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**Being LGBT and having functional diversity:
discourses and practices of Portuguese
professionals**

Inês Isabel Gaspar Soares

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University of Porto
Faculty of Psychology and Educational Sciences

**BEING LGBT AND HAVING FUNCTIONAL DIVERSITY: DISCOURSES AND
PRACTICES OF PORTUGUESE PROFESSIONALS**

Inês Isabel Gaspar Soares

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Dissertation submitted to the Masters in Psychology, Faculty of Psychology and Educational Sciences, University of Porto, supervised by Professor **Conceição Nogueira** (FPCEUP) and co-supervised by **Ana Rocha Pinho** (FPCEUP).

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Resumo

A sexualidade e identidade de género de pessoas com diversidade funcional (DF) é ainda um tópico pouco explorado na investigação e nas instituições que se propõem a dar apoio a esta população (Smith et al., 2022), dada a visão predominante que ignora a vida sexual desta população. Apesar do crescente investimento em conhecer este tópico, predominam atitudes cis-heteronormativas (Sommarö et al., 2020) que contribuem para a invisibilização de pessoas que pertençam também à comunidade LGBT, o que contribui para a precária resposta às necessidades específicas de pessoas LGBT com DF (de Sá, 2017).

Dada a inexistência de estudos desenvolvidos em Portugal que cruzem as existências LGBT com a DF (que se tenha conhecimento), foi desenvolvida a presente investigação, que pretende compreender as atitudes e práticas dos/das profissionais que interagem, na sua prática profissional, com pessoas com DF, quais as dificuldades sentidas e as necessidades de mudança apontadas. Para tal recorreu-se à investigação qualitativa. Foram analisadas 11 entrevistas segundo a Análise Temática Reflexiva (Braun & Clarke, 2013). Estas foram realizadas com psicólogos/as (2), terapeutas ocupacionais (3) e assistentes pessoais (6).

As descobertas principais centram-se na falta de conhecimento e a prevalência de atitudes cis-heteronormativas, apesar de alguma indicação de práticas afirmativas. Foi prevalente a necessidade de (in)formação para maior inclusividade nas entidades.

Os resultados do presente estudo poderão contribuir para a construção de instituições e práticas de provisão de serviços mais inclusivos e responsivos às necessidades próprias de pessoas LGBT com DF.

Palavras-chave: Diversidade Funcional; Deficiência; LGBT; Profissionais; Instituição

Abstract

The sexuality and gender identity of people with functional diversity (FD) is still a poorly explored topic in research and in institutions that propose to support this population (Smith et al., 2022), given the prevailing view that ignores the sexual life of this population. Despite the growing investment in learning about this topic, cis-heteronormative attitudes prevail (Sommarö et al., 2020) which contribute to the invisibilization of people who also belong to the LGBT community, and to the inadequate attention to the specific needs of LGBT people with FD (de Sá, 2017).

Given the lack of studies developed in Portugal that intersect LGBT and FD experiences, this study aimed to understand the attitudes and practices of professionals who interact, in their work practice, with people with FD, the difficulties experienced and the needs for change. To this end, qualitative research was used. Eleven interviews were analyzed according to the Reflexive Thematic Analysis (Braun & Clarke, 2013). These were conducted with psychologists (2), occupational therapists (3) and personal assistants (6).

Key findings center on lack of knowledge and the prevailing cis-heteronormative attitudes, despite some indication of affirmative practices. The need for training and education for greater inclusivity in entities was prevalent.

The results of the present study may contribute to the construction of more inclusive and responsive institutions and service provision practices to meet the unique needs of LGBT people with FD.

Keywords: Functional Diversity; Disability; LGBT; Professionals; Institution

Résumé

La sexualité et l'identité de genre de personnes qui ont des incapacités/déficiences est un sujet encore peu exploré dans les champs de recherche et institutions destinés à aider cette population (Smith et al., 2022), à cause de la conception dominante qu'ignore la vie sexuelle de celle-ci.

Malgré l'augmentation des investissements afin de comprendre cette problématique, les comportements cis-hétéronormatives sont encore dominants (Sommarö et al., 2020) et compromettent l'efficacité de ces institutions à répondre aux problématiques spécifiques de les personnes LGBT qui ont des incapacités. (de Sá, 2017).

Compte tenu de l'absence d'études menées au Portugal qui lient les personnes LGBT et les diverses incapacités existants, on a commencé le présente enquête afin de comprendre les attitudes et pratiques des professionnels qui travaillent avec des personnes incapacités, analyser leurs difficultés et propositions de changements. Pour ce faire on a recours à une méthodologie qualitative. Il y a 11 entretiens qui ont été analysées selon l'Analyse Thématique Réflexive (Braun & Clarke, 2013). Ces entretiens ont été réalisés par des psychologues (2), ergothérapeutes (3) et assistants personnels (6).

Les découvertes principales se centrent sur le manque de connaissances et la forte prévalence d'attitudes cis-hétéronormatives. Toutefois, on a pu constater l'existence d'un certain nombre de mesures positives.

On peut percevoir aussi un énorme besoin de formation et information pour une plus grande inclusion dans les institutions.

Les résultats de la présente étude pourront aider à la construction d'institutions, pratiques et services plus inclusifs et attentifs aux besoins spécifiques de personnes LGBT qui ont des déficiences.

Mots-clés: Incapacité; Déficience; LGBT; Profissionais; Institution

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List of Acronyms and Abbreviations

ENIND – Estratégia Nacional para a Igualdade e a Não-Discriminação

FD – Functional Diversity

IFD – Intellectual Functional Diversity

LGBT – Lesbian, Gay, Bisexual and Trans

PAOIEC – Plano de ação para o combate à discriminação em razão da orientação sexual, identidade e expressão de género, e características sexuais

UN – United Nations

WAS – World Association for Sexual Health

Introduction

Portugal has been committed to guaranteeing the rights of people belonging to minority groups¹. Since the signing of the Convention on the Rights of Persons with Disabilities (UN, 2006) to the creation of the National Strategy for Equality and Non-Discrimination (ENIND), which contains the Action Plan to combat discrimination on the grounds of sexual orientation, gender identity and expression, and sexual characteristics (PAOIEC) (Resolution of the Council of Ministers No. 61/2018 of the Presidency of the Council of Ministers, 2018), the protection of the rights of these people is foreseen. It becomes, then, interesting to explore the Portuguese panorama and evaluate how what the conventions stipulate is being put into practice, bearing in mind the intersection of these experiences.

In this context, Gentopia - Association for Diversity and Gender Equality (Associação para a Diversidade e Igualdade de Género) developed the project LGBTI People and Functional Diversity: Knowledge and Practices (Pessoas LGBTI e Diversidade Funcional: Conhecimentos e Práticas), under which the data for this study was collected. The project aimed to combat discrimination, promote knowledge, raise awareness and produce informative material about the intersection of non-normative sexual orientations and gender identities with functional diversity (FD)². To this end, awareness raising actions, interviews and informative documents were developed in partnership with the following entities:

¹ The mention of minority groups does not refer to the size of this population but to the power they hold within the general population. These are considered marginalized identities, classified as outside of the social norm (Dispenza et al., 2022).

² In this article, and project, we will refer to functional diversity (FD) instead of disability. This term was coined in 2001 by the Spanish community Foro de Vida Independiente Y Divertad. It focuses on the discrimination and erasure of forms of functioning that deviate from the socially established norm (García-Santesmases, 2017; 2019 in Pinho et al., 2020b) and emphasizes the non-accommodation of these people and their way of functioning, rather than focusing on the individual while distancing itself from the negative connotation associated with the word "disability". FD people include “those 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” (UN, 2006, p. 4).

Associação de Paralisia Cerebral de Vila Real (APCVR), Associação do Porto de Paralisia Cerebral (APPC), Associação Portuguesa de Pais e Amigos do Cidadão Deficiente Mental do Porto (APPACDM), Centro de Reabilitação Profissional de Gaia (CRPG), Centro de Vida Independente (CVI), Projeto Casa do Xisto.

The Convention on the Rights of Persons with Disabilities states that all persons are entitled to all the rights and freedoms set forth in the Universal Declaration of Human Rights and recognizes that discrimination based on disability is a violation of dignity and worth (UN, 2006). Added to this is the Declaration of Sexual Rights (WAS, 2014), which posits that sexual health and well-being should be ensured for all people, as well as bodily autonomy, privacy, access to pleasurable, satisfying and safe sexual experiences, and scientifically accurate and enlightening information. It becomes relevant, within the scope of this study and the project it is part of, to explore how these rights are ensured by the professionals who provide services to LGBT people with FD.

The invisibilization of the LGBT⁴ population with FD is notorious, in society and in institutions and scientific research (Magnabosco & Souza 2019; Smith et al., 2022), which translates into health disparities, lack of policies and services that meet their own needs (Moreno et al., 2017; Abbott & Howarth, 2007). This can be attributed to the overshadowing of FD over other identity characteristics (Wolowicz et al., 2022), the assumption of cis-heterosexuality⁵ of people who use support and assistance services for daily life activities (Sommarö et al., 2020), and the attitudes of service users themselves, who sometimes do not disclose their non-normative sexual orientation and gender identity in order not to

⁴ Umbrella term used to refer to non-normative sexual orientations and gender identities (Sommarö et al., 2020) such as lesbians, gays, bisexuals, trans, queer, intersex, asexual or more. In this article we will not be referring to intersex or asexual persons since our sample did not include professionals who work with people of those identities.

⁵ Cis-heterosexuality consists in the assumption that there are only two genders – male and female –, analogous to the sex assigned at birth, that they are opposites and only sexually attracted to each other (Sommarö et al., 2020).

compromise the support services they want to access (Moreno et al., 2017). In Portugal, 41% of people belonging to the LGBT community do not tell health professionals that they are LGBT (CIG, 2022), although research says that people living with FD and chronic illness would like professionals providing support services to give information and support about sexuality for them and for their partners (McGrath et al., 2021).

Although there are already studies and models that aim to address the needs of this group and provide responses based on intersectional practice (Dispenza et al., 2016) and despite the growing interest in research and social movements in exploring issues related to non-normative sexual orientation and gender identity and expression, as well as issues related to FD, there is still a lack of access to information that intersects these two factors and analyzes the vulnerabilities and privileges that arise from it, especially in the Portuguese context.

If we consider that each person carries several socially constructed markers (Pinho et al., 2020b) the attention required to each person's personal experience becomes clear. Both in research and in support and assistance services, it is necessary to pay attention to the idiosyncrasies of this population, since people that belong to one or more marginalized groups experience distinct oppressions resulting from the intersection of these characteristics (Dispenza et al., 2016; Wolowicz et al., 2022), which makes it imperative to avoid abusive generalizations (Bates, 2020; Nogueira, 2010) in order to avoid characterizing this as a homogeneous group. Thus, it should be noted that, although in this article we talk about LGBT people with FD, other identity categories that can lead to different experiences are not weighed; and even in this group, there are differences between the individuals. A lesbian woman with physical FD faces different challenges and opportunities than a non-binary person with intellectual FD (IFD), for example.

Theoretical Framework

1. Hegemonic views on gender identity and sexual behaviors of functionally diverse people

This population faces specific forms of exclusion and discrimination as to who they are and what they do by dominant discourses and attitudes (Smith et al., 2022). Despite this, spaces that provide support services for people with FD have the potential to have a positive and regenerative impact on their lives (O’Shea et al., 2020), especially if they use collaborative work with the people they aim to serve, address their concerns, implement innovative approaches (Dinwoodie et al., 2020; McCann et al., 2016) and are guided by scientific research and knowledge (Abbott, 2015).

This population is at risk of their behaviors being interpreted as behavioral problems associated with their FD (Keates et al., 2022; Stauffer-Kruse, 2007), and even when their sexual and/or gender identity is acknowledged, it is usually accompanied by cis-heteronormative⁶ attitudes (Moreno et al., 2017; Seelman et al., 2020; Smith et al., 2022). Discourses about the sexuality of people with IFD commonly position them as two ends of the same spectrum – either “asexual”⁷ or hypersexual (Smith et al., 2022). On one side of the spectrum, they are positioned as not having sexual needs and feelings or not knowing how to respond to them (Almeida, 2019; de Sá, 2017; Sommarö et al., 2020), which contributes to the invisibilization of their sexual expression (Smith et al., 2022). On the other hand, they are seen as sexually promiscuous and potentially dangerous, lacking self-control (Sommarö et al., 2022). Even in the presence of partnerships, these are not seen as romantic and/or sexual,

⁶ That poses cis-heterosexuality as “the fundamental and normative sexual orientations that dominates nearly all social and institutional spaces” (Dispenza et al., 2022).

