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"The normate" – Institutional caregivers and the sexuality of people with intellectual dis/abilities

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"THE NORMATE" – INSTITUTIONAL CAREGIVERS AND THE SEXUALITY OF PEOPLE WITH INTELLECTUAL DIS/ABILITIES

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À minha mãe, que incutiu em mim a luta pelos direitos humanos, o ativismo, a busca por conhecimento e, acima de tudo, empatia, confiança e ambição.
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Resumo

Os direitos e a cidadania sexuais das pessoas com deficiência intelectual continuam a ser uma das dimensões mais negligenciadas e reprimidas da sociedade, sendo sistemicamente limitados por normas e estruturas discriminatórias. Este estudo utiliza a teoria Crip para se concentrar nas perceções e atitudes do "normate", especificamente dos cuidadores institucionais que exercem influência e poder significativos sobre a sexualidade e a vida sexual das pessoas que apoiam. Foi realizado um estudo qualitativo e exploratório, no qual vinte e um cuidadores remunerados de instituições portuguesas foram entrevistados a fim de compreender as suas crenças, práticas e as barreiras sistémicas que enfrentam. Os resultados apresentam uma tensão entre cuidadores que têm visões predominantemente progressistas e baseadas em direitos, que enquadram a sexualidade como um aspeto natural e vital da identidade humana, e, por outro lado, uma barreira sistémica de ação institucional e familiar, que limita muito as suas ações e apoio. Os cuidadores relataram ter de lidar com um "labirinto" complexo de crenças familiares, medos e autoridade que se sobrepõem ao julgamento profissional e à autonomia individual das pessoas com deficiência intelectual, bem como com limites institucionais, tais como a falta de formação e a inexistência de protocolos formais. Este estudo conclui que é necessária uma reformulação radical de cuidados para passar de um paradigma de gestão de riscos para um de autonomia apoiada, algo que parece estar de acordo com os desejos dos cuidadores.

Palavras-chave: Deficiência intelectual, Teoria Crip, Sexualidade, Cuidadores remunerados

Abstract

The sexual rights and citizenship of people with intellectual dis/abilities remain one of the most neglected and suppressed dimensions of society, and are systemically constrained by ableist norms and structures. This study employs a Crip theoretical framework to focus on the perceptions and attitudes of the "normate", specifically, on the institutional caregivers who wield significant influence and power over the sexuality and sexual lives of the people they support. A qualitative, exploratory study was conducted, where twenty-one paid caregivers from Portuguese institutions were interviewed in order to understand their beliefs, practices and the systemic barriers they navigate. The findings of this study present a tension between caregivers who hold predominantly progressive, right-based views, that frame sexuality as a natural, vital aspect of human identity, and, on the other hand, a systemic barrier of institutional and familial action, that greatly limits their actions and support. Caregivers reported having to navigate a complex "labyrinth" of familial beliefs, fears and authority that overrides professional judgement and the individual autonomy of people with intellectual dis/ability, as well as institutional limits such as lack of training and nonexistence of formal protocols.

This research concludes that a radical re-imagining of care is necessary to move from a paradigm of risk-management to one of supported autonomy, something that seems to be in accordance with the wishes of caregivers.

Keywords: Intellectual Disability, Crip Theory, Sexuality, Paid Caregivers

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Introduction

The lives and rights of people with intellectual dis/abilities[1] are some of the most hidden and actively ignored dimensions in societal structures. The very terms most commonly used, disability, impairment or handicap, portray the social perception of un-wholeness, of a broken identity that cannot be made perfect and a non-functional being (McRuer, 2008). Not falling in the categories seen as "normal" means being at risk of being marginalised and ostracised, creating a deviant identity and making it even more difficult to criticise societal norms, at risk of being ostracised by them (Karlsson & Rydström, 2023).

Ability and dis/ability (D/A) are always conceptualised by the very thing they are meant to oppose; in fact, they are almost always taken as a binary, an inseparable duo, in which able-bodiedness and dis/ability are opposites, without the possibility of a different structural concept (Karlsson & Rydström, 2023). When the discourse turns to the sexuality of those seen as unable in everyday life, things take a turn for the worse. A study from Maia (2016) concluded, in its final considerations, that *"people with disabilities are sexual beings, have a voice on their desires and report possibilities and difficulties of expression of their sexuality"* (p. 87). The thought that something so innate, so self-evident to most human beings, has to be "confirmed" when talking about people with D/A further proves the immense necessity for social and cultural change. It is, indeed, of the utmost importance that the sexual lives and sexualities of dis/abled people be brought into the spotlight of social activism and research, not only through the people themselves, but by the so-called able-bodied.

As Karlsson and Rydström (2023) said, "it is the Normate, able-bodiedness as a compulsory cultural command, that should be studied and analysed" (p. 400). As such, and because of the very nature of care, the focus of this study will be the able-bodied, the "normal" people surrounding dis/abled persons and influencing their lives in various ways. Although there is an immensurable variety of dis/abling conditions, we have found people with intellectual dis/abilities (ID/A) to be some of the most at risk of exclusion and neglection of their sexual rights (Albuquerque & Caravalho, 2020; Beato et al., 2024; Kulick, 2015; Kulick & Rydström, 2015; Monteiro et al., 2023). People with intellectual dis/abilities (ID/A) are, more

[1] In this article, we will be using the term "dis/ability", distinguishing between in and out of group concepts (Rydström, 2019) and making sure that ability and disability are conceptually understood in relation to each other (Goodley, 2014). Although the term "functional diversity" allows for emphasis on the fluidity and variety of bodily functions, it fails to acknowledge the social and political oppression inflicted on certain people (Rydström, 2019), hence the usage of a more socially aware concept such as "dis/ability". We will use D/A for "dis/ability" and ID/A for "intellectual dis/ability"

often than not, seen as infants and non-sexual beings, or, in complete contrast, as wild and unbridled sexual deviants who cannot control themselves (Kulick, 2015; Powell et al, 2019). This disturbing dichotomy demonstrates the repressing labels that often guide the actions of caretakers and assistants, creating a controlled and oppressive environment for the person with ID/A, should they require care. This dichotomy also falls into one of the three categories defined by Sinclair et al. (2015), which presents pervasive societal misconceptions, a systemic lack of sexuality education and limited access to resources that support sexual autonomy as the main systems of oppression of people with ID/A, which perfectly aligns with the findings of this research.

Crip Theory, a queer and feminist inspired approach to dis/ability

The DSM-5 defines intellectual dis/abilities as neurodevelopmental disorders that begin in childhood and are characterized by intellectual difficulties as well as difficulties in conceptual, social, and practical areas of living, such as deficits in "reasoning, problem solving, planning, abstract thinking, judgment, academic learning, and learning from experience" and deficits in adapting to developmental and sociocultural standards, limiting the individual's independence and ability to meet social responsibility (VandenBos, 2015, p. 33).

This definition, albeit far more comprehensive and socially aware than previous ones, still carries a sense of "otherness" that has long plagued any group of people that vary from the binary structures of society, be it ability/disability, masculinity/femininity or heterosexuality/homosexuality. Within these dyads, we can always find uneven power dynamics, an oppressor and an oppressed, upon which our societies have been built and by which we are always influenced. It is in this context that emerges Crip Theory, deeply embedded in queer and feminist studies (McRuer, 2008), permeated by notions of anti-capitalism and austerity and the heavy critique of the restrictive able-bodied architecture of society and life (Wendell, 1997, as cited in Karlsson & Rydström, 2023). Just as feminist and queer analysis reflect the struggle against normalcy and societal standards, aiming to defy historical pathologisation, Crip Theory puts into question the perceived "normal" and the "compulsory able-bodiedness" (Sandahl, 2003) and creates a context for social analysis that encompasses the invisible privilege of the able-bodied, decentring the issue from the dis/abled persons to the social structures that oppress them.

