be a civil servant or you wouldn't be able to do all this. This is something that dependency does not consider, but you have to do these things" (Reporter 1).*

> *"you're told that this isn't foreseen. What is foreseen is a document for one child. As they only foresee this situation, I can only ask for one document (…) I cannot leave my two children at home. Or we all leave or we all stay, obviously. They tell you that it's impossible. (…). Of course, no-one understands, for example, how I can leave X at home alone. When there are lots of people involved (…) people with more than one disabled child; let's imagine twins; what do you do? Leave one twin at home and take the other with you? Which do you prefer if they're the same? (laughs). This IMSERSO scheme is silly, but these things happen…I told the woman who attended*

me in Madrid about this case. She said, yes I know, I understand, but it's impossible" (Reporter 10).

Apart from these criticisms and/or difficulties, we also find lack of resources in rural settings and/or accessibility problems, which means having to move to an urban environment, travel long distances or resort to a care home service and to, basically, limit one's life project.

"You're fed up because you get up every morning at 5 am …he has cerebral paralysis and his resource is the specialised association. They've managed to let him go for 3 days to the Occupational Centre in Boltaña, which is ridiculous because he's, what 20 years old? He's got a high degree of paralysis and has to travel 2 hours every day; for heaven's sake" (Reporter 9).

*"He was there until the age of 18; from the age of 8 or 9 years until he was 18 at *anonymised*. When the time came for him to go to a special school with a social guarantee, he couldn't; they took him to the care home" (Reporter 17).*

*"X understands and knows everything. He participates a bit in choosing. We took him to see centres. We went to the *association* and that. He also participated a bit in choosing the centre. He didn't want to go to *association* because it was too far away. They were the only two centres we went to see because the others were not equipped for him, for his accessibility" (Reporter 5).*

4.4 DISCUSSION

The reality of young PWD is heterogenous and often linked with complicated situations related to substantial support needs and their socio-family situation, and all this to a greater extent in a highly family-based welfare system like the Spanish one (Foubert et al., 2014; Saldívar & Alvarado, 2020; Banati & Bacalso, 2021). According to new social requirements, socio-public policies play a fundamental role, and, more specifically, the social services system for covering care needs (Tobio et al., 2011). For this reason, studying the experiences of these PWD and their families was considered to detect possible shortages in and improvements to them in relation to the quality of life, family quality of life, social services and intersectionality themes.

Firstly, by contemplating institutional complexity and the few laws that regulate youths with SD at Aragón (Spain), as stressed by several authors (Blanca, 2017; Aparicio, 2016; Argullo et al., 2011; Jollien, 2011; Romañach & Palacios , 2008; Mira-Aladrén et al., 2023; Tobio et al., 2011), this study found four main gaps in relation to the social services theme. Of the four, three do not appear in the initial approach of this study. These gaps coincide with certain stages of people's human and/or social development. This implies administration changes, which might involve the legal area or may lie in received services. These stages are: at the age of 18 years, having to review one's degree of disability and modifying legal capacity, if support is needed for decision making; at the age of 21 years, or when leaving school, which requires a change in resources and the welfare system often having to manage them; with parents' ageing or them facing unexpected disability situations, which imply restructuring care and fear for the future, and for migrants when they arrive in a country or a different city when they are unaware of resources, proceedings and opportunities.

Continuing with the last gap, and by bearing in mind the intersectionality concept (Crenshaw, 1991) and considering former studies that detect factors of more vulnerability (Mira-Aladrén et al., 2023; Saldívar & Alvarado, 2020; Thabethe, 2021; Huete et al., 2016; Baird et al., 2021), added difficulties emerge for migrants; inhabitants in rural settings who must take long journeys to resort to resources or must rely on residential services; people with multiple disabilities who, given the specialisation in a disability type of resources, all their needs are not sometimes met, and they are expelled from entities due to their disability. We stress that this theme was not initially considered in this study, but cross-sectionally emerged during most interviews, which demonstrates its impact on both quality of life and social services. Finally, some problems related to people supervised by institutions arose, which are not always accompanied nor supported. The best experiences are for those people supervised by small entities rather than by public administrations despite them posing a risk of privatising rights, which comes over as a relevant aspect in the social services theme. Hence the need to implement an intersectional perspective while intervening with these people is specified (Crenshaw, 1991).

All this affects the offered resources and, therefore, the capacity of care and conciliation with the main caregivers and, thus, impacts the quality of life of youths with SD, just as other studies report (Blanca, 2017; Aparicio, 2016; Argullo et al., 2011;

Jollien, 2011, Romañach & Palacios , 2008; Mira-Aladrén et al., 2023). Accordingly, experiences in residential centres favour conciliation, but to the detriment of youths' socialisation, and reluctance is noted at mixed ages and differing degrees, and also with the possibilities that they offer youths with SD. Moreover, despite DCs covering the necessary hours for conciliation, they must be supplemented with home help, which social services do not offer, to avoid caregivers doing too much, to facilitate work-care conciliation and to encourage youths' participation in leisure activities. All this also poses a problem for the main caregivers because they lose the right to pay social security payments that allows them to be granted FC allowance, even though they have not been able to fully conciliate and have not formed part of the labour market for long, which complicates their situation.

All these matters were presented by family realtives and youths with stressful experiences, and are framed within some excessively bureaucratised and homogenising institutions. Family relatives stated that their own interests and specific and/or unexpected situations were not dealt with, that is, both youths themselves and those in their settings, who require attention that not only involves completing forms (having more than one child with a disability, multiple disabilities, travelling from rural settings, etc.). They claimed a flexible intervention model that centres on people's life projects, and also offers opportunities (e.g.: jobs, education, support or housing) that are more inclusive and adapt to their interests and needs, and those of their families, by attending to the CRPD (Blanca, 2017; Aparicio, 2016; Argullo et al., 2011; Jollien, 2011; Romañach & Palacios , 2008; Mira-Aladrén et al., 2023; Tobio et al., 2011; Verdugo et al., 2012; Pérez & Moral , 2008; Tint & Weiss, 2016; Madariaga et al., 2021).

In short, although setting up SCDPA may mean progress being made to attend to people with SD and their families, existing bureaucracy and resources are perceived as standardised, and do not cover the interests and needs of both caregivers and youths, when considering their life stage. So, it is worth evaluating offered resources, the amount of money invested, the involved proceedings and excessive bureaucracy from a biopsycho-social, systemic and flexible perspective to really favour fulfilling the rights recognised in the CRPD.

This work sets out future research lines in relation to how to reorganise SCDPA to favour recognising the rights of youths and their families. Analysing the impact of SD on youths' personal relations and their leisure by particularly considering offers from specialised social services on youth with disbilities and how this is related to their assigned SCDPA resource. Analysing the difficulties presented by youths with SD by an intersectional approach. Finally, it is possible to make progress in establishing evaluation indicators by studying the good practices taken in this field.

4.5 REFERENCES

Abellán, A. & Hidalgo, R. (2011). Definiciones de discapacidad en España. *Informes Portal Mayores*, 109 http://envejecimiento.csic.es/documentos/documentos/pm-definiciones-01.pdf

Alford, V. M., Ewen, S., Webb, G. R., McGinley, J., Brookes, A., & Remedios, L. J. (2014). The use of the International Classification of Functioning, Disability and Health to understand the health and functioning experiences of people with chronic conditions from the person perspective: a systematic review. *Disability and rehabilitation*, 37(8), 655-666. https://doi.org/10.3109/09638288.2014.935875

Aparicio Payá, M. (2016). Estigmatización, invisibilización y cosificación de las personas con diversidad funcional. Una aproximación desde la justicia como reconocimiento de Axel Honneth. *Revista Española de Discapacidad*, 4(I), 177-190.

Argullo, C., Arroyo, J., Ema, J.E., Gámez, C., Gómez, E., Jiménez, P., Rodríguez, E., Salvador, M., Orfi, M. & Colina, M.P. (2011). *Cojos y precarias: haciendo vidas que importan. Cuaderno sobre una alianza imprescindible*. Traficantes de Sueños.

Baird, S., Camfield, L., Ghimire, A., Hamad, B.A., Jones, N., Pincock, K. & Woldehanna, T. (2021). Intersectionality as a Framework for Understanding Adolescent Vulnerabilities in Low- and Middle-Income Countries: Expanding Our

Commitment to Leave No One Behind. *The European Journal of Development Research*, 33, 1143–1162. DOI: 10.1057/s41287-021-00440-x

Banati, P. & Bacalso, C. (2021). Adolescent Well-Being Gap Maps: What We Know and Opportunities for Future Research. *Journal of Youth Development*, 16(2-3). DOI: 10.5195/jyd.2021.1025

Blanca Gutiérrez, J. J. (2017). *Metaestudio sobre la experiencia vital de las personas mayores que viven en residencias como fundamento de los cuidados enfermeros geriátricos*. Biblioteca Lascasas, V13. http://www.indexf.com/lascasas/documentos/e11575.php

Braun, V., & Clarke, V. (2021a). Can I use TA? Should I use TA? Should I not use TA? Comparing reflexive thematic analysis and other pattern-based qualitative analytic approaches. *Counselling and Psychotherapy Research,* 21(1), 37-47. DOI: 10.1002/capr.12360

Braun, V., & Clarke, V. (2021b). One size fits all? What counts as quality practice in (Reflexive) thematic analysis? *Qualitative Research in Psychology,* 18(3), 328-352. DOI: 10.1080/14780887.2020.1769238

Braun, V., & Clarke, V. (2022). *Thematic analysis: A practical guide*. SAGE.

Convention on the Rights of Persons with Disabilities (CRPD).

Crenshaw, K. (1991). Mapping the margins: intersectionality, identity politics, and violence against women of colour. *Standford Law Review*, 43(6), 1241-1299. DOI: 10.2307/1229039

Decreto 55/2017, de 11 de abril, del Gobierno de Aragón, por el que se aprueba el Mapa de Servicios Sociales de Aragón.

Dyke, P., Bourke, J., Llewellyn, G., & Leonard, H. (2013). The experiences of mothers of young adults with an intellectual disability transitioning from secondary school to adult life. *Journal of Intellectual & Developmental Disability*, 38(2), 149–162.

EQUASS (2021). *European Quality in Social Services: Principles, Criteria and Indicators*. EQUASS

Flick, U. (2018). *The SAGE handbook of qualitative data collection*. DOI : 10.4135/978152641607

Foubert, J., Levecque, K., Van Rossem, R., & Romagnoli, A. (2014). Do welfare regimes influence the association between disability and self-perceived health? A multilevel analysis of 57 countries. *Social science & medicine*, 117, 10–17. DOI: 10.1016/j.socscimed.2014.07.023

García, G., Ramírez, J.M., Zubiría, A., Velasco, L., Aranda, A., Revilla, A., Fuentes, M. & Santos, J. (2021). *Índice de Desarrollo de los Servicios Sociales*. Ed. Asociación de Directoras y Gerentes de Servicios Sociales de España.