⁷ Despite the use of assexual in various articles, this does not refer to the sexual orientation (internal process) but rather to the perception (and often desexualization) of these persons as sexless (external process), meaning they are seen as lacking sexual desire, activity, attractiveness or even gender in some cases (Pinho et al., 2020b).

but rather as care providers – there is no room left for romance or sexual behaviors and emotional needs are muted (Wolowicz et al., 2022). Compulsory heterosexuality is demonstrated in the division of spaces by sexes and the attribution of homosexual behavior to the lack of contact with people of the opposite sex (Almeida, 2019; Wolowicz et al., 2022). This obscures the presence of non-normative sexual orientations and gender identities. This is apparent in a study exploring the attitudes of professionals dealing with people with FD. While 76% of staff admitted to supporting the heterosexual relationships of the people they cared for, only 41% said they supported a homosexual relationship (Abbott & Howarth, 2007; Abbott, 2015). Meanwhile in Switzerland, despite professionals advocating that services are inclusive, only 17 out of 59 services for people with FD reported working with LGBT people (Sommarö et al., 2022).

Hegemonic and limiting views are imposed on LGBT people with FD in various ways, and are often difficult to overcome given the proximity (and often dependence) of this population to their families of origin and to support services/spaces, since, as research shows, people with IFD are more influenced by the attitudes of others about sexuality and sexual behavior than their peers (Sommarö et al., 2022), which may cause support for sexuality to be dictated more by caregiver stigma than by the needs and wants of the individuals themselves (Smith et al., 2022; Sommarö et al., 2020). This influence stems from restriction to the private sphere and little contact with the community and social spaces (Almeida, 2019; Dinwoodie et al., 2020; Pinho et al., 2020a).

People with FD are oftentimes purposely misinformed in order to limit their behavior, and privacy and freedom of expression are not guaranteed (de Sá, 2017). Since they socialize primarily with family and caregivers, this leads them to modulate their knowledge and behaviors (sexual and of gender performance) with those closest to them (de Sá, 2017; Pinho et al., 2020a; Sommarö et al., 2020). This can be potentially negative since, as previously

described, organizations and families mirror the marginalization they face in the social sphere (Seelman et al., 2020; Smith et al., 2022) and can compromise personal identity formation (Morgan et al., 2011; Stauffer-Kruse, 2007).

2. Attitudes of professionals when discussing sexuality and gender identity with people with functional diversity

Margaret McGrath et al. (2021) state that although professionals recognize the sexuality of people with FD, they judge who and under what circumstances its expression is relevant, ultimately reflecting societal views that restrict sexuality for people without FD; they also say that only a minority of professionals say they frequently talk about sexuality with the people they provide services to. A study developed by David Abbott and Joyce Howarth (2007) testifies the lack of confidence of professionals when dealing with topics related to sexuality, the lack of knowledge of guidelines and the lack of inclusivity in support services, which still shows many commonalities with more recent studies, demonstrating the meager evolution in this topic. This can also be potentially dangerous in the sense that it worsens the professional/user relationship and decreases attendance at consultations (Moreno et al., 2017), compromising the monitoring and quality of assistance services for a population that is already sidelined.

The study by Margaret McGrath et al. (2021) lists the most discussed dimensions when the topic of sexuality is addressed. Among these we find: the impact of diagnosis and medication on sexuality, responses to patient concerns, resuming sexual activity after an acute episode, or advice on adapting one's sex life to the new condition. In this systematic review, only two studies reported broader dimensions of sexuality – self-concept and self-image. Thus, a functional view of sexuality is predominant, instead of a holistic view of sexual health and well-being, which considers its various components.

From the literature it is possible to access the attitudes of professionals regarding the sexuality of FD people who belong to the LGBT community. The most frequently mentioned points are: the shame and discomfort felt by staff when discussing sexuality with clients (Abbott & Howarth, 2007; Dyer & das Nair, 2013; Smith et al., 2022; Sommarö et al., 2020); the view of this topic as private, vulnerable (Dyer & das Nair, 2013; Sommarö et al., 2020) and potentially problematic (Keates et al., 2022); the lack of initiative in introducing the topic (Smith et al., 2022; Sommarö et al., 2020) and hope that the user will be the one to do it; the fear of retaliation from the family of origin after touching on the topics and presenting other possibilities of belonging and behavior (Sommarö et al., 2020); the lack of training, knowledge and cultural literacy within sexuality and LGBT issues (Abbott & Howarth, 2007; Dyer & das Nair, 2013; Smith et al., 2022; McGrath et al., 2021); limited contact time, which ultimately leaves issues related to sexuality and gender identity on the back burner (Dyer & das Nair, 2013; Smith et al., 2022); the absence of guidelines from organizations about what should be addressed and in what ways (Abbott & Howarth, 2007; Smith et al., 2022) (despite professionals' demonstrated interest in having access to such); the belief that sexuality is a topic outside of their abilities and responsibilities; and the religious and cultural limitations/prohibitions of professionals themselves (Smith et al., 2022). Elizabeth Smith et al. (2022) further point out that some staff members believe that supporting non-normative gender expressions could leave people more vulnerable to sexual violence. Kerry Dyer and Roshan das Nair (2013) point out that some of these attitudes are even more prevalent when discussing non normative sexual orientations and gender identities with intellectually diverse people.

A study developed in South Africa (Ubisi, 2021) exploring sex education for people with sensory (visual) FD concludes that a hegemonic representation of ablebodiedness⁸ still prevails, which reinforces stereotypes about sexuality of people with FD, despite teachers showing interest in adopting a position based on human rights, social justice and queer framing, even in the absence of guidelines spelling out how to address topics sensitive to the LGBT community. On the other hand, a study conducted in Poland with lesbian FD women, who use support services (Wolowicz et al., 2022), reports how these institutions are often permeated by bias and inequalities, putting them at risk of losing access to them after coming out (Miller et al., 2021). The disparities between countries show the pertinence of investigating the approach professionals have in Portugal, in an attempt to locate the self-reported needs of both the professional community providing services and those who use those services.

Despite the absence of literature in Portugal focused on the LGBT community with FD, a study developed by Fabiana de Sá (2017) conducted a survey on the attitudes of professionals who provide support regarding the sexuality of people with FD who use support and assistance services for daily life activities. This concluded that professionals in Portugal have more positive attitudes towards education and prevention than towards sexual rights and self-control. It adds that they see this population as sexual beings, with the right to masturbate and decide about their sterilization (being opposed to such) and that they should have access to sexual education. The study also concluded that neither age nor gender have an impact on the views and attitudes of professionals towards the sexuality of people with FD, but that

⁸ Term that refers to the body without impairment. This form of discrimination, related to ableism, disregards bodies with impairment and illness as capable of being attractive. It grants this attractiveness and values normative bodies, which are closer to the idea of the unattainable perfect body. (Pinho et al., 2020a)

professionals with a higher educational level and professionals with training in sexuality have more open and positive attitudes towards the sexual rights of these people.

That said, some predominant points are raised in the literature regarding the positioning of the professional body in the intervention with the LGBT community with FD. These are: the silencing of sexuality; the lack of ownership to talk about it (McGrath et al., 2021); the cisheteronormative treatment in support services (in which non normative sexual orientations and gender identities are invisibilized, seen as non-problematic or as something or no interest for the assistance provided); the imposition of barriers to inclusion (derived from the lack of knowledge and confidence of professionals in dealing with the topic, the lack of inclusive guidelines and the reticence shown by families of origin to address sexuality) (Abbott, 2015), but also some possibilities for inclusion, such as the implementation of policies and improvement of service conditions (Sommarö et al., 2020).

In this way, the preponderance of the encouragement of abstinence and restriction of sexual expression and the protective position of the staff, which does not allow risk and does not know how to identify its role in the discussion of topics related to sexuality, stand out (Smith et al., 2022). This is antagonistic to the wishes expressed by the service users, who show interest in talking about sexuality and sexual relationships in a safe and personal way (Sommarö et al., 2020).

3. Inclusive institutional practices

Knowing the positioning of professionals about the non-normative sexual orientation and gender identity of the people they propose to assist, and having identified the gaps in the inclusion and adequate treatment of LGBT people with FD, some studies propose measures to eliminate prejudices about sexuality, gender and FD, while promoting and recognizing the

needs for love, affection, interpersonal and sexual relationships of people with FD (de Sá, 2017).

First, it is critical to facilitate coming out, as it requires a set of skills that people with IFD may not have practiced, and should be taught and supported by staff, who are in a prime position to support self-determination and autonomy and facilitate the development of sexual and affective communication skills (de Sá, 2017). Training is also needed to accommodate trans people, who are so often excluded from accommodations (Keates et al., 2022; Smith et al., 2022).

Given the reports of high levels of loneliness, one measure to combat such feelings involves facilitating contact with other LGBT people while promoting a more positive identity (Smith et al., 2022). Efforts should be made to understand how LGBT people face their own challenges (such as sexual minority stress, alienation, adjustment disorder issues, and even how certain therapies can interfere with sex reassignment treatments) (Dispenza et al., 2022; McCann et al., 2016; Moreno et al., 2017).

Alexander Moreno et al. (2017) propose some steps to better meet the social and health needs of LGBT people with FD, such as educating staff about sexual identity, relationships and accessible practices, being aware of negative attitudes and cis-heteronormative patterns, discussing topics such as vulnerability, capacity, consent, abuse and exploitation, sharing knowledge about safe practices and intimacy, using open questions and neutral language, promoting the inclusion of partnerships in rehabilitation, promoting privacy, making inclusive institutional materials available, and defining ways to report discriminatory practices. Markus Bidell and Lara Stepleman (2017) reinforce that professionals must be aware of their own biases, as well as LGBT psychosocial and health issues, while also having LGBT clinical skills based on ethics, while also searching for

continuing education in order to best serve clients. This also requires providing professionals with inclusive scripts and communicational behaviors. Finally, the institutions' policies should be known and communicated in a clear and accessible way to clients (Abbott & Howarth, 2007).

4. Relevance of the study

In general there is a lack of research on how issues related to sexuality and gender identity are addressed in rehabilitation and follow-up services for people with FD (Smith et al., 2022) and Portugal is no exception, especially in what concerns non-normative sexual orientations and gender identities.

Available research tells us that adolescents belonging to non-normative genders and sexual orientations with FD report high levels of loneliness, depression, anxiety and suicidal ideation, attributed to lack of knowledge and hostile attitudes of the surrounding people (Conover & Israel, 2018; Stauffer-Kruse, 2007; Ubisi, 2021). Also common in adults are sexual dysfunction and lack of satisfaction with their sex life, as well as anxiety, depression and reduced quality of life (McGrath et al., 2021). Such an impact on individuals and their psychological well-being can be attributed to the lack of sensitivity to non-cisheterosexual people, which can be explained by the lack of focused training in this population and issues (Dispenza et al., 2016) and the exposure to religious, moral and cultural prejudices and stigmas of staff (Moreno et al., 2017). Thus, training and education in sexuality for professionals who provide support to people with FD is fundamental, aiming to improve their attitudes and comfort when dealing with these issues and to promote changes that are sustained over time (McGrath et al., 2021).

In this regard, commitments have been made in Portugal towards the promotion and guarantee of human rights (Resolution of the Council of Ministers no. 61/2018 of the

Presidency of the Council of Ministers, 2018), which include sexual and reproductive rights (WAS, 2014) and the rights and inclusion of people with FD (UN, 2006). That said, it becomes important to explore how sexual orientation and gender identity of this population are viewed by professionals providing services to people with FD, and what can be done to mitigate experiences of discrimination and foster well-being.

As health services and contexts that provide support to people with FD are privileged spaces when it comes to empowerment and capacity building, it is essential that they are equipped to provide psychosocial support (Sommarö et al., 2020), which includes preparation for clinical and ethical competence of professionals to deal with LGBT issues (Bidell & Stepleman, 2017).

Method

1. Aim of study

The present study aims to (A1) explore existing practices in working with LGBT people with FD, (A2) understand the needs and difficulties associated with LGBT and FD issues in the context in which professionals work, (A3) identify suggestions for improvement.

With this in mind, the following research questions were developed: (Q1) In what ways do professionals know about and are sensitized to LGBT issues when working with people with FD? (Q2) How is the non-normative sexual orientation and/or gender identity of people with FD seen by these professionals? (Q3) What are professionals' discourses and practices like regarding non-normative sexual orientation and gender identity? (Q4) How do professionals identify difficulties or needs for change in providing services to LGBT people with FD? (Q5) How do speeches of the participating people indicate suggestions for improvement?

2. Participants

Having defined the main objectives of the study, we decided to use qualitative research and semi-structured interviews with professionals who in their practice have contact with individuals with some type of FD. To this end, we resorted to the analysis of interviews previously conducted as part of the project.

The inclusion criteria was the professional practice in providing services to people with FD. Recruitment was done by convenience (Braun & Clarke, 2013), through three distinct means. First, it was shared after the awareness raising actions facilitated by the project and the ones interested in participating could sign up for a later interview. In a second stage, it was shared through the social networks of the Gentopia Association and the Commission for Citizenship and Gender Equality (Comissão para a Cidadania e Igualdade de Género - CIG). Finally, partner entities were asked to share it with their employees. For this purpose, a leaflet was used (see Appendix 1). After the demonstration of interest, contact was established with the participants and the informed consent was shared, in which the aims and terms of the study were explained (see Appendix 2).