Similarly, Don Kulick and Jens Rydström (2015) highlight the relationships between some people with ID/A and their helpers, the intricacies and concepts of personhood that defy the Western, capitalistic conceptualisations, and the importance of networks and support

systems when living within an ableist society. This living experience, so often ignored and hidden, is fundamental when developing and producing any kind of knowledge regarding this topic, hence the importance of a "Cripistemology" (coined by Johnson and McRuer, 2014) when researching the perceptions of caregivers and their consequent attitudes.

Sexuality and dis/ability as a diverse spectrum

The American Phycological Association (Lolk, 2013, p.974) defines sexuality as the "capacity to derive pleasure from various forms of sexual activity and behaviour, particularly from sexual intercourse" and "all aspects of sexual behaviour, including gender identity, orientation, attitudes, and activity", while the World Health Organization (WHO) includes further aspects such as the concept as "eroticism, pleasure, intimacy, thoughts, fantasies, desires, beliefs, attitudes, values, behaviours, practices, roles and relationships" and acknowledges the influence of "biological, psychological, social, economic, political, cultural, legal, historical, religious and spiritual factors" (World Health Organization, 2006, p. 5). However, these definitions seem incomplete when talking about sexuality and dis/ability, and the interconnections between the two. As such, it's in the learnings and conceptualisations of Crip and Queer-Feminist theory that we must base our definitions of sexuality and what it entails, to portray these fundamental concepts within a socially and politically aware sphere, not only academically. The development of these concepts must incorporate and be aware of gender, race, ethnicity, dis/ability, sexual orientation, age and privilege, so that academic endeavours are not only valuable for knowledge's sake, but for the people and communities that most require support, whether it be at a political or social level. To develop these concepts we must defy the social model and what is called the medical model of dis/ability, that constraints expressions of sexuality of dis/abled people and holds them to societal standards of heterosexuality, ableism and standardized beauty, which often results in an internalised effort of dis/abled to appear "normal" by limiting themselves to heterosexuality, non-monogamy and other normative expressions (Dupras, 2015; Pereira et al., 2018; Rembis, 2009). As such, a more wholesome notion of sexuality and dis/ability itself surfaces when we cease to think in a binary system and instead start to adapt to a perspective that sees all bodies as interdependent and limited, and sexuality as a diverse spectrum, where difference is the norm and sexual expressions are valued equally (Rembis, 2009).

These conceptualisations of sexuality are key in understanding what the perceptions of able-bodied people are – and what they should be, in a world without bias. And what external

perceptions are more important in the lives of dependent dis/abled people, as those of their families and caregivers, who oversee and regulate every aspect of their lives.

The Caregiver: power, perception, and interference

The attitudes and practices of institutional caregivers are not formed in a vacuum; they are the product of a complex interplay of theoretical forces and interconnected concepts. As Whittle and Butler (2018) indicate, caregivers often operate within a framework littered with paradoxes, viewing the sexuality of people with ID/A as either an "asexual" non-issue to be ignored or a "hypersexual" risk that needs to be controlled and stifled. A third, less common, "rights-based" view affirms their sexual citizenship and belonging. These caregiver beliefs form a "hierarchy of influence" that profoundly shapes the identity, relationships and experiences of people with ID/A. When the asexual and hypersexual scripts take the forefront, the outcomes are poor education, internalised shame and increased vulnerability, placing the caregiver's perception at the very centre of the individual's sexual well-being, which leads to inconsistent and, very often, controlling practices (Guenoun et al., 2022).

As such, the caregiver-supported person (SP) relationship is, inherently, defined by a power imbalance. McRuer's (2008) insight that "tolerance of the deviant" is conditional upon their continued subordination is of vital understanding here. Caregivers, as agents of the "normate", often grant limited, supervised forms of sexual expression that don't fundamentally challenge the power structure they inhabit (McRuer, 2015). This dynamic can be further developed through Iris Young's (1997) concept of "asymmetrical reciprocity". In an ideal ethical relationship, recognition is mutual; however, in the caregiving context, the caregiver's perception and interpretation of the individual's needs often holds disproportionate weight, potentially overriding the individual's own expression of consent or desire. This asymmetry is where well-intentioned support can easily turn into paternalistic control. Young argues that ethical social interactions require recognising the other as a perspective-bearing subject, while realising this recognition is never symmetrical. In the context of care for people with ID/A, this asymmetry is acute. The caregiver, as the "normate" agent, holds significantly more power to define reality, interpret needs, and set boundaries. The individual with ID/A, particularly one with complex needs or communication differences, may struggle to have their perspective, desires, and experience fully recognised and weighted equally. A study by Agaronnik et al. (2019), for example, found that physicians' communication with patients with dis/abilities is often unstandardized and indirect, frequently bypassing the person to speak with caregivers, which undermines patient autonomy and reinforces perceptions of non-wholeness.

By employing Crip Theory to the deconstruction of ableist norms, a queer-informed concept of sexuality to move beyond risk, and the concepts of asymmetrical reciprocity and interference to analyse the caregiver's role, this framework positions the caregiver not merely as a service provider, but as a pivotal agent. Their perceptions and attitudes become the site where societal norms about gender, ability and sexuality are either enforced, negotiated, or subverted, ultimately determining the possibilities for the sexual citizenship of people with intellectual dis/abilities.

Objectives and Research Questions

In Portugal, sexuality is generally not a well-reported aspect of society, especially when it comes to the sexuality of people with ID/A. In contrast to Denmark, for example (Kulick & Rydström, 2015), a great number of institutions do not see the sexual rights of dis/abled people as a priority, nor do they want to bring such a topic to the attention of the public. This has created a grave lack of resources that is deeply felt by many and has impacted the way people have access to their own bodies and rights (Pereira et al., 2018). It is amidst these institutions that the perceptions and attitudes of caregivers have the most importance, as they assist people with ID/A daily, and greatly determine their access to resources, contacts and experiences regarding their sexualities.

As such, this study intends to explore the perceptions and attitudes of caregivers, to understand the implications of these aspects on the sexual lives and rights of people with intellectual dis/abilities, identify gaps in knowledge and areas for improvement in caregiver training, and ascertain how to address these gaps socially, scientifically and politically.

We will focus our efforts on the following research questions:

a) What are the prevailing perceptions among caregivers regarding the sexuality of people with intellectual dis/abilities?
b) What are the main practices and attitudes of caregivers?
c) What are the caregivers' levels of comfort/encouragement vs the levels of discomfort/punishment towards the expression of sexuality of people with intellectual dis/abilities?
d) What are the prevailing needs and support mechanisms of caregivers regarding the sexuality of the people they care for?

Method

Research Design

This study focuses on the perceptions of caregivers on the sexuality of the people they care for, their perceptions on the families' beliefs, the practices and actions taken and the institutional levels of encouragement/punishment towards this aspect of life. As such, we employed an exploratory qualitative research design to approach this subject. The use of a qualitative approach was deemed most appropriate to gain in-depth insights into the perspectives and experiences of the participants. We selected an exploratory design due to the limited existing research in the literature. This approach facilitates a more detailed and rich understanding of the participants' standpoints and allows the identification of emergent themes and patterns. Since triangulation wasn't employed in this study, we used the COREQ checklist to guarantee comprehensive reporting of interview data (Tong et al., 2007).

Participants

The sample is composed of twenty-one institutional, paid caregivers (technicians, including psychologists, social workers, physiotherapists, and occupational monitors, without a specialised education). Initial contact was made with 15 institutions from the centre and north of Portugal, residential and non-residential, for people with intellectual dis/abilities, aged eighteen and plus. Contact was made through email, with an invitation and a brief summary of the proposed study, and calls. Out of these, only three institutions responded positively. Two others responded negatively, and the remaining ten did not respond. The interested institutions, all non-residential and from the same mother association, gathered the available and interested professionals, who varied in terms of age, gender, years of experience and functions in the institution. Participants were aged 25 to 60, with different experiences (4 months to 40 years) and had different qualifications (11 with master's degree or doctorate, the others with minimal required education). The participants' roles varied from specialised counselling and guidance, like psychological support, to daily activity monitoring, like craft sessions. The type of dis/abilities within the institutions also varied (Down syndrome, cerebral palsy, autism spectrum disorder, Turner syndrome, among others).