Goodley, D., Lawthom, R., Liddiard, K & Runswick-Cole, K. (2019). Provocations for Critical Disability Studies. *Disability & Society*, 34(6), 972-997, DOI: 10.1080/09687599.2019.1566889

Goodley, D., Liddiard, K. y Runswick-Cole, K (2018). Feeling disability: theories of affect and critical disability studies. *Disability & Society*, 33(2), 197-217. DOI: 10.1080/09687599.2017.1402752

Huertas Angulo, F.M. (2010). *Contribución de las políticas sociales a la calidad de vida de los jóvenes con discapacidad*. Universidad Nacional de Trujillo.

Huete García, A., Quezada García, M.Y. & Caballero Juliá, D. (2016). *Jóvenes con discapacidad en España 2016*. INJUVE-CERMI.

Jeanes, R., Spaaij, R., Magee, J., Farquharson, K., Gorman, S. & Lusher, D. (2018). Developing participation opportunities for young people with disabilities? Policy enactment and social inclusion in Australian junior sport. *Sport in Society*. DOI: 10.1080/17430437.2018.1515202

Jollien, A. (2011). *El oficio de ser hombre*. Octaedro

Levitt, H.M. (2020). Reporting qualitative research in psychology: How to meet APA style journal article reporting standards. *American Psychological Association*. DOI: 10.1037/0000121-000

Levitt, H.M., Bamberg, M., Creswell, J.W., Frost, D.M., Josselson, R. & Suárez-Orozco, C. (2018). Journal article reporting standards for qualitative primary, qualitative meta-analytic, and mixed methods research in psychology: The APA Publications and Communications Board task force report. *American Psychologist,* 73(1), 26-46. DOI: 10.1037/amp0000151

LEY 39/2006, de 14 de diciembre, de Promoción de la Autonomía Personal y Atención a las personas en situación de dependencia.

Madariaga, A., Romero, S., Romera, L. & Lazcano, I. (2021) Personas jóvenes con discapacidad y el papel que juega la familia en su ocio. *Revista de Ciencias Sociales (Ve),* 27(1). https://www.redalyc.org/articulo.oa?id=28065533006

Mira-Aladrén, M., Martín-Peña, J., & Gil-Lacruz, M. (2023). Discapacidad y servicios sociales: analizar la accesibilidad en la complejidad institucional. *DERECHOS Y LIBERTADES*, (49), 259-290. DOI: 10.20318/dyl.2023.7725

Parasuraman, A., Zeithaml, V. A., & Berry, L. (1988). SERVQUAL: A multiple-item scale for measuring consumer perceptions of service quality. *Journal of Retailing*, 64(1), 12-40.

Pérez Bueno, L. C. & Moral Ortega, O. (ed.) (2008). *Las dimensiones de la Autonomía Personal Perspectivas sobre la Ley 39/2006*. Ediciones Cinca.

Ramírez-Navarro J.M., Revilla Castro, A., Fuentes Jiménez, M. & Gómez Castro, E. (2021). *XXI Dictamen del Observatorio Estatal de la Dependencia*. Ed. Asociación de Directoras y Gerentes de Servicios Sociales de España.

Romañach Cabrero, J. & Palacios Rizzo, A. (2008). El modelo de la diversidad: una nueva visión de la bioética desde la perspectiva de las personas con diversidad funcional (discapacidad). *Intersticios. Revista sociológica de pensamiento crítico*, 2(2). http://www.intersticios.es/article/view/2712

Saldivar Reyes, A., & Alvarado García, F. (2020). Aproximación a las experiencias de vida de jóvenes con discapacidad motriz. *RPP,* (30). DOI: 10.21555/rpp.v0i30.2028

Shakespeare, T. (2014). *Disability Rights and Wrongs Revisited.* Routledge, Taylor & Francis Group.

Sullivan, M.J., Adams, H., Horan, S., Maher, D., Boland, D., & Gross, R. (2008). The role of perceived injustice in the experience of chronic pain and disability: scale development and validation. *Journal of occupational rehabilitation,* 18(3), 249-261. DOI: 10.1007/s10926-008-9140-5

Thabethe, N. (2022). 'We have no power over perceptions': the lived experiences of women with disabilities in a rural South African community. *Disability & Society,* 37(2), 345-350. DOI: 10.1080/09687599.2021.1976109

Tint A. & Weiss JA. (2016). Family wellbeing of individuals with autism spectrum disorder: A scoping review. *Autism,* 20(3), 262-75. DOI: 10.1177/1362361315580442

Tobio, C., Agulló Tomás, M.S., Gómez, V. & Martín Palomo, M.T. (2011). *El cuidado de las personas.* La Caixa. http://www.abc.es/gestordocumental/uploads/Otras/volumen-completolacaixa.pdf

Verdugo Alonso, M.A, Rodríguez Aguilella, A. & Sainz Modinos, F. (2012). *Escala de vida familiar*. *Manual de aplicación*. INICO

5

“WHAT IS THE POINT OF BEING ABLE TO ENTER A BUILDING IF THE SERVICE OR ACTIVITY IS NOT ADAPTED?”

5.1 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, 2016; 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 (CRPD; Lazcano & Madariaga, 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 & Madariaga, 2018; Doistua, 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; Steindhart, 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).

As pointed out by Gilor et al. (2017), Steinhardt et al. (2021) and Mira-Aladrén et al. (2023), these difficulties are 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 (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; Steindhart, 2021; King et al., 2014; Mira-Aladrén et al., 2023; Saldívar & Alvarado, 2014; Thabethe, 2021; Huete et al., 2016; Baird et al., 2021; Madariaga et al., 2021).

In response to these issues, 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 (Steindhart, 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 1/2013) 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 (Asis-Roig, 2020; Mira-Aladrén et al., 2023). What has been legislated is the recognition of assistance dogs (Royal Legislative Decree 1/2013) and their access to spaces and activities, or the right to a sign language interpreter in formal settings, such as universities (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 and Madariaga (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 and Madariaga (2018) are committed to the generation of intersectional, community-based and person-centred services.

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. To find the main demands and needs of young people with SD linked with leisure and relationships
2. To find out about the experiences in the aragonese specialized services and/or leisure resources of young people with SD and their families
3. To suggest improvements for the inclusion of young people with SD in leisure activities and specialized social services.

5.2 METHOD

5.2.1 Research design

The present research forms part of a larger study that explores youth PWD and their families' experiences in the SCDPA by attending to the PWD’s diversity and their specific needs with a semistructured interview. 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, 2010; Sullivan et al., 2008; Dyke et al., 2013; Verdugo 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 (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).

5.2.2 Study participants

5.2.2.1 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.

5.2.2.2 Participants

In Aragón (Spain), according to 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 take into account their different contexts (rural/urban) in the various provinces.

Table 9. *Characteristics of the interviewed sample on personal relationships and leisure*

Case	Age	Gender	Residence	Studies	Parents' marital status	Disability Degree	Behavioural problems	Dependency resource
1	20	Man	Zaragoza	Special Education	Married	97	No	Family care (FC)
2	24	Man	Zaragoza	Special Education	Married	97	No	Day centre (DC)
3	29	Woman	Zaragoza	Master	Married	69	No	FC
4	19	Man	Zaragoza	Special Education	Married	92	No	FC
5	28	Man	Zaragoza	Special Education	Divorced	92	No	DC
6	30	Woman	Sabiñánigo	Do not know	Supervised	0	No	DC
7	24	Man	Jaca	Special Education	Married	0	No	DC
8	27	Man	Sabiñánigo	Special Education	Married	0	No	DC
9*	Several	Woman	Several	Professional tutors	Supervised	Several	Several	Care home
10	29	Woman	Huesca	Special Education	Married	78	No	DC
11	28	Man	Huesca	Special Education	Married	78	No	DC
12	28	Man	Huesca	Special Education	Married	79	Yes	Care home
13	22	Man	Huesca	Special Education	Married	88	No	DC
14	30	Man	Huesca	Special Education	Married	67	Yes	DC
15	30	Man	Monzón	Special Education	Cohabit	72	Yes	Care home
16	24	Man	Monzón	**PCPI	Divorced	79	No	DC
17	29	Man	Barbastro	Special Education	Divorced	86	Yes	Care home
18	18	Woman	Zaragoza	PCPI	Divorced	53	No	FC
19	19	Woman	Zaragoza	PCPI	Married	Do not know	No	Do not know
20	19	Man	Zaragoza	PCPI	Married	56	No	In hand
21	20	Woman	Utebo	PCPI	Supervised	89	No	FC
22	19	Man	Zaragoza	PCPI	Widowed	Do not know	No	Do not know
23	21	Man	Zaragoza	PCPI	Divorced	68	No	FC
24	25	Man	Zaragoza	PCPI	Divorced	82	No	FC
25	29	Woman	Zaragoza	Year 2 Sec. Education	Divorced	70	No	In hand due to refugee status

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

**Initial Vocational Qualification Programmes

5.2.2.3 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.

5.2.3 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, 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.

5.2.3.1 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.

5.2.4 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 semistructured interview was conducted with all the 25 participants. The average length of interviews was 52.4 minutes, with the longest being 103 minutes and the shortest 24 minutes. 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.

5.2.5 Analysis

5.2.5.1 Data-analytic 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.

5.2.5.2 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 (Flick, 2018).

5.3 FINDINGS

Throughout our analysis, several themes and subthemes emerged that cut across interviewees' experiencese, 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.

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.

> *“"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. 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. 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, 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 problems 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 cooking 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).*

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. 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 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).*

When facing these difficulties, demands and needs to be emerged by focusing mainly 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 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 hours during which he could do a job without it being a martyrdom for him because I don't think he could work 8 hours. 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 the people 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:

> *"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. Sometimes it is an added cost because it is not included in the services offered by the resource. Nor is not offered during the hours when professional carers 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 19.30h to 21.30h, 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. The family status in the community could directly influence the possibility of accessing these activities was even recognised.

> *"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).*

As part of this support, it was observed that despite being more influenced by issues, such as climate, distance or the existence of fewer resources, 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, especially for people with behavioural problems and multidisabilities.

> *“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).*

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.

5.4 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, 2016; 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 (Legislative RD 1/2013).