Eleven people were interviewed. Only one person interviewed identified as Trans non-binary and only one person identified as male. The ages ranged from 27 to 55 years. One person had completed the 9th grade, two the 12th grade, four had a bachelor's degree, and four had a master's degree. Two were psychologists, three were occupational therapists, five were personal assistants, and one was a music teacher (in special education) and personal assistant at the time of the interview. Years of experience ranged from 1 to 25. Of this sample, six people had contact with LGBT people in their work environment and five did not. The sociodemographic data were obtained at the end of the interviews.

3. Data Collection Method

With the central objective of this research being to understand and explore the discourses and practices of professionals about the LGBT people with FD, we selected a qualitative methodology, specifically the Reflexive Thematic Analysis (Braun & Clarke, 2013), since it gives us access to individual meanings and narratives, while allowing the identification of patterns between interviewees.

We used a semi-structured interview (see Appendix 3) as a data collection technique, as it allows us to touch on the points previously defined as relevant to the research, while also providing space for the information deemed relevant by the interviewee and not anticipated by the researchers (Braun & Clarke, 2013). The data collection process ended due to theoretical saturation. The interviews were conducted online, through the Zoom platform, and had an average duration of 35 minutes. All interviews were audio recorded and later transcribed by the interviewer for anonymity purposes⁹.

4. Data Analysis Method

This paper is qualitative in nature and uses an interpretative analysis. We decided to use Reflexive Thematic Analysis (Braun & Clarke, 2013) as the methodology for data analysis because it is a flexible tool that allows the exploration of implicit meanings in speeches. Moreover, it allows us to reveal patterns that cut across different interviewees and to define convergent and divergent lines with each other and also with the literature. A social constructionist perspective was adopted, in which an attempt was made to understand how the experiences and meanings attributed result from and are revealed in the socially reproduced discourse(s) (Braun & Clarke, 2013). This research also adopted an inductive-

⁹ This study is a follow-up to the project under which the interviews were conducted and will use its data. Thus, I did not conduct or transcribe them myself. I was granted access to the interviews under a commitment to not share the data except for the writing of this article. The secrecy statement is attached (Appendix 4).

deductive approach, as themes present in the literature were identified, but new themes also emerged from the interviews.

After data collection, we began the process defined by the authors in six steps. These steps are not linear, but flexible and iterative. In the first step, I proceeded to the *Familiarization with the data (1)*, by (re)reading the transcripts and identifying relevant excerpts. Then I *Generated initial codes (2)*, grouping the data extracts. Then, in the *Generating of themes (3)*, the codes were grouped, creating comprehensive units of analysis with significant patterns. In the *Review of potential themes (4)*, the latter were crossed with the codes and the thematic map of the analysis was produced. In a fifth stage, the *Definition and nomination of themes (5)*, the analysis was refined and the themes were specified, to reflect the content of the information identified and contained in the codes. In a final step, I *Wrote the report (6)*, in which I sought to highlight the validity and consistency of the analysis, for which I organized and wrote the results, selecting the relevant registration units and combining them with the literature, resulting in an integrated and coherent history of the data (Braun & Clarke, 2013; Byrne, 2022).

Analysis and discussion

The results of the reflexive thematic analysis will be presented and discussed next. Four themes were revealed: (i) Attitudes and practices of professionals (Atitudes e práticas dos profissionais); (ii) Challenges specific to this population (Desafios específicos desta população); (iii) Cis-heteronormativity (Cis-heteronormatividade) e (iv) Need for training (Necessidade de (in)formação). From this the thematic map represented in Figure 1 was elaborated, which has as its central organizer “Practices of sexual and gender expression containment (“Práticas de contenção da expressão sexual e de gênero”). The central organizer is based on the perception that sexual and gender expression and behaviors were controlled and delimited by professionals-whether this was by legislation, internal policies of the institutions, and/or the professionals' own beliefs about what is acceptable and allowed or not.

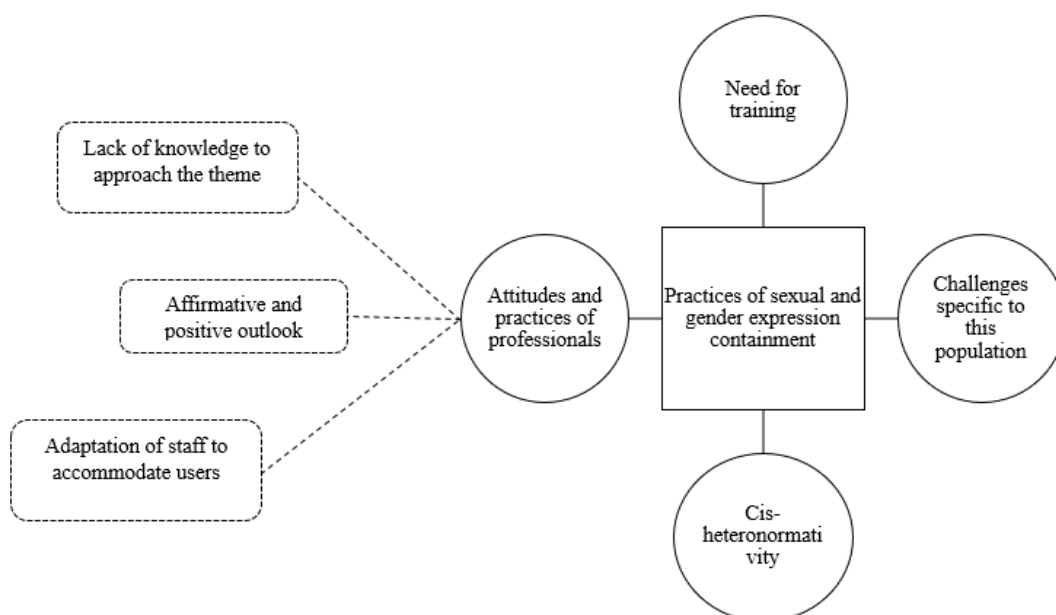


Figure 1. Thematic map

1. Theme I. Attitudes and practices of professionals (Atitudes e práticas dos profissionais)

The present theme intends to encompass what was understood as the practices that professionals have and/or intend to have in their relationship with LGBT people with FD.

Although almost half of the interviewees have no contact with LGBT people in their practice (to the best of their knowledge), they idealized what they would do if they came across such population. It was possible to draw out three sub-themes, somewhat dichotomous to each other. Subtheme (i) *Lack of knowledge to approach the theme (Falta de conhecimento para abordar o tema)* is the one that differs most from the other sub-themes, insofar as it reveals a lack of knowledge and ability to deal with the subject with the users, and consigns the professional to passivity, being common to most of the interviewees in one way or another. The subthemes (ii) *Affirmative and positive outlook (Perspetiva afirmativa e positiva)* and (iii) *Adaptation of staff to accommodate users (Adaptação do staff para acomodar pertenças)* denote a more active role on the part of the staff. On the one hand, subtheme (ii) is dominated by professionals who have already taken steps to a more inclusive practice and see it as necessary, on the other hand, subtheme (iii) encompasses both decisions already taken and ideas of what would need to be done to accommodate users, even if it goes against their personal beliefs and values.

1.1. Sub-theme I. Lack of knowledge to approach the theme

This sub-theme reveals the lack of knowledge reported by professionals regarding the LGBT community in general and the LGBT community with FD in specific. It is transversal to the lack of cultural literacy, scientific knowledge, academic training and absence of regulations in workplaces that guide their practices. It is at the base of the reluctance in approaching the theme with users, in the invisibilization of this population in institutions and in the precariousness of the LGBT community with FD, who faces little support, given the

lack of preparation and knowledge on the part of institutions and professionals to accommodate them. It reveals certain practices (and lack of them) but also some difficulties to be overcome.

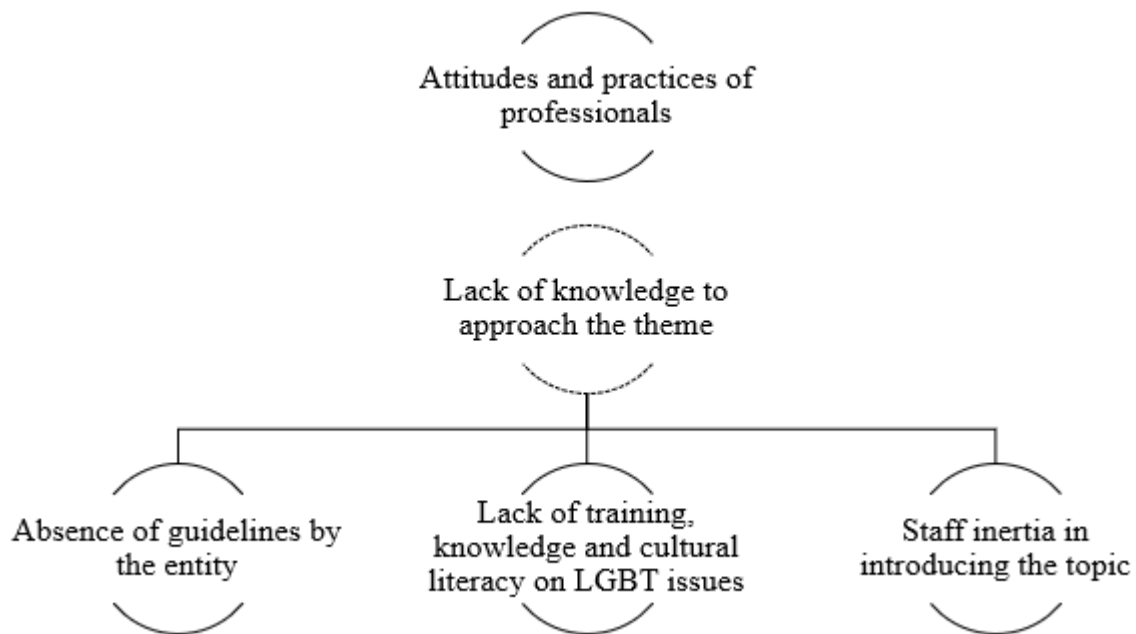


Figure 2. Sub-theme I. Lack of knowledge to approach the theme - Codes

From this sub-theme I highlight the code *Absence of guidelines by the entity* (*Ausência de linhas orientadoras por parte da entidade*), which reveals, more than the lack of preparation of professionals in particular, the lack of preparation of the entities themselves. This gap supports neither the users of support services nor the professionals, who already feel helpless at the outset, which pushes the issues of sexuality and LGBT to the second plane, being addressed only if strictly necessary and on the basis of conflict resolution, as the following registration units¹⁰ tell us.

“There could be the courage, for example, to always ask the question of sexuality on an individual level, like we ask about diet, like we ask about clothing, like we ask about other issues that... the question of sexuality, right? Then it would exist! This way it seems that it

¹⁰ The original transcripts in Portuguese can be found in Appendix 5. These have not been included in the body of the text for reasons of character limitation. However, it is important to consult them given the inevitable alteration of some excerpts by translation.

doesn't exist (...). But until the technician has the word in front of him and a square to fill in, it will make him scratch his head and this is important.” (F)

“We never talk about that [sexuality and LGBT belonging] in the courses, so we go a lot into the conflict part, the support part, the way in which we have to deal with a lot of situations” (E)

Thus, despite the literature and interviewees telling us that there is an interest in having access to defined procedures and inclusive material (Abbott & Howarth, 2007; Sommarö et al., 2020) these are still lacking. It remains unknown what is acceptable to address and how (Abbott & Howarth, 2007; Moreno et al., 2017; Smith et al., 2022; Ubisi, 2021) and what institutional routines to follow (Sommarö et al., 2020).

Having guidelines in institutions may make it easier to manage the relationship with the family of origin (in case they do not accept LGBT belonging of the individual), as it unburdens the staff, who are "just following the rules of the organization" (Dyer & das Nair, 2013). Furthermore, it helps counter the already expressed sentiment of LGBT people having unmet needs from the services (Dinwoodie et al., 2020).

This lack of internal policies that address ways to touch LGBT belonging with people with FD is both a symptom and facilitator of the *Lack of training, knowledge and cultural literacy on LGBT issues (Falta de treino, conhecimento e literacia cultural no âmbito da temática LGBT)*. A study of medical students found that 90% reported a lack of LGBT education upon graduation (Bidell & Stepleman, 2017) and this misinformation continues into professional practice, primarily because such training is not required. Most respondents reported little knowledge, and what they did have was derived from informal sources and the media.

“My knowledge is not very broad (...) I have little knowledge” (B)

“*Very little [knowledge], quite honestly, almost none (...) We have some contact on television, but I have never had any education or training*” (E)

“*I know what the acronyms mean. Of course, I'm not really into the... I know it's a movement, right? That it exists, right? Groups of lesbians, gays... and I see, sometimes advertisements on television (...) I was aware of these movements that are going around the country... that's what we hear on the news. Now I don't know much more about it, no*” (G)

Lack of training and knowledge (Abbott & Howarth, 2007; McGrath et al., 2021; Smith et al., 2022; Sommarö et al., 2020) and the view that this topic is outside their capabilities (and should be handled by specialists) predominate. Many participants reported, when encountering LGBT people with FD in institutions, asking for advice from teammates who they considered more competent to discuss the issue or keen to refer users to them. This lack of training compromises us'rs' psychosocial and health conditions (Bidell & Stepleman, 2017).