Data Collection

Data were collected through semi-structured live interviews. An interview guide was developed to ensure key topics were consistently covered across all interviews while allowing flexibility to explore novel or unexpected avenues raised by participants, which in turn makes

for a more comprehensive and insightful understanding of participants' experiences. The guide included open-ended questions on topics such as perceptions of family beliefs, perceptions on sexual rights of people with ID/A, institutional guidelines, among others.

All interviews were conducted individually by the first author and took place in the institutions, between June 5th and June 30th, 2025. The interviews lasted between 15 and 50 minutes, with the majority nearing 30 minutes. With permission, all interviews were audio-recorded and subsequently transcribed verbatim by the researcher to ensure familiarity with the data.

Data Analysis

The transcribed interviews were analysed using thematic analysis, following the six-phase framework proposed by Braun and Clarke (2006): a) familiarizing with the data - the researcher read the transcripts while listening to the audio recordings to ensure accuracy and immerse themselves in the data, and initial ideas were noted; b) generating initial codes - systematic coding was conducted across the entire dataset, and significant phrases, sentences, or paragraphs relevant to the research question were identified and labelled with descriptive codes; c) identifying themes - the initial codes were collated and grouped into potential themes, gathering all data relevant to each potential theme; d) reviewing themes - candidate themes were checked against the coded extracts and the entire dataset to ensure they formed a coherent pattern and were refined, split, or combined as necessary; e) defining and naming themes - the essence of each theme was clearly defined and articulated, and descriptive names were generated for each theme; f) producing the report - the analysis was woven into a narrative account, selecting extract examples to illustrate each theme. A coding software, MAXQDA Analytics, was used to code and organise the coding system, though the pattern-based analysis was done without recourse to any software.

Ethical Considerations

This study was approved by the Ethics Commission (Comissão de Ética da Faculdade de Psicologia e de Ciências da Educação da Universidade do Porto, ref.ª 2025-04-06). All participants received a detailed information sheet and provided written informed consent before their interview, as well as permission to be audio recorded. Participants were informed of their right to withdraw at any time without penalty. To ensure confidentiality, no identifying information was included in the transcripts, and participants were assigned pseudonyms. Audio recordings and transcripts were stored on a password-protected secure server, to be destroyed after completion of the study. No conflicts of interest were detected.

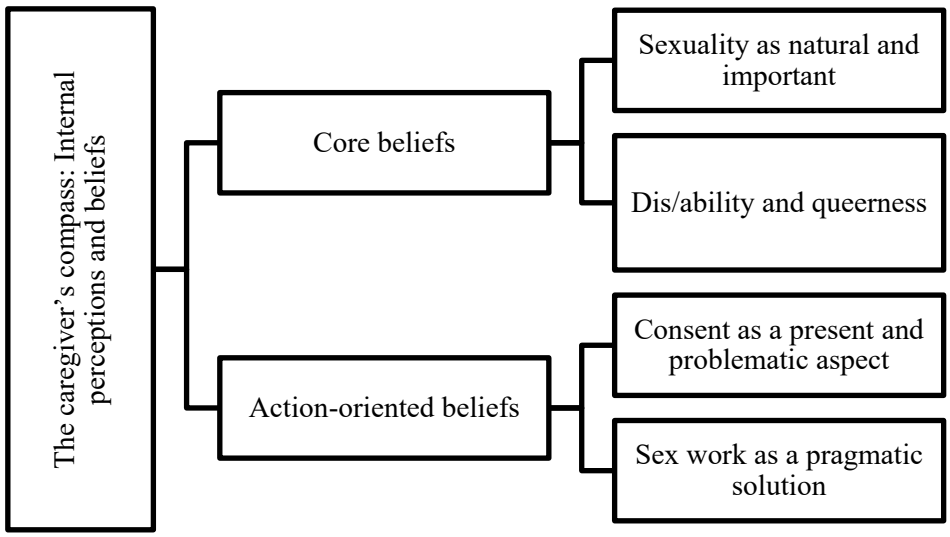
Results and discussion

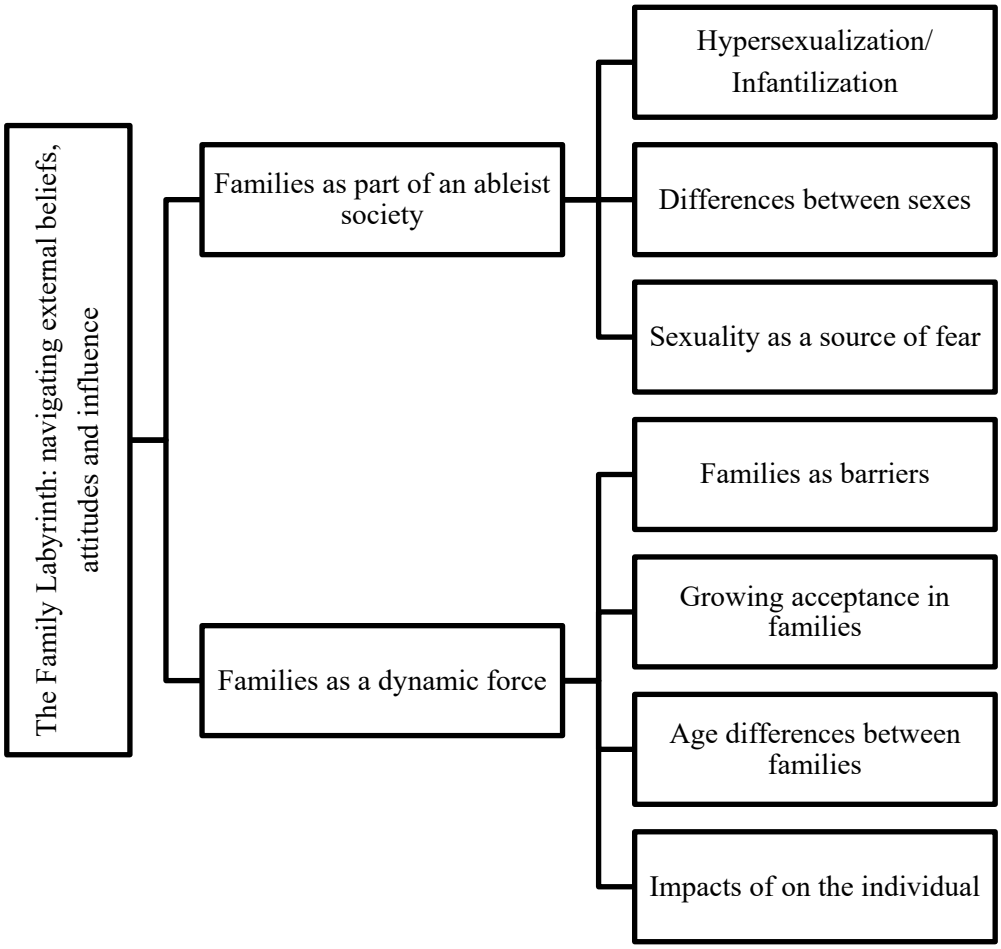
The two major key points derived from this study are the growing concern and support of institutional caregivers on the sexuality of the people they care for, and, on the other hand, a perception of a not-so-growing acceptance of families regarding the sexuality and sexual lives of their children, something that must be further researched.