Nevertheless, according to our results, and in line with previous studies (Gilor et al., 2017; Steindhart, 2021; Roult 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 Steindhart (2021). 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; Steindhart, 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 Steindhart (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; Roult et al., 2019; Steindhart, 2021; Doistua et al., 2020; Lazcano & Madariaga, 2018; Shikako-Thomas & Law, 2015). In our case, other issues were addressed, such as being institutionalised that facilitated accessibility, but not inclusion or having multidisabilities, which meant that not all accessibility needs were met (people can enter, but cannot participate). 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 this 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, interviewees also proposed policies to be developed to improve access to inclusive leisure for young people with SD, which mainly included: regulating access, availability and recognition of the leisure support person as in Norway (Steindhart, 2021); the implementation of specialised intersectional and person-centred social services, as proposed by Doistua et al. (2020), Lazcano and Madariaga (2018), Roult et al. (2019) or Gilor et al. (2017); the improvement of coordination between services, which agrees with Gilor et al. (2017) and Shikako-Thomas and Law (2015); improving accessibility in spaces and access, that is also economic, and the design of activities themselves, as suggested by Gilor et al. (2017), King et al. (2014) and Steindhart (2021); increasing budgets and trained staff, as suggested by Doistua et al. (2020), Lazcano and Madariaga (2018), Gilor et al. (2017), Shikako-Thomas and Law (2015) and Roult et al. (2019); promoting volunteering and community awareness, in line with Gilor et al. (2017), Steindhart (2021) or Pickett et al. (2022). All this must be done by considering that young people with SD are users, but they must also be able to be leading figures, 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.

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.

5.5 REFERENCES

Aparicio Payá, M. (2016). Estigmatización, invisibilización y cosificación de las personas con diversidad funcional. Una aproximación desde la justicia como reconocimiento de Axel Honneth. *Revista Española de Discapacidad*, 4 (I), 177-190.

Baird, S., Camfield, L., Ghimire, A., Hamad, B.A., Jones, N., Pincock, K. & Woldehanna, T. (2021). Intersectionality as a Framework for Understanding Adolescent Vulnerabilities in Low- and Middle-Income Countries: Expanding Our Commitment to Leave No One Behind. *The European Journal of Development Research*, 33, 1143–1162. DOI: 10.1057/s41287-021-00440-x

Braun, V., & Clarke, V. (2021a). Can I use TA? Should I use TA? Should I not use TA? Comparing reflexive thematic analysis and other pattern-based qualitative analytic approaches. *Counselling and Psychotherapy Research, 21(1),* 37-47. DOI: 10.1002/capr.12360

Braun, V., & Clarke, V. (2021b). One size fits all? What counts as quality practice in (Reflexive) thematic analysis? *Qualitative Research in Psychology, 18(3),* 328-352. DOI: 10.1080/14780887.2020.1769238

Braun, V., & Clarke, V. (2022). *Thematic analysis: A practical guide*. SAGE.

Convention on the Rights of Persons with Disabilities (CRPD).

De Asis Roig, R. (2020). Sobre el sentido, contenido y configuración jurídica de la accesibilidad. *Universitas. Revista de Filosofía, Derecho y Política*, 32, 2-21. DOI: 10.20318/universitas.2020.5509

Decreto 55/2017, de 11 de abril, del Gobierno de Aragón, por el que se aprueba el Mapa de Servicios Sociales de Aragón.

Doistua J, Lazcano I & Madariaga A (2020). Self-Managed Leisure, Satisfaction, and Benefits Perceived by Disabled Youth in Northern Spain. *Front. Psychol.* 11:716. DOI: 10.3389/fpsyg.2020.00716

Dyke, P., Bourke, J., Llewellyn, G., & Leonard, H. (2013). The experiences of mothers of young adults with an intellectual disability transitioning from secondary school to adult life. *Journal of Intellectual & Developmental Disability*, 38(2): 149–162.

EQUASS (2021). *European Quality in Social Services: Principles, Criteria and Indicators*. EQUASS.

Flick, U. (2018). *The SAGE handbook of qualitative data collection*. DOI: 10.4135/978152641607

García, G., Ramírez, J.M., Zubiría, A., Velasco, L., Aranda, A., Revilla, A., Fuentes, M. & Santos, J. (2021). *Índice de Desarrollo de los Servicios Sociales*. Ed. Asociación de Directoras y Gerentes de Servicios Sociales de España.

Gilor, O., Klibanski, H. & Kfir, D. (2017) Setting policies regarding leisure activities for youths with disabilities: who will accept this mission? *World Leisure Journal*, 59:3, 227-239. DOI: 10.1080/16078055.2017.1345487

Huertas Angulo, F.M. (2010). *Contribución de las políticas sociales a la calidad de vida de los jóvenes con discapacidad.* Universidad Nacional de Trujillo.

Huete García, A., Quezada García, M.Y. & Caballero Juliá, D. (2016). *Jóvenes con discapacidad en España 2016*. INJUVE-CERMI.

King, G., Batorowicz, B., Rigby, P., Pinto, M., Thompson, L., & Goh, F. (2014). The leisure activity settings and experiences of youth with severe disabilities. *Developmental Neurorehabilitation*, 17(4), 259-269. DOI: 10.3109/17518423.2013.799244

Kristis, D. (2018). Greeks adolescents use free time: the impact of the attendance of school and an extracurricular coaching classes. *World Leis. J.* 60, 281–292. DOI: 10.1080/16078055.2018.1464943

Law, M., Anaby, D., Imms, C., Teplicky, R., & Turner, L. (2015). Improving the participation of youth with physical disabilities in community activities: An interrupted time series design. *Australian occupational therapy journal*, 62 (2), 105-115.

Lazcano Quintana, I., & Madariaga Ortuzar, A. (2018). La experiencia de ocio en las personas jóvenes con discapacidad. *Pedagogía Social*, 31, 109-121. DOI: 10.7179/PSRI_2018.31.09

Levitt, H. M., Bamberg, M., Creswell, J.W., Frost, D.M., Josselson, R., y Suárez-Orozco, C. (2018). Journal article reporting standards for qualitative primary, qualitative meta-analytic, and mixed methods research in psychology: The APA Publications and Communications Board task force report. *American Psychologist, 73(1),* 26-46. DOI: 10.1037/amp0000151

Levitt, H.M. (2020). Reporting qualitative research in psychology: How to meet APA style journal article reporting standards. *American Psychological Association*. DOI: 10.1037/0000121-000

LEY 39/2006, de 14 de diciembre, de Promoción de la Autonomía Personal y Atención a las personas en situación de dependencia.

LEY Orgánica 2/2023, de 22 de marzo, del Sistema Universitario.

Madariaga, A., Romero, S., Romera, L. & Lazcano, I. (2021) Personas jóvenes con discapacidad y el papel que juega la familia en su ocio. *Revista de Ciencias Sociales (Ve),* 27 (1). https://www.redalyc.org/articulo.oa?id=28065533006

Mary, A.A. (2014). Re-evaluating the concept of adulthood and the framework of transition. *J. Youth Stud.* 17, 415–429. DOI: 10.1080/13676261.2013.853872

Mira-Aladrén, M., Martín-Peña, J., & Gil-Lacruz, M. (2023). Discapacidad y servicios sociales: analizar la accesibilidad en la complejidad institucional. *DERECHOS Y LIBERTADES: Revista De Filosofía Del Derecho Y Derechos Humanos*, (49), 259-290. DOI: 10.20318/dyl.2023.7725

Parasuraman, A., Zeithaml, V. A., & Berry, L. (1988). SERVQUAL: A multiple-item scale for measuring consumer perceptions of service quality. *Journal of Retailing*, 64(1), 12-40.

Pickett, A.C., Williams, S.E. & Damon, Z.J. (2022). Special Olympics involvement and families of individuals with intellectual disabilities: Impacts on sense of community, social isolation, and health. *Managing Sport and Leisure*. DOI: 10.1080/23750472.2022.2145345

Ramírez-Navarro JM, Revilla Castro A, Fuentes Jiménez M & Gómez Castro E. (2021). *XXI Dictamen del Observatorio Estatal de la Dependencia*. Ed. Asociación de Directoras y Gerentes de Servicios Sociales de España.

Ramírez-Navarro JM, Revilla Castro A, Fuentes Jiménez M, Sanz Yagüez D & Cavero Cano G. (2023). *XXIII Dictamen del Observatorio Estatal de la Dependencia*. Ed. Asociación de Directoras y Gerentes de Servicios Sociales de España.

Real Decreto Legislativo 1/2013, de 29 de noviembre, por el que se aprueba el Texto Refundido de la Ley General de derechos de las personas con discapacidad y de su inclusión social.

Roult, R., Carbonneau, H., Belley-Ranger, E., Brunet, I. & Adjizian, J.M. (2019) Rural leisure opportunities for people with disabilities: needs and challenges in Quebec, *Rural Society,* 28:1, 1-14. DOI: 10.1080/10371656.2018.1558946

Saldivar Reyes, A., & Alvarado García, F. (2020). Aproximación a las experiencias de vida de jóvenes con discapacidad motriz. *RPP,* (30). DOI: 10.21555/rpp.v0i30.2028

Shikako-Thomas, K., & Law, M. (2015). Policies supporting participation in leisure activities for children and youth with disabilities in Canada: from policy to play. *Disability & Society*, 30(3), 381-400. DOI: 10.1080/09687599.2015.1009001

Steinhardt, F., Ullenhag, A., Jahnsen, R. & Dolva, A.S. (2021). Perceived facilitators and barriers for participation in leisure activities in children with disabilities: Perspectives of children, parents and professionals. *Scandinavian Journal of Occupational Therapy*, 28:2, 121-135. DOI: 10.1080/11038128.2019.1703037

Sullivan, M. J., Adams, H., Horan, S., Maher, D., Boland, D., & Gross, R. (2008). The role of perceived injustice in the experience of chronic pain and disability: scale development and validation. *Journal of occupational rehabilitation*, 18(3), 249-261. DOI: 10.1007/s10926-008-9140-5

Thabethe, N. (2022). We have no power over perceptions': the lived experiences of women with disabilities in a rural South African community. *Disability & Society, 37*(2), 345-350. DOI: 10.1080/09687599.2021.1976109

Verdugo Alonso, M. A, Rodríguez Aguilella, A. & Sainz Modinos, F. (2012). *Escala de vida familiar. Manual de aplicación*. INICO.

6 GENERAL CONCLUSIONS (SPANISH VERSION)

6.1 CONCLUSIONES GENERALES E IMPLICACIONES PARA LAS POLÍTICAS PÚBLICAS

La juventud se define como una época de cambios y dificultades, pero, también, como un período de oportunidades para disfrutar, explorar, conocer y experimentar fuera del entorno familiar, preparándose de este modo para la vida adulta. Esto es así, también, para las personas con discapacidad, incluso para aquellas con discapacidad grave, muy grave y severa, es decir, que tienen grandes necesidades de apoyo (Santrock, 2006; Delval, 2008).

En cambio, los resultados de esta tesis coinciden con la literatura científica en que las oportunidades que ofrece esta etapa no siempre pueden disfrutarse, siendo aún más difícil para algunos grupos sociales concretos, como el de la juventud con gran discapacidad (Observatorio de Emancipación, 2023; Saldívar & Alvarado, 2020; García-Fuentes & Martínez García, 2020; Domínguez, 2020). De este modo, la consecuencia es un incremento de la discriminación que ya sufren por encontrarse en situación de discapacidad (Rosenthal, 2020; Shakespeare, 2014; Goodley et al., 2019; 2018; Goodley, 2016).