In addition to the lack of training, and also symptomatic of the *Absence of guidelines by the entity (Ausência de linhas orientadoras por parte da entidade)*, participants reported little availability of time to take training on sexuality and LGBT identities (Smith et al., 2022), given the workload is already demanding and they cannot attend training during working hours, risking leaving recipients unaccompanied.

The addition of these two components results in a professional body unprepared to initiate a discussion about sexuality and LGBT belonging with people with FD, prevailing the *Staff Inertia in introducing the topic (Inércia do staff)*, consigning themselves to a passive role (Sommarö et al., 2020). Participants revealed feeling shame, discomfort, and lack of confidence, data that is in line with the literature (McGrath et al., 2021; Abbott & Howarth, 2007; Ubisi, 2021; Smith et al., 2022).

“perhaps not so many opportunities are given to people with disabilities and with that... there you have it, because we still lack information and are very closed off, there is still a lot of shame in talking, in discussing these issues” (B)

“if he talked to me about it I would have no problem talking to him, referring him, but I do not see myself in that role” (H)

Kerry Dyer and Roshan das Nair (2013) found that although 60% of professionals advocated that sexuality should be discussed, only 6% initiated such a conversation frequently. As in previous studies, only a minority introduce and talk about the subject, even though they recognize its impact on health and well-being (McGrath et al., 2021).

1.2. Sub-theme II. Affirmative and positive outlook

In this sub-theme there are more accepting views and feelings of recipients' LGBT belonging and openness to include them in conversations and support services. There is interest in exploring and addressing the issue adaptively, with the recipients' well-being and comfort in mind. Here, some professionals reported seeking knowledge through formal and informal means, welcoming the issue when it was raised by recipients, clarifying doubts, exploring it when it was seen as productive for the well-being of the individual and the group, and taking steps at the institutional level for sexuality (and the LGBT community) to be worked on in a large group setting - targeting both staff, recipients and even, in some cases, families.

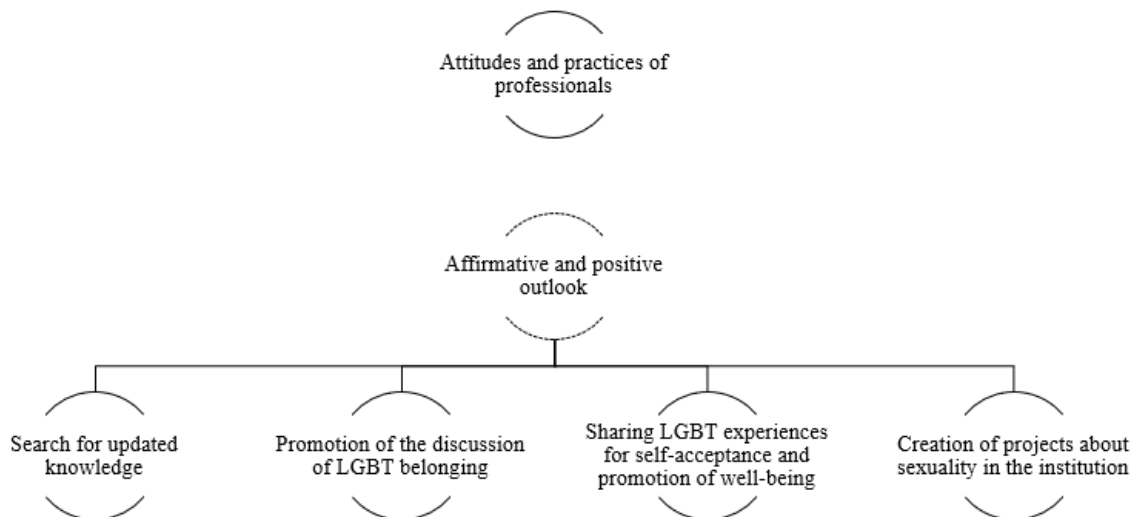


Figure 3. *Sub-theme II. Affirmative and positive outlook - Codes*

The *Search for updated knowledge (Procura de conhecimento atualizado)* is fundamental in any professional practice, and so is it in providing support services to LGBT people with FD. Some participants reported seeking self-education about LGBT clinical skills and issues pertinent to the user's health, as well as recognizing LGBT cultural experiences (Bidell & Stepleman, 2017). This search came from personal interest in LGBT issues and a sense of need to explore such issues to improve services provided. This need for continued education (Moreno et al., 2017) is done both through the use of scientific materials and recreational and cultural materials.

“I had already read some things on the subject and seen films and read some articles, even regarding transsexualities, operations, hormonal aspects, right? About gender identification” (H)

“We have to keep up to date, as we evolve we see how things are being discovered and we realize that sexual orientation or gender identity is not a psychiatric disorder, it's not a fad, it's not a tantrum against society, it's something that people were simply born either in the wrong body or with tastes that don't..., in the case of the wrong body I was going to say that wrong is never the word, but here it can be, yes! The mind does not match the physical

characteristics...or they actually have a different sexual orientation than what was considered normal. This happens everywhere and for many years... this thing is not a current trend, because if we go back in history, this was already very normal in the time of the kings, it was not a big deal... we are the ones who like to complicate things!” (J)

Participants who reported greater interest and knowledge about diverse sexual orientations and gender identities were those who reported greater training and education in sexuality, better attitudes and comfort in discussing the topic (Bates, 2020; Dispenza et al., 2016), which is in line with the literature, that also tells us that greater access to information promotes changes that are sustained over time (McGrath et al., 2021).

Thus, the participants who sought out the most knowledge, were also the most invested in the *Promotion of the discussion of LGBT belonging (Promoção da discussão da pertença LGBT)*, both as a group and individually. This exchange comes with the belief that it is an important topic with a positive impact and is done both with those in the institutions and with family members. This is in line with the literature, which argues that professionals should take an active role in helping to build a functional and positive identity (Stauffer-Kruse, 2007).

“I think it's fundamental [to approach LGBT issues]. Mainly for the users (...) I think it's important more for... in this aspect of opening ways for people to express themselves” (D)

“At the time I got to talk to the person who was responsible for that area so that they could explore in a group setting with the other peers, and everything, that matter [non-normative gender identity of a user]. And also help him to, maybe, define what was happening or to understand himself a little bit better” (I)

“Parents have become more open about some things. We have also made an effort towards this. We always do some courses in this area, in the area of sexuality, in the area of

knowing how to deal with - both with our users and with their families - at the level of gender identity, at the level of sexual orientation. And we have made an effort to talk to parents about this” (J)

Similar studies also found that only professionals interested in LGBT issues reported discussing the topic (Sommarö et al., 2020).

These conversations should be guided by ethics, suspend judgments and biases (Dispenza et al., 2016), explore barriers arising from context, and use tailored resources to discuss stressors arising from the oppression that LGBT people with FD experience. This discussion can help in shaping attitudes and critical thinking about the microaggressions experienced and accessing feelings of depression based on them, reducing feelings of inadequacy (Conover & Israel, 2018) and risky behaviors (Moreno et al., 2017). Thus, staff should promote discussion of vulnerability, capacity, consent, abuse, and exploitation (Moreno et al., 2017) and promote resilience. Ultimately, this culminates in the development of safe, welcoming, and inclusive environments (Dispenza et al., 2022).

Subsequently, *Sharing LGBT experiences for self-acceptance and promotion of well-being (Partilha de vivências LGBT para autoaceitação e promoção de bem-estar)* was the ultimate goal of professionals starting these conversations. Positive outcomes were reported coming from conversations about LGBT identities and experiences, both for the individuals doing the sharing and for group cohesion and routines in the institution.

“But still it's very good that he did [coming out] and had that openness from his colleagues, and really, the reaction of the group wasn't bad, it wasn't... it was positive. And I think it may have been good for him, too, to experience acceptance (...) to also start to have a little bit of acceptance within himself” (I)

“I would have to manage the matter, manage it in a rather technical or even clinical way (...), if that were to happen, what I... what we hope for, of course, is to make sure that the professional elaborates that matter in an adaptive way for the person being supported, isn't it? What matters is to ensure the well-being of the person supported. More than that I would not do... maybe ensure that (...) the services... would continue to be provided with quality of life” (F)

Coming out requires a set of skills that people with IFD may not have practiced that should be taught and supported by the staff (Smith et al., 2022). This must go alongside removing barriers faced regarding sexual expression (Moreno et al., 2017), promoting the acceptance and honor of differences, and embracing diversity (Dispenza et al., 2016). The focus on empowerment and well-being (Dispenza et al., 2016; Stauffer-Kruse, 2007) fosters the therapeutic alliance and positively impacts individuals and their self-esteem (Bates, 2020).

As a final step in promoting discussion of diverse sexuality and identity, professionals resorted to *Creation of projects about sexuality in the institution (Criação de projetos sobre sexualidade na entidade)* in which they work. This attempt to bring the conversation into institutions in a more formal and systemic way is not a recurring point in the literature, despite this proving that LGBT groups have a positive impact on service users' self-concept and identity (Bates, 2020), promote a sense of belonging, pride, resilience, and access to practical information (O'Shea et al., 2020). Although the projects implemented were not exclusively LGBT, they brought the topic into the conversation, an innovative aspect that shows acceptance and embracement of diversity (Dispenza et al., 2016) and which attempts to counteract the *Absence of guidelines by the entity*. The excerpts below demonstrate how this came about and was navigated.

“The knowledge that I had [about the LGBT topic in FD] came a lot and to a large extent from the previous experience that I gave you about the project of sexuality in people with disabilities (...) it was something that led me to see, to study, to research. I even met with associations (...), congresses that I ended up attending and this also gave me the opportunity to meet very, very interesting people with a very, very great knowledge about these issues (...) I learned a lot, really a lot” (F)

“I started with the sexuality project... and began to explore this with them (...) I did interventions with caregivers and even professionals” (I)

As the literature tells, truly inclusive services ease access to information and education about LGBT community and prioritize the participation of LGBT people with FD in the design of these projects (O'Shea et al., 2020), as was attempted by these professionals, who had people with FD by their side in the design of the groups and their rules.

1.3. Sub-theme III. Adaptation of staff to accommodate users

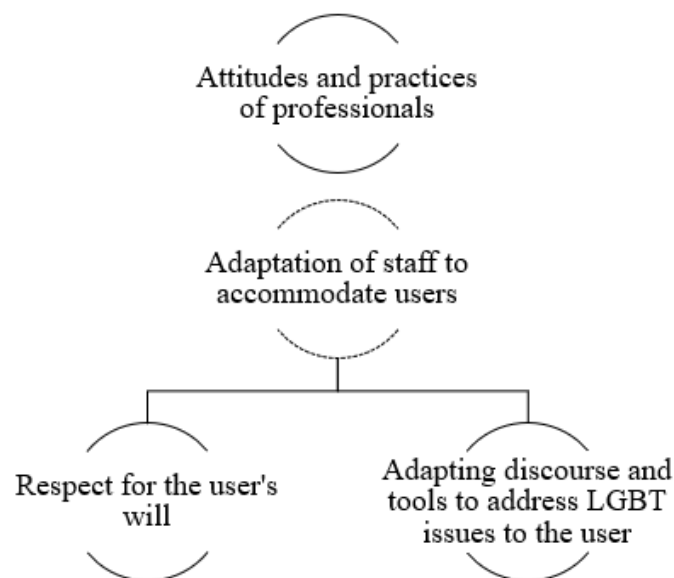


Figure 4. Sub-theme III. Adaptation of staff to accommodate users - Codes

This is the most heterogeneous sub-theme as it cuts across most of the interviewees, both those who have contact with LGBT people with FD and those who do not. It explores

how staff adapt the language and means by which they communicate about sexualities in an inclusive and adapted way and shows their willingness to accommodate users and respect their will and individuality, even in the presence of negative beliefs and biases about being LGBT, putting the will and values of the individuals to whom they provide services and support to in the foreground to the detriment of their own.

This *Respect for the user's will (Respeito pela vontade do destinatário)* meets the stipulation of the UN (2006) which states that individual autonomy and independence should be assured, health care should be guided by respect for the person (Moreno et al., 2017), their choices of clothing and expression (Ubisi, 2021), and the creation of safe spaces for exploration of sexuality and gender identity (Bates, 2020). As the following excerpts state, professionals are willing to set aside their beliefs and prioritize support, honoring the profession that puts itself at the service of people.

“for me, what is important is that the person feels good about themselves... about themselves and that they are able to assume themselves and live according to their orientation, what they feel deep inside” (H)

“of course there are certain situations that cause us strangeness, because we are not used to contact, to deal with, but I would do my best and help the person in whatever they needed” (B)

“It is to do what the person wants. If they want it and they can't do it by themselves, we have to do it” (D)

Still in a perspective of adjusting to who they have in front of them, professionals who adopt an active role in discussing LGBT belonging with people with FD report the need of *Adapting discourse and tools to address LGBT issues to the user (Adaptação do discurso e*

meios para abordar questões LGBT ao destinatário) so that the information is accessible and adapted to each person's type of FD.