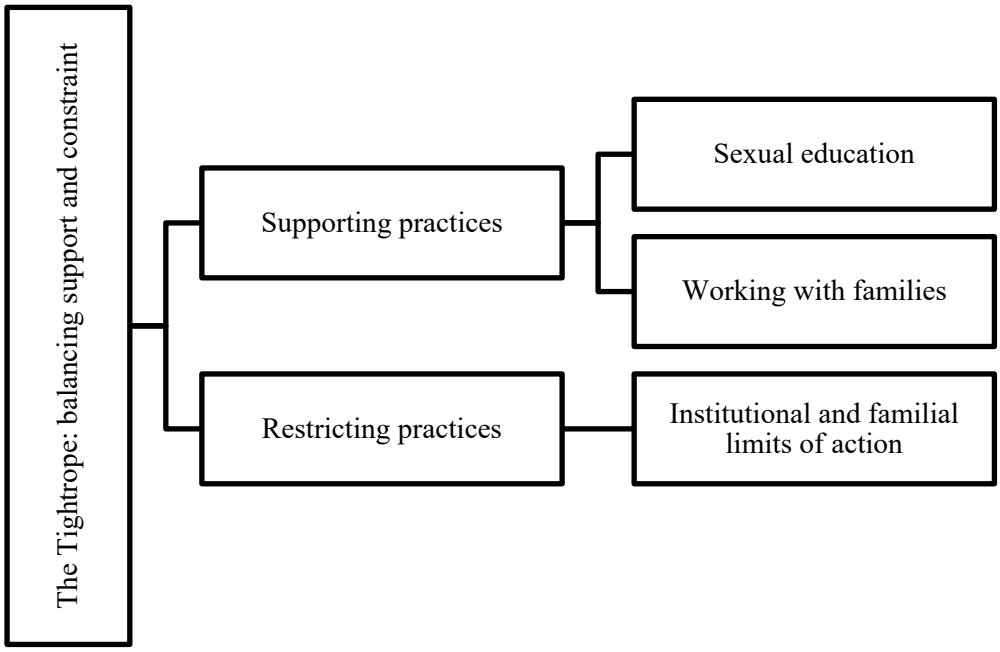
These aspects intertwine and relate to each other in complex manners, which will be discussed through four themes:

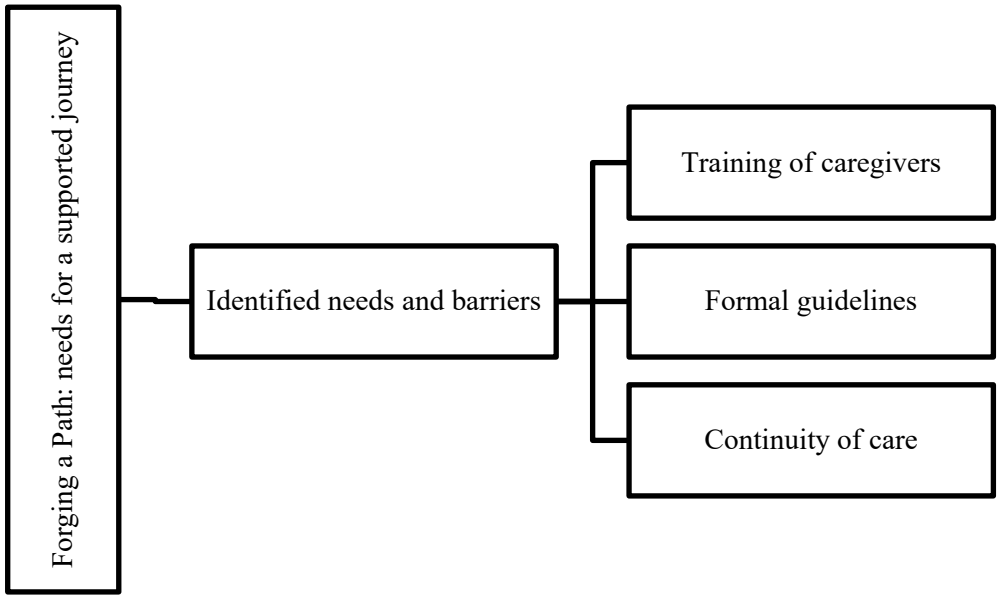
- The caregiver's compass: internal perceptions and beliefs
- The family labyrinth: navigating external beliefs, attitudes and influence
- The tightrope: balancing support and constraint
- Forging a path: needs for a supported journey

Figure 1 Coding Tree




The Family Labyrinth: navigating external beliefs, attitudes and influence
Families as part of an ableist society
Hypersexualization/ Infantilization
Differences between sexes
Sexuality as a source of fear
Families as a dynamic force
Families as barriers
Growing acceptance in families
Age differences between families
Impacts of on the individual


The Tightrope: balancing support and constraint
Supporting practices
Sexual education
Working with families
Restricting practices
Institutional and familial limits of action


Forging a Path: needs for a supported journey
Identified needs and barriers
Training of caregivers
Formal guidelines
Continuity of care

1. The caregiver's compass: perceptions and beliefs

1.1. Core beliefs

1.1.1. Sexuality as natural and important. The most dominant pattern identified is the framing of sexuality not as a problem, but as a natural, central and important component of human experience, which must be supported, accepted and de-stigmatised in this population.

> *"(...) sexuality is such an important factor in our identity that if we don't understand ourselves, if we don't accept it, if we're not at least somewhat comfortable with this situation, or informed, it affects everything else"* (P2)
>
> *"Yes, there is a lot of talk here about sexuality and the way I have always seen people with disabilities as people, human beings, individuals with rights and responsibilities, so I treat them as equals. The fact that they have a disability... I have never treated them with pity, as poor things, so I have also treated the issue of sexuality in the same way."* (P8)

Caregivers reported seeing sexuality as a vital factor in well-being, as well as a human right, in deep contrast with what they perceived to be the families' beliefs, emphasizing sexual rights, citizenship and empathy. Most caregivers believed the people they cared for to be capable of experiencing a sexual live and relationship, similar to other findings (Heyman, 1995), but in direct contrast to many other studies, such as Guenoun's et al. (2022), whose key findings demonstrates paradoxical and negative representations of sexuality, where caregivers often view the sexuality of people with ID/A through a lens of risk and vulnerability, and perceive their roles more as reactive, when incidents occur, rather than proactive (through, for example, sexual education).

From the fundamental belief that sexuality is inherent to everyone, including people with ID/A, comes the notion of privacy and the right to intimate moments away from the public sphere, where people can experience sexuality safely. This concept, the right to privacy was also reported by most participants.

"(...) in [institution], I believe there is that freedom for the supported people to explore their sexuality, even because a necessary time is reserved to do what they must in those moments when they have that need. There's that preparation and that strong concern in the institution. Every one of them has that reserved time" (P12)

"(...) it normally happens when they lay her down to rest, you put a cover, a blanket, so she can do her thing in privacy" (P3)

The reports given by participants showed a concern to provide private moments to the best of their ability, given that non-residential institutions do not have private rooms. This shows a concept of privacy, but not prohibition, or secrecy, which is often confused in an institutional context (Kulick, 2015). Privacy is a key aspect in any person's sexual life, and most people with dis/abilities are not able to experience sex and intimacy in safe, comfortable places, which results in increased risk and rushed experiences (Maia, 2016). Most participants reported knowing that most SP did not have the possibility of masturbating at home, much less have sex, which further emphasises the importance of having private moments for themselves in the institutions (even though sex with another person is barred in the institutional context, as we will later discuss).

Several participants revealed personal growth, reporting that, in the beginning, they might have felt uncomfortable or unsure regarding the aspect of sexuality, but with experience came naturalness and normalisation.

"Because in the past, I've been here for 20 years, in the past I thought that even in schedules, in breaks, it shouldn't happen [masturbation]. *And only time really showed me* [that it's an important part of someone's life and rights]*."* (P13)

"Before, it was a bit more taboo, so to speak. At first, I felt that it was an area we didn't address as much, perhaps because of ignorance, right? And we weren't really aware that they also seek sexuality, explore it, but with the work itself and with everyday experience, we realise that there are clients who masturbate, who have needs, that is, nowadays, perhaps, we have a slightly different view of what a person with a disability or impairment is." (P21)

"I have been learning a lot. And sometimes from their naturalness, right? In talking about certain things, because some of them find it very easy to address certain topics, and we ourselves are sometimes the barrier." (P21)

1.1.2. Dis/ability and queerness. Within normalisation and naturalness also came mentions of queer rights and various participants reporting that queer relationships were seen as normal, and were perceived as any heterosexual relationship, having one participant also mentioning transness and gender non-conformity.