En este sentido, conviene recordar la gran heterogeneidad del colectivo de personas con discapacidad, y, por tanto, de necesidades y demandas a cubrir. En cambio, la literatura también nos muestra que no se están atendiendo de una manera inclusiva y centrada en la persona, en su etapa y proyecto de vida y sus requerimientos provocando que algunas cuestiones como el acceso al empleo, la precarización del mismo, el acceso a una vivienda, al ocio, al deporte, al transporte, a la cultura o, incluso, a niveles educativos secundarios y superiores se compliquen para esta población (Observatorio Estatal de la Discapacidad, 2022; Jiménez-Lara, 2017).

Tras advertir esta problemática, desde las políticas públicas y sociales se han planteado diversas líneas de actuación, especialmente desde la CDPD y los ODS (IDDH, 2019). Así, se han puesto en marcha algunas medidas relativas al empleo, la educación o la creación de recursos para jóvenes (instituto de la juventud, casas de juventud, etc.), variando en su alcance, diseño y evaluación a nivel internacional. En España, concretamente, este tema se ha tratado de abordar de manera transversal, adaptando la normativa referida a la población general y las políticas derivadas de la misma a los requerimientos de la CDPD. No obstante, los servicios sociales especializados en atención a la discapacidad y el sistema de dependencia han tenido un gran peso en la intervención con jóvenes con discapacidad grave y severa. Aunque, recibiendo críticas por sus largas listas de espera, su complicación burocrática, su, todavía, perspectiva capacitista y médico-rehabilitadora, y su falta de atención por la diversidad dentro del propio colectivo de personas con discapacidad (Blanca, 2017; Aparicio, 2016; Argullo et al., 2011; Jollien, 2011, Romañach & Palacios, 2008; Rosenthal, 2020; Shakespeare, 2014; Goodley et al., 2019; 2018; Goodley, 2016).

En este contexto, la perspectiva interseccional apuesta por atender al incremento de las situaciones de discriminación en función de los diversos factores de riesgo que puede encontrar una persona por el hecho de enfrentarse a más de una situación de vulnerabilidad (Crenshaw, 1989; 1991; Cho et al., 2013; Rodó-Zarate, 2021). Es decir, plantea que no sólo habría que estudiar qué dificultades debe afrontar una persona con gran discapacidad y un joven, sino que, también, hay que analizar qué ocurre cuando, además, de tener una gran discapacidad eres joven (y mujer, o migrante, o refugiada, o del medio rural, o del colectivo LGTB, etc.). Así, esta perspectiva, nos aporta un marco sobre el que repensar como entender y abordar la situación de colectivos diversos.

Con el fin de comprender esta realidad minorizada y, en muchos casos, invisibilizada, así como cubrir la brecha de conocimiento existente, se planteó analizar la situación de los jóvenes con discapacidad grave y muy grave o severa y sus familias, concretamente, en Aragón. Esta comunidad fue seleccionada por características como contar con una gran ciudad y su creciente despoblación en el medio rural (INE, 2022), sobre la que parece necesario, también, reflexionar. Además, se trató de dar voz al colectivo, considerando a los jóvenes y sus familias como protagonistas de la investigación, empleando la metodología cualitativa. Ésta aportó una forma de aproximación a las experiencias y discursos de las personas que conforman este colectivo, comprendiendo, también, su heterogeneidad y su complejidad. Este hecho es especialmente relevante si consideramos que se trata de una muestra de difícil acceso, tal y como señalan Gavidia-Payne & Jackson (2019). Así, a lo largo de los cuatro capítulos que componen esta tesis se ha tratado de comprender el contexto normativo y social en el que se enmarcan las acciones con y para jóvenes con grandes discapacidades, desde la sistematización de sus experiencias y propuestas, de forma complementaria a las aportaciones de la literatura científica. Es decir, se ha tratado de proporcionar conocimiento que favorezca una mejor intervención.

En los dos últimos capítulos de esta investigación se ha constatado, mediante un análisis temático reflexivo de 25 entrevistas, que el concepto de juventud ha evolucionado y que se trata de un concepto que debe contextualizarse, tal y como ya indicaban estudios previos (Santrock, 2006; Delval, 2008). Además, se ha comprobado como la juventud plantea demandas y necesidades que le son propias por la etapa del desarrollo en la que se encuentran. Estos requerimientos, pese al carácter cambiante del concepto, son independientes de otras variables como tener o no discapacidad y su grado, estar en el medio rural o el urbano, el sexo o la procedencia. Principalmente se centran en cuestiones relativas a la escucha por parte del entorno, la inquietud por conocer y forjarse una identidad y, el reclamo de una mayor independencia. En cambio, mientras que colectivos como el de las mujeres o los niños cuentan con su reconocimiento en la legislación, el análisis de contenido realizado en este trabajo reveló que otros, como los jóvenes, no se encuentran representados, por ejemplo, en la regulación relativa a personas con discapacidad.

En el segundo de los capítulos, la revisión sistemática de las evaluaciones de las intervenciones sociales a nivel internacional constató que esta ausencia de legislación repercute en las intervenciones destinadas a jóvenes con gran discapacidad. En primer lugar, porque se realizan en menor medida, centrándose principalmente en niños o en personas en procesos de envejecimiento. En segundo lugar, porque no se hace participes a las personas con discapacidad del proceso. Este hecho refuerza la idea de los jóvenes, que consideran que no son escuchados y que, por tanto, su participación es menor en la toma de decisiones que les afectan de forma directa (ej.: la elaboración del plan individualizado de atención), expuesta en los análisis de las entrevistas realizadas. Esta cuestión está estrechamente relacionada con la falta de evaluación de las intervenciones, de co-producción en las investigaciones y su infrarrepresentación en las mismas (Fleming et al., 2019; Llewellyn, 2014; 2017). Y, en tercer lugar, por las barreras detectadas tanto para el acceso al empleo y la educación, como, en mayor medida, para otras actividades como el ocio o la promoción de sus relaciones sociales. Todo ello, reflejado en el tipo de intervenciones, primordialmente educativas y de rehabilitación, que se están desarrollando a nivel internacional. Estos resultados muestran, por tanto, que, el planteamiento del modelo social y de derechos propuesto por la CDPD, todavía, no se ha implementado, manteniendo un enfoque centrado en el mercado y la perspectiva médico-rehabilitadora (Rosenthal, 2020; Shakespeare, 2014; Goodley et al., 2019; 2018; Goodley, 2016).

En esta línea, y centrado en el caso de los jóvenes con discapacidad grave y muy grave, los resultados de esta tesis doctoral muestran, también, una escasez de referencias a personas con grandes necesidades de apoyo. Estas ausencias generan, de igual modo, una repercusión en las intervenciones e investigaciones que se realizan destinadas a este colectivo (Gilor et al., 2017; Steinhardt et al., 2021; Mira-Aladrén et al., 2023; Llewellyn, 2014; 2017). A ello, se suman dificultades como la falta de accesibilidad o de formación y financiación para la realización de los llamados “ajustes razonables”

(Milios, 2022; Asis, 2020), que dificultan, por ejemplo, que una persona sin comunicación oral pueda ver reconocidos algunos de sus derechos (ej.: empleo, ocio, etc.). Estos "ajustes razonables" plantean una exigencia de proporcionalidad en las acciones a desarrollar para incluir a las personas con discapacidad, que puede llegar a limitar la efectividad del derecho a la accesibilidad, por ejemplo, en la fuerza de los criterios económicos a la hora de delimitar esa razonabilidad.

En este sentido, destacar que el análisis de contenido de la regulación, presentado en el primer capítulo, reveló una falta de definición clara de conceptos como accesibilidad, siendo éstos la base para eliminar gran parte de las barreras que encuentran las personas con discapacidad. Es decir, pese a que algunas empresas de calidad han generado indicadores de accesibilidad, por ejemplo, en las residencias, a nivel legal no existe una definición clara de estos criterios o de las adaptaciones que deben cubrir todos los servicios, recursos, herramientas, etc. (especializados en discapacidad y generales) para poder considerar que cumple con el reconocimiento de este derecho. Y, es más, mediante el concepto de "ajuste razonable" se permite supeditar el derecho a la accesibilidad a criterios, por ejemplo, técnicos o económicos (Milios, 2022; Asis, 2020). Esta situación, afecta, por ejemplo, al acceso a una vivienda (ej.: la instalación de un ascensor si no hay presupuesto en la comunidad de vecinos), al ocio (ej.: disponer de un transporte adaptado o contar con personal de apoyo) o, incluso, al propio derecho a conocer los derechos, (ej.: con unas normas no adaptadas a lectura fácil). Todo ello, tal y como indicó el primer estudio que compone esta tesis, muestra la necesidad de afrontar el debate sobre los límites de la razonabilidad en el cumplimiento del derecho a la accesibilidad, tanto en España como a nivel internacional. De este modo, se abordarían cuestiones como los mínimos a cumplir o el peso de los criterios económicos a la hora de reconocer este derecho.

Las políticas públicas y sociales españolas parecen la herramienta fundamental para abordar estas barreras y paliar sus efectos. En cambio, su complejidad organizacional y burocrática, propias de un sistema autonómico y del derecho regulativo (Calvo, 2005; 2019; Del Pino & Catalá, 2016), suponen en muchas ocasiones un estresante y una traba para el reconocimiento efectivo de los derechos de las personas con discapacidad, afectando a su calidad de vida. En concreto, respecto a la complejidad institucional y burocrática, los resultados del primer estudio empírico señalan la alta interrelación entre los diferentes sistemas de bienestar y la dificultad de acceso a la legislación. Esta cuestión, se muestra a su vez en las experiencias de los destinatarios de estas políticas analizadas en el tercer estudio empírico de esta tesis. En él se concluyó, tras un análisis temático reflexivo, y gracias a la aplicación de la perspectiva interseccional y la muestra heterogénea de la que se disponía, que esta situación llega a generar brechas en el desarrollo y la atención a los jóvenes con discapacidad y sus familias (a los 18 años, a los 21 años, en caso de enfermedad o discapacidad sobrevenida de la persona o sus tutores, y, en caso de migración, a la llegada al lugar de destino).

Además, estas políticas reflejan otro problema. En investigaciones previas se ha puesto de manifiesto que resulta positivo incorporar a la familia en las intervenciones realizadas (Steindhart et al.,2021; King et al., 2013; Shikako-Thomas & Law, 2015). Sin embargo, las contribuciones del cuarto estudio empírico reflejan que, en el caso aragonés, el peso de la familia resulta en muchos casos excesivo, generando una sobrecarga en los cuidadores, en su mayoría mujeres, coincidiendo con otros estudios previos (Gilor et al., 2017; King et al., 2014; Roult et al., 2019). Asimismo, el hecho de que en muchas ocasiones el joven con discapacidad precise de un familiar para poder realizar sus actividades choca frontalmente con cuestiones como la inclusión, la accesibilidad y la promoción de autonomía personal, tal y como ya comentaban algunos estudios (Leenknecht, 2020; Huete et al., 2016; Iáñez-Domínguez et al., 2018; Guillem et al., 2010). Por ello, autores como Steindhart (2021), señalan la relevancia de incluir a personal de apoyo en el ocio, tal y como sucede en países como Noruega.