“We have two cases here... it is relevant [to approach LGBT topics in the context where you work] (...), it depends on the case and of course it could be something beneficial, it depends if we were talking to young people with a slight disability, right? Now we're not going to be talking to a group of users with moderate or severe disability that are not going to understand what I'm talking about (...). We should have a simpler language, shouldn't we? To know what we could talk about with them in a way that they would understand” (G)

“Having the right contents [to provide inclusive sex education], because there are a lot of things - films and series - but then, also, you have the problem of accessibility, right? If it's with subtitles many of them won't read it, if it's dubbed many of them will complain about the Brazilian” (I)

The literature supports this and says that adaptive ways of addressing physical intimacy and sexual acts can facilitate sexual expression (Moreno et al., 2017). To this end, professionals should have access to scripts and practice specific communicational skills about sexuality (McGrath et al., 2021). Attention to the specific needs of each person with FD who uses support services aids in deciding which forms of communication best fit and conveys information in a way that is understandable and clear.

2. Theme II. Challenges specific to this population

This theme explores some barriers faced by professionals to the full sexual and gender expression of their clients. It goes beyond the staff's lack of information and the institutions' lack of preparation and touches on aspects closely linked to the recipients' FD which may represent difficulties to the full experience of their LGBT identity. The limitation to the proximal circle facilitates dependence on third parties - which brings with it the need to

manage the relationship with the family of origin. The predominance of FD over other categories of belonging leads the staff to conclude that it is necessary to give visibility to LGBT people with FD who they consider to still have little representation.

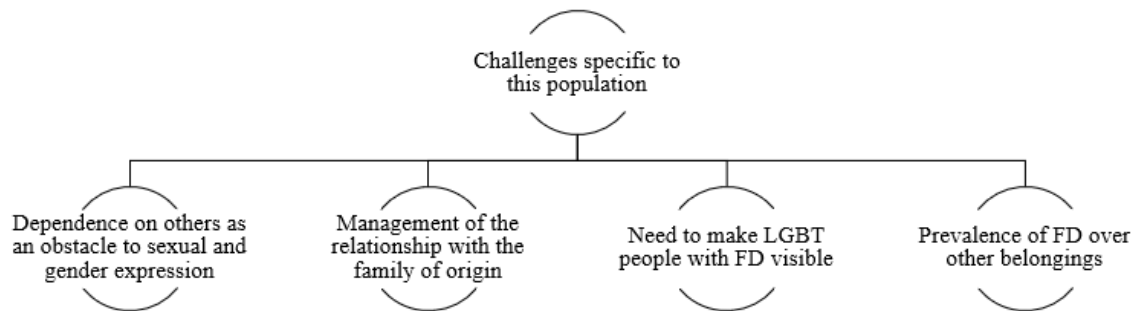


Figure 5. Theme II. Challenges specific to this population - Codes

As mentioned, the limitation of interaction with the inner circle and the limitation to the private and institutional sphere promote a *Dependence on others as an obstacle to sexual and gender expression (Dependência de terceiros como entrave à expressão sexual e de gênero)*. The people interviewed point to this limitation in the access to information (de Sá, 2017), the construction of opinions and values and the way of dressing and behaving as enhancers of the prevalence of the opinion of the families of origin over the wishes of people with FD. Thus, support for sexuality is dictated more by the stigma of caregivers and family than by the needs of people (Smith et al., 2022; Wolowicz et al., 2022) since they assimilate sexual knowledge with those who are closest to them (de Sá, 2017) and are segregated from the rest of the population (Sommarö et al., 2020).

“yes, [people with FD] have even more barriers, because... especially if they are very dependent on other people it becomes even more complicated (...) if they are dependent on someone else to make them... if the person doesn't respect their ideas, well, it's much more complicated” (B)

“It is still very difficult to talk about these issues in Portugal. Portugal, interior, (...) we are talking about an aging population (...) they come from a conservative catholic education (...) to talk about masturbation, to talk about sexual orientation, to talk about gender identity, none of this is accepted, right? (...) I have different families, but it is difficult, it is difficult...” (J)

Although the UN (2006) advocates that individual autonomy and independence should be guaranteed, to the extent possible for each type of FD, this is not always the case and paternalistic restrictions on who people with FD are and what they can do still prevail (Smith et al., 2022; Sommarö et al., 2020).

The literature tells us that situations of abuse and discrimination perpetuated by the family are experienced (Dinwoodie et al., 2020), both for being LGBT and having FD.

Thus, the *Management of the relationship with the family of origin (Gestão da relação com família de origem)* becomes necessary, in an attempt to give freedom and respect the will, identity and individuality of the LGBT person with FD. Especially in a context like the Portuguese one, in which Christian and conservative values prevail and in which a good part of the caregivers are elderly people, with a conservative education and without access to diverse existences that challenge the norm, as the professionals tell us. This becomes complicated, according to the professionals, when it comes to minors or when boundaries are not clear and professionals fear overriding the will of family members.

“It is quite important and it is not very... sometimes it is not very easy [to address the topic] (...) it is important to keep an optimal distance, we can't get too close, nor can we be too distant, well, my goal is to be a support, an aid. But we also can't impose ourselves on the family, on the person, right? And to encourage or to withdraw... it has to come from them”

(H)

“Now, if it were a minor, then it becomes more complicated, because, exactly, there's the parents' issue, right? When we are going against the parents' wishes, and when the parents don't accept it, it becomes a complicated situation to manage, but I would always try to help the young person in any way I could” (B)

Like the examples, the literature tells us that professionals think that families will not like these topics being touched (Sommarö et al., 2020) and fear their reaction (Abbott & Howarth, 2007). Studies also report that users do not have the desired support from family members (Bates, 2020) and feel fear of being punished and segregated by them (Dispenza et al., 2022), so this assumption may be correct. However, staff are in a privileged position to assess risk and explore what topics are likely to be addressed and in what way (Sommarö et al., 2020), valuing the safety of users, preparing and facilitating the discussion of these belongings and subsequent acceptance.

On the other hand, within the social setting, the interviewees reported the *Need to make LGBT people with FD visible (Necessidade de visibilizar pessoas LGBT com DF)*, since they suffer from double invisibilization and are often discriminated for their LGBT identity in the community with FD, and discriminated for their FD in the LGBT community (Abbott, 2015; O'Shea et al., 2020). Thus, the staff points to the need for the inclusion of these people in the LGBT movement, but even more recurrent was the advocacy that people with FD need to be heard by society, in the fight for their rights, and their inclusion in the design of community-directed activities.

“These people need to be heard” (D)

“In this case I think there should be no separation, just because they have some disability, from the rest of the [LGBT] movement. That is, they should be part of the

movement. There doesn't have to be a division, just because they have a disability doesn't mean that there has to be a separate movement” (G)

“I am very angry at how we manage functional diversity and then sexuality as a consequence and yes... it makes me very sad that we still don't give the word to those who it should be given to” (I)

As Magnabosco and Souza (2019) point out, even when subalternized subjects speak, they are not really heard, since their discourses will always be interpreted by the social representations of the groups they belong to. Thus, it becomes necessary to counter this, as pointed out by the excerpts above.

These desires for inclusion and visibilization are in line with what is stipulated by the UN (2006), which prioritizes the involvement of people with FD in decision-making processes about policies and programs.

Also, promoting contact with other LGBT people (like support groups) is shown to have positive impacts on decreasing loneliness and promoting a more positive identity (Bates, 2020; Moreno et al., 2017; Smith et al., 2022).

As stated, the previous codes reveal the *Prevalence of FD over other belongings (Primazia de DF sobre outras pertenças)*, and the impact this has on people's autonomy and freedom of expression. Below I present some excerpts in which professionals denote feeling the weight of FD and consequent restrictions, however, it should be noted that this was denounced by the very speeches of the professionals who, even when the question was well directed to sexuality and LGBT experiences, answered having in mind only the FD of their recipients and its implications in their lives, not combining the two. This may also be symptomatic of a lack of familiarity with LGBT belonging and little knowledge of the topic.

“Portuguese society is not a very open society (...) it's still a bit conservative (...) it's not accepted in many families, isn't it? Homosexuality, right, changing gender, whatever... it's a deviation, isn't it? Maybe they see it as a deviation, (...) we don't want to create problems, even more, for that boy or girl” (H)

“It has been evolving in the area of disability, yes, sexuality. But in terms of paraplegics, that is, people who are in wheelchairs, but who already had a previous sexual life, right? Who came from a so-called normal life and then were in a wheelchair... there is already a certain concern about that... to maintain all areas. For those who were born with disabilities, motor disabilities... intellectual disabilities and when you put the two together then... it is complicated!” (J)

“to work a little bit on that, that we can deconstruct a little more and we can understand a little more because we can, can't we? Regardless of the functional diversity that exists... we need to talk about it... we need to give ourselves space, and yes, also, I think that even more so - and that would allow sexuality here - is to really deconstruct the figure and the person with functional diversity” (I)

The discourses are in line with the literature, as the stigma and shame associated with FD overlaps the gender identity and sexual orientation (Moreno et al., 2017; Wolowicz et al., 2022) and there is a minimization of other deviance from the norm to facilitate acceptance (Sommarö et al., 2020). This can contribute to the exclusion of LGBT people with FD from the LGBT community (Bates, 2020), and it is a priority to begin to recognize the diversity of people with FD (UN, 2006) and see the person and their idiosyncrasies.

3. Theme III. Cis-heteronomativity

This third theme reveals some beliefs, practices, and difficulties (that indicate needs for change) in accommodating and including LGBT people with FD in the institutions that

provide support services. These are denounced by the cis-heteronormativity that surrounds both institutions and discourses.

It's apparent the belief that both the discussion of LGBT belonging and the visibilization and fight for the rights of this community is unnecessary, in the presence of prejudice in professional staff and institutions and the consequent need for management and

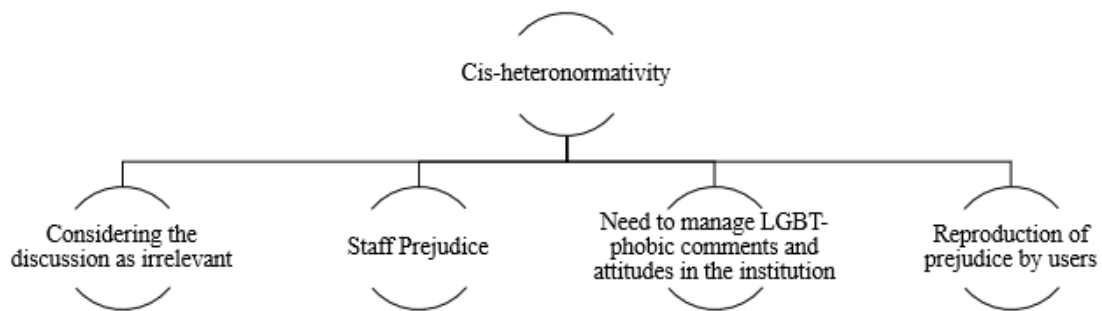


Figure 6. Theme III. Cis-heteronormativity - Codes

mitigation of this prejudice and by the reproduction of discriminatory comments by service users themselves. The view that LGBT people deviate from what is "natural" permeates life both inside and outside institutions.

The passive attitude of staff in raising sexuality-related topics is related to them *Considering the discussion as irrelevant (Visão da discussão como irrelevante)*, either by the belief that LGBT belonging is not problematic or by the belief that there is an exaggeration of LGBT demonstrations and struggles. Cultural limitations compromise open and inclusive discussion (Moreno et al., 2017; Smith et al., 2022; Wolowicz et al., 2022), which can result in users' fear of coming out to professionals (Bates, 2020).

“That's why I think there was no need for this matter to be this way... with demonstrations. Maybe it would be better, in my perspective, for people to accept themselves as they are and go about their normal lives. And not withdraw in front of third parties or through manifestations want to affirm themselves” (K)

“I never approached it, I never felt the need (...) As they were always well accepted by their peers, by the team, by everyone... it was never necessary to approach this subject with them” (G)

The denial by professionals to touch LGBT belonging because they do not find it relevant or a "problem" allows for the assumption of cis-heteronormativity and viewing recipients as sexless (Abbott & Howarth, 2007; Moreno et al., 2017; Smith et al., 2022). Moreover, it goes against the expressed wishes of service users, who consider LGBT belonging to be an essential part of their identity (Bates, 2020; McGrath et al., 2021) and results in many difficulties being left unaddressed.

Reluctance to discuss topics related to sexuality can lead to an increase in risky behaviors through lack of openness and a safe space for exploring and a lack of knowledge transmission about consent, assertiveness, and healthy behaviors (Stauffer-Kruse, 2007). Refusing to discuss the topic does not prevent behaviors, it only allows them to occur in an uninformed manner.

The idea that being LGBT is irrelevant to the provision of support to people with FD is rooted in *Staff prejudice (Preconceito do staff)*, which is reported by the interviewees and denounced by their speeches. Professionals reveal that, even unintentionally, they perpetuate discriminatory behaviors and attitudes, that staff have heterogeneous beliefs and attitudes, and furthermore, some professionals revealed, on a personal level, that they do not approve of LGBT belonging. Thus, it is not reported the refusal of the sexuality of people with FD, but the refusal of acceptance of sexualities and gender identities that deviate from the norm.