"Heteronormativity doesn't seem to exist here, thank God. Fortunately, because we are all different, and people have the right to be whatever they want, to be however they want, and to do whatever they want, as long as they respect each other. (...) We have cases here of boys who like to be girls, girls who like to be boys, who express this idea. And no one has ever told them, 'don't do that, don't be like that'. I've never seen that (...) It's because there is a practice that has been repeated and is now ingrained; people are imbued with this spirit." (P12)

"And we have also had a couple of two boys. Also at ease, without having to hide." (P6)

Apart from support and acceptance for queer existences, some participants identified the struggles of dis/abled people as paramount to the struggles of queer people.

"(...) making a bit of a term of comparison (...) everything that flees from normativity... from what is most common, from what is most acceptable, becomes…[implying discrimination]*"*. (P2)

In this connection, we find Crip and Queer Theory in practice, where lived experiences by caregivers bring them to the realisation of parallels between ableism and homophobia/transphobia, and how these concepts interact on the "*everything that flees from normativity*"(P2) lens. Hirschmann (2013) discusses that while racism and sexism are often fears of a "different" other, ableism and homophobia are fears of "what one can become". An able-bodied person can become dis/abled in an instant, and, similarly, one can suddenly realise they have an attraction or desire that contradicts the heteronormative ideals. This is also

identified by people with ID/A, as can be seen in this report of an interaction between a participant and a S.P:

"I even talked about what they thought about a person liking someone of the same sex. A young man with trisomy 21 said openly and in these words that it was a very big discrimination and that it is the same thing that happens with the disease. He talks about his disease, which is trisomy, which is not a disease, but he sees it as a disease. They don't give him the same rights as a so-called normal person." (P6)

1.2. Action-oriented beliefs

1.2.1. Consent as a present and problematic aspect. The concept of consent is also a recurring and complex theme, with participants reporting it as a source of uncertainty, and recognising a need for education on consent from an early age, as they may struggle to distinguish boundaries or understand when their privacy is being invaded.

"We didn't know if that was sexual abuse or if it was consensual" (P1)

The challenge lies in ensuring genuine consent, especially when individuals may not fully comprehend what they are verbalising, or when family wishes override an individual's autonomy, as seen in cases of medical procedures like implant placement. This lack of clear understanding and formal guidelines can lead to ambiguous situations, such as discerning between consensual sexual activity and abuse, highlighting the critical need for comprehensive information and formal protocols to protect both the individuals and those caring for them (Beato et al., 2024).

"All of this I think also comes from a place of lack of information" (P19)

"This question should be approached right from the start of the process, of course, because it isn't." (P4)

This creates an impossible situation for caregivers. Without the tools to assess capacity for consent, they risk either failing to protect individuals from harm or pathologising and punishing natural, consensual exploration. Individuals are left without the fundamental

vocabulary or concepts to understand their own boundaries or respect those of others. They cannot consent meaningfully if they do not understand what consent is.

> *"I often question how we can be sure that consent exists with this population... how we can understand if it really exists, if what is verbalised is verbalised with awareness."* (P19)

This is not a matter of neglect but of a systemic gap. There are little to no standardised, validated and widely known methods for assessing sexual consent capacity in individuals with diverse intellectual dis/abilities, placing an immense ethical burden on caregivers without providing them with the necessary support or framework. The solution, as glimpsed in the excerpts, is not to retreat into greater restrictions, but to move towards a model built on comprehensive sexuality education (including consent), the development of formal supported decision-making frameworks, and a cultural shift that respects bodily autonomy as a non-negotiable right for all, regardless of cognitive ability. Without this, the line between care and coercion will remain dangerously blurred.

1.2.2. Sex work as a pragmatic solution. Another topic that was recurrently talked about by participants was the recourse to sex work. A clear pattern among caregivers and some families is the framing of sex work as a legitimate and rational option under certain circumstances, and not discussed as a vice or exploitation, but as a practical service.

> *"Something that also happens in so-called normal people, right? Those who never had the opportunity to have a relationship can do it this way, so it's the same, it ends up being the same."* (P3)

The primary discursive strategy emerging from the data is the normalisation of sex work by directly equating it with the experiences of the non-disabled population. This serves to de-stigmatise the practice and frame it as a universal service rather than a deviant act. By invoking the "so-called normal", the caregiver simultaneously challenges normative standards and positions the SP's needs on a universal continuum, which also asserts autonomy. This framing is further refined into a logic of "necessity". Another caregiver specifies the conditions for this necessity*: "in some cases, with a more profound intellectual disability… they'll never develop a romantic relationship…In that case, it makes perfect sense"* (P1). Here, sex work is

constructed not as a preferred choice, but as the only viable alternative to a complete absence of sexual experience for individuals with more significant dis/abilities. However, this justification exists in tension with the literature. Gammino's et al. (2016) study found that while people with dis/abilities saw sexual assistance as a rightful service, none would personally use it if they had the choice, strongly preferring a loving relationship. Furthermore, services often sought out by people with ID/A go beyond intercourse, and often focus on touch, conversation and affection, in other words, an emotional connection, not just a physical one**.** This suggests that the caregivers' pragmatic "solution", while addressing a physiological need, may inadvertently sideline the deeper human desire for emotional intimacy and partnership that their clients may also hold.

This sub-theme, recourse to sex work, was highly interlinked with what caregivers perceived to be the families' beliefs and fears, and how said beliefs shape the dynamics between working with families and being faithful to their own ideals of sexual rights.

2. The family labyrinth: navigating external beliefs, attitudes and influence

2.1 Families as part of an ableist society

The participants' reports reveal a stark ideological chasm among families, which critically shapes the individual's path. On one end are families who actively facilitate the practice, such as the father who monthly *"went with him to a house…and payed"* (P10)*,* effectively routinising it. This aligns with the "right to self-determination" script (Benoit, 2023), treating sexual expression as a legitimate aspect of adult life requiring support.

"But now, that's rare. But they're very interesting those families. But it's rare." (P3)

In direct opposition are families whose reactions of rejection, described as *"very poorly received"* (P8), embody the competing script that frames the sexuality of people with ID/A as a vulnerability, and something that needs to be managed or controlled (Benoit, 2023). The caregiver's lament that these parents *"don't understand…that their child also has their needs"* (P8) highlights a fundamental conflict between a rights-based and a protectionist paradigm. The consequence of this rejection - the individual going *"in rebellion against the family"* (P8) – which demonstrates how protectionist policies can paradoxically create greater risk by pushing behaviour into covert and potentially less safe contexts. Caregivers also demonstrated the ethically and legally fraught role they must adopt in these cases, being an unofficial

mediator that crosses between the individual, the workplace, and the family, operating in a professional vacuum.

> *"I called the parents, met with the father and mother, explained the situation, and it was very poorly received. (...) They did not understand (...)they did not give their authorisation, and that's what I conveyed to the entity, to the boss, that most of the family did not authorise it, and the result was that he ended up going, in rebellion against the family. One day, when I went to do that follow-up, the boss told me, look, it's done, it happened* [going to a sex worker*], that's it."* (P8)

This contrasts sharply with the trained "sexual assistants" in other European countries noted by Pinho et al. (2020), pointing to a systemic lack of structured support. The ultimate failure of this mediation - ending in the individual's covert actions - demonstrates the limits of the caregiver's authority and the high-stakes risks they are forced to navigate without formal guidance or protection.

In this context, the data gathered tells us that the recourse to sex work is a complex, pragmatic response to a systemic failure. Caregivers rationalise it through a rights-based discourse of normalisation and functional benefit, positioning themselves as advocates for their clients' autonomy. However, this pragmatism exists in a contested space, clashing with protectionist family values, relying on a service sector that may be unprepared (Hilberink et al., 2022; Pinho et al., 2020), and potentially overlooking the clients' deeper relational aspirations (Gammino et al., 2016). Ultimately, the caregivers' narratives highlight the urgent need for more formal, ethical, and holistic models to support the sexual citizenship of people with ID/A, moving beyond solutions that place an immense burden on both caregivers and SP alike. The institutional lack of protocol and oversight regarding the recourse to sex work creates a sphere of ambiguity, forcing caregivers, families and individuals with ID/A to navigate and negotiate intimacy without guidance and knowledge (Bahner, 2015).