En relación con este punto, los resultados del primer estudio empírico, reflejan que desde la legislación se promueve el mantenimiento del modelo familista de bienestar (Martínez, 2013; Del Pino & Catalá, 2016), con medidas como la reducción de la jornada laboral para el cuidado de los hijos, incluso no menores, o la prestación de cuidados en el entorno familiar. Aunque, atendiendo a los resultados del tercer estudio empírico, se hace de una forma insuficiente, por ejemplo, con la falta de una cobertura de cuidados complementaria fuera del recurso de centro de día. Así se provocan mayores dificultades para la conciliación familiar y para la atención del joven con discapacidad, por ejemplo, si uno de los cuidadores principales enferma, aunque sea por un periodo breve de tiempo. O, cuando las, en su mayoría, madres, que han dejado de trabajar para cuidar a sus hijos hasta los 21 años, y dejan de cotizar a la seguridad social, porque su hijo pasa del colegio al servicio de centro de día, pero deben seguir atendiéndolo fuera del horario del centro, que difiere en pocas horas del horario que tenían en el centro escolar. Además, no atiende a los cambios sociodemográficos de la población española, con un cambio en las dinámicas de cuidado, debido, en parte, a la incorporación de la mujer al mercado de trabajo, al cambio de tipología de las familias y al envejecimiento de la población, tanto cuidada como cuidadora, descrito por Tobio et al. (2011) y Martínez (2013).

Estas dificultades y el impacto, tanto de las políticas como de las intervenciones sociales derivadas de las mismas, son difíciles de detectar dado el déficit en su evaluación y la falta de indicadores claros para su valoración, o, al menos, a la investigación en torno a la misma. Las contribuciones realizadas a partir de la revisión sistemática de la literatura, señalan que, pese a que existen cuestionarios como el realizado por EQUASS (2021) y otras empresas de calidad, estos no se emplean en las investigaciones aplicadas a la práctica y se rigen por cuestiones organizativas, más que individuales. Las investigaciones se centran en emplear cuestionarios psicométricos o realizar sus propias entrevistas *ad hoc*, pero sin seguir unos criterios homogéneos de estudio de la satisfacción, la inclusión, la accesibilidad o la calidad. Este es un problema a todos los niveles, incluso internacional, pese a que se reconoce su relevancia en textos como la CDPD, los ODS y la EUEDPD. Tal y como indican algunas investigaciones (Llewellyn, 2014; 2017), esto puede deberse a la falta de presupuesto destinado para esta parte de la intervención, que lleva a la escasez de personal y tiempo destinados a la misma.

A esta falta de evaluación se suma la ausencia de una perspectiva interseccional, que se ha detectado a lo largo de toda la investigación que conforma esta tesis doctoral, y que ya habían señalado otros autores (Llewellyn, 2014; 2017; Fleming et al., 2019; Gavidia-Payne & Jackson, 2019). Por ejemplo, en el primer estudio empírico se concluyó que en la legislación relativa a las personas con discapacidad no aparece su intersección con la juventud y con la situación de grandes necesidades de apoyo. Obviándose a su vez todas las intersecciones que pueden derivarse de la misma. Este déficit se observa a su vez en las evaluaciones de las intervenciones, tal y como se refleja en el segundo capítulo, donde hay una escasez de estudios que evalúen intervenciones con jóvenes con gran discapacidad del colectivo LGTBIQ+ o de zonas rurales.

Todo ello, repercute en la promoción de la inclusión de las intervenciones posteriores, dejando a un lado las necesidades de los jóvenes o de las personas con discapacidad o de las personas con grandes necesidades de apoyo, en función de a qué colectivo en concreto van dirigidas las políticas diseñadas. Por ejemplo, a nivel internacional se concluye que las intervenciones en países en vías de desarrollo tienen un enfoque más médico (Kafaa, 2021; Mathias et al., 2018; Trani et al., 2021), lo cual indica la necesidad de atender a la intersección discapacidad y país. Este hecho concuerda con los resultados obtenidos en el análisis de las experiencias realizado en los dos últimos estudios que componen esta tesis, donde se detectaron dificultades específicas en las intersecciones relativas al medio rural y a la condición de migrante y/o refugiado, entre otras.

En concreto, en esta tesis se han observado dificultades específicas para los jóvenes con gran discapacidad, y, a raíz de las contribuciones de los capítulos 4 y 5, puede determinarse que se agravan especialmente si tienen problemas de conducta y/o de comunicación, o una pluridiscapacidad. Por ejemplo, los diseños de los recursos, en muchas ocasiones, se especializan en un tipo de discapacidad, dificultando el acceso a jóvenes que, además de esa discapacidad, tienen otra discapacidad más. O, las posibilidades de participación de personas con problemas comunicativos se limitan en el momento en el que no cuentan con su intérprete o no se cuenta con una herramienta de comunicación alternativa y/o aumentativa y formación para ponerla en marcha.

Otras variables relevantes en el acceso a servicios de juventud en la comunidad, que incluyeran a jóvenes con discapacidad grave y severa, fueron: vivir en el medio rural, ser migrante o refugiado, estar institucionalizado, y estar tutelado, más aún si esta tutela se realiza desde grandes administraciones. Vinculado con este último punto, tener cuidadores enfermos o muy mayores también puede incrementar esta situación de vulnerabilidad. Cabe resaltar que, de acuerdo a los resultados del último estudio, por un lado, vivir en el medio rural suponía un menor acceso a servicios, tal y como proponían estudios previos (Roult et al., 2019; Thabethe, 2022). Pero, por otro lado, también podía resultar un factor protector, ya que algunas experiencias relataban que se generaban mayores interacciones por tratarse de comunidades más pequeñas. Por otra parte, influía, también, el status de la familia en la sociedad, como otra característica a considerar. Por ello, la variable situación familiar resulta fundamental a la hora de diseñar e implementar políticas destinadas a la inclusión social de jóvenes con discapacidad, comprendiendo la heterogeneidad de escenarios.

Con el fin de comprender la pluralidad de situaciones, y atendiendo a los resultados de los dos últimos estudios que tratan de dar voz a este colectivo minoritario, se plantea la promoción de modelos de intervención flexibles, centrados en los proyectos de vida de las personas, y que, además, ofrezcan oportunidades (ej.: ocio, relaciones sociales, empleo, educación, apoyo o vivienda) más inclusivas y adaptadas a sus demandas y necesidades, y a las de sus familias, atendiendo a la CDPD. Esta reflexión parece necesaria especialmente para evitar caer en una visión discriminadora, capacitista y médico rehabilitadora. Estas perspectivas suponen, por ejemplo, concebir a los jóvenes con gran discapacidad únicamente como usuarios y no como protagonistas; el mantenimiento de actividades diarias que absorben demasiada energía, sin dejar espacio al ocio, el deporte o la cultura; o, un excesivo peso de la familia en los cuidados, que termina en una experiencia de encapsulamiento (Tarvainen, 2021). Por ello, en las fases de elaboración de todas las políticas públicas y sociales, también las destinadas a otros tipos de población, convendría incorporar mecanismos de participación ciudadana con un diseño universal, que permitan, también, la participación de estos jóvenes y de sus representantes legales.

Todas estas aportaciones, en su conjunto, destacan que el desarrollo y reconocimiento de los derechos de las personas con discapacidad en la CDPD supuso un avance en su reconocimiento de derechos (ej.: acceso al empleo y la educación inclusiva, accesibilidad, igualdad de trato, reconocimiento de algunos recursos de apoyo, etc.), también, en Aragón. Además, el desarrollo del sistema de atención a la dependencia y el impulso de los servicios sociales especializados para este colectivo apoyaron la posibilidad de hacer efectivos esos derechos reconocidos, a través de prestaciones y recursos especializados. Pese a ello, los recursos existentes se perciben como estandarizados, y no cubren los intereses y necesidades propios de la etapa vital de los jóvenes y sus cuidadores, centrándose principalmente en cuestiones formales (empleo, cuidados físicos, etc.). Y, su desarrollo regulativo complejo y la burocracia que les envuelve suponen trabas en su acceso, especialmente para personas que no son concebidas por la sociedad como dentro de la normalidad (ej.: con pluridiscapacidad, migrantes, etc.). Es decir, se ha avanzado en el reconocimiento de derechos, pero comprendiendo a este colectivo como homogéneo y no como un colectivo conformado por personas, con problemáticas que van más allá de tener una discapacidad.

6.2 LIMITACIONES

Esta tesis no ha estado exenta de limitaciones. En primer lugar, existe una alta complejidad de sistemas de bienestar que envuelven la atención a los jóvenes con gran discapacidad en España, sumada a su organización autonómica, que genera 17 sistemas diferentes. Todo ello hace que el volumen de información existente sea altamente elevado y dispar, dificultando su estudio en una sola investigación doctoral. Por ello, este estudio se aplicó únicamente al contexto aragonés, atendiendo a sus características de interés sociodemográfico, como contar con una gran ciudad o la progresiva despoblación de su medio rural. Pese a esta limitación, se han generado herramientas, como el libro de códigos, que se muestra en el Apéndice 2, o el esquema de entrevista empleado en los estudios 3 y 4, que pueden aplicarse a otros contextos en futuras investigaciones.

En segundo lugar, atendiendo a las características del universo objeto de estudio, han concurrido varias dificultades que han limitado o han exigido una reconfiguración del diseño inicial de la investigación. Una de esas dificultades fue la necesidad de intermediarios para poder acceder a la población, debido a la protección especial de los datos personales relativos a salud, requiriendo, así, un muestreo de disponibilidad o conveniencia. Este hecho, además, ha generado que no se tuviera acceso a población de la provincia de Teruel, pese a múltiples intentos.

Además, los problemas de comunicación de parte de la muestra han supuesto otra limitación, exigiendo recurrir a sus representantes legales o adaptar mediante sistemas de comunicación aumentativa y/o alternativa algunas de las preguntas de las entrevistas. De este modo, en el caso de personas con la capacidad para obrar modificada legalmente, se incluyó a sus representantes legales, familiares o cuidadores principales, entendiendo que éstos conocen perfectamente su situación y hablan en nombre de los intereses de estos jóvenes. Esta incorporación enriqueció la investigación incorporando la perspectiva de las familias.

Por último, la obligación de recurrir a intermediarios limitó aún más la posibilidad de acceder a informantes que por su situación de discapacidad no pueden salir de casa o que no participan de entidades sociales. Esta limitación se trató de paliar logrando una muestra lo más heterogénea posible, incluyendo a jóvenes con diferentes tipos y grados de discapacidad, diferente sexo, procedencia, edad y lugares de residencia.