“even without thinking, even us who want to be open and not discriminate and let people be who they think they should be... sometimes we also get like that... when we are faced with those situations... sometimes we also don't react the way we wanted to” (B)

“I don't accept it for myself, but other people have their life, they have their... they think as they wish” (K)

Despite self-acceptance by users, LGBT belonging is problematized by others (Dinwoodie et al., 2020), with discriminatory attitudes being perpetuated in institutions, a lack of safety and vulnerability (McCann et al., 2016). O'Shea et al. (2020) concluded that entities providing services to people with FD often do not understand in what ways they are inaccessible or inappropriate for LGBT people, and it is necessary to challenge these biases through education (Moreno et al., 2017) as they compromise clinical skills and services provided (Bidell & Stepleman, 2017).

Given the presence of prejudice in the staff, there is a *Need to manage LGBT-phobic comments and attitudes in the institution (Necessidade de gerir comentários e atitudes LGBT fóbicos na entidade)*. This was primarily noted by interviewees who were more accepting of diverse identities and aimed to promote the comfort of users, with the goal of changing staff attitudes and developing a culture of respect (Moreno et al., 2017).

“And if there were some comments by other users or by a professional of a more homophobic nature, that person would be called in, the situation explained to them as to why they shouldn't say that, and they usually didn't say it again” (A)

“[to work through LGBT phobic beliefs and behaviors with professionals] just so that, first, the behaviors wouldn't be reproduced and, second, that [users] wouldn't feel oppressed” (I)

Studies point out that LGBT people report abuse and discrimination by staff (Bates, 2020; Dinwoodie et al., 2020) and that this weakens their sense of safety and increases their vulnerability (McCann et al., 2016). As organizations mirror the marginalization that LGBT

people experience in Western society (Smith et al., 2022), teams and professionals must access their own prejudices and discriminatory behaviors (Conover & Israel, 2018).

Finally, prejudice is also noted by the *Reproduction of prejudice by users (Reprodução de preconceitos pelos destinatários)*. Although pointed out by the professionals, these denote that it is a result of the education and environments they attend (Stauffer-Kruse, 2007), being something to work on in the institution itself. It may also be symptomatic of the absence of inclusive sex education.

“Sexual orientation, too, to start giving it representation, to start talking about it (...) the group I had was somewhat prejudiced, they only reproduced what they heard at home and on TV, obviously, but it was difficult at first, yes, but I think my challenge (...) was to build empathy (...) they sometimes had a lot of this conversation about trans people being strange”
(I)

“Among them they don't discriminate each other, neither for gender identity, nor for sexual orientation (...) this is the majority. Of course, there is always one or two that we can see has a marked parental education, even by the type of comments they make, we realize that these are not their words, right? Even by the level of grammar construction and the type of vocabulary used, we realize that they are not... they heard this at home” (J)

A study by McCann et al. (2016) finds that $\frac{3}{4}$ of the population with IFD were unaware of and/or had negative beliefs about LGB people and that some participants reported difficulty and sadness in accepting their LGB identity, potentially seeing this as another divergence (Stauffer-Kruse, 2007). However, these feelings challenge those reported by more recent research, where LGB people with FD claim pride in this belonging, which they see an essential part of their identity (Bates, 2020; Dinwoodie et al., 2020).

4. Theme IV. Need for training

In this last theme the staff explores what measures they consider necessary for the improvement of service provision, the greater inclusion of LGBT people with FD both in institutions and in the rest of society and the improvement of living conditions taking into account their belonging. The need for training was transversal to all interviewees, as well as the point that the need for multiple focuses - from younger to older generations, from informal to formal contexts. It was also pointed out the need to provide inclusive sex education to people with FD.

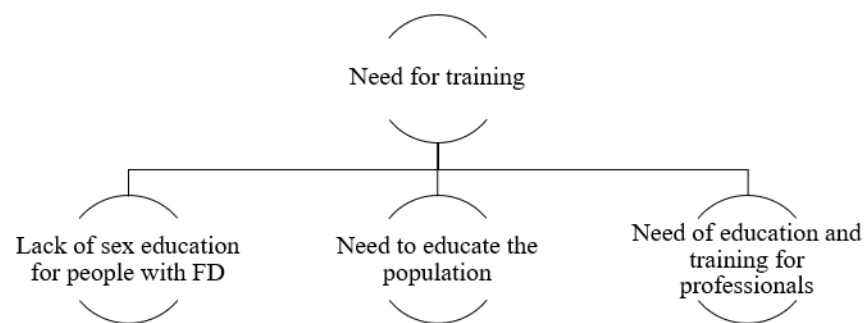


Figure 7. Theme IV. Need for training - Codes

From this theme I first highlight the *Lack of sex education for people with FD* (*Ausência de educação sexual para pessoas com DF*) and the need to implement programs that address it, include LGBT topics and are accessible. The professionals interviewed reported the lack of these contents and the ignorance that arises from this.

“There I do feel, there I feel [distinctions when talking about the topics with special education students] in the kids that topic is not, at least I didn't see, I never watched, I never saw, that they had had some education (...) someone talking to them I don't know... I never saw (...) it's not as frequent as for normative [kids]” (H)

“I researched more interactive contents to really try to make it work and pull them in, because despite everything it's still a difficult subject... it's still inaccessible, they're very annoying, these are things they've never heard of, never... sometimes even the most basic things, and the most basic terms, one associates with being known and they're not... and then

having to deconstruct and talk about it is difficult and, therefore, we really need to go to a really basic level and start from the bottom and do everything calmly. So I really looked for materials, books, games, to make things a little bit more interesting” (I)

Although studies in Portugal and the interviews state that professionals value the education of recipients on sexuality issues (de Sá, 2017), this gap also remains (de Sá, 2017; Smith et al., 2022). Tackling this misinformation can contribute to increased self-esteem, more positive perceptions of sexual relationships, and the development of decision-making skills (Smith et al, 2022), as well as ensuring rights and freedoms (UN, 2006).

However, the interviews tell us that this education should not be limited to people with FD, imposing the *Need to educate the population (Necessidade de formação para a população)*, as it ensures that the family knows how to provide the necessary support (Keates et al., 2022; McCann et al., 2016; Smith et al., 2022) and combines the work done with the individual and the family (Stauffer-Kruse, 2007), not holding only the LGBT person with FD accountable in educating those around them.

“to talk more about this (...) to have more incentive for people to participate and for us to start talking a little bit, too, without taboos” (E)

“you have to reach all the places, because they leave from there [institution] and then go to other systems, and other systems that reproduce behaviors that are not... not the most positive ones” (I)

Thus, it is clear the need to talk more about the subject in an informed way, in order to deconstruct ingrained beliefs and for there to be harmony between the different environments to which people belong.

This training should be done and made possible, as mentioned above, in collaboration with people who belong to the community and should access the beliefs and values that the family and other support systems carry (Stauffer-Kruse, 2007).

Finally, the *Need of education and training for professionals (Necessidade de formação para profissionais)* is the point most commonly noted by interviewees as fundamental to meeting users' needs, bridging gaps and discrimination, and creating a welcoming environment. Given the lack of training and guidelines reported earlier, this proves imperative. Professionals reveal a willingness to have training directed to the entire technical team and on a more recurrent basis than is currently available.

“I think it is important to have some training, both for the users and for the personal assistants” (D)

“The problem is that there is no continuous work (...). We had your education session some time ago, now it will be in five years, I don't know, with luck” (F)

“There is the technical and occupational team, right? And the technical team sometimes gets so entangled... and sometimes we are all so much on the same page that we forget the rest and what can happen in other situations in which we are not the ones in charge. (...) And it's the same for the question of sexuality, which is... either we are all oriented towards freedom, towards a simple and accessible conversation and there are no fears and no taboos and no prohibitions, or it's not worth it (...) And therefore, if there were probably the trainings and the deconstructing even of our own internal prejudices, right? To recognize that we are prejudiced at certain moments and that we practice discrimination and that maybe we can stop” (I)

Training for professionals enables greater comfort in discussing these issues and for them to be able to assist in identity exploration (Smith et al., 2022; Sommarö et al., 2020;

Stauffer-Kruse, 2007), understand the challenges unique to LGBT people and how to support them, empowers them to assess and treat sexuality-related problems in the particular context of their sexual orientation and gender identity (Moreno et al., 2017), and deconstructs the monolithic image of the LGBT person with FD (Dispenza et al., 2022).

Training should be guided by ethics and intersectionality and promote clinical competence and LGBT care (Bidell & Stepleman, 2017; Conover & Israel, 2018). It should explore accommodation of trans people (Smith et al., 2022) and the psychological process of coming out, awareness about own biases and beliefs, knowledge of the impact of language on identity development, discussion of resources available to LGBT people in the community, and how to deal with LGBT phobic behaviors (Morgan et al., 2011). Training for all staff allows for leveling and equalizing knowledge and practices, granting consistency to the institution, and should be accompanied by public investment to ensure that it is regular and constantly updated (Abbott, 2015).

Conclusion

This dissertation aimed to explore the discourses and practices of professionals who provide support services and assistance in the daily lives of people with FD around the LGBT theme. It also sought to identify what they indicate as needs for change and suggestions for improvement. The results obtained, although heterogeneous, point to a view of containment of sexual behaviors in general, and demarcated by cis-heteronormativity in the case of people with FD who are also part of the LGBT community in specific. This can be explained, in part, by the still predominant vision that does not fully recognize the right of people with FD to have access to their sexuality and bodily autonomy, but also by the need to be guided by Portuguese legislation (which restricts sexual exploitation within institutions) and by the

absence of norms defined by the entity (Abbott & Howarth, 2007; Smith et al., 2022), which leads to action only regarding prevention and conflict resolution.

Similar studies tell us that the rehabilitation and follow-up of neurodivergent people should include assessment and discussions of issues related to sexuality and sexual function in the particular context of their sexual orientation and gender identity, considering the specificities arising from FD and weighing the impact of these factors on sexual life and performance (Moreno et al., 2017). This should go hand in hand with a positive and comprehensive approach to sexuality that goes beyond risk and disease protection, but also focuses on pleasure, safety and sexual satisfaction and well-being (Almeida, 2019).

Overall, a lack of preparation by staff to address the issue was reported which may end up blaming the service users in taking the first step and opening up the discussion. This finding is in line with the literature, which tells us that staff, given a lack of training, are hesitant to address the issue and, when faced with it, feel unsure about their abilities (Abbott & Howarth, 2007; McGrath et al., 2021; Smith et al., 2022; Sommarö et al., 2020). In the case of the professionals who claimed to adopt a more active role, LGBT belonging was discussed and aimed at promoting well-being, acceptance, creating awareness, and increasing quality of life, which is in line with what similar studies define as inclusive and positive practice (Almeida, 2019; Bates, 2020; O'Shea et al., 2020). It should be noted that the latter attitude was more reported by professionals with more experience, interest and knowledge in the LGBT and sexualities theme - as the results also reported by de Sá (2017) - and represents a smaller slice of respondents, while the former is more representative. Nevertheless, it was transversal to all interviewees the respect for the will of the recipients in their non-normative sexual expression and gender identity, if expressed by the self, which, although positive, may be derived from wishful thinking, given that almost half of the interviewees have no contact, to their knowledge, with LGBT people in their professional practice. Furthermore, this result,

also obtained by Susanna Sommarö et al. (2020), may be indicative of equal treatment for everyone, which may also mean treating everyone as if they were cis-heterosexual. As the literature states, this may also be symptomatic of services that support people with FD failing to understand how inaccessible or inappropriate they are for LGBT people (O'Shea et al., 2020).

The interviews point in some directions as to the difficulties experienced and the consequent need for change to overcome them.

Among these we find the need to manage the relationship with and form the family of origin, since the latter is often very close to people with FD and can play a controlling and even castrating role in their sexual and gender exploration and expression; the need to make available inclusive and adapted sex education for people with FD; the need to make visible and hear people with FD and to LGBT people with FD specifically, both in the design of the programs aimed at them, and in LGBT communities and groups and society in general, a factor accompanied by the will to change prevailing beliefs and views about people with FD.

Furthermore, it should be noted that the primacy of FD over other characteristics of belonging prevails, especially when it is congenital, which compromises the way the person is perceived and treated. In this sense, there is also a primacy of non-normative sexual orientations over dissenting gender identities, often invisible even when there is a focus on the LGBT population (Keates et al., 2022; Smith et al., 2022; Sommarö et al., 2020).

Lastly, and most frequently mentioned, was the need for training of professionals on sexuality and LGBT issues, given the lack of education on the topics, the lack of provision of guidelines and procedures in institutions, the need to manage discriminatory behaviors in institutions and to respond to the issues and needs of the LGBT people with FD they propose to support. Despite the importance of this point, the identification of fundamental change

needs for truly inclusive services is absent, such as: knowing how to assess and intervene with LGBT people with FD keeping in mind specificities such as speech and oromotor impairments, cognitive challenges, behavior dysregulation and compromised social skills; the inclusion of partnerships in the entities; use of neutral language in the institutions; use of materials and images with non-binary people, non-heterosexual couples and that escape ablebodiedness; use of neutral bathrooms; definition of ways to report discriminatory practices and naming someone responsible for such (Moreno et al., 2017; Ubisi, 2021). The oversight of some of these changes can be explained by the attendance at the awareness raising action prior to the interviews, which may have contributed to the bias in the answers due to social desirability, appreciation of the newly acquired knowledge, and lack of understanding of other possible measures. .