Most families' refusal to even consider sex work as an option stems, as previously discussed, from either fear, a downgrading of the importance and need of sexuality, or a mixture of both. The caregiver's perception of said beliefs connects to what they also perceive to be the societal beliefs in general, creating a clear notion of families as part of an ableist society, which are not detached from biases.

The caregivers' perceptions of societal beliefs show a self-reinforcing cycle where sexuality is deprioritised, reduced to a matter of risk management, and stifled by prejudice. In

general society, a clear pattern emerges where sexuality is consistently positioned as the lowest priority. *"Sexuality is really the last point and ends up never being a priority"* (P1). This is not an isolated sentiment but a reflection of a hierarchy of needs. This systematic deferral is further rationalised through a sequential mindset, as another caregiver explained: *"the question of pleasure always stays in the background... if we advance to sexuality, then we will still have time to advance to the point of pleasure"* (P1).

This deprioritization directly creates the knowledge and skill gaps identified in the systematic review by Matin et al. (2021), which found sexuality is the "last point", and that the comprehensive, tailored education recommended by the literature in this area never materialises. Instead, the focus remains on what the institutions or caregivers deem urgent, leaving individuals without the knowledge to understand their own anatomy, relationships, or rights, thereby fulfilling the prophecy of "inadequate education".

The one area where pleasure is actually acknowledged is in the context of masturbation, precisely because it is seen as *"merely satisfaction"* (P15) and carries fewer perceived social risks. This reveals that the system is not opposed to pleasure *per se*, but to pleasure that involves partnership and social entanglement, which challenges the controlled, social order. This societal stigma infiltrates the professional realm, creating a barrier even among those tasked with providing support. Even if caregivers attempt to provide support and advocate for a more pleasure-based approach, they face the "slippery slope" argument often given by families. One participant reported being heavily criticized for suggesting sex work, saying the family responded *"(...) he's going to try being with a woman and then he'll always want to go, every week he'll want to have a woman, it can't be (...) this is not for him, this is not for him, he doesn't need these things"* (P8).

This reaction encapsulates the view that any sexual expression is a deviant, uncontrollable urge, and that parents often think sex education and sex awareness will lead to the formation of bad habits (Menon & Sivakami, 2019).

Breaking the cycle of societal disregard for the sexual rights of people with ID/A requires more than just internal policy changes. It demands a concerted effort to "cripple" or "queer" the naturalised norm of the normal (Aydos et al., 2023; Moser, 2006), challenging the ableist and heteronormative assumptions that render dis/abled sexuality invisible or problematic.

2.1.1. Hypersexualisation/ Infantilization. The most dominant pattern emerging from the data is the persistence of the "eternal child" archetype. Caregivers consistently report that

families and society refuse to acknowledge the adulthood of people with ID/A. A participant's observation that *"They see their children, or continue to see them, for the most part, as toddlers and, as such, they often barr them from these types of things"* (P7) illustrates how this perception directly enables the suppression of sexuality.

This infantilization is not a passive attitude but an active cognitive framework. As one caregiver starkly noted, *"(...) for them he is the little boy, for them they are always children, therefore, they think that those things, they don't have those needs"* (P7). This aligns perfectly with the dualistic stereotype identified by Whittle and Butler (2018), where the "asexual script" is dominant. This infantilization was also a key finding in the study by Menon and Sivakami (2019), where parents struggled to reconcile their child's physical puberty with their perception of them as perpetual children. This script, which Drexler (2018) terms the "seraphic idiot" myth, entails that people with ID/A are innocent, childlike, and devoid of sexual desire. The linguistic manifestation of this is captured in the phrase *"poor little boy, poor little girl"* (P18), a sentiment of pity that inherently denies adult status and sexual agency.

This represents a profound form of epistemic violence, where the individual's lived experience is invalidated and recast as a medical problem. Caregivers reported actively pushing back against this by holding up a "normative mirror", arguing that a *"22-year-old girl, without any disability, also feels this"* (P3). One participant's insight – *"Sometimes we only look at the person starting from the disability, not starting from the person"* (P3) - gets to the heart of the issue. The person is obscured by the diagnosis, a phenomenon critiqued in crip theory, which challenges the very foundations of the "normate" and "compulsory able-bodiedness" that render such deviations visible and problematic (Karlsson & Rydström, 2023).

When the "eternal child" does express desire, the system does not update its framework; instead, it pathologises the desire itself. A critical finding is the "medicalisation of natural feelings", where sexuality is reinterpreted as a clinical symptom. Caregivers reported that families and doctors often frame it as a neurological issue: *"(...) they interpret this as there being a decompensation in this area"* (P3). The impulse is to "treat" it medically: *"have to treat this with the neurologist, as if we could atrophy it..."* (P3).

> *"(...) there are two... perceptions... one is that the person with a disability has no sexuality... And the other perception... is that all people with disabilities are maladjusted in their sexual interaction."* (P19)

This is the impossible choice: to be erased or to be pathologised. An individual who shows no interest confirms the "asexual" script. However, if they do express sexuality, they risk being labelled as "maladjusted" or, as another participant noted, as *"slyer"* (P18) and promiscuous for having multiple partners. This confirms the flip side of the myth identified by Drexler (2018) - the "mephistopholic idiot" - the view of the disabled person as sexually deviant and uncontrollable. There is no socially sanctioned space for a normal, healthy, agentic sexuality. Furthermore, this dichotomy is often extremely gendered, with men being seen as oversexed and "maladjusted" and women as the "seraphic idiots", who are only vulnerable and asexual (Löfgren-Mårtenson, 2013)

2.1.2. Sexuality as a source of fear. Beneath the infantilization and pathologisation lies a powerful engine: fear. Caregivers identify that familial restriction is not born of malice but of a heightened, often trauma-informed, protective instinct. One caregiver astutely noted that families have *"the same fears I have regarding my daughters, with these people, are exacerbated"* (P3).

This fear leads to a pre-emptive strike mentality and a denial of agency, rooted in the perception that individuals are incapable of consent or self-defence. However, the quantitative findings from Díaz-Faes and colleagues (2023) provide a critical, paradoxical insight that reframes this dynamic. Their latent class analysis reveals that the "High Victimisation" cluster—characterised by severe sexual and physical abuse—was disproportionately composed of women (70.4%) and individuals living in group homes or under institutional guardianship. This evidence creates a profound tension with the familial narrative. While families fear the outside world and may seek to protect their children through restriction, the data suggest that institutional settings and the lack of familial oversight may themselves be significant risk factors. The fear of autonomy and social exposure, which leads families to choose segregated settings, may be misplaced; the greater risk might lie within the very systems designed for protection. This is further complicated by the finding that the "Low Victimisation" class required the most extensive daily support, suggesting that closer supervision may be protective, but that this supervision must be balanced against the individual's right to autonomy and must be provided in a safe environment.

2.1.3. Differences between sexes. The data reveal that this fear and control are not applied uniformly; they are intensely gendered. As one participant stated, "there is an overprotection mainly of the women" (P2). This aligns with the studies by Menon and Sivakami

(2019) and the Brazilian parental attitudes research, which show that concerns for daughters are overwhelmingly about safety from sexual abuse and exploitation. The Díaz-Faes (2023) study provides stark, empirical weight to this fear, confirming that women with ID/A are at a significantly higher risk of severe sexual victimisation.

This creates a devastating feedback loop. The very real, evidence-based risk of victimisation for women with ID/A justifies, in the minds of families, an extreme protective response. This response, however, often takes the form of restriction and denial of autonomy (e.g., being more accepting of sex education about masturbation for boys than for girls, as found in the Brazilian study), which in turn denies them the knowledge and skills (e.g., sexual education, assertiveness training) that are essential for self-protection. Thus, the response to the risk of victimisation may inadvertently perpetuate the conditions of vulnerability.

Breaking this cycle requires a radical re-evaluation. It is not enough to challenge the myths of the "seraphic" and "mephistophelic idiot". We must also confront the uncomfortable evidence that our current systems of "protection" may be failing. The path forward must involve replacing the framework of restrictive control with one of empowered safety, providing comprehensive, rights-based sex education, fostering supported autonomy, and critically reforming care environments to ensure they are spaces of safety and growth, not of heightened risk.