Dadas las características del universo de estudio y el espacio temporal en el que se desarrolló la investigación, debe atenderse al impacto del Covid-19 en la misma. En muchos casos se trataba de población con problemas de salud vinculados a su situación de discapacidad o que acudían a servicios en los que convivían con población de riesgo. Esta situación generó un retraso en el trabajo de campo y dificultades para realizar las entrevistas, requiriendo de adaptaciones en algunos casos, por ejemplo, realizando las entrevistas en terrazas de cafeterías al aire libre o con mascarilla.

Por último, a nivel metodológico, la escasez de indicadores de evaluación internacional o nacionalmente avalados y de datos estadísticos longitudinales, han dificultado el planteamiento de un estudio comparado. En este sentido, únicamente la elaboración de unos indicadores de este tipo habría conllevado una investigación con una demanda temporal excesiva. Así, esta tesis doctoral se basó en los indicadores psicométricos más empleados a nivel internacional, los principios definidos por EQUASS (2021) y los esquemas de entrevistas de estudios previos, detectados mediante una revisión sistemática de la literatura, para elaborar su propio instrumento de investigación. Éste se centró en conocer en profundidad las experiencias de los jóvenes con discapacidad grave y muy grave y sus familias, dando voz a estos jóvenes, a menudo excluidos de las investigaciones, y trasladando esa voz de forma sistematizada para conocer sus necesidades menos cubiertas y mejorar potencialmente las intervenciones a ese respecto.

Por ello, y dado el carácter cualitativo de los dos últimos estudios, que limita la aplicación de factores de corrección cuantitativos, y sus objetivos, sus conclusiones sólo podrán atribuirse a la subpoblación estudiada. No podrán generalizarse a la totalidad de los jóvenes con discapacidad grave y muy grave aragoneses o de fuera de Aragón, aunque sirven como punto de partida para futuras investigaciones (Flick, 2018).

6.3 FUTURAS LÍNEAS DE INVESTIGACIÓN

En primer lugar, como se ha comentado anteriormente, los jóvenes se enfrentan a dificultades específicas por el hecho de serlo, sobre las que instituciones como la Unión Europea han centrado su atención. Pese a ello no cuentan con un documento que promueva la protección de este colectivo y el impulso de políticas de promoción del reconocimiento de sus derechos, como sí ocurre con las mujeres, los niños o las personas con discapacidad. Esto supone que tengan una menor presencia de forma transversal en el desarrollo normativo. En este sentido, convendría estudiar en mayor profundidad el impacto de este tipo de documentos internacionales en el reconocimiento de derechos de los colectivos a los que se refieren y la conveniencia o no de promover la creación de un documento internacional, centrado en los derechos de los jóvenes.

En segundo lugar, hay que atender a los efectos de la excesiva burocracia y complejidad de la misma, propios del derecho regulativo, en la calidad de vida de los jóvenes con gran discapacidad y sus familias. Por ello, habría que estudiar una nueva organización de los servicios sociales especializados y generales que fomenten la transversalidad de la atención a los jóvenes con discapacidad grave y severa desde los diferentes sistemas involucrados. Y, además, mejoren la coordinación entre administraciones y perfeccionen su atención a la diversidad, desde la promoción de un diseño desde la perspectiva interseccional. En este sentido, parece necesario explorar cuestiones como las mejoras que puede aportar la digitalización en las administraciones públicas para favorecer un intercambio de datos optimizado y su conjugación con aspectos como la accesibilidad y la ley de protección de datos.

En línea con lo anterior, resulta indispensable repensar en el diseño de estos servicios y el papel que juegan sus usuarios en el mismo, debiendo entenderles, también, como protagonistas. Esta cuestión se ha fomentado desde la perspectiva de la co-producción de investigaciones y co-creación de servicios, pero resulta compleja en el caso de personas con gran discapacidad, especialmente si existen problemas de comunicación o de comportamiento. Por ello, debe estudiarse cómo adaptar investigaciones y procesos de diseño, elaboración, desarrollo y evaluación de políticas públicas a estas características, promoviendo su inclusión, o, en su defecto, la de sus representantes. Así, debe estudiarse como mejorar la accesibilidad, también, en el acceso (económico) y el diseño de las propias intervenciones e investigaciones, valorando la implementación y reconocimiento efectivo de figuras como la persona de apoyo.

En este sentido, el papel de los profesionales involucrados tanto en el diseño de las políticas, como en el desarrollo de las mismas en intervenciones concretas, es fundamental. Tal y como se ha observado, la posición que tomen estos profesionales y la influencia de sus creencias en torno a la discapacidad y la juventud pueden influir en la implementación de las mismas, entorpeciendo o facilitando la consecución de sus objetivos. Por ello, parece conveniente estudiar las funciones de estos profesionales y las competencias que les son necesarias, y cómo mejorarlas. Asimismo, en la revisión sistemática de la literatura, se acusó una escasez de trabajadores sociales en el desarrollo de las intervenciones sociales con este colectivo, que se presentaban en las investigaciones a nivel internacional. Esta cuestión llama la atención ya que son un agente social fundamental en los servicios sociales, la promoción del voluntariado, la sensibilización y la acción comunitaria. Todas ellas demandas emergidas a lo largo de la presente tesis doctoral. Esto lleva a la necesidad de investigar en torno a cómo mejorar su responsabilidad en las mismas.

Además, unido a lo anterior, tal y como mostró el segundo estudio, existe un déficit en la investigación e implementación de evaluaciones en las intervenciones sociales, que dificultan detectar algunas de las situaciones expuestas en este trabajo ni realizar comparativas longitudinales e internacionales. Por ello, parece conveniente avanzar en el establecimiento de indicadores de evaluación, a nivel cuantitativo y cualitativo.

Atendiendo a las limitaciones presentadas en esta investigación, resulta, también, necesario complementar este estudio con el análisis de posibles factores facilitadores y de riesgo para la promoción de la inclusión de los jóvenes con gran discapacidad en España, desde una perspectiva interseccional. Así, se plantea emplear la recién publicada Encuesta de Discapacidad, Autonomía personal y Situaciones de Dependencia, generada por el Instituto Nacional de Estadística de España, para complementar los resultados de esta tesis con un análisis cuantitativo de la situación actual, bajo el prisma de la interseccionalidad.

Por último, comprendiendo el gran impacto de la familia en la intervención con jóvenes con discapacidad grave y muy grave, y viceversa, y los cambios en las dinámicas de cuidados y a nivel sociodemográfico. Resulta de interés estudiar la situación de las cuidadoras principales de estos jóvenes en España, poniendo especial hincapié en su posible reincorporación al mercado laboral, tras la brecha de los 21 años; sus necesidades biopsicosociales derivadas de la exigencia de los cuidados, ya sean complementados o no por un servicio de atención a la dependencia; y, sus propios procesos de envejecimiento. De este modo, se podría mejorar la situación de estas cuidadoras, impactando, a su vez, en una mejor calidad de los cuidados destinados a los jóvenes con discapacidad grave y muy grave o severa.

6.4 REFERENCIAS

Aparicio, M. (2016). Estigmatización, invisibilización y cosificación de las personas con diversidad funcional. Una aproximación desde la justicia como reconocimiento de Axel Honneth. *Revista Española de Discapacidad*, 4(1), 177-190. https://www.cedd.net/redis/index.php/redis/article/view/245

Argullo, C., Arroyo, J., Ema, J.E., Gámez, C., Gómez, E., Jiménez, P., Rodríguez, E., Salvador, M., Orfi, M. & Colina, M.P. (2011). *Cojos y precarias: haciendo vidas que importan. Cuaderno sobre una alianza imprescindible*. Traficantes de Sueños.

Blanca Gutiérrez, J.J. (2017). *Metaestudio sobre la experiencia vital de las personas mayores que viven en residencias como fundamento de los cuidados enfermeros geriátricos*. Biblioteca Lascasas, V13. http://www.indexf.com/lascasas/documentos/e11575.php

Calvo García, M. (2005). *Transformaciones del Estado y del Derecho*. Universidad Externado de Colombia.

Calvo García, M. (2019). Retorno al derecho regulativo. Implementación y evaluaciones de impacto. In Oliver-Lalana, A.D. *La legislación en serio. Estudios sobre derecho y jurisprudencia*. Tirant Lo Blanch, 587-627.

Cho, S., Crenshaw, K. W., & McCall, L. (2013). Toward a field of intersectionality studies: Theory, applications, and praxis. *Signs: Journal of women in culture and society*, 38(4), 785-810. DOI: 10.1086/669608

Convención de las Naciones Unidas sobre los Derechos de las Personas con Discapacidad (CDPD)

Crenshaw, K. (1989). Demarginalizing the intersection of race and sex: a black feminist critique of antidiscrimination doctrine, feminist theory, and antiracist politics. *University of Chicago Legal Forum*, 1(8), 139-167. http://chicagounbound.uchicago.edu/uclf/vol1989/iss1/8

Crenshaw, K. (1991). Mapping the margins: intersectionality, identity politics, and violence against women of colour. *Standford Law Review*, 43(6), 1241-1299. DOI: 10.2307/1229039

de Asis Roig. (2020). Sobre el sentido, contenido y configuración jurídica de la accesibilidad. *Universitas. Revista de Filosofía, Derecho y Política*, 32, 2-21.

Del Pino, E. & Catalá Pérez, D. (2016). El welfare-mix español durante la crisis y la privatización del riesgo social: los casos de la sanidad, los servicios sociales y la atención a la dependencia. *Revista del CLAD Reforma y Democracia*, 66 (Oct.), 163-194.

Delval, J. (2008). *El desarrollo humano*. Siglo Veintiuno de España.

Domínguez Álvarez, J.L. (2020). El desigual acceso de la juventud rural a los servicios públicos: la necesidad de impulsar la educación en la España vaciada. *Cuadernos de Investigación en Juventud*, (8), 60-78. DOI: 10.22400/cij.8.e047

EQUASS (2021). *European Quality in Social Services: Principles, Criteria and Indicators*. EQUASS.

Estrategia de la Unión Europea sobre los Derechos de las Personas con Discapacidad 2021-2030 (EUEDPD).

Fleming, P., McGilloway, S., Hernon, M., Furlong, M., O'Doherty, S., Keogh, F., & Stainton, T. (2019). Individualised funding interventions to improve health and social care outcomes for people with a disability: a mixed-methods systematic review. *Campbell Systematic Reviews*, 3.

Flick, U. (2018). *The SAGE handbook of qualitative data collection*. DOI: 10.4135/978152641607

García-Fuentes, J., & Martínez García, J. S. (2020). Los jóvenes “Ni-Ni”: Un estigma que invisibiliza los problemas sociales de la juventud. *Archivos Analíticos de Políticas Educativas*, 28(20). DOI: 10.14507/epaa.28.4652

Gavidia-Payne, S., & Jackson, M. (2019). Research Priorities and Protections. In Matson, J.L. (ED.). *Handbook of Intellectual Disabilities*, 247-261.