Overall, the study provides access to the practices and attitudes of professionals providing support services to people with FD and how they access LGBT belonging. As it is recognized that LGBT people with FD encounter enablement, microaggressions, stigma, oppressions, and other stressors related to their minority group membership (Dispenza et al., 2022), it becomes imperative to take steps towards the design and implementation of more inclusive and welcoming services for all people that are guided by affirmative policies and that recognize sexual and affective needs as equally important as housing, employability, and general health needs (Abbott & Howarth, 2007). This shift in perspective has been proven to help promote self-acceptance and well-being and combat feelings of loneliness, depression, anxiety, and suicidal ideation (Ubisi, 2021).

The results of this study are consistent with the existing research, adding to the literature as it is, to our knowledge, the first of its kind in Portugal, thus contributing with pioneering and essential knowledge.

The main limitations are the use of articles only in English and Portuguese, given my lack of knowledge of other languages, which limits my access to information. It is also worth mentioning the information that is lost in translation, given the difficulty of capturing characteristic expressions. Third, conducting raising awareness session on the subject prior to conducting the interviews may have led to limiting some answers in favor of social desirability. Allied to this, it is possible that only people more open/with more interest in the LGBT theme joined the study. Also, the design of the interview script and the rest of the study was not accompanied by people with FD. Finally, and perhaps the most demarcated limitation, is the generality of the study. Although this focuses on two categories of belonging, both are very broad and diverse - to speak of physical FD is different from speaking of intellectual and sensory FD (and also whether they are acquired or congenital), their implications on the person's life and personal follow-up are diverse; also the LGBT community is in itself very diverse and each identification contributes a distinct care, especially if we speak of non-normative sexual orientations and gender identities (Keates et al., 2022).

Future research needs to access the discourses and experiences of LGBT people with FD and their relationship with the institutions they attend, to conduct studies with the families of these people and research focused on the implementation of affirmative practices and their impact on service delivery. It is also worth noting the importance of developing studies focused on a younger population, since this include only professionals who work with adults. Ideally all of this should be designed and monitored by people with FD. Finally, it is of utmost importance to develop specific studies that focus on the intersection of the different types of FD with the different identifications within the diverse community that is LGBT.

In conclusion, the study demonstrates that non-normative sexuality and gender identity continue to be placed on the margins in institutions and that professionals reveal little

knowledge about the topic and how to manage it within their practice. That said, more education and training is needed for greater inclusivity of services.

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Appendices

Appendix 1 – Leaflet



PESSOAS LGBTI E DIVERSIDADE FUNCIONAL: AÇÕES DE SENSIBILIZAÇÃO, CAPACITAÇÃO E INVESTIGAÇÃO

Se é uma **pessoa LGBTI com diversidade funcional/deficiência** ou se é **um/a profissional que trabalha com pessoas com diversidade funcional/deficiência** e gostaria de colaborar na segunda fase deste projeto, através de uma entrevista, **contacte-nos** para o email

diversidadelgbti.gentopia@gmail.com

Entidade promotora: **gentopia**
Associação para a Diversidade e Igualdade de Género

Fonte e enquadramento do financiamento:

 **REPÚBLICA PORTUGUESA**

 **CIG**
COMISSÃO PARA A CIDADANIA E A IGUALDADE DE GÉNERO
Ministro Adjunta e dos Assuntos Parlamentares

 **PORTUGAL MAIS IGUAL**
ESTRATÉGIA NACIONAL PARA A IGUALDADE E A NÃO DISCRIMINAÇÃO
2018 - 2020

Translation: If you are a LGBTI person with functional diversity/disability or if you are a professional working with people with functional diversity/disability and you would like to collaborate in the second phase of this project, through an interview, please contact us at

Appendix 2 – Informed Consent

Informed Consent and Confidentiality Commitment

General Framework:

The present study is part of the activities of the project *LGBTI People and Functional Diversity: Awareness raising, capacity building and research actions (Pessoas LGBTI e Diversidade Funcional: Ações de sensibilização, capacitação e investigação)*, promoted by gentopia - Association for Diversity and Gender Equality (gentopia – Associação para a diversidade e igualdade de género), with the financial support of the Commission for Citizenship and Gender Equality (Comissão para a Cidadania e a Igualdade de Género).

This phase of the project includes interviews with:

- LGBTI people with functional diversity/neurodiversity, with the following objectives: (1) to know the experiences of LGBTI people with functional diversity/neurodiversity in their various life contexts; and (2) to explore spaces of well-being, needs and/or difficulties experienced by people in contact with entities and/or with formal caregivers;
- professionals who work or have worked with people with functional diversity/neurodiversity, who aim to: (1) explore existing practices in working with this population; (2) learn about the needs and difficulties associated with the LGBTI and functional diversity/neurodiversity theme in the context where they work or have worked; and (3) identify recommendations for improvement

Participants:

Participation in the interviews is voluntary, and the right to withdraw at any time is guaranteed. To do so, simply send a message to the e-mail diversidadelgbti.gentopia@gmail.com requesting refusal to participate, without having to justify this decision. All data and clarifications collected are strictly confidential, being assured its secrecy and anonymity, so they will only be used for scientific research purposes, in accordance with the General Regulation on Data Protection (Regulamento Geral de Proteção de Dados). Only the research team attached to the project will have access to the data resulting from the interview, namely the project manager Matilde Soares, the student researchers Ana Rocha Pinho and Catarina Rêgo Moreira, as well as the project supervisors Liliana Rodrigues and Conceição Nogueira. After consenting, data will be collected regarding the participants' sociodemographic characteristics, as well as personal positions and experiences on the research theme. These data will be aggregated and will never be presented individually, since they only intend to characterize the people participating in the study as a whole. Thus, all data collected will be coded using fictitious names, when they are recorded in writing, thus ensuring anonymity in their storage, even if temporary, and analysis.

Data processing:

The interview will be recorded, with only the audio being collected, which will later be transcribed and stored in digital files, in order to allow for its analysis and interpretation of conclusions. The results may be published in a digital informative document and specialty conferences/magazines, but will not, in any case, allow the identity of the participants to be revealed. The original data (recordings and transcripts) related to the collaboration of the

people participating in the project will be destroyed after a period of 5 years, once the results have been presented and/or published.

Returning Results:

If you would like us to send you the digital information document and other documents that show the results of the project, please leave us your email address:

For clarification of questions associated with the research, you may contact:
Matilde Soares (diversidadelgnti.gentopia@gmail.com), project manager.

Thank you very much for your collaboration!

Appendix 3 – Interview script

General Aims

1. explore existing practices in working with LGBT people with FD ;
2. understand the needs and difficulties associated with LGBT and FD issues in the context in which professionals work ;
3. identify suggestions for improvement .

Questions

1. Brief introduction / icebreaker: Who are you? What is your position and duties in the association?
2. Before attending the awareness raising action, promoted by this project, what did you know about this topic?
3. How relevant do you think it is to approach this theme in the context in which you work?
4. Have you ever had or dealt with a client/person who had any situation related to sexual orientation, gender identity, gender expression and/or non-normative sexual characteristics? If yes, what was the situation/s? How was it addressed by the team? Tell me about it.
5. Did you feel/do you feel any difficulties? If yes, what difficulties did you feel (or do you feel) when dealing with this issue (when dealing with clients, with the family, with the team)?
 - 5.1. What do you think would help overcome these difficulties?
6. Do you identify any needs in the association... regarding this topic? If yes, which ones? What could be improved?
7. And on a more general, public policy level, what do you think could contribute to an effective inclusion of LGBTI people with functional diversity/ disability?
8. We are reaching the end, would you like to add anything we haven't talked about or take something back from what you said?
9. How did you feel throughout this conversation?
10. Thanks

Appendix 4 - Secrecy statement

Declaração de Sigilo

No âmbito do projeto *Pessoas LGBTI e Diversidade Funcional: Ações de sensibilização, capacitação e investigação*, promovido pela Gentopia – Associação para a diversidade e igualdade de género foram realizadas entrevistas com profissionais que trabalham/trabalharam com pessoas com diversidade funcional. As entrevistas foram conduzidas, recolhendo-se a gravação de áudio, e transcritas por membros da equipa de investigação anexa ao projeto, nomeadamente a gestora do projeto Matilde Soares, as estudantes investigadoras Ana Rocha Pinho e Catarina Rêgo Moreira, e as supervisoras do projeto Liliana Rodrigues e Conceição Nogueira. No decurso do processo de transcrição, de forma a garantir o anonimato das pessoas entrevistadas, procedeu-se à ocultação de todas as informações que permitissem a identificação da pessoa e da instituição em que prestam serviços.

Eu, *Inês Isabel Gaspar Soares*, portadora do cartão de cidadão nº 15977407, declaro que tive acesso às transcrições anonimizadas das entrevistas realizadas no âmbito do projeto *Pessoas LGBTI e Diversidade Funcional: Ações de sensibilização, capacitação e investigação e* comprometo-me a garantir a confidencialidade das informações a que tive acesso, apenas utilizando as mesmas para fins de análise e interpretação dos discursos com o objetivo de desenvolver um trabalho investigativo do qual resulta a presente dissertação de mestrado, com vista a aceder às visões de profissionais que trabalham/trabalharam com pessoas com diversidade funcional. Comprometo-me ainda a destruir as transcrições que me foram cedidas após um período de 5 anos, uma vez apresentados e/ou publicados os resultados. A eventual publicação do estudo preservará os mesmos princípios, não permitindo o acesso aos dados integrais das entrevistas.

Assinatura: *Inês Isabel Gaspar Soares*

Assinatura da gestora do projeto: *Matilde Soares*

Data: *16 junho 2023*

Translation:

Within the scope of the *project LGBT People and Functional Diversity: Awareness raising, capacity building and research actions*, promoted by Gentopia - Association for Diversity and Gender Equality, interviews were conducted with professionals who work/worked with people with functional diversity. The interviews were conducted, audio recorded, and transcribed by members of the research team attached to the project, namely the project manager Matilde Soares, the student researchers Ana Rocha Pinho and Catarina Rêgo Moreira, and the project supervisors Liliana Rodrigues and Conceição Nogueira. During the transcription process, in order to ensure the anonymity of the interviewees, all information that would allow the identification of the person and the institution where they provide services was concealed.

I, (name of the author of this study), bearer of the citizen card (card number), declare that I had access to the anonymized transcripts of the interviews conducted within the scope of the project *LGBTI*

People and Functional Diversity: Awareness Raising, Capacity Building and Research Actions and I commit to guarantee the confidentiality of the information to which I had access, only using them for the purposes of analysis and interpretation of the speeches with the aim of developing an investigative work from which the present master's thesis results, in order to access the views of professionals who work/worked with people with functional diversity. I also commit to destroying the transcripts that were given to me after a period of 5 years, once the results are presented and/or published. The eventual publication of the study will preserve the same principles, not allowing access to the full data of the interviews.