2.2. Families as a dynamic force

2.2.1. Families as barriers. According to caregivers, for most individuals with ID/A, families function as a carceral space for their sexuality, where there is an active and complex architecture of restriction.

> *(…) very often, the families also incarcerate them (…), inside either the family, or socially, they incarcerate them in the ghetto of the family, and few families take them on a stroll, or to the cinema, or shopping…"*(P12)

Another participant recalled that one of the SP *"couldn´t even pick up a phone. Cause if… the family often caught her consulting pornographic sites"* (P13).

Other participants reported more violent approaches - «*her mother hit her, everytime she was masturbating, her mother, her mother beat her, beat her, "be still, stop"»* (P8) - and, to an even bigger extreme, *"we had a family here that was four brothers and all of them used full body*

vests at night to sleep (…) so that they couldn't have any type of access. We here, those brothers, we were providing those moments" (P7).

Other participants also reported medical and aesthetic control, such as families having sought "medication to lose libido" and attempts to *"desexualize"* (P12) them though *"more masculinized clothing"* (P12) and haircuts, and several participants mentioned that SP are *"never alone"* (P15) and that parents are *"watching her at all times"* (P15).

This pattern of control is a direct manifestation of what has been previously discussed and what Heyman (1995) identified as the "sexuality-as-a-hazard" paradigm, in which informal caregivers primarily view sexuality through a lens of danger—fearing exploitation, pregnancy, and emotional harm—leading to pre-emptive restriction. The family's authority is often absolute, or *"sovereign"* (P3), overriding the individual's will.

2.2.2. Impacts on the individual. The most insidious consequence of familial control reported by caregivers is its internalization by the individual, where people with ID/A embody prohibition and feel uncomfortable expressing sexuality even in permisse environments, because, as one participant noted, *"the rule is you can't…I don't even think he's capacitated for that"* (P16), ergo, the external rule becomes an internal law. This internalized oppression is the ultimate success of the restrictive system, as analyzed by Whittle and Butler (2018), who describes how individuals with ID/A internalize the conflict between their desires and carer messages, leading to a negative sexual identity and shame - the individual learns to pathologize their own feelings, seeing them as a symptom of their dis/ability rather than a part of their humanity.

2.2.3. Age differences and growing acceptance in families. Despite the dominant pattern of restriction, a clear generational shift was reported by caregivers, a vanguard of families who are transitioning from the old paradigm to a new one. Caregivers consistently report that *"Younger families tend to accept... that their adult child has the right to have a relationship"* (P4). These families move beyond permission and towards active, pragmatic support. This ranges from the father who monthly *"went with him to a house and paid"* (P) to parents who seek professional guidance.

As one participant recalled, a mother argued, *"he is normal, he needs it... it's normal"* (P10). This directly counters the "seraphic idiot" myth of asexuality identified by Drexler (2018) and aligns with the "rights-based script" that Whittle and Butler (2018) argue is the only path to positive sexual outcomes.

3. The tightrope: balancing support and constraint

The results of this theme tell a story of how caregivers navigate the tension between supporting the sexual rights of individuals with ID/A and operating within significant institutional and familial constraints.

In their direct support, caregivers employ a consistent, pragmatic strategy focused on managing behaviour within social norms. The universal approach to masturbation is to "redirect and privatise". As one participant stated, "when it happens, we direct them to a bathroom... and that's it" (P8). The underlying philosophy is clearly communicated: "the problem is not masturbation, you just need to understand where you can do it" (P19).

The institution manages life by regulating the body's acts, channelling them into "appropriate" private spaces to maintain order. While framed as support, this is a form of subtle social control. This aligns with findings from Maia (2016), whose participants with ID/A often lacked understanding of social norms, and Heyman (1995), who noted that "inappropriate public behaviour" was a primary carer concern.

3.1. Supporting practices

3.1.1. Sexual education. Another dominant aspect reported by caregivers is the critical gap in comprehensive sexual education. The current approach is overwhelmingly deficit-based, focusing narrowly on hygiene and risk. As one caregiver critiqued, *"the focus is always much more on health… on condoms, on sanitary pads… and never again… the part of pleasure"* (P2). This neglects the emotional and relational dimensions, leaving individuals with what another caregiver called *"difficulty in managing to identify the various emotions"* (P2).

This finding is echoed in the research of Brown et al. (2020) and Schmidt et al. (2021) who identified the core principles of effective sexual education as being rights-based, co-produced with people with D/A, and rigorously evaluated, and in Beato et al.'s study with autistic individuals (2024), who similarly reported that standard sex education was insufficient and failed to cover emotions, dating, and consent in an accessible way. Participants called for a tripartite solution – education for individuals, families, and professionals, which emphasises sex-positive education to combat vulnerability and promote self-advocacy, moving beyond the fear-based paradigm that currently dominates.

3.1.2. Working with families. But sexual education, as well as many other practices, is a process that, in an institution, requires professionals to navigate authority and find ways to

slowly introduce new perspectives, beneficial to the SP. Their authority is subordinated to the family, which holds ultimate veto power, which forces caregivers into a long-term strategy they vividly label *"wooing the family"* (P7).

This "wooing" involves tactical communication. For instance, to convince a family about contraception, a caregiver reported using a "detour": *"You have to say that she doesn't [want it], but others might want to..... - remove the responsibility"* (P18). This reflects the rational approach recommended by Heyman (1995), who advises acknowledging carer fears rather than dismissing them, but, at the same time, denies autonomy to the person with ID/A.

3.2. Restricting practices – institutional and familial limits of action

The pervasive power of familial fear creates a situation where, as one caregiver lamented, "the family is sovereign. Even though we think... that person is missing opportunities" (P3). This dynamic exemplifies the "hierarchy of influence" described by Whittle and Butler (2018), where the cultural beliefs of families (often viewing sexuality as a hazard) overwhelmingly shape the experiences of the individual, often overriding the more rights-based views of professional staff. Löfgren-Mårtenson (2013) also described a "love triangle" where support staff, while often more positive than families, are frequently unprepared and untrained to navigate the sexuality of individuals with ID/A.

The system itself is an active barrier. Caregivers identify a tangible *"architecture of restriction".* This includes physical barriers, such as the lack of private space in residences – *"The double rooms are a problem"* (P1) and the fact that state-funded residences *"do not provide rooms for couples"* (P1).

This infrastructural limitation is a direct manifestation of what Moser (2006), in her science and technology studies analysis, calls the "order of the normal." The system is designed for standardised, asexual, institutional bodies; non-normative sexual expression becomes a problem that clashes with this environment. This leads to a reactive, case-by-case approach instead of a proactive plan. Support is often limited to *"lighter cases [of dis/ability]"* (P1) while those with more significant needs are passively excluded. Furthermore, the "supervision paradox" emerges, where intimacy is only permitted under constant watch, negating its very essence and systematically stripping away the possibilities for private, self-directed intimate life.

4. Forging a path: needs for a supported journey

With all the previously discussed aspects in mind, we must then analyse the critical support structures required for caregivers, which reveal a systemic failure to provide the training, formal guidelines, and continuity of care necessary to implement a rights-based approach to sexuality. This failure directly undermines the potential for effective sexual education and consistent support, connecting back to the systemic constraints previously identified.

4.1. Training of caregivers

The data from caregivers reveals a systemic training vacuum, forcing caregivers into a model of knowledge acquisition reliant on personal initiative. As one participant noted, formal education lacked the topic entirely, leading to reliance on *"self-taught work"* (P2). This finding aligns with the study of Löfgren-Mårtenson (2013). There is a vacuum in training that directly undermines the ability to provide comprehensive, sex-positive education, critically lacking as reported by Maia (2016), whose participants were left vulnerable due to inadequate information. When training does exist, it is often described as too basic, leaving experienced staff *"disappointed"* (P7). This creates a situation where, as Whittle and Butler (2018) suggest, the positive "rights-based script" held by some staff cannot be consistently operationalised without the proper tools and knowledge, perpetuating the gap between intention and practice.