Gilor, O., Klibanski, H. & Kfir, D. (2017). Setting policies regarding leisure activities for youths with disabilities: who will accept this mission? *World Leisure Journal*, 59(3), 227-239. DOI: 10.1080/16078055.2017.1345487

Goodley, D. (2016). *Disability Studies: An Interdisciplinary Introduction*. SAGE.

Goodley, D., Lawthom, R., Liddiard, K y Runswick-Cole, K. (2019). Provocations for Critical Disability Studies. *Disability & Society*, 34(6), 972-997. DOI: 10.1080/09687599.2019.1566889

Goodley, D., Liddiard, K., & Runswick-Cole, K. (2018). Feeling disability: theories of affect and critical disability studies. *Disability & Society*, 33(2), 197-217. DOI: 10.1080/09687599.2017.1402752

Guillem, R.B., Barberà i Guillem, R., Poveda Puente, R., Ródenas Rigla, F., Carretero Gómez, S., Bollaín Pastor, C., Cordero Roma, L., Castelló Mercé, P. & Gómez Herrero, J.A. (2010). Análisis coste-beneficio de la incorporación de productos de apoyo como extensión de los servicios de atención a domicilio para personas mayores dependientes. *Revista de biomecánica,* 54, 49-51.

Huete García, A., Quezada García, M.Y. & Caballero Juliá, D. (2016). *Jóvenes con discapacidad en España 2016*. INJUVE-CERMI.

Iáñez-Domínguez, A., Chaves, J.L.A. & Romero, J.G. (2018). Impacto económico y social de la asistencia personal a través de la metodología del Retorno Social de la Inversión. *Revista Española de Discapacidad* (REDIS), 6(2), 81-102.

Instituto Danés de Derechos Humanos (IDDH) (2019). La guía de los derechos humanos a los ODS. *Instituto Danés de Derechos Humanos*. https://sdg.humanrights.dk/es/goals-and-targets

Instituto Nacional de Estadística (INE) (2022a). *Demografía y población*. Instituto Nacional de Estadística. https://www.ine.es/dyngs/INEbase/es/operacion.htm?c=Estadistica_C&cid=1254736176951&menu=ultiDatos&idp=1254735572981

Jiménez-Lara, A. (2017). *Personas con discapacidad y discriminación múltiple en España: situación y propuestas*. Observatorio Estatal de la Discapacidad.

Jollien, A. (2011). *El oficio de ser hombre*. Octaedro.

Kafaa, K. (2021). Special Health Insurance as an Inclusive Social Protection Program for People with Disabilities. *Jurnal Ilmiah Peuradeun. The International Journal of Social Sciences*, 9(1), 71-86. DOI:10.26811/peuradeun.v9i1.462

King, G., Batorowicz, B., Rigby, P., Pinto, M., Thompson, L., & Goh, F. (2014). The leisure activity settings and experiences of youth with severe disabilities. *Developmental Neurorehabilitation*, 17(4), 259-269. DOI: 10.3109/17518423.2013.799244

Leenknecht, A.S. (2020). *EDF input to the European Disability Rights Agenda*. European Disability Forum.

Llewellyn, G. & National Disability Research and Deveopment Agenda, sponsoring body & University of Sydney. Centre for Disability Research and Policy, issuing body. (2014). *Report of audit of disability research in Australia*.

Llewellyn, G. & National Disability Research and Deveopment Agenda, sponsoring body & University of Sydney. Centre for Disability Research and Policy, issuing body. (2017). *Audit of disability research in Australia update report 2017*.

Martínez García, J.S. (2013). La tensión entre vida personal, familiar y laboral. En Martínez Garcia, J.S. *Estructura social y Desigualdad en España*. Catarata,115-120.

Mathias, K., Mathias, J., Goicolea, I. & Kermode, M. (2018). Strengthening community mental health competence—A realist informed case study from Dehradun, North India. *Health Social Care Community*, 26, e179–e190. DOI: 10.1111/hsc.12498

Milios, G. (2022). El derecho a la no discriminación por motivo de discapacidad: la compleja coexistencia de la normativa y jurisprudencia nacional y supranacional. *Derechos y Libertades: Revista De Filosofía Del Derecho Y Derechos Humanos*, 47, Época II, 241-271. DOI: 10.20318/dyl.2022.6882

Mira-Aladrén, M., Martín-Peña, J., & Gil-Lacruz, M. (2023). Discapacidad y servicios sociales: analizar la accesibilidad en la complejidad institucional. *DERECHOS Y LIBERTADES: Revista De Filosofía Del Derecho Y Derechos Humanos*, (49), 259-290. DOI: 10.20318/dyl.2023.7725

Observatorio de Emancipación (2023). *Informe estatal segundo semestre 2022*. Consejo de la Juventud España. https://www.cje.org/observatorio-de-emancipacion/#258-186-segundo-semestre-2022-1691745583

Observatorio Estatal de la Discapacidad (2022). *Informe Olivenza 2020-2021 sobre la situación de la discapacidad en España*. Observatorio Estatal de la Discapacidad. https://www.observatoriodeladiscapacidad.info/wp-content/uploads/Informe-Olivenza-2020-2021-v2.2.pdf

Rodó-Zarate, M. (2021). *Interseccionalidad. Desigualdades, lugares y emociones*. Bellaterra Edicions.

Romañach Cabrero, J. & Palacios Rizzo, A. (2008). El modelo de la diversidad: una nueva visión de la bioética desde la perspectiva de las personas con diversidad funcional (discapacidad). *Intersticios. Revista sociológica de pensamiento crítico*, 2(2). http://www.intersticios.es/article/view/2712

Rosenthal, K. (2020). *Capitalism & Disability. Selected writtings by Marta Russell.* Haymarketbooks.

Roult, R., Carbonneau, H., Belley-Ranger, E., Brunet, I. & Adjizian, J.M. (2019) Rural leisure opportunities for people with disabilities: needs and challenges in Quebec, *Rural Society,* 28:1, 1-14. DOI: 10.1080/10371656.2018.1558946

Saldívar Reyes, A., & Alvarado García, F. (2020). Aproximación a las experiencias de vida de jóvenes con discapacidad motriz. *RPP*, (30). DOI: 10.21555/rpp.v0i30.2028

Saldívar Reyes, A., & Alvarado García, F. (2020). Aproximación a las experiencias de vida de jóvenes con discapacidad motriz. *RPP*, (30). DOI: 10.21555/rpp.v0i30.2028

Santrock, J.W. (2006). *Psicología del desarrollo: El ciclo vital* (10ª ed.). McGraw-Hill.

Shakespeare, T. (2014). *Disability Rights and Wrongs Revisited.* Routledge.

Shikako-Thomas, K., & Law, M. (2015). Policies supporting participation in leisure activities for children and youth with disabilities in Canada: from policy to play. *Disability & Society,* 30(3), 381-400. DOI: 10.1080/09687599.2015.1009001

Steinhardt, F., Ullenhag, A., Jahnsen, R. & Dolva, A.S. (2021). Perceived facilitators and barriers for participation in leisure activities in children with disabilities: Perspectives of children, parents and professionals. *Scandinavian Journal of Occupational Therapy*, 28(2), 121-135. DOI: 10.1080/11038128.2019.1703037

Tarvainen, M. (2021) Loneliness in life stories by people with disabilities, *Disability & Society*, 36 (6), 864-882, DOI: 10.1080/09687599.2020.1779034

Thabethe, N. (2022). We have no power over perceptions': the lived experiences of women with disabilities in a rural South African community. *Disability & Society, 37*(2), 345-350. DOI: 10.1080/09687599.2021.1976109

Tobio, C., Agulló Tomás, M.S., Gómez, V. & Martín Palomo, M.T. (2011). *El cuidado de las personas*. La Caixa. http://www.abc.es/gestordocumental/uploads/Otras/volumen-completolacaixa.pdf

Trani, J.F., Vasquez-Escallon, J. & Bakshi, P. (2021). The impact of a community-based rehabilitation program in Afghanistan: a longitudinal analysis using propensity score matching and difference in difference analysis. *Conflict and Health,* 15 (63). DOI: 10.1186/s13031-021-00397-y

7 APPENDIXES

7.1 APPENDIX 1. LIST OF REGULATIONS ANALYSED

Correction of errors of Law 26/2011, of 1 August, on regulatory adaptation to the International Convention on the Rights of Persons with Disabilities.

Decree 54/2013, of 2 April, of the Government of Aragon, on regulatory empowerment for the approval of the general provisions necessary for the organisation of the System for Autonomy and Care for Dependency in the Autonomous Community of Aragon.

Opinion of the European Economic and Social Committee on 'Implementation and monitoring of the UN Convention on the Rights of Persons with Disabilities by the EU institutions, and the role of the EESC in this regard' (own-initiative opinion) (2013/C 44/05).

Opinion of the European Economic and Social Committee on 'The situation of people with disabilities in the Euromed countries' (2011/C 48/17).

Opinion of the European Economic and Social Committee on the Proposal for a Directive of the European Parliament and of the Council on the accessibility of public sector bodies' websites [COM(2012) 721 final - 2012/0340 (COD)] (2013/C 271/22).

Directive (EU) 2019/882 OF THE EUROPEAN PARLIAMENT AND OF THE COUNCIL of 17 April 2019 on accessibility requirements for products and services.

Council Directive implementing the principle of equal treatment between persons irrespective of religion or belief, disability, age or sexual orientation".

Instrument of ratification of the Convention on the Rights of Persons with Disabilities, done at New York on 13 December 2006.

O.L. 1/2017, of 13 December, amending Organic Law 5/1995, of 22 May, on the Jury Court, to guarantee the participation of persons with disabilities without exclusions.

O.L. 2/2018, of 5 December, for the modification of Organic Law 5/1985, of 19 June, on the General Electoral Regime to guarantee the right of suffrage of all persons with disabilities.

Law 1/2009, of 25 March, on the reform of the Law of 8 June 1957, on the Civil Registry, in matters of incapacitation, guardianships and administrators of protected estates, and of Law 41/2003, of 18 November, on the protection of the assets of persons with disabilities, and on the modification of the Civil Code, the Civil Procedure Law and tax regulations for this purpose.

Law 26/2011, of 1 August, on regulatory adaptation to the International Convention on the Rights of Persons with Disabilities.

Law 5/2009 on social services in Aragon.

Royal Decree 1050/2013, of 27 December, which regulates the minimum level of protection established in Law 39/2006, of 14 December, on the Promotion of Personal Autonomy and Care for Dependent Persons.

Royal Decree 1051/2013, of 27 December, regulating the benefits of the System for Autonomy and Care for Dependency, established in Act 39/2006, of 14 December, on the Promotion of Personal Autonomy and Care for Dependent Persons.