Appendix 5 - Data extracts

Theme I. Attitudes and practices of professionals

Sub-theme I. Lack of knowledge to approach the theme

Code: *Absence of guidelines by the entity*

“Podia haver a coragem para, por exemplo, num plano individual se colocasse sempre a questão da sexualidade, como se põe da alimentação, como se põe do vestuário, como se põe de outras questões que... a questão da sexualidade, não é? Ai já existia! Assim parece que já não existe (...). Mas até o técnico ter ali a palavra à frente e um quadrado para preencher já o vai fazer coçar a cabeça e isso é importante.” (F)

“Nunca falamos sobre isso [sexualidade e pertença LGBT] nas formações, portanto nós vamos muito na parte do conflito, do apoio, da forma como temos de lidar com uma série de situações” (E)

Code: *Lack of training, knowledge and cultural literacy on LGBT issues*

“O meu conhecimento não é muito amplo (...) tenho pouco conhecimento” (B)

“Muito pouco [conhecimento], muito sinceramente, quase nada (...) Vamos tendo algum contacto na televisão, mas formação e isso nunca tive contacto nenhum” (E)

“Sei o que significam as siglas. Claro que não estou bem por dentro do... sei que é uma movimentação, não é? Que existe, não é? De grupo de lésbicas, de gays... e vejo, às vezes é anúncios na televisão (...) tive conhecimento desses movimentos que circulam pelo país... é o que a gente ouve nas notícias. Agora não estou mais por dentro do assunto, não” (G)

Code: *Staff Inertia in introducing the topic*

“não são dadas, se calhar, tantas oportunidades às pessoas com deficiência e com esse... lá está, por ainda falta de informação e estarmos muito fechados, há ainda muita vergonha de conversar, de discutir esses temas” (B)

“se ele falasse comigo sobre isso não haveria problema nenhum em falar com ele, em encaminhá-lo, eu fazê-lo não me vejo nesse papel” (H)

Sub-theme II. Affirmative and positive outlook

Code: *Search for updated knowledge*

“Já tinha lido algumas coisas sobre a temática e visto filmes e lido alguns artigos, até ao nível de transexualidades, de operações, das questões hormonais, não é? Da identificação de género” (H)

“Temos de nos atualizar, conforme vamos evoluindo vamos vendo como é que se vai descobrindo as coisas e vai se percebendo que orientação sexual ou identidade de género não é um distúrbio psiquiátrico, não é uma moda, não é uma birra contra a sociedade, é algo que as pessoas simplesmente nasceram ou no corpo errado ou com gostos que não..., no caso do corpo errado eu ia dizer que errado nunca é a palavra, mas aqui pode ser, sim! A mente não corresponde às características físicas... ou realmente tem uma orientação sexual diferente do que foi considerado normal. Isto acontece em todo o lado e há muitos anos... esta coisa não é moda de agora, porque se formos a ver à parte da história, já no tempo dos reis isto era normalíssimo, não era nada de... nós é que gostamos de complicar!” (J)

Code: *Promotion of the discussion of LGBT belonging*

“Eu acho que é fundamental [abordar temática LGBT]. Principalmente para os destinatários (...) acho que é importante mais para... nesse aspeto de abrir caminhos para a pessoa poder se expressar” (D)

“Na altura cheguei a falar com a pessoa que estava responsável por essa área para que pudesse explorar em grupo com os restantes colegas, e tudo, essa questão [IG não normativa de uma destinatária]. E também ajudá-lo, se calhar, a definir o que estava a acontecer ou a compreender-se um bocadinho melhor” (I)

“Os pais foram ficando mais abertos em algumas coisas. Nós temos feito, também, um esforço, também, para isso. Fazemos sempre algumas formações nessa área, na área da sexualidade, na área de saber lidar – quer com os nossos utentes quer com os familiares – a nível de identidade de género, a nível de orientação sexual. E temos feito um esforço para ir falando com os pais sobre isto” (J)

Code: *Sharing LGBT experiences for self-acceptance and promotion of well-being*

“Mas ainda assim é muito bom ele ter feito [coming out] e ter tido aquela abertura dos colegas e, realmente, a reação do grupo não foi má, não foi... foi positiva. E acho que pode ter sido bom para que ele, também, experienciasse aceitação (...) para também começar a dar um bocadinho de aceitação dentro dele mesmo” (I)

“Eu teria de gerir a questão, gerir de uma forma pouco técnica ou clínica até (...), se isso vier a acontecer aquilo que eu... aquilo que nós esperamos, com certeza, é assegurarmos que aquele profissional elabora essa questão de uma forma adaptativa para a pessoa que apoia, não é? O que importa é garantir o bem-estar da pessoa apoiada. Mais do

que isso não faria... talvez assegurar que (...) os serviços... continuariam a ser prestado com qualidade de vida” (F)

Code: *Creation of projects about sexuality in the institution*

“O conhecimento que eu tinha [da temática LGBT em DF] veio muito e em larga medida da experiência prévia que eu vos dei conta do projeto da sexualidade em pessoas com deficiência (...) foi uma coisa que me levou a ver, a estudar, a pesquisar. Cheguei a reunir com associações (...), congressos que acabei por participar e isso também me deu a oportunidade de conhecer gente muito, muito interessante e com um conhecimento muito, muito grande sobre essas questões (...) aprendi imenso, imenso mesmo” (F)

“comecei pelo projeto da sexualidade... e comecei a explorar isso com eles (...) fiz intervenção com cuidadores e até profissionais” (I)

Sub-theme III. Adaptation of staff to accommodate users

Code: *Respect for the user's will*

“para mim, o que é importante é que a pessoa se sinta bem com... consigo própria consiga assumir-se e viver de acordo com a sua orientação, aquilo que sente no fundo” (H)

“claro que há certas situações que nos causa estranheza, porque não estamos habituados a contactar, a lidar, mas iria dar o meu melhor e ajudar a pessoa no que ela precisasse” (B)

“É fazer o que o destinatário quer. Se ela quer e ela não consegue fazer por si só a gente tem de fazer” (D)

Code: *Adaptating discourse and tools to address LGBT issues to the user*

“Nós temos dois casos aqui... é assim relevante [abordar temática LGBT no contexto em que trabalha] (...), depende do caso e claro que poderia ser algo benéfico, depende se estivéssemos a falar com jovens com uma deficiência ligeira, não é? Agora não vamos estar a falar para um grupo de utentes com uma deficiência moderada ou grave que não vão perceber nada do que é que eu estou para ali a dizer (...). Teríamos de ter uma linguagem mais simples, não é? Saber o que é que nós poderíamos abordar com eles de forma a que eles nos compreendessem” (G)

“Termos os conteúdos certos [para fazer E.S inclusiva], porque há muita coisa – filmes e séries – mas depois, também, tens aqui a dificuldade de acessibilidade, não é? Se for com legendas muitos deles não vão ler, se for dobrado muitos deles vão-se queixar do brasileiro” (I)

Theme II. Challenges specific to this population

Code: *Dependence on others as an obstacle to sexual and gender expression*

“sim, [pessoas com DF] têm ainda mais barreiras, porque... principalmente se forem muito dependentes de outras pessoas ainda se torna mais complicado (...) se está dependente de que outra pessoa lhe faça... se a pessoa não respeita as ideias dele, pronto, é muito mais complicado” (B)

“É muito difícil falar sobre estes assuntos ainda em Portugal. Portugal, interior, (...) estamos a falar numa população envelhecida (...) vêm de uma educação católica

conservadora (...) falar de masturbação, falar de orientação sexual, falar de identidade de género, nada disto é aceite, não é? (...) tenho famílias diferentes, mas é difícil, é difícil...” (J)

Code: *Management of the relationship with the family of origin*

“É bastante importante e não é muito... às vezes não é muito fácil [abordar temática] (...) é importante manter uma distância ótima, não nos podemos aproximar demasiado, nem podemos ser também demasiado distantes, pronto, o meu objetivo é ser um apoio, um auxílio. Só que também nós não podemos sobrepor à família, à própria pessoa, não é? E estar a incentivar ou retrain... tem de partir dele próprio” (H)

“Agora, se fosse uma criança menor aí torna-se mais complicado, porque, exato, há a questão dos pais, não é? Em que nós ao estarmos a ir contra a vontade dos pais, e quando os pais não aceitam, torna-se uma situação complicada de gerir; mas ia tentar sempre ajudar no que pudesse o jovem” (B)

Code: *Need to make LGBT people with FD visible*

“Essas pessoas precisam ser ouvidas” (D)

“Neste caso eu acho que não deveria haver separação, só por ter alguma deficiência, do resto do movimento. Ou seja, eles é que se deviam integrar no movimento. Não tem de haver uma separação, porque não é por ter uma deficiência que tem de existir um movimento à parte” (G)

“Eu sou muito chateada como nós gerimos a diversidade funcional e depois a sexualidade como consequência e sim... deixa-me muito triste que continua-se a não dar a palavra a quem tem de ser dada” (I)

Code: *Prevalence of FD over other belongings*

“a sociedade portuguesa não é uma sociedade muito aberta (...) ainda é um bocado conservadora (...) não é aceite em muitas famílias, não é? A homossexualidade, pronto, a mudança de género, o que seja... é desvio, não é? Se calhar vêm como desvio, (...) não queremos estar a criar problemas, mais ainda, àquele miúdo ou miúda” (H)

“Tem estado a evoluir na área da deficiência, sim, a sexualidade. Mas a nível de paraplégicos, ou seja, de pessoas que ficaram em cadeiras de rodas, mas que já tinham uma vida sexual anterior, ou não é? Que vinham de uma vida dita normal e depois ficaram numa cadeira de rodas... aí já há uma certa preocupação sobre isso... manter todos os campos. Para quem já nasceu com deficiência, deficiência motor... deficiência intelectual e quando se junta as duas coisas então... é complicado!” (J)

“trabalhar um bocadinho isso que dá para desconstruir um bocadinho mais e dá para perceber um bocadinho mais porque sim, não é? Independentemente da diversidade funcional existe... é preciso falar-se... é preciso dar-se espaço e sim, também, acho que ainda mais – e que permitiria aqui a sexualidade – é mesmo desconstruir a figura e a pessoa com diversidade funcional” (I)

Theme III. Cis-heteronormativity

Code: *Considering the discussion as irrelevant*

“É por isso que eu acho que não havia necessidade desta matéria ser assim... com manifestações. Seria se calhar melhor, na minha perspetiva, as pessoas aceitarem-se como

são e fazerem a vidinha normal. E não se retraírem perante terceiros ou por meio de manifestações quererem-se afirmar” (K)

“Nunca abordei, nunca senti essa necessidade. (...) Como eles sempre foram bem aceites pelos colegas, pela equipa, por todos... nunca foi preciso abordar esse tema com eles” (G)

Code: *Staff prejudice*

“mesmo até sem pensar, mesmo nós que queremos estar abertos e não recriminar e deixar as pessoas serem aquilo que elas acham que devem ser... às vezes também ficamos assim como que... ao deparar-nos com essas situações... às vezes também não reagimos da forma que queríamos reagir” (B)

“Eu não aceito para mim, mas os outros têm a vida deles, têm a... pensam como eles quiserem” (K)

Code: *Need to manage LGBT-phobic comments and attitudes in the institution*

“E sendo que havia às vezes algum comentário por parte de outros utentes ou por parte de algum profissional que fosse assim de cariz mais homofóbico, essa pessoa era chamada, explicada a situação do porque é que não deveria dizer aquilo e habitualmente não voltava a repetir-se” (A)

“era [trabalhar crenças e comportamentos LGBT fóbicos com os profissionais] só para que, primeiro, os comportamentos não fossem reproduzidos e, depois, que [destinatários] não se sentissem reprimidos” (I)

Code: *Reproduction of prejudice by users*

“A orientação sexual, também, começar a dar representatividade a isso, começar-se a falar disso. (...) O grupo que eu tinha era q.b. preconceituoso, só reproduziam o que ouviam em casa e na televisão, como é óbvio, mas de qualquer das formas inicialmente foi difícil, pronto, mas sim acho que o meu desafio (...) foi criar empatia (...) eles tinham às vezes muita esta conversa dos trans que era estranho” (I)

“Entre eles não se recriam, nem por identidade de género, nem por orientação sexual (...) isto a maioria. Claro que depois há sempre um ou outro que se nota que tem ali vincado a educação dos pais, até pelo tipo de comentário que fazem, nós percebemos que aquilo não são palavras deles, não é? Até pelo nível de construção de gramática e o tipo de vocabulário utilizado, nós percebemos que não... isto ele ouviu lá em casa” (J)

Theme IV. Need for training

Code: *Lack of sex education for people with FD*

“Aí sinto, aí sinto [distinções quando se fala dos temas com alunos de educação especial] nos miúdos esse tema não é, pelo menos não vi, nunca assisti, nunca vi, que eles tinham tido alguma formação (...) ir falar alguém para eles não sei... nunca vi (...) não é tão frequente como para os normativos” (H)

“pesquisei mais conteúdos interativos para tentar mesmo que corresse bem e que puxasse por eles, porque apesar de tudo não deixa de ser uma temática difícil... não deixa de ser inacessível, são muito chatos, são coisas que nunca ouviram falar, nunca... às vezes até as coisas mais básicas, e termos mais básicos, uma pessoa associa a serem conhecidos e não

são... e depois ter de desconstruir e falar sobre isso é difícil e, portanto, nós precisamos mesmo de ir ali a um nível mesmo básico e começar de baixo e fazer tudo com calma. Por isso procurei mesmo materiais, livros, jogos, para que as coisas fossem um bocadinho mais interessantes” (I)

Code: *Need to educate the population*

“falar mais disto (...) haver mais incentivo para que as pessoas possam participar e começarmos a falar um pouco, também, sem tabus” (E)

“é necessário chegar a todos os cantos, porque eles saem dali e a seguir vão para outros sistemas, e outros sistemas que reproduzem comportamentos que não são... não são os mais positivos” (I)

Code: *Need of education and training for professionals*

“Eu acho que é importante formações, tanto para os destinatários quanto para assistentes pessoais” (D)

“O problema é que não há um trabalho contínuo (...). Tivemos há algum tempo a vossa formação, agora só daqui a 5 anos, sei lá, com sorte” (F)

“Existe a equipa técnica e ocupacional, não é? E a técnica às vezes emaranha-se tanto... e às vezes estamos todas tão dentro da mesma linha que nos esquecemos do restante e do que pode acontecer noutras situações em que não somos nós que estamos a atuar. E, portanto, é realmente importante que esteja toda a gente na mesma linha. (...) E é igual para a questão da sexualidade, que é... ou estamos todos orientados para uma liberdade, para uma conversa simples e acessível e não há medos e não há tabus e não há proibições, ou não

vale a pena (...) E portanto, se houvesse provavelmente as formações e o desconstruir até os próprios preconceitos internos, não é? Reconhecer que somos preconceituosos em determinados momentos e que exercemos discriminação e que se calhar podemos parar” (I)