4.2 Formal guidelines

A direct consequence of the training gap is the pervasive absence of formal protocols. Without guidelines, practice becomes *"a bit random"* (P7), reliant on personal judgment. This results in the stark disparities noted by some caregivers: *"I can have one reaction, and a colleague has a completely different one"* (P17), although others reported seeing homogeneity in caregivers' practices.

This protocol vacuum ensures that the institution's approach remains fragile and person-dependent. It directly contravenes the recommendations from Heyman (1995), who argued that progress depends on moving beyond individual carer attitudes to change the broader "restrictive learning environment". The lack of a formal framework means that even when a progressive culture exists, as in some institutions described by caregivers, it is vulnerable to staff turnover and cannot systematically challenge the ingrained societal taboos and "hazard" paradigms that these authors identified.

4.3 Continuity of care

The data uncover a critical rupture in the continuum of care. Some caregivers identified their role as ending at referral: *"my obligation is to refer* [to one of the specialists]*... it's no longer our area"* (P20). This creates a system where support is fragmented. This discontinuity is the operational consequence of the systemic gaps in training and protocols. It stands in stark contrast to the model of continuous, life-long sexual citizenship called for in the literature. For instance, the study on autistic individuals emphasised the need for tailored, ongoing support to navigate the complexities of relationships and sexuality, a need that is abruptly severed by this referral-based model. This fragmentation ensures that the "supported journey" is yet a myth, leaving individuals without the consistent guidance necessary to develop a healthy sexual identity, as also observed in Maia's (2016) research.

A participant also demonstrated interest in having a more continuous, holistic approach:

> *"Sometimes it would be interesting (...) if there was a project in which some of us could create a logic of continuity and follow-up. It wouldn't be for us to protect them or be tutors, it was a bit like a logic of empowering those involved in the structure in which they find themselves"* (P5)

The needs for a supported journey - training, guidelines, and continuity - are interlocking. The absence of one reinforces the failure of the others, creating an unsustainable system that perpetuates inequity. No training leads to an inability to create effective protocols; no protocols lead to inconsistent practices and forces a reliance on individual judgment and no continuity systems; no continuity results in the isolation of good individual interventions, instead of an adoption of said practices into institutionalised practice.

Conclusion

This research into the perceptions of Portuguese institutional caregivers reveals a landscape defined by profound contradictions. At the individual level, we find a significant amount of caregivers who hold progressive views on the sexuality of people with ID/A, articulating a vision of care that acknowledges sexual expression as a natural, fundamental and healthy aspect of human identity. Yet, these affirming attitudes are systematically constrained,

neutralised, and often rendered ineffective by a powerful constellation of familial, institutional, and systemic barriers.

The central finding of this study is not merely that problems exist, but that the very systems designed to support people with ID/A are, in fact, designed in ways that actively suppress their sexual citizenship. The journey towards genuine sexual rights, therefore, requires a radical re-imagining of care—one that moves from a paradigm of control and risk-management to one of supported autonomy and empowerment.

The narratives of institutional caregivers show a clear departure from the concepts of the asexual "eternal child" or the deviant "hypersexual" individual. Instead, they portray sexuality through a lens of normalcy, rights, and well-being. This is seen in their practical efforts to provide privacy within the limitations of institutional settings, their reported acceptance of queer identities, and their pragmatic, de-stigmatised view of sex work as a legitimate service for those who may not otherwise have access to intimate experiences. This alignment with a "rights-based script", as identified in the literature, is the study's most promising finding. It suggests that implementing more progressive policies is a viable possibility, as some frontline staff already possess the necessary empathy and understanding.

However, there is a divergence between caregiver perceptions and their attitudes, which are greatly limited by the overwhelming influence of families, who often operate as the ultimate judges of their adult children's sexual lives. The data gathered portrays families as largely entrenched in a "protectionist" paradigm, driven by a potent mixture of fear, societal stigma, and a persistent inability to see their children as sexual adults.

The levels of comfort and encouragement are high on an individual and informal level, but are often rendered ineffective in practice. This manifests as an architecture of control that incarcerates people with ID/A, from the confiscation of technology and the use of restrictive clothing to the medicalisation of natural desires and the outright prohibition of relationships. This dynamic creates an impossible situation for caregivers, who find their professional judgment subordinated to what they describe as the "sovereign" will of the family. Their strategy of "wooing the family" reveals a system where professional expertise must defer to parental anxiety, often resulting in outcomes where the individual's desires are overridden, and their sexual life is forced underground, potentially increasing their vulnerability rather than mitigating it.

Simultaneously, the systemic and institutional context is, itself, an active barrier. The near-total absence of formal protocols and comprehensive training creates a practice environment with no formal standardisation, which, in turn, means the quality of support an

individual receives is largely dependent on the personal attitudes and initiative of their specific caregivers, leading to inconsistent and potentially inequitable treatment. The critical gaps in sex education, which mainly ignore pleasure, emotion, and consent, leave individuals with ID/A without the vocabulary or understanding to navigate their own bodies and relationships safely and affirmingly. This systemic failure perpetuates a cycle of vulnerability, where the lack of education is used to justify the denial of autonomy, which in turn prevents the acquisition of the very knowledge needed for self-protection.

The problem is not a lack of compassion or awareness among caregivers, but a fundamental structural flaw. A multi-level, multi-functional intervention is needed to break this cycle, first, at the policy and institutional level, where there must be a concerted effort to develop and implement formal, rights-based protocols on sexuality and intimate relationships. This includes providing comprehensive, sex-positive education for individuals with ID/A that covers pleasure, consent, and relationships, and designing physical infrastructures that include private spaces. Institutions must be encouraged to shift from a reactive, risk-averse stance to a proactive one that plans for and supports intimacy. There is also a pressing need for more targeted support for families. This involves creating safe spaces for parents to process their fears and providing them with education that reframes sexuality not as a hazard, but as a dimension of their child's adult life that can be supported safely. Finally, this study highlights the urgent need for specialised and continuous training for caregivers. This training must move beyond biology to include topics like Crip and Queer Theory, the complexities of assessing consent in intellectual dis/ability, and practical strategies for mediating between the individual, the family, and the institution. It must also create formal pathways for professional support, moving beyond the current model of fragmentation and referral to one of continuous, holistic care.

In essence, this research argues that the realisation of the sexual rights of people with intellectual dis/abilities should not be a peripheral issue of social care, but a fundamental test of our commitment to equality and human rights. The caregivers' narratives provide a blueprint for a more humane approach, but their efforts are currently lost in a labyrinth of constraints. The path forward requires a deliberate "cripping" of the entire support system - a dismantling of the ableist pre-conceived notions that render dis/abled sexuality invisible. It demands that we stop asking "if" people with ID/A should have sexual lives, and start asking "how" we can build the support structures that will guarantee them a joyful, wholesome and safe relationship with all parts of sexuality. The goal is to transform the tightrope that caregivers and individuals currently walk into a supported path toward full sexual citizenship.

Limitations, Implications and Suggestions

The main limitation of this study lies with the lack of institutional variety from whence the participants came, as the three institutions included in the study were all branches of a national institution. This means that results may not have a high level of generalisation, something made clear by participants' reports of differences in practice between institutions, and the lack of positive response from other contacted organisations. Further research into various types of institutions is necessary to create a clear, more holistic view of paid caregivers, as well as further research into family scripts and intervention with families.

Furthermore, this study, having been conducted with non-residential institutional caregivers, leaves open the necessity for a deeper delving into residential sites, where the influence of caregivers is perhaps more impactful and, as previously discussed, where people with ID/A are found to be at more risk of abuse. However, to properly understand the dynamics of residential institutions, we will first need to break the subtle secrecy of some of them, something that will require more research and implementation of systems of institutional regulation and evaluation regarding sexual rights.

Socially and scientifically, this research hopes to fill some of the holes in current literature and provide a basis of information, so that more complex studies may be better supported, which, in turn, will allow for a well-sustained rights-based approach to sexual education and legislation advocacy.

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