Royal Decree 1056/2014, of 12 December, regulating the basic conditions for issuing and using the parking card for people with disabilities.

Royal Decree 1112/2018, of 7 September, on accessibility of public sector websites and applications for mobile devices.

Royal Decree 1276/2011, of 16 September, on regulatory adaptation to the International Convention on the Rights of Persons with Disabilities.

Royal Decree 1341/2018, of 29 October, establishing transitional measures for the maintenance, in favour of persons with disabilities, of the mobility allowance and compensation for transport expenses.

Royal Decree 1364/2012, of 27 September, amending Royal Decree 1971/1999, of 23 December, on the procedure for the recognition, declaration and qualification of the degree of disability.

Royal Decree 174/2011, of 11 February, approving the scale of assessment of the situation of dependency established by Law 39/2006, of 14 December, on the Promotion of Personal Autonomy and Care for Dependent Persons.

Royal Decree 175/2011, of 11 February, amending Royal Decree 727/2007, of 8 June, on criteria for determining the intensities of protection of services and the amount of financial benefits under Act 39/2006, of 14 December, on the Promotion of Personal Autonomy and Care for Dependent Persons, and Royal Decree 615/2007, of 11 May, regulating Social Security for carers of dependent persons.

Royal Decree 1856/2009, of 4 December, on the procedure for the recognition, declaration and qualification of the degree of disability, and amending Royal Decree 1971/1999, of 23 December.

Royal Decree 291/2015, of 17 April, amending Royal Decree 1051/2013, of 27 December, regulating the benefits of the System for Autonomy and Care for Dependency, established in Law 39/2006, of 14 December, on the Promotion of Personal Autonomy and Care for Persons in a Situation of Dependency.

Royal Decree 537/2019, of 20 September, amending Royal Decree 1544/2007, of 23 November, which regulates the basic conditions of accessibility and non-discrimination for access to and use of modes of transport for people with disabilities.

Royal Decree 578/2013, of 26 July, establishing positive action measures applicable to persons with disabilities who participate in the annual calls for selective tests for access to specialised health training positions, in development of article 22.3 of Law 44/2003, of 21 November, on the organisation of health professions.

Royal Decree 734/2019, of 20 December, which modifies basic guidelines for civil protection planning and state civil protection plans for the improvement of care for people with disabilities and other groups in situations of special vulnerability in emergencies.

Royal Decree 99/2009, of 6 February, amending Royal Decree 614/2007, of 11 May, on the minimum level of protection of the system for autonomy and care for dependency guaranteed by the General State Administration.

Opinion of the European Economic and Social Committee on 'Young people with disabilities: employment, integration and participation in society' (exploratory opinion).

Opinion of the European Economic and Social Committee on the 'Communication from the Commission to the European Parliament, the Council, the European Economic and Social Committee and the Committee of the Regions - A European

Disability Strategy 2010-2020: A renewed commitment to a barrier-free Europe' COM(2010) 636 final (2011/C 376/15).

Opinion of the European Economic and Social Committee on Intergenerational and intercultural measures to promote the social integration of young EU citizens who move for work purposes to another Member State (own-initiative opinion) (2014/C 311/01).

European Parliament Resolution of 25 October 2011 on mobility and inclusion of people with disabilities and the European Disability Strategy 2010-2020 (2010/2272(INI)) (2013/C 131 E/02).

Decree 143/2011, of 14 June, of the Government of Aragon, approving the Catalogue of Social Services of the Autonomous Community of Aragon.

Royal Legislative Decree 8/2015, of 30 October, approving the revised text of the General Law on Social Security.

Law 5/2019, of 21 March, on the rights and guarantees of persons with disabilities in Aragon.

Royal Legislative Decree 1/2013, of 29 November, approving the Consolidated Text of the General Law on the Rights of Persons with Disabilities and their Social Inclusion.

7.2 APPENDIX 2. CODEBOOK

Variable	**Definition**	**Values**
Name	Name of the law in the BOE	Name
Year	Year of publication in BOE	Year
Type	Type of regulation	1 Organic Law 2 Ordinary Law 3 Royal Decree Law 4 Royal Legislative Decree 5 Directive 6 Resolution 7 Order 8 Decree 9 Verdict 10 Instruments of Ratification 99 Other/Not specified (NS)
Specificity	Is it a specific law on disability?	0 No 1 Yes
Territorial level	Territorial level of the law	1 UN 2 Europe 3 Spain 4 Autonomous 99 Other
Territorial impact	Does it affect other territorial levels?	0 No 1 Yes, all 2 Yes, national 3 Yes, regional 4 Yes, infra-autonomous 99 Other/Not specified (NS)

Variable	**Definition**	**Values**
Institutional level	Does it affect more than one institution?	0 No 1 Yes 99 NS/ND (not specified/not detected)
Institutions	Which institutions are affected?	Name of institutions
System	In which system is the Law framed?	1 Health 2 Education 3 Pensions/Labour 4 Dependency 5 Legal 6 Social Services 99 Other/NS
Other systems	Does it affect any other welfare system?	0 No 1 Yes 99 Other/NS
What systems	What other systems are affected?	Name systems
Law Accessibility	Is it in accessible format?	0 No 1 Yes 2 Only for some disabilities 99 NS/ND (not specified/not detected)
Definition of disability	Presence or absence of definition of disability	0 No 1 Yes 2 No, but defines assailable concepts 3 Yes, in different ways 99 Other/NS
How disability	How does the law define disability?	Definition
Definition of accessibility	Presence or absence of definition of accessibility	0 No 1 Yes 2 No, but defines similar concepts 3 Yes, in different ways 99 Other/NS
How accessibility	How does the law define accessibility?	Definition

Variable	**Definition**	**Values**
Measures	Presence or absence of concrete accessibility measures	0 No 1 Yes 99 Other
What measures	What measures does the law propose for accessibility?	Measures
Type of accessibility	What types of accessibility does it cater for?	1 Physical 2 Cognitive 3 Communicative 4 Symbolic 5 Several of the above 6 All of the above 99 Other/NS
Accessibility requirements	Are there any requirements for access to adaptations?	0 No 1 Yes, have a recognised disability 2 Yes, apply for it 3 Yes, have a recognised disability and apply for it 4 Other 99 NS/ND (not specified/not detected)
Other requirements	What other requirements does the law put?	Requirements
Presence of other disciplines	Presence or absence of disciplines other than law	0 No 1 Yes 99 NS/ND (not specified/not detected)
What disciplines	What other disciplines does it include?	Disciplines
Arbitrariness	Does the law leave room for arbitrariness??	0 No 1 Yes 99 NS/ND
How arbitrary	How does it leave room for arbitrariness?	Process
Youth	Presence or absence of reference to youth with disabilities	0 No 1 Yes 99 NS/ND
Which youth	What specific references or measures does it contain for youth?	References

Variable	**Definition**	**Values**
High support needs	Presence or absence of reference to persons with high support needs	0 No 1 Yes 99 NS/ND
Which high support needs	What specific references or measures do you collect for persons with high support needs?	References
Youth with high support needs	Presence or absence of reference to young people with high support needs	0 No 1 Yes 99 NS/ND
Which youth with high support needs	What specific references or measures does it contain for young people with high support needs?	References
Remarks	Remarks	Remarks
Web link	Web link to the law	Web link

7.3 APPENDIX 3. THEMES AND RELATED SUBTHEMES FROM THEMATIC ANALYSIS

Theme/Subtheme	
1. Family quality of life	Family quality of life-related experiences
1.1 Caregivers' status	Care experiences related to caregivers' biopsycho-social situation
1.1.1 Fear	Experiences or expressions of fear
1.1.2 Negative	Expressing a negative status
1.1.3 Positive	Expressing a positive status
1.1.4 Too much work	Expressing caregivers working too much
1.1.5 Resignation	Expressing resignation
1.2 Extra-family relationships	Experiences of relationships with friends, large family and received support
1.2.1 Negative	Expressing negative relationships or no support
1.2.2 Positive	Expressing positive and support relationships
1.3 Intra-family relationships	Experience in family care dynamics, conflict solving, etc.
1.3.1 Negative	Expressing negative relationships or no support
1.3.2 Positive	Expressing positive and support relationships
1.4 Caregivers' conciliation	Capacity to conciliate care, work and free time
2. Quality of life	Reality of a disabled person's quality of life
2.1 Dignity	Experiences that affect someone's dignity
2.2 Material	Material quality of life experience
2.3 Physical	Physical quality of life experience
2.4 Emotional	Emotional quality of life experience
2.4.1 Positive	Experiences of positive emotions
2.4.2 Negative	Experiences of negative emotions
2.4.3 Resignation	Expressing resignation
2.5 Rights	Knowledge of rights and access to information

Theme/Subtheme	
3. Social services	Quality and the relationship with social services
3.1 Participation	Experiences of participating in legislative processes and/or entities
3.2 Involvement	Participating in decision making
3.3 Gaps	Moving from the education system to the dependency system
3.4 Accompaniment	Experiences in the way intervention and accompaniment are done
3.5 Inter-administrations	Relationship among administrations
3.6 Staff	Experience with the staff of the attended resource
3.7 Proceedings/bureaucracy	Experience from doing administration proceedings (recognising disability and dependency, support measures, etc.)
3.8 Resource	Experience in the attended resource
3.8.1 Negative	Negative experiences in the assigned resource
3.8.2 Positive	Positive experiences in the assigned resource
3.8.3 Supplementary resources	Experience in the supplementary resources facilitated by private entites beyond dependency
4. Intersectionality	Comments on crossing socio-demographic variables like being a migrant, woman or having several disabilities
4.1 Rural setting	Experiences in small cities or towns
4.2 Multiple disabilities	Having more than one disability
4.3 Woman	Being a woman with a disbility
4.5 Migration	Being a migrant with a disability

7.4 APPENDIX 4. THEMES AND RELATED SUBTHEMES FROM THEMATIC ANALYSIS

Theme/Subtheme	
1. Proposals	Proposals expressed
2. Youth	Youth experiences
2.1Changes	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

Young people with severe and serious disabilities who require the support of a third person to carry out basic activities of daily living are cared for in Spain both by social services specialising in disability and by the dependency system. Despite this, and the commitment of public and social policies to a social and rights-based model of disability, the catalogue of the dependency system does not provide for differences in the supply and adaptation of services and benefits in response to the needs and demands of people, which change throughout their life cycle.

This doctoral thesis analyses the intervention carried out in the Aragonese public and social sphere for the care of young people with severe and serious disabilities and their families. The aim is to infer possible improvements from the perspective of inclusion and the application of the International Convention on the Rights of Persons with Disabilities.

This is done by means of different qualitative research techniques. First, a content analysis of the Aragonese legislation; then, a systematic literature review, focusing on assessment; and finally, two thematic analyses (one focusing on resources and the other on social relations) of interviews with 25 young people with severe disabilities and/or their guardians in Aragón.