

# **Deinstitutionalization and Well-being of Individuals with Disabilities: The Role of Music Therapy**

Maria Tezza

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**Deinstitutionalization and Well-being of Individuals with Disabilities:  
The Role of Music Therapy**

Maria Tezza

Relatório de Estágio apresentado à Faculdade de  
Psicologia e de Ciências da Educação da  
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P O R T O

## **ABSTRACT**

The report entitled "Deinstitutionalization and Well-being of Individuals with Disabilities: The Role of Music Therapy" explores the influence of music therapy on the quality of life of individuals with disabilities. This investigation was conducted within a curricular internship in the Master's in Education Sciences (MCED) program, focusing on Education, Communities, and Social Change: Ageing and Socio-educational Intervention.

The internship took place at the Estímia Foundation in Barcelona, in a Residence for People with Disabilities, between September 2022 and March 2023.

During this period, a variety of activities were developed, including a comprehensive music therapy program. This program included weekly group music therapy sessions, led by a qualified music therapist and the intern, to establish an inclusive and supportive environment for residents to participate in music-making. These sessions served as a powerful means of self-expression, emotional release, and social interaction, promoting a sense of community and empowerment among the participants.

Data collection was a fundamental aspect of this process. Various methods were involved, including participant observation, field notes, spontaneous informal conversations with users, and interviews. These diverse data sources shed light on the profound impact of music therapy on the well-being of individual with disabilities.

The outcomes of this project are encouraging and enlightening. The data reveal that music therapy had a significantly positive effect on the well-being of the participants. Specifically, it facilitated better emotional expression and increased social interaction among the participants. Beyond the immediate impact on quality of life, this project is driven by a broader vision. A central focus lies in empowering and promoting self-determination among the participants by creating an environment that encourages active participation and decision-making, moving away from traditional institutional practices and adopting an approach that empowers each individual.

This academic experience in an institution for people with disabilities has significantly contributed to my growth, allowing me to reflect profoundly on the potential of music therapy as an educational response within institutional contexts, ultimately enhancing the quality of life for users. This personal enrichment journey has significantly enhanced my professional expertise as an Educational Science specialist.

**Keywords:** Music Therapy, disability, institutionalized individuals, quality of life, empowerment, self-determination, Curricular Internship.

## RESUMO

O relatório intitulado "Dessinstitucionalização e Bem-estar de Pessoas com Deficiência: O Papel da Musicoterapia" explora a influência da musicoterapia na qualidade de vida de indivíduos com deficiência. Este trabalho decorre de um estágio curricular realizado como parte do programa de Mestrado em Ciências da Educação (MCED) no campo da Educação, Comunidades e Mudança Social: Envelhecimento e Intervenção Sócio-Educacional.

O estágio ocorreu na Fundação Estímia, em Barcelona, numa Residência para Pessoas com Deficiência, entre setembro de 2022 e março de 2023. Durante este período, foi desenvolvido um conjunto de atividades diversas, incluindo um abrangente programa de musicoterapia. Esse programa incluiu sessões semanais de musicoterapia em grupo, lideradas por um musicoterapeuta qualificado e pela estagiária, com o objetivo de criar um espaço inclusivo e acolhedor para os residentes se envolverem na criação musical. Essas sessões serviram como um poderoso meio de autoexpressão, liberação emocional e interação social, promovendo um sentido de comunidade e empoderamento entre os participantes.

A recolha de dados foi um aspeto fundamental neste processo. Foram mobilizados diversos métodos, incluindo observação participante, notas de terreno, conversas informais espontâneas com os usuários e entrevistas. Essas diversas fontes de dados lançaram luz sobre o profundo impacto da musicoterapia no bem-estar de pessoas com deficiência.

Os resultados deste projeto são encorajadores e esclarecedores. Os dados revelam que a musicoterapia teve um efeito significativamente positivo no bem-estar das pessoas participantes. Nomeadamente, facilitou uma melhor expressão emocional e promoveu uma maior interação social entre os participantes. Além do impacto imediato na qualidade de vida, este projeto é impulsionado por uma visão mais ampla. Um foco central está em capacitar e promover a autodeterminação entre os participantes ao criar um ambiente que incentiva a participação ativa e a tomada de decisões, afastando-se das práticas institucionais tradicionais e adotando uma abordagem que capacita cada indivíduo.

Esta experiência académica em uma instituição para pessoas com deficiência contribuiu significativamente para o meu crescimento, permitindo-me fazer reflexões aprofundadas sobre o potencial da musicoterapia como uma resposta educacional dentro de contextos institucionais, aumentando, em última análise, a qualidade de vida dos utentes. Esta jornada de enriquecimento pessoal fortaleceu significativamente a minha experiência profissional como especialista em Ciências da Educação.

Palavras-chave: Musicoterapia, deficiência, indivíduos institucionalizados, qualidade de vida, empoderamento, autodeterminação, Estágio curricular.

## RESUMÉ

Le rapport intitulé "Désinstitutionalisation et bien-être des personnes handicapées : le rôle de la musicothérapie" explore l'influence de la musicothérapie sur la qualité de vie des personnes handicapées. Ce travail découle d'un stage curriculaire réalisé dans le cadre du programme de Master en Sciences de l'Éducation (MCED) dans le domaine de l'Éducation, des Communautés et du Changement Social : Vieillesse et Intervention Socio-Éducative.

Le stage s'est déroulé à la Fondation Estímia à Barcelone, au sein d'une Résidence pour Personnes Handicapées, entre septembre 2022 et mars 2023. Pendant cette période, diverses activités ont été développées, dont un programme complet de musicothérapie. Ce programme comprenait des séances hebdomadaires de musicothérapie de groupe, dirigées par un musicothérapeute qualifié et le stagiaire, dans le but de créer un espace inclusif et accueillant pour les résidents afin de s'engager dans la création musicale. Ces séances ont servi de puissant moyen d'expression de soi, de libération émotionnelle et d'interaction sociale, favorisant un sentiment de communauté et d'autonomie parmi les participants.

La collecte de données a été un aspect fondamental de ce processus. Diverses méthodes ont été utilisées, notamment l'observation des participants, les notes de terrain, les conversations informelles spontanées avec les utilisateurs et les entretiens. Ces sources diverses de données ont éclairé l'impact profond de la musicothérapie sur le bien-être des personnes handicapées.

Les résultats de ce projet sont encourageants et éclairants. Les données révèlent que la musicothérapie a eu un effet positif significatif sur le bien-être des participants. Plus précisément, elle a facilité une meilleure expression émotionnelle et une augmentation de l'interaction sociale parmi les participants. Au-delà de l'impact immédiat sur la qualité de vie, ce projet est porté par une vision plus large. Un accent central est mis sur l'autonomisation et la promotion de l'autodétermination parmi les participants en créant un environnement qui encourage la participation active et la prise de décision, en s'éloignant des pratiques institutionnelles traditionnelles et en adoptant une approche qui responsabilise chaque individu.

Cette expérience académique au sein d'une institution pour personnes handicapées a largement contribué à mon développement personnel et professionnel, me permettant de réfléchir profondément au potentiel de la musicothérapie comme réponse éducative dans des contextes institutionnels, améliorant en fin de compte la qualité de vie des utilisateurs. Ce parcours d'enrichissement personnel a considérablement renforcé mon expertise professionnelle en tant que spécialiste en sciences de l'éducation.

Mots-clés: Musicothérapie, handicap, individus institutionnalisés, qualité de vie, autonomisation, autodétermination, Stage Curriculaire.

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## **LIST OF ABBREVIATIONS**

FPCEUP - Faculdade de Psicologia e de Ciências da Educação da Universidade do Porto

ICF - International Classification of Functioning, Disability, and Health

ICIDH - International Classification of Impairments, Disabilities, and Handicaps

IP - Individualized Plan

NT- Notas de tereno

PO - Participant observation

QoL – Quality of Life

WHO - World Health Organization

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## INTRODUCTION

The curricular internship of the Master's in Educational Sciences at the Faculty of Psychology and Educational Sciences of the University of Porto aims to promote the initiation into autonomous professional practice and integration into the professional environment through contact with professional contexts (cf. Art.º 1º Do Regulamento de Estágio Curricular do Ciclo de Estudos Conducente ao Grau de Mestre em Ciências da Educação da Faculdade de Psicologia e de Ciências da Educação da Universidade do Porto)<sup>1</sup>.

The field of study, "*Questões Aprofundadas sobre Envelhecimento e Intervenção Socioeducativa*" holds immense significance in contemporary society. As populations continue to age, the needs and rights of older individuals have garnered increasing attention. Developing comprehensive strategies and interventions that promote their well-being and social inclusion is crucial. Moreover, within the context of disabilities, individuals face unique challenges that require specialized support and care.

The internship took place at Fundació Estimia, a non-profit organization located in Barcelona. The mission of this institution is to facilitate the development of people with disabilities and provide support to them and their families throughout important life processes. This internship presents a remarkable opportunity to gain hands-on experience in the field, allowing me to explore the intricacies of providing social and educational interventions for adults with disabilities. By actively engaging with the institution and its residents, I had the privilege of observing, interacting, and assisting individuals with disabilities in their daily lives. This experience fostered a deeper understanding of the complexities surrounding aging and the specific challenges this population faces.

From a personal standpoint, this internship has provided me with invaluable insights into the lives of individuals with disabilities. Witnessing their resilience and determination has enriched my understanding and reaffirmed my commitment to fostering inclusivity and advocating for their rights. Furthermore, this internship's social and scientific relevance lies in the opportunity to contribute to the existing body of knowledge regarding aging and social and educational intervention for individuals with disabilities.

The thematic focus of this internship was diverse yet interconnected with my field of study, particularly within the curriculum unit of Intervention Methodologies in Education. The internship encompassed various phases, each contributing to a comprehensive understanding of the subject matter. These phases are as follows:

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<sup>1</sup> Universidade do Porto, MCED, (2012) *Regulamento de Estágio Curricular do Ciclo de Estudos Conducente ao Grau de Mestre em Ciências da Educação da Faculdade de Psicologia e de Ciências da Educação da Universidade do Porto*

- Moment of Entry: this phase involved the initial introduction to Fundació Estimia, its staff, and its residents. It allowed me to familiarize myself with the institution's values, objectives, and existing practices.
- Integration into the Dynamics of the Institution: during this phase, I gradually integrated myself into the daily dynamics of the institution. By actively participating in activities and engaging with the residents, I gained insights into their experiences and the challenges they faced.
- Assuming My Role in the Institution: I assumed a specific role within Fundació Estimia in this phase, aligning my skills and interests with the institution's needs. This allowed for a more focused and impactful contribution to the residents' well-being.
- Systematic Involvement in the Existing Dynamics: the final phase involved systematic involvement in the ongoing dynamics of the institution. Through continuous collaboration with the staff and residents, I actively contributed to existing initiatives, identifying areas for improvement and implementing effective interventions.

As a culmination of this internship experience, I dedicated significant time to the development of various interventions, with a particular focus on music therapy. One specific area of interest within this field was exploring the impact of music therapy on the quality of life of people with disabilities. With a strong belief in the power of music for this population, I collected extensive data to support my research.

The report that documents this internship is organized into five distinct chapters, each serving a specific purpose and collectively providing a comprehensive overview of the internship experience. The content is summarized as follows:

Chapter 1: *Presentation and characterization of the internship institution context.*

The first chapter focuses on presenting and characterizing the internship context and the institution where it took place. It provides essential details such as the institution's name, activity sector, location, mission and activity program. By outlining these aspects, the chapter sets the stage for understanding the specific context in which the internship was conducted.

Chapter 2: *Theoretical Framework and Problematisation.*

This chapter delved into disability, its classifications, and support approaches, alongside institutionalisation and the ensuing deinstitutionalisation movement. Emphasizing the rights and needs of individuals with disabilities, I highlighted self-determination, autonomy, and social inclusion as pivotal. Central to my discourse was the holistic concept of quality of life, spanning physical, emotional, social, and psychological dimensions. I established a profound connection between self-determination, autonomy, social inclusion, quality of life, and music therapy. Music therapy emerged as a transformative tool, empowering individuals with disabilities through creative

expression and independent decision-making. This chapter forms the foundation for understanding music therapy's potential to enhance well-being and autonomy for this population.

Chapter 3: *Theoretical – Methodological and Ethical foundation of the project.*

The third chapter presents the theoretical, methodological, and ethical foundations that underpin the internship project. It outlines the diverse options and methodologies used for data collection, such as participant observation, field notes, and qualitative interviews. Additionally, it raises and addresses ethical questions that arise in the context of socio-educational work within the institution. This chapter sheds light on how the intern integrated into the dynamics of the institution while adhering to ethical considerations.

Chapter 4: *Internship Journey: Building Identity, Reflections, and Interventions.*

Chapter Four delves into the essence of the internship experience, which can be summarized through four key themes: integration into the institutional context and assimilation within the Estimia team, followed by an exploration of various actions, including informal conversations and activities with users. The chapter then offers a detailed description of the music therapy project designed to enhance the quality of life of individuals with disabilities. This project involved weekly music therapy sessions aimed at creating a therapeutic and inclusive environment for the participants. The chapter also explores the possibilities and institutional constraints that influenced the intern's work, providing valuable insights into the lived experiences and the development of activities within the internship setting.

Chapter 5: *Music Therapy and Quality of Life: The Results*

In the fifth chapter, the observed "results" of the internship are presented and discussed. The impact of the intern's actions and interventions is explored, aligning them with their predefined objectives and goals. Additionally, the evaluation methods employed to assess these outcomes are detailed. The results observed include a significant improvement in the quality of life for individuals with disabilities, characterized by enhanced emotional well-being, self-determination, autonomy and social inclusion. These outcomes highlight the potential of music therapy as a transformative tool.

Chapter six: *Final Considerations.*

The final section of the report encompasses a reflection on the contribution of the internship to the intern's skills development and professional growth within the field of Educational Sciences. It serves as a moment for introspection, considering the knowledge gained, the challenges faced, the contributions to the Institution and the construction of professionalism during the internship period. The structure of the report ensures a comprehensive examination of the internship experience. It encompasses the presentation of the context and internship institution, the theoretical framework and problematisation, the theoretical, methodological, and ethical basis of the project, the intervention and activities undertaken during the internship, and the presentation and discussion of the observed "results." The report concludes with a thoughtful reflection on the intern's professional

development and the significance of the internship experience within the field of Educational Sciences.

In summary, this internship at Fundació Estimia in Barcelona, which took place from September to March, offered a valuable opportunity to work with adults and elderly with disabilities and immerse myself in the institution's activities. The report outlines the phases of the internship, the institution's mission, and my specific role within the organization. Moreover, it emphasizes the exploration of music therapy and its potential impact on enhancing the quality of life for individuals with disabilities.

## CHAPTER I

# PRESENTATION AND CHARACTERIZATION OF THE INTERSHIP CONTEXT

### 1.1. FUNDACIÓ ESTIMIA

*Estimia Foundation* is a non-profit organization in Barcelona, Spain, dedicated to supporting the development of individuals with disabilities and accompanying them and their families through important life processes.<sup>2</sup>

The foundation strives for excellence and quality in its services while maintaining a strong commitment to social welfare and actively addressing the needs of the disability community.<sup>3</sup>

With a rich history of over 60 years serving individuals with disabilities, the organization initially operated as *Auxilia Association* before transitioning into the Private *Auxilia Barcelona Foundation* and eventually adopting the name *Estimia Foundation*, officially registered in the Foundation Registry of the Government of Catalonia.<sup>4</sup>

Estimia Foundation offers comprehensive services spanning various stages of life, including:

- Special Education School: Escuela Estimia,
- Occupational Centre: Taller Estimia,
- Residential Care Service: Residencia Estimia.<sup>5</sup>

The foundation operates on the following principles:

- People are the axis of our work.
- The team, enthusiastic and constantly training, is the foundation of a high-quality project.
- Remaining open to new needs and adapting accordingly.
- Collaborating with experts in relevant fields to deliver the best possible services.<sup>6</sup>

#### 1.1.1. History

In 1950, Auxilia took its first steps in providing care for people with disabilities, drawing inspiration from the French model. They initiated a network of groups formed by families, friends, and other individuals sensitive to disabilities, which coordinated and worked on a voluntary basis throughout the country. During this initial period, the focus was primarily on distance learning, establishing a

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<sup>2</sup> Fundacioestimia.org. (2022). La Fundació - Fundació Estimia. [online]  
Available at: <https://fundacioestimia.org/la-fundacio> (Accessed 14 July 2023)

<sup>3</sup> ibidem

<sup>4</sup> ibidem

<sup>5</sup> ibidem

<sup>6</sup> ibidem

nationwide team of volunteer teachers with the goal of providing education to all individuals with disabilities who did not have access to schooling.<sup>7</sup>

Later, a professionalization process began in response to the demands of families, coinciding with the regulation and organization of disability care services gradually implemented in different autonomous communities.

The first services were created in Catalonia:

- 1972: Special Education School
- 1981: Applied Arts Workshop "l'Àmfora"
- 1984 : Workshop "l'Arc de Sant Martí"<sup>8</sup>

In 2000, both workshops merged to form what is now the Estimia Occupational Centre.

In 2002, the association promoted the creation of the Private Auxilia Barcelona Foundation to directly manage and oversee these services at the local level. These services have been operating continuously to this day, making our experience in the sector relevant.<sup>9</sup>

Driven by the need to address new needs, the Private Auxilia Barcelona Foundation worked on constructing and implementing a new service: the Residential Care Service.<sup>10</sup>

In 2014, the Residential Care Service was launched, marking a new phase for the organization, which has grown in terms of the number of individuals served, services provided, and the professional team.<sup>11</sup>

This year, with the collective effort, the foundation has been able to provide support to individuals with disabilities and their families in all stages of life.<sup>12</sup>

The foundation has grown, revitalized itself, and adopted a new name: *Fundación Estimia*, which currently oversees all the services.<sup>13</sup>

## 1.2. ESCUELA ESTIMIA

Estimia School is a subsidized school by the Department of Education of the Government of Catalonia that caters to students between the ages of 3 and 21 with special educational needs. The school aims to provide the appropriate tools and resources to achieve higher autonomy and improve the quality of life for children through the development of cognitive, motor, social, and emotional abilities, and skills.<sup>14</sup>

The curriculum for early childhood and primary education, as outlined by the Department of Education, is adapted to meet the needs of the students through an initial adaptation, followed by program planning

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<sup>7</sup> Fundacioestimia.org. (2022). La Fundació - Fundació Estimia. [online]  
Available at: <https://fundacioestimia.org/la-fundacio> (Accessed 04 July 2023)

<sup>8</sup> ibidem

<sup>9</sup> ibidem

<sup>10</sup> ibidem

<sup>11</sup> ibidem

<sup>12</sup> ibidem

<sup>13</sup> ibidem

<sup>14</sup> ibidem



for the cycles, and finally, adjusting the programming to the individual needs of each student through the Individualized Plan (IP). The students are grouped into cycles: Early Childhood Education, Initial, Middle, Upper Primary Education, and Secondary Education.<sup>15</sup>

The professionals accompany and guide the children in their teaching and learning process, creating the conditions for all students to be in a comforting, stable, and motivating context where they can develop their aptitudes and enhance their cognitive, communicative, and socio-emotional competencies. The teaching staff, composed of a multidisciplinary team, maintains continuous communication and review, with the active participation of families as an integral part of this collaborative work.<sup>16</sup>

The classrooms are organized by age, with groups of 5 to 7 students who have diverse cognitive, emotional-behavioural, and multi-disability characteristics.<sup>17</sup>

The team of professionals is involved in different areas of intervention:

Psychopedagogical Area, Psychology Area, Speech Therapy and Technical Resources Area, Physiotherapy Area, Health Care / Nursing, Socio-family Support<sup>18</sup>

They advocate for a shared education model (“modelo de escolaridad compartida”) as an inclusive approach for students who can access regular schools and benefit from an enriching option to enhance their cognitive, behavioural, and social skills.<sup>19</sup>

### **1.3. TALLER ESTIMIA**

The Occupational Centre Taller Estimia is a semi-public centre associated with the Department of Social Welfare and Family of the Government of Catalonia. Individuals, over 16 years old, affected by various neurological, genetic, and motor disorders, with physical, psychological, and sensory sequelae are accompanied in this facility.<sup>20</sup>

The goal is to promote social inclusion by providing different supports to achieve maximum personal autonomy, improve quality of life, and facilitate community participation. Educators, assistants, psychologists, and social workers provide comprehensive and integrated support to the users.<sup>21</sup>

The centre offers two services to adapt activities and support the needs of everyone in order to develop, maintain, and enhance their capabilities:

- Occupational Therapy Service
- Orientation and Insertion Service<sup>22</sup>

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<sup>15</sup> Fundacio Estimia (2023) Taller I Centre ocupacional [pdf file]

<sup>16</sup> ibidem

<sup>17</sup> ibidem

<sup>18</sup> ibidem

<sup>19</sup> ibidem

<sup>20</sup> ibidem

<sup>21</sup> ibidem

<sup>22</sup> ibidem

### **1.3.1.Activities**

The scheduled activities enhance the capacity for choice, interpersonal relationships, and personal growth to achieve greater autonomy and well-being. The following activities are provided: crafts, new technologies and communication, manipulatives, gardening and horticulture, memory workshop and cognitive stimulation, relaxation, leisure, recreational activities, and outings.<sup>23</sup>

### **1.3.2.Intervention program**

The guiding principle of any intervention is respect for the individual and their needs. The model is person-centred and is based on strategies and necessary supports to promote the relationship with the environment and the development of their capabilities.<sup>24</sup>

The objective is to provide opportunities that allow individuals to experience the satisfaction of achieving goals and enjoying rich and diverse experiences and activities. A Personal and Specific Care Program for each user is developed annually and evaluated in both services.<sup>25</sup>

## **1.4. RESIDENCIA ESTIMIA**

The internship took place in Residencia Estimia where I had the opportunity to stay from September until March and where I am now working. The following pages are going to give an overview of the Institution.

Estimia Residence is a residential care service for people with disabilities that also offers various rehabilitation activities, both within and outside the residence, as well as leisure and recreational activities. It has a capacity for 30 individuals over the age of 18.<sup>26</sup>

The care model at Estimia Residence is based on person-centred work, through active listening, flexibility, inclusion in the community, while maintaining family ties and enthusiasm. The aim of the team is to achieve the maximum quality of life in a close and familiar environment while maintaining individualised quality treatment.<sup>27</sup>

Since its opening in 2014, the team's objective has been to achieve the highest quality of life in a close and familiar environment while maintaining a high-quality individualized approach.<sup>28</sup>

The general objectives of Residencia Estimia are the following:

- Provide a suitable and adapted substitute home environment for the needs of its users.
- Ensure continuous care and the continuity of therapeutic and rehabilitative treatment.

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<sup>23</sup> Residencia Estimia (2022) Memoria 2022 [pdf file]

<sup>24</sup> ibidem

<sup>25</sup> ibidem

<sup>26</sup> ididem

<sup>27</sup> ibidem

<sup>28</sup> ibidem

- Enhance and maintain user autonomy, self-determination, rights, and emotional, material, and physical well-being.
- Promote social inclusion, interpersonal relationships, and personal development.

### 1.4.1. Physical space

The residential facility consists of 7 floors: on the -1 floor, there is the laundry room, storage area, and changing rooms. On the ground floor, there is the main entrance and reception area. On the first floor, you can find the administration and social work offices, a meeting room, and two workspaces for activities with the residents. The second floor houses the nursing station, a physiotherapy room, a dining area, two workspaces, and a multisensory room. Finally, floors 3, 4, and 5 are dedicated to the residents' rooms, with one dining area per floor.<sup>29</sup>

The operating hours are specified in the Internal Regulations of the residence, which were approved by the Centre's Participation Council.<sup>30</sup>

### 1.4.2. Target Audience

During 2022, a total of 30 individuals were attended with a cumulative total of 10,950 daily stays. The average age of the residents is 52.4, with an age range spanning from 27 years for the youngest person to 77 years for the oldest (figure 1). Out of the 30 individuals attended in 2022, there was an equal distribution of 50% males and 50% females. (Figure 2)

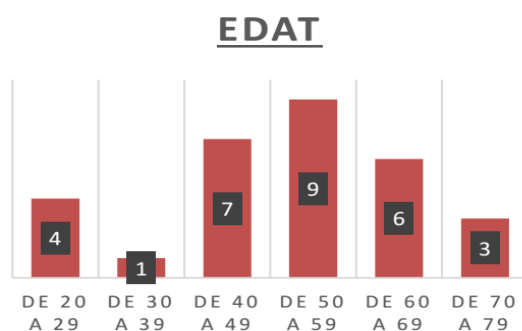


Figure 1<sup>31</sup>

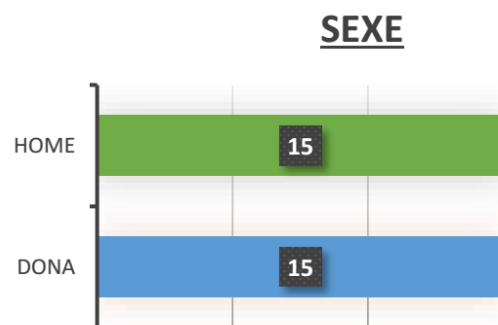


Figure 2<sup>32</sup>

The degree of dependency among the users is categorized as follows: Level 1 of Grade I (3%), Level 1 of Grade II (3%), Level 2 of Grade II (13%), Level 1 of Grade III (37%), and Level 2 of Grade III (44%) as we can see in the figure 3.

<sup>29</sup> Residencia Estimia (2022) Memoria 2022 [pdf file]

<sup>30</sup> ibidem

<sup>31</sup> Figure 1: Residencia Estimia (2022) Edat, Memoria 2022 [pdf file]

<sup>32</sup> Figure 2: Residencia Estimia (2022) Sexe, Memoria 2022 [pdf file]

This categorization aligns with Spain's Dependency Law, which aimed to integrate the domain of long-term care into the Spanish social care system. Three degrees of dependency were here defined:

- Degree I – Moderate dependency. This applies when the person needs help in order to perform various basic activities of daily living at least once a day, or when the person needs intermittent or limited support for his or her personal autonomy.<sup>33</sup>
- Degree II - Severe dependency. This applies when the person needs help in order to perform various basic activities of daily living two or three times a day, but he or she does not want the permanent support of a carer; or when the person needs extensive support to maintain his/her personal autonomy.<sup>34</sup>
- Degree III - Major dependency. This applies when the person needs help in order to perform various basic activities of daily living several times a day; or, due to his or her total loss of physical, mental, intellectual, or sensorial autonomy, the person needs the continuous support of another person; or when the person needs generalised support to maintain his or her personal autonomy<sup>35</sup>

Each degree is divided into two levels of dependency:

- Level 1 corresponds to those individuals who can perform the activity without the direct support of a third person.
- Level 2 refers to those situations where some type of specific support is required.<sup>36</sup>

In terms of the level of support, the majority, 80% of the individuals attended, exhibit a Generalized level of support, while the remaining 20% require an Extensive level of support (Figure 4).<sup>37</sup>

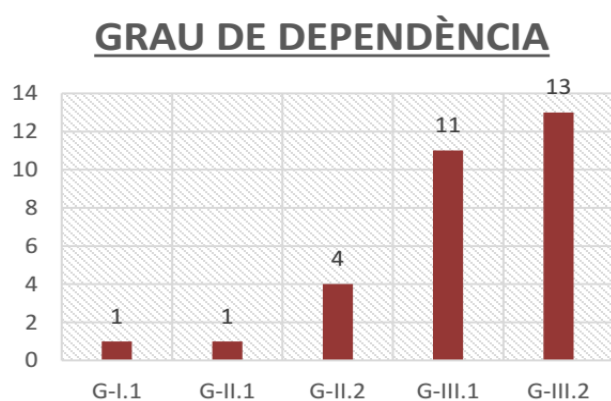


Figure 3<sup>38</sup>

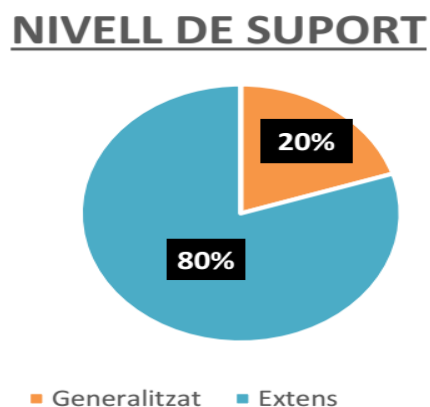


Figure 4<sup>39</sup>

<sup>33</sup> Dependency Law, Spain, 2006, SPLASH DB <https://splash-db.eu/policydocument/dependency-law/> (Accessed 08 October 2023)

<sup>34</sup> *ibidem*

<sup>35</sup> *ibidem*

<sup>36</sup> *ibidem*

<sup>37</sup> Residencia Estimia (2022) Memoria 2022 [pdf file]

<sup>38</sup> Figure 3: Residencia Estimia (2022) *Grau de dependència*, Memoria 2022 [pdf file]

<sup>39</sup> Figure 4: Residencia Estimia (2022) *Nivell de suport*, Memoria 2022 [pdf file]

Among the 80% of the individuals receiving support, almost half, specifically 44%, have their parents (with rehabilitated parental authority) serving as their support assistants. Another 28% have other family members involved, predominantly siblings, while the remaining 28% are assisted by a Support Service Foundation<sup>40</sup> (Figure 5)

## ASSIGNACIÓ D'ASSISTENTS

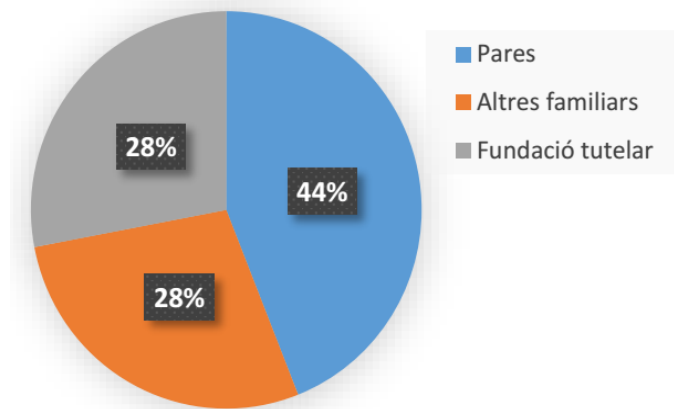


Figure 5<sup>41</sup>

Out of the 30 individuals attended, 83% required a wheelchair for both indoor and outdoor mobility, while 17% required other technical aids (Figure 6).<sup>42</sup>

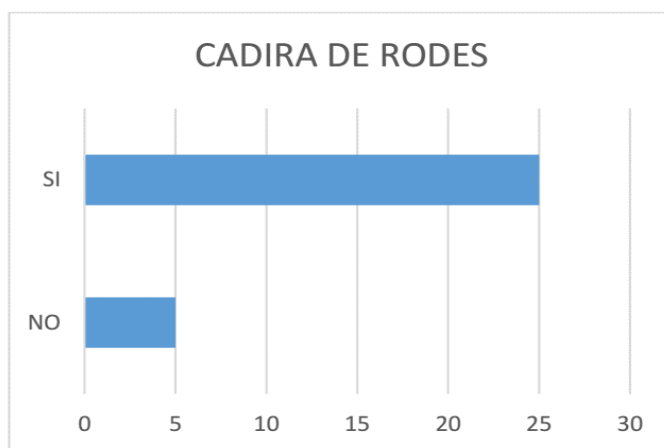


Figure 6<sup>43</sup>

<sup>40</sup> Residencia Estimia (2022) Memoria 2022 [pdf file]

<sup>41</sup> Figure 5: Residencia Estimia (2022) *Assignació d'assistents*, Memoria 2022 [pdf file]

<sup>42</sup> Residencia Estimia (2022) Memoria 2022 [pdf file]

<sup>43</sup> Figure 6: Residencia Estimia (2022) *Cadira de Rodes*, Memoria 2022 [pdf file]

As evident from the illustration presented in Figure 7, the most prevalent primary diagnosis is cerebral palsy, affecting 57% of the individuals attended, followed by diagnoses of epilepsy (10%) and multiple sclerosis (7%)<sup>44</sup>.

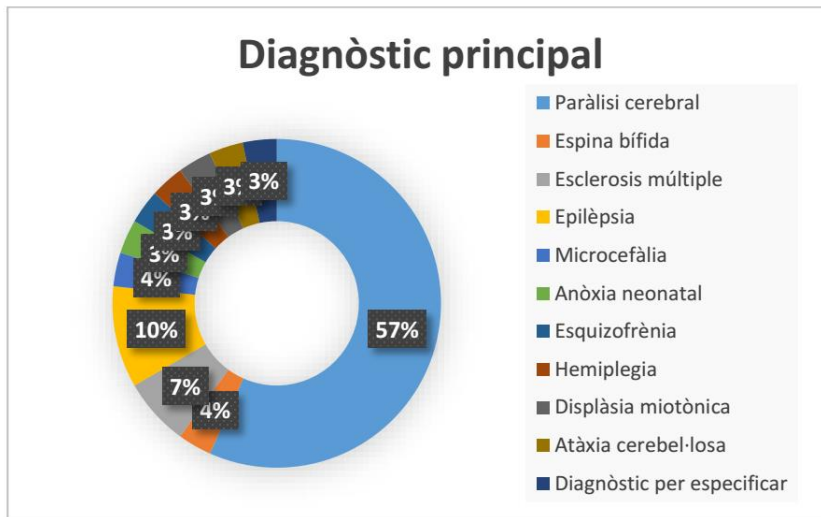


Figure 7<sup>45</sup>

### 1.4.3. Human Resource

□ Direct Care Staff (Personal Atenció directa)

These terms refer to professionals who provide direct care and support to individuals, typically in settings such as healthcare facilities, social service agencies, or disability support organizations.<sup>46</sup>

It is composed of:

- 32 caregivers, distributed in 6 shifts (morning-afternoon-night, full-time and part-time)
- 2 part-time nurses
- 1 part-time physiotherapist
- 1 part-time social worker
- 1 part-time activities technician
- 1 part-time doctor
- 1 part-time psychiatrist
- 1 director<sup>47</sup>

<sup>44</sup> Residencia Estimia (2022) Memoria 2022 [pdf file]

<sup>45</sup>Figure 7: Residencia Estimia (2022) *Diagnòstic Principal*, Memoria 2022 [pdf file]

<sup>46</sup> Residencia Estimia (2022) Memoria 2022 [pdf file]

<sup>47</sup>ibidem

□ Non-Direct Care Staff (Personal Atenció no directa)

The term refers to non-direct care staff or personnel who provide support and services indirectly to individuals. They may have administrative, managerial, or support roles within the organization. These individuals contribute to the overall functioning and operations of the facility or agency but do not directly interact with the individuals receiving care.<sup>48</sup>

It is composed of:

- 2 part-time laundry workers
- 1 receptionist
- Kitchen staff
- Cleaning staff
- Maintenance staff
- 1 part-time driver
- 1 part-time volunteer technician

#### **1.4.4. Collaborations**

□ Internships

In 2022, Estimia had 13 internship students, with a cumulative of 1710 hours completed. These internships encompassed a diverse range of areas, including:

- Administrative Services
- Social and Healthcare Assistance for Dependent Individuals in Social Institutions
- Care of Persons with Dependency
- Social Education
- Integration of Individuals with Disabilities
- Special Education
- Education Sciences
- Comprehensive Orientation, Support, and Accompaniment Services for the Integration of Individuals with Disabilities or Mental Health Disorders<sup>49</sup>

□ Volunteering

During 2022, a total of 62 volunteers collaborated with Residència Estimia, dedicating a combined total of 4832.5 volunteer hours. The volunteers at the residence are divided between regular volunteers and occasional volunteers who support us on specific days for excursion or activities.<sup>50</sup>

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<sup>48</sup> Residència Estimia (2022) Memòria 2022 [pdf file]

<sup>49</sup> ibidem

<sup>50</sup> ibidem

#### **1.4.5. Activity program**

During the interview, E. highlighted that in the early years of Estimia's foundation, the primary focus was on providing direct care and assistance to the users. Once this basic aspect was running smoothly, the organization began implementing an activity program. As a result, a new role was introduced at Estimia: Activities Coordinator, responsible for managing all aspects of the activity program. This development allowed for a more structured and comprehensive approach to organizing and facilitating activities for the residents.

The annual activity program is updated through various meetings with the residents and discussions with the professionals. To meet the users' needs, the collective team, including residents and professionals, proposes a series of activities to promote personal autonomy, preserve and improve cognitive functional abilities, and ensure emotional stability. These activities are carried out in differentiated groups based on needs and preferences, with ongoing monitoring of the residents. The proposed activities are preventive, educational, recreational, and social. The activities will help strengthen physical and mental abilities to face day-to-day life more easily.<sup>51</sup>

The activity program's objectives at Estimia encompass various areas, primarily emphasizing stimulation and cognitive maintenance. E. emphasized in the interview that since many users have physical and cognitive disabilities the focus within each level of care is primarily on preserving cognitive abilities and long-term memory. At Estimia, the goal is to create a supportive environment that prioritizes the maintenance of cognitive function and promotes the well-being of the residents.

Another crucial objective of the activity program is to encourage active participation in the upkeep of the residence. Since the residence is considered their home, it is essential for everyone to contribute to daily chores. This practice not only helps residents understand the concept of responsibilities but also fosters a sense of community living. Those who can perform chores, actively engage in them as part of their daily routine.

The establishment of a routine in this context has proven to be highly beneficial. It provides a sense of security for the residents while simultaneously reinforcing manual dexterity and cognitive abilities. Simple tasks such as folding towels, tidying personal spaces, or organizing laundry serve the dual purpose of physical movement and memory retention. All these activities are interconnected, creating a holistic approach that promotes mobility, memory recall, and, overall, a positive communitarian life. So, in general the objectives that Estimia aims to reach through the activity's plan are the following:

- Improve self-esteem and quality of life.
- Enhance autonomy.
- Foster well-being.
- Promote interpersonal relationships among residents.

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<sup>51</sup> Residencia Estimia (2022) Memoria 2022 [pdf file]



- Strengthen the residents' social connections with the community.
- Encourage residents to maintain their customs and traditions.<sup>52</sup>

The objectives outlined by Estimia are in my vision deeply interconnected with Education and it serves as a powerful tool to promote these goals. Educators and education specialists are instrumental in transforming Estimia's vision into a reality, where education serves as the cornerstone for empowering individuals, fostering social connections, and enhancing overall community life, thus promoting a positive communitarian existence.

The program is structured into distinct areas, each addressing specific aspects of development and engagement:

- Psychomotor area: this area focuses on promoting physical coordination, motor skills, and sensory integration.
  - i. Physiotherapy: Individualized physiotherapy sessions tailored to the specific needs of each resident. These sessions may involve active exercises, passive mobilizations, respiratory physiotherapy, relaxing or circulatory massages, localized thermotherapy applications, and more.<sup>53</sup>
  - ii. Pétanque: Weekly pétanque training sessions with different groups. The activity takes place at Santa Amelia Park under the supervision of BCN Esports.<sup>54</sup>
  - iii. Estimia Olympics: A weekly sports activity led by a professional in various areas of the residence. The activity includes different sports, warm-up exercises, complementary exercises, and competitions.<sup>55</sup>
- Emotional area: this area aims to enhance self-awareness, self-regulation, and interpersonal skills.
  - i. Relaxation: Weekly Reiki sessions are conducted for all residents in small groups. The activity is guided by volunteers from the Reiki Therapists Association of Catalonia. The aim is to provide a space for relaxation for the residents.<sup>56</sup>

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<sup>52</sup> Residencia Estimia (2022) Memoria 2022 [pdf file]

<sup>53</sup> Residencia Estimia (2022) Memoria 2022 [pdf file]

<sup>54</sup> ibidem

<sup>55</sup> ibidem

<sup>56</sup> ibidem

- *Communication area*: this area targets language development, social interaction, and alternative communication methods.
  - i. Assembly: Periodic meetings led by a professional in various groups to discuss and reach agreements on common coexistence matters. The residents of each floor hold regular assembly meetings every two months, and twice a year they have a general assembly. These gatherings address a variety of topics related to their daily lives, tasks, interpersonal issues, and any demands they may have regarding various matters. Discussions may include concerns about food quality, the effectiveness of activities, and any other relevant issues. The objective is to promote group cohesion and enhance the relationship among residents, enabling them to express their needs and propose changes.<sup>57</sup>
  - ii. Staying informed: Reading the most relevant headlines of the week to stay updated on events in the community. There is also ongoing monitoring of topics that have sparked debate.<sup>58</sup>
  - iii. Conversation space: This activity starts with the aim of creating small groups of residents from different floors. Initially designed as weekly meetings of small groups without any specific theme, but where residents could share experiences, concerns, and updates among peers who had been unable to see each other for some time.<sup>59</sup>
  
- *Stimulation area*: this area offers activities to enhance cognitive abilities, memory, attention, and problem-solving skills.
  - i. Music therapy: The activity is conducted once a week and is led by a professional music-therapist. Two working groups are formed, considering the individual needs of each participant.<sup>60</sup>
    - Group 1: Sensory with adapted instruments. This group aims to enhance participation and voluntary movement through reactions to external stimuli using personalized instruments. The focus is on exploring primitive and natural sounds.

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<sup>57</sup> Residencia Estimia (2022) Memoria 2022 [pdf file]

<sup>58</sup> ibidem

<sup>59</sup> ibidem

<sup>60</sup> ibidem

- Group 2: Playful singing. This group aims to foster a love for music in a relaxed and pleasant environment. It expands the repertoire of music listened to and works on memory recall of lyrics, melodies, and musical structures.<sup>61</sup>
  - ii. Reading group: A guided activity where the initial step is to visit the local library and select a book with easy reading. Over the following sessions, the book will be read, leading to a final discussion in the last session.<sup>62</sup>
  - iii. Sensory stimulation: The objective is to provide different stimuli to allow individuals to experience the senses of sight, hearing, touch, smell, and taste. Proprioception and kinaesthesia are also incorporated using materials and instruments in the multisensory room.<sup>63</sup>
  - iv. Pet therapy: The activity is conducted once a week and led by a professional from the organization "Tan Amigos." Two working groups are established to work on enhancing different aspects of the individuals, utilizing the motivation generated by the animal to encourage greater participation.<sup>64</sup>
- Functional area: this area concentrates on developing daily living skills, such as self-care, hygiene, and practical tasks for greater independence.
- i. Household tasks: Activities related to the autonomy and care of the home itself. These activities are carried out on-site in the cohabitation home. The users themselves are responsible for agreeing upon and organizing these day-to-day tasks during the assemblies.<sup>65</sup>
  - ii. Shall we make coffee? : An activity focused on taking care of making coffee every afternoon. Within the Fem Barri project, all the necessary items for its preparation are purchased, and based on an adapted sequence, a designated person prepares coffee for the rest of their companions every afternoon, thus promoting household tasks and the autonomy of individuals.<sup>66</sup>

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<sup>61</sup> Residencia Estimia (2022) Memoria 2022 [pdf file]

<sup>62</sup> ibidem

<sup>63</sup> ibidem

<sup>64</sup> ibidem

<sup>65</sup> ibidem

<sup>66</sup> ibidem

- iii. Self-care workshop: The activity aims to teach residents essential habits for their personal care through explanations and self-practice to maintain and promote personal hygiene while also working on autonomy.<sup>67</sup>
  - iv. Cooking: It is an activity where residents have the chance to cook. They are responsible for finding recipes and collectively choosing their favourite one. In the activity, a professional explains and guides the steps to promote healthy eating habits, provides strategies for cooking simple recipes, increases collaboration and teamwork, and stimulates fine psychomotor skills.<sup>68</sup>
- Creative Area: this area provides opportunities for creativity through various art forms and activities.
    - i. Expression and artistic activities: Developing and maintaining manual and artistic skills such as painting, cutting, manipulating, and gluing, etc., while promoting group work. A small exhibition is organized in the hallways of the residence for each completed artwork.<sup>69</sup>
    - ii. Festivity workshop: Once a week, a group of residents work on festivities through various activity formats, such as stories, videos, and personal experiences. They prepare materials and take care of decorating the spaces.<sup>70</sup>
  - Community and leisure area: with an emphasis on community integration and leisure participation, this area promotes social inclusion, engagement in recreational activities, and active involvement in the community.
    - i. Monthly Vermouth: On the last Saturday of the month, a snack event called "Vermouth" is organized. The users themselves are responsible for making a list of what they feel like eating and taking care of buying all the necessary items, taking advantage of the outing for "Supporting Local Businesses".<sup>71</sup>

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<sup>67</sup> Residencia Estimia (2022) Memoria 2022 [pdf file]

<sup>68</sup> ibidem

<sup>69</sup> ibidem

<sup>70</sup> ibidem

<sup>71</sup> ibidem

- ii. Neighbourhood walks: Once a week, students and teachers from St. Paul's school take walks in the neighbourhood. In 2022, 24 outings were organized, with 27 users enjoying them.<sup>72</sup>
- iii. Board games: A space to encourage interpersonal relationships among users and enjoy leisure time within the residence.<sup>73</sup>
- iv. Mass: Every Sunday, a group of volunteers from the Parish of Sarrià accompany the residents who wish to attend the Sunday Mass from the residence to the church.<sup>74</sup>
- v. Fem Barri: "Fem Barri" is a socio-community project that aims to revitalize street life and foster social cohesion between residents of Estímia and the Sarrià neighbourhood. The project consists of four outdoor activities: Magazine Distribution, Support for Local Businesses, Exploring Parks, and Visiting Recycling Points.<sup>75</sup>
- vi. Activity with the youth centre: Once per quarter, a group of volunteers from the Sant Vicens Youth Centre in Sarrià visit the residence either to take a neighbourhood walk or to organize board games. It is a way to build a bond with a group of young people from the neighbourhood and enjoy mutual experiences.<sup>76</sup>
- vii. Knowing Barcelona: Monthly outings in small groups to discover corners of our city. Also, to visit museums and participate in cultural activities. During 2022, a total of 29 outings were carried out, with a total of 29 participants who were able to enjoy an average of 5 outings throughout the year. The outings took place in: (Figure 8):<sup>77</sup>

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<sup>72</sup> Residencia Estímia (2022) Memoria 2022 [pdf file]

<sup>73</sup> *ibidem*

<sup>74</sup> *ibidem*

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<sup>76</sup> *ibidem*

<sup>77</sup> *ibidem*

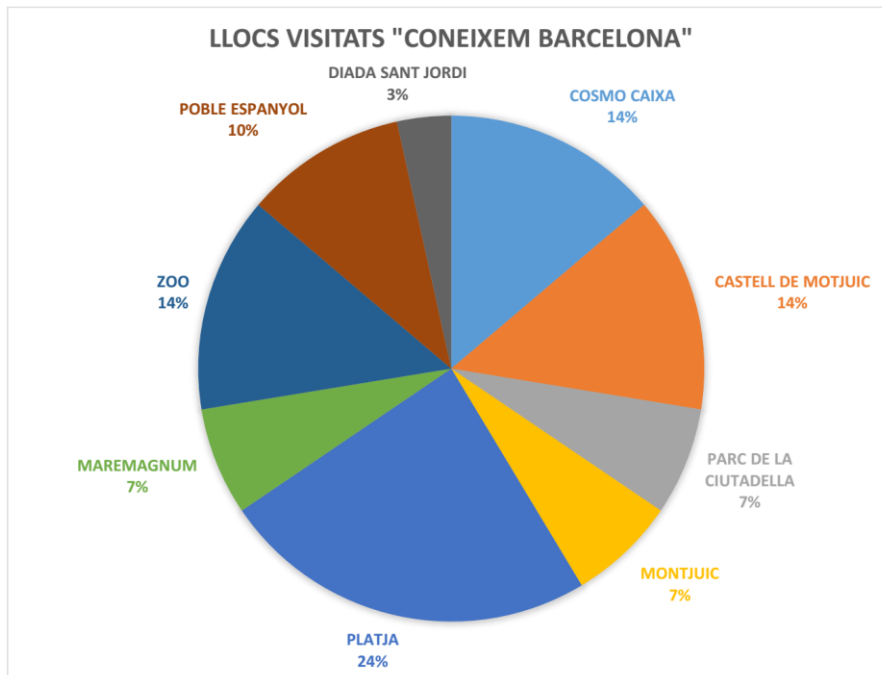


Figure 8<sup>78</sup>

#### 1.4.6. Quality Indicators

In 2022, a family satisfaction survey was conducted. Regarding overall ratings, with 0 being not satisfied at all and 5 being highly satisfied, the following highlights can be noted:

- 90.9% gave a score between 4-5 when asked if they believe their family member is satisfied and well-cared at the centre.
- 91% gave a score between 4-5 for the overall evaluation of the centre.<sup>79</sup>

#### ▫ Participation council

The Participation Council is established in accordance with the provisions of Decree 202/2009, of December 22, on the participation and coordination bodies of the Catalan Social Services System. It is composed of various democratically elected representatives, including representatives of the owning entity, representatives of the administration, representatives of the employees, representatives of the residents, and representatives of the families.<sup>80</sup>

The functions of the Council are as follows:

- a) Annually inform about the general programming of the Service's activities.
- b) Receive regular updates on the overall progress of the Service.
- c) Develop and approve the Internal Rules and its modifications.

<sup>78</sup> Figure 8 : Residencia Estimia (2022) *Lloc visitats "Conexim Barcelona,"* Memòria 2022 [pdf file]

<sup>79</sup> Residencia Estimia (2022) Memòria 2022 [pdf file]

<sup>80</sup> *ibidem*

- d) Provide feedback on the annual report of the centre, which includes the evaluation of therapeutic, social, and economic results of public nature.
- e) Make improvement proposals.
- f) Publicize the results of the participation.<sup>81</sup>

▫ *Family meeting*

In November, a family meeting was held with a 52% participation rate. During the presentation, the activities carried out by the residents in their daily lives and their care schedule were explained. Each professional had the opportunity to address questions and comments related to their respective areas, and they were able to share photographs capturing various meaningful moments.<sup>82</sup>

#### **1.4.7. Estimia's Code of Conduct**

Estimia's Code of Conduct is a document that responds to the need to address new challenges the social and educational sector.

This code, provides a series of guidelines for the behaviour of all those who collaborate with Estimia and is a fundamental part of the transparent, professional, and efficient management.<sup>83</sup>

Specifically, Estimia assumes and makes its own the 10 principles of the United Nations Global Compact, which have been developed throughout this Code of Conduct.<sup>84</sup>

Estimia's values and principles of action are the followings<sup>85</sup>:

- Respect for legality
- Ethics and Integrity.
- Respect for individuals and cultures.
- Responsibility
- Transparency
- Commitment to quality and excellence
- Teamwork
- Innovation
- Confidentiality
- Leadership
- User orientation

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<sup>81</sup> Residencia Estimia (2022) Memoria 2022 [pdf file]

<sup>82</sup> ibidem

<sup>83</sup> Estimia Fundacion (2021) Codigo de conducta [pdf file]

<sup>84</sup> ibidem

<sup>85</sup> ibidem

## **1.5. CONCLUSION**

In conclusion, the chapter has presented a comprehensive overview of Fundació Estimia and its institutional context. The organization's commitment to serving individuals with disability is evident in its mission, activities, and values.

The multidisciplinary team of Fundació Estimia which included educators, assistants, psychologists, and social workers, plays a crucial role in providing comprehensive care and support.

The program structure of the Residencia Estimia, organized into specific areas such as psychomotor, emotional, communication, stimulation, functional, creative, and community and leisure, potentially ensures a holistic approach to meeting the diverse needs of the individuals attended.

Overall, the presentation and characterization of Estimia Institution demonstrate its commitment to improve the lives of individuals with diverse need. The organization's dedication to person-centered care, continuous training, and comprehensive support makes it an invaluable resource in the field of social services.



## CHAPTER II

### THEORETICAL FRAMEWORK AND PROBLEMATISATION

#### 2.1. THE CONTEXT

Before addressing complex and delicate issues such as quality of life, autonomy, self-determination, social inclusion, and institutionalization processes, it is necessary to provide a general theoretical framework regarding the concept of disability.<sup>86</sup>

Over the years, significant changes have occurred in how we define, interpret, and categorize individuals affected by disability. The World Health Organization (WHO) introduced the first classification in 1980, the International Classification of Impairments, Disabilities, and Handicaps (ICIDH).<sup>87</sup> This framework takes into account three crucial aspects:

- Impairment: refers to any loss or abnormality of a psychological, physiological or anatomical function.<sup>88</sup>
- Disability: The term refers to any limitation or loss (resulting from impairment) of the ability to perform an activity in the manner or to the extent considered normal for a human being.<sup>89</sup>
- Handicap: denotes the disadvantaged condition resulting from an impairment or disability that limits or prevents a person from fulfilling their normal role in relation to age, gender, and socio-cultural factors.<sup>90</sup>

Among the different models, the medical one recognizes the disability as a problem of the person, caused directly by illness, trauma, or other health conditions that require assistance. According to this model, individuals with disabilities should be treated in rehabilitation and care centers, predominantly in 'special' contexts separate from those normally frequented by all other citizens.<sup>91</sup>

This vision represents people with disabilities as 'objects of pity' or as 'problems to be cured' bringing to their discrimination, exclusion and marginalization from the society.

The vision of disability that result from this model is therefore far from being multidimensional, realistic and inclusive.<sup>92</sup>

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<sup>86</sup> Paolucci, E. (2018). *Vivere in un istituto per disabili: la promozione della qualità di vita di disabili adulti istituzionalizzati* (Doctoral dissertation, Scuola Universitaria Professionale della Svizzera Italiana).

<sup>87</sup> ibidem

<sup>88</sup> Buono S., & Zagaria T. (2003). *ICF-Classificazione Internazionale del funzionamento, della Disabilità e della Salute*. Ciclo Evolutivo e Disabilità / Life Span and Disability. Vol. 6, N. 1, pp. 124

<sup>89</sup> ibidem

<sup>90</sup> ibidem

<sup>91</sup> Lepri C. (2016). *La persona al centro: Autodeterminazione, autonomia, adultità per le persone disabili*, FrancoAngeli, Milano. p. 119

<sup>92</sup> ibidem

It was in 2001 when the International Classification of Functioning, Disability and Health (ICF) developed by the World Health Organisation was approved by 191 countries.<sup>93</sup>

The bio-psycho-social model has profoundly changed the medical prospective by defining disability as 'the result of a complex relationship between an individual's health condition, personal factors, and environmental factors representing the circumstances in which the individual lives'. This model clarify how disability is not defined solely by the subjective condition of health or illness but depends on its interaction with an environment in which there are barriers and facilitators. It follows The ICF model reinforce the vision that it is not enough to focus on the person health and condition, but it is necessary to act on the environment, removing the obstacles and barriers that prevent the person's participation in various life situations.<sup>94</sup>

## **2.2. THE PROCESS OF INSTITUTIONALISATION**

The bio-psycho-social perspective proposed by the ICF strongly emphasizes the importance of context and the social environment. I would like to introduce the main problematic concerning the institutional settings, drawing from my personal experiences. This analysis aims to provide constructive criticism and shed light on areas that can be improved to ensure greater inclusion and empowerment for individuals with disabilities within institutional contexts.

As mentioned in the previous chapters, residents at Estimia Residence are particularly stimulated due to a rich program of activities and entertainment. In addition, Estimia offer comprehensive care, ensuring that the basic needs of individuals with disabilities are met, including food, shelter, and medical attention. Moreover, institutionalisation can provide access to specialized services, therapies, and resources that may not be available in other settings. These facilities often have dedicated staff dedicated to the needs of residents, which can lead to better overall care and support. Despite all these advantages, residents spend most of their time within the institution, with exceptions for those who have parents or relatives visiting them or outings that occur once a week and on a rotational basis. Consequently, the living situation of the residents can be described as institutionalized, wherein they largely reside within the confines of the residence, adhering to its rules and experiencing various constraining dynamics, typical of the institutional context.

Now, we will consider some of the risks of institutionalization processes and then proceed to discuss key elements to activate deinstitutionalization processes for the ultimate goal, which is residents' well-being and quality of life in facilities like Estimia Residence.

In the past, society used permanent residential institutions with the purpose of controlling and containing certain categories of individuals deemed dangerous to themselves, society, or unable to care for

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<sup>93</sup> Lepri C. (2016). *La persona al centro: Autodeterminazione, autonomia, adultità per le persone disabili*. Franco Angeli: Milano.

<sup>94</sup> ibidem

themselves. The coercive nature and social control function of these institutions were carefully studied and explained by I. Goffman in the book "Asylums."<sup>95</sup>

The author proposes the following definition of an institution. "Social organisations/institutions are places, premises, buildings where a certain activity takes place on a regular basis".<sup>96</sup>

Goffman further explains that institutions have a tendency to take control over the time and interests of the individuals residing in them. In exchange, institutionalized individuals receive a particular type of world already circumscribed and predefined by the structure. The encompassing action exercised by the institution consists of preventing social exchange and outflow to the outside world. "I refer to this type of institution as 'total institutions'," he explains.<sup>97</sup>

Inside total institutions, there is a breakdown of barriers that separate the essential three spheres of life: sleeping, leisure, and working.<sup>98</sup> Each individual tends to organize their life considering these fundamental moments. The main characteristic of these three distinct moments is that in 'normal context' they are usually carried out in different places and times, involving different authorities and individuals. Essentially, "there is no rational global pattern."<sup>99</sup>

In total institutions, this does not occur. Every aspect of a person's life occurs in the same location and under a single authority. Activities are conducted in the company of many people, and the rhythms of daily life are strictly regulated by formal and explicit rules set by the institution. Forced activities are systematically centered around the institution's agenda, meticulously studied, and planned to fulfill the institution's objectives.<sup>100</sup>

In the text "Conoscenze psicoanalitiche e pratiche sociali," Fulvia Bassi examines five fundamental aspects of life within contemporary social institutions, emphasizing the connection between these institutions and the "total institutions" from which we aim to distance ourselves. The key aspects analyzed are space, time, role, task, and rules<sup>101</sup>:

- Space

Unlike total institutions, the space in contemporary Institution is less restrictive as individuals have the freedom to go outside. However, there are constraints related to the psycho-physical condition of the person, especially in institutions for individuals with disabilities, where many

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<sup>95</sup> Goffman E. (2010). *Asylums: Le istituzioni totali: i meccanismi dell'esclusione e della violenza*. Einaudi, Torino.

<sup>96</sup> ibidem

<sup>97</sup> ibidem

<sup>98</sup> ibidem

<sup>99</sup> ibidem

<sup>100</sup> ibidem

<sup>101</sup> Fulvia Bassi. (1996). *All'interno di un istituto per anziani: la storia di Giulio*. In Lai G., Cellentani O. (Eds) *Conoscenze psicoanalitiche e pratiche sociali: Viaggio nell'itinerario della consultazione psicosociale* Franco Angeli, Milano. pp.157-160

live in a state of partial self-sufficiency.<sup>102</sup> To go out of the Residence, the presence of an operator to accompany them throughout the outing is often required. This can be highly relevant in Residencia Estimia, leading to significant discrimination among the residents. Those who have the ability and permission to go out by themselves have far more opportunities to spend time outside than the partially or non-self-sufficient residents.

The internal spaces are under the domain of the community, implying that the rooms, bathrooms, living room, and kitchen are accessible both to other residents and staff members.<sup>103</sup>

The individuals find themselves forced to share their living spaces with other individuals who have different backgrounds, interests, specificities, and habits. Often, these diversities are quite pronounced and poorly tolerated by the residents and privacy is difficult to find.<sup>104</sup>

□ Time

Compared to total institutions, the organization of time is less rigid, although certain aspects have a well-defined underlying structure. In contemporary institutions, many aspects of daily life, such as mealtimes, wake-up calls, bedtime, and even bathroom breaks, are determined by a set of organizational and practical needs, such as work schedules. Time is thus managed by a set of rules dictated by the institution, and everyone, residents and staff alike, must adhere to them equally.<sup>105</sup>

During the interview I made, E., the technician of the activity, justified her perspective, stating: "When you are institutionalized, having a timetable for waking up, breakfast, activities, and meals is crucial due to the large number of people, otherwise it would be anarchy. In Estimia, for instance, we have 30 users, which is quite significant."

Working in Estimia has taught me the importance of rules and a schedule. I believe that a well-structured organization is essential, as it prevents chaos and ensures smooth operations. However, the consequence of this was that residents had to strictly follow their schedules every day. This occasionally resulted in mixed feelings of sadness and frustration among the residents. In this context, I observed that having a timetable for literally every aspect of life could impact the users' quality of life.

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<sup>102</sup> Paolucci, E. (2018). *Vivere in un istituto per disabili: la promozione della qualità di vita di disabili adulti istituzionalizzati* (Doctoral dissertation, Scuola Universitaria Professionale della Svizzera Italiana). p.22

<sup>103</sup> Paolucci, E. (2018). *Vivere in un istituto per disabili: la promozione della qualità di vita di disabili adulti istituzionalizzati* (Doctoral dissertation, Scuola Universitaria Professionale della Svizzera Italiana). p.22

<sup>104</sup> ibidem

<sup>105</sup> ibidem

□ Role

An essential experience for the construction of the self and identity is the assumption of role. The possibility of assuming the adult role starts from an early age, through rules and assigned roles.<sup>106</sup>

The condition of asymmetry between people with disabilities and the operators working in the facility is an unfortunate aspect that needs to be taken into consideration. The assumption of role, in fact, on the other hand, is represented by expected behaviours related to a person's status. It has a dynamic nature and can change over time depending on the circumstances in which the individual lives and the attitudes of the people with whom they interact.<sup>107</sup>

The risk is due to the influence of the processes of typification and impoverishment of the self. The person who enters an institution "abandons everything that characterises his world adapting to a new situation, and new rules, which are imposed on him/her".<sup>108</sup>

□ Task

Each institution, and more specifically, each department, assigns tasks to the residents based on their abilities and skills. Commonly, tasks can become impositions, and on the other hand, some duties are entrusted to the services available within the facility (cooking, cleaning, etc.). In both cases, there are perceived criticalities. In the first case, it may feel like a forced obligation. In the second case, the tasks being carried out emphasize their dependence.<sup>109</sup>

In Estimia tasks are given to the users in order to make them feel active and part of a community. This has some problems because most of the time the users feel this task as an obligation and less as a duty, above all because the staff and operators at Estimia tend to give tasks to the users, but their approach is not solely based on educational or pedagogical methods. Instead, the staff use a more a directive approach, where tasks are assigned and enforced without focusing on teaching or educational aspects. This can lead to a sense of obligation and potentially contribute to the users' negative feelings about the tasks.

□ Rules

The proper functioning of an institution is characterized by a set of rules to which both the staff and the residents are obligated to adhere. These rules can be perceived and experienced as

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<sup>106</sup>Lepri C. (2016). *La persona al centro: Autodeterminazione, autonomia, adultità per le persone disabili*. Franco Angeli, Milano.

<sup>107</sup>ibidem

<sup>108</sup> Lai G., Cellentani O. (1996). *Conoscenze psicoanalitiche e pratiche sociali: Viaggio nell'itinerario della consultazione psicosociale*. Franco Angeli, Milano. p.159

<sup>109</sup> ibidem

impositions dictated from above. Typically, when it comes to institutional rules, there is very little negotiation with the residents, which can generate feelings of frustration.<sup>110</sup>

Estimia institution places particular importance on involving its users in choices, changes, and decisions made. However, it is evident that most rules are established without considering the users' opinions as they are deemed to be beyond their competence. As previously mentioned, this leads to a great deal of disappointment among the users. Working in Estimia, this frustration becomes evident and tangible in many aspects of their daily lives. From not being able to eat croissants because it's not part of their diet, to not being able to take a nap after lunch because the person shouldn't be sleeping at that time.

### 2.3. THE PROCESS OF DE-INSTITUTIONALISATION

It's still really important to talk about de-institutionalisation today. Over time, its meaning has taken on a different significance and has been expressed in various forms. While in the past, de-institutionalisation meant breaking away from institutional reality, nowadays this process must be seen as a reconciliation between administrative commitment and human, social, and educational aspects.<sup>111</sup> Educational action, to be effective, indeed requires an organized institutional apparatus. The planning of an educational intervention must be based on a collaborative relationship between the institution (formal organization) and the educator (the one proposing the educational action).<sup>112</sup> *"We cannot consider educational action as a separate entity, autonomous and free from any administrative/bureaucratic constraint"*<sup>113</sup>. That would be utopian and unrealistic. I came to understand this process when I initially confronted it as an intern, where everything seemed easier (from an outsider's perspective), and I was more idealistic or naive. However, as I became more deeply involved in the institution, I came to understand the system in which users are integrated. It's a system where everything needs to be meticulously regulated, and educational activities must invariably conform to Estimia's administrative structure. Those who work within these social realities, especially those who live daily and closely interact with the users, can understand the elements that should be corrected within the institution. Therefore, the educator's task is to act as a mediator between the users' needs and the institutional requirements.<sup>114</sup>

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<sup>110</sup> Paolocci, E. (2018). *Vivere in un istituto per disabili: la promozione della qualità di vita di disabili adulti istituzionalizzati* (Doctoral dissertation, Scuola Universitaria Professionale della Svizzera Italiana). p.23

<sup>111</sup> Canevaro A. (2006). *Le logiche del sentiero e del confine: Una pedagogia dell'inclusione (per tutti, disabili inclusi)*. Erickson, Trento. pp.58-59

<sup>112</sup> ibidem

<sup>113</sup> Paolocci, E. (2018). *Vivere in un istituto per disabili: la promozione della qualità di vita di disabili adulti istituzionalizzati* (Doctoral dissertation, Scuola Universitaria Professionale della Svizzera Italiana). p.23

<sup>114</sup> ibidem

The De-institutionalisation process is a push for change that should not be taken to the extreme and constantly pursued over time because "continuous resort to changing the institution would create a destabilizing situation."<sup>115</sup>

The educational action must not only present itself as a means of de-structuring the places, but also create contexts where the users feel welcomed and protected. In conclusion, deinstitutionalization, as we understand it today, involves the necessity of sharing and co-constructing change processes to guarantee the well-being of the users, in other words, the quality of life.<sup>116</sup>

## 2.4. THE QUALITY OF LIFE

The aspiration for a "good life," a life of well-being, satisfaction, and happiness, has probably accompanied humanity since its birth and can already be found in the theories of the most ancient philosophers.<sup>117</sup>

However, it is from the second half of the 20th century that the interest in Quality of Life (QoL) has become more significant, thanks above all to the promulgation of the Universal Declaration of Human Rights. This construct has been developed as a political issue and as a field and discipline of research around the mid-1960s<sup>118</sup>.

In the same period, the movement for human rights of people with disabilities began to take its first steps, and research on intellectual and developmental disabilities flourished.<sup>119</sup> Moreover, during these years, greater awareness about the living conditions of people with intellectual disabilities, especially those living in institutions, started to emerge.<sup>120</sup>

Clear connections have been conceptualized between quality of life and the concepts of normalization, deinstitutionalization, integration, inclusion, freedom of choice, and empowerment in relation to people with disabilities.

But what exactly is meant by quality of life? And how does the concept of quality of life apply to people with disabilities and the policies and practices that affect them?<sup>121</sup>

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<sup>115</sup> Paolocci, E. (2018). *Vivere in un istituto per disabili: la promozione della qualità di vita di disabili adulti istituzionalizzati* (Doctoral dissertation, Scuola Universitaria Professionale della Svizzera Italiana).

<sup>116</sup> ibidem

<sup>117</sup> Croce, L., & Lombardi, M. (2015). *Strumenti verso l'inclusione sociale: il disegno sperimentale della Ricerca*. Progettare Qualità di Vita, Report conclusivo e risultati progetto di Ricerca 'Strumenti verso l'inclusione sociale, matrici ecologiche e Progetto Individuale di Vita per Adulti con Disabilità Intellettive e/o Evolutive', ANFFAS Nazionale, Roma.

<sup>118</sup> ibidem

<sup>119</sup> Ibidem

<sup>120</sup> Lyons, G. (2010). *Quality of life for person with intellectual disabilities: a review of literature*. In R. Kober (A cura di), *Enhancing the Quality of Lifes of People with intellectual disabilities*. Springer

<sup>121</sup> Croce, L., & Lombardi, M. (2015). *Strumenti verso l'inclusione sociale: il disegno sperimentale della Ricerca*. Progettare Qualità di Vita, Report conclusivo e risultati progetto di Ricerca 'Strumenti verso l'inclusione sociale, matrici ecologiche e Progetto Individuale di Vita per Adulti con Disabilità Intellettive e/o Evolutive', ANFFAS Nazionale, Roma.

The concept of "quality of life" is an area of interest and study in various disciplines. Each one has developed a different perspective regarding its conceptualization and application in relation to people with disabilities and the policies and practices that concern them.<sup>122</sup>

For example, the World Health Organization's Quality of Life group defined it in 1995 as: "An individual's perception of their position in life, in the context of the cultural and value systems in which they live, and in relation to their goals, expectations, standards, and concerns".<sup>123</sup>

Regarding the perspective of quality of life, it is essential to mention the meta-model proposed by Schalock and Verdugo Alonso.<sup>124</sup>

In this model, the perspective of quality of life is represented by the articulation of 8 domains:<sup>125</sup>

1. *Physical well-being*: It pertains to the individual's overall health status. This includes personal hygiene, dietary habits, access to suitable medical care based on their physical and mental condition, the ability to manage pain and stress, and engagement in physical activities.
2. *Material well-being*: It refers to the capacity to access and utilize material resources. This domain covers aspects such as employment opportunities, the ability to afford essential expenses, and ownership of lasting possessions.
3. *Emotional well-being*: It focuses on the ability to experience contentment with one's life, satisfaction with their choices, and a positive self-image. The quality of the individual's interaction with the external world plays a crucial role in this dimension.
4. *Autonomy*: It means the capacity and satisfaction of making choices, expressing one's preferences according to individual capabilities and communication methods, and utilizing opportunities offered by the environment based on personal desires and intentions.
5. *Personal development*: The ultimate objective of this domain is to achieve self-sufficiency. This includes effective time management and the capacity to organize oneself autonomously.
6. *Interpersonal relationships*: It involves the opportunities to foster connections with people in one's surroundings.
7. *Social inclusion*: It encompasses the sense of belonging to a particular group or community.
8. *Rights and Empowerment*: It deals with the feeling of being safeguarded and having the liberty to express one's thoughts freely.<sup>126</sup>

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<sup>122</sup> Bergland, A., & Narum, I. (2007). *Quality of life: Diversity in context and meaning*. Critical Reviews in Physical and Rehabilitation Medicine, 19(2), 115–139.

<sup>123</sup> WHOQOL, *The World health organization quality of life assessment*. (1995). Position paper from the World health organization. Social science and medicine, 41 (10), 1045.

<sup>124</sup> Schalock, R. L., & M. A. Verdugo. (2002). *Handbook on quality of life for human service practitioners*. Washington, DC.

<sup>125</sup> Croce, L., & Lombardi, M. (2015). *Strumenti verso l'inclusione sociale: il disegno sperimentale della Ricerca*. Progettare Qualità di Vita, Report conclusivo e risultati progetto di Ricerca 'Strumenti verso l'inclusione sociale, matrici ecologiche e Progetto Individuale di Vita per Adulti con Disabilità Intellettive e/o Evolutive', ANFFAS Nazionale, Roma.

<sup>126</sup> ibidem



The authors argue that these eight domains are of an experimental and empirical nature. Thanks to these, it is possible to measure the level of satisfaction with a person's quality of life.<sup>127</sup>

In recent years, there has been an increase in interest in Quality of Life (QoL) in research, policies, and practices to clarify the application of this construct in real-life contexts for people with disabilities. In line with this, a growing number of advocates and service providers in the fields of education, rehabilitation, and residential care have started adopting evidence-based practices aimed at improving personal outcomes in terms of QoL.<sup>128</sup>

These practices, or rather good practices, include (according to Schalock et al., 2008):

Individual supports as a vehicle to improve Quality of Life (QoL); the community as a context for a life of quality (consistent with the deinstitutionalization movement for people with disabilities); organizations that act as "bridges" towards the community; person-centered approaches within services; direct involvement of people with disabilities and their families in the design, planning, and evaluation of interventions.<sup>129</sup>

In the Estimia residence and many other institutions for people with disabilities, there is a need to develop policies based on principles and practices aimed at improving the quality of life. This includes the necessity to build the service and support system around key predictors of QoL, such as *self-determination, empowerment, autonomy, and social inclusion*. Additionally, it is essential to focus on individual experiences and circumstances and to incorporate operational principles and methodological pluralism in professional training.<sup>130</sup>

## **2.5. SELF-DETERMINATION, AUTONOMY AND SOCIAL INCLUSION**

The first point I want to address concerns the promotion of *self-determination*. This concept revolves around safeguarding a fundamental right, namely the right to "make choices and decisions about our own lives (...)" Self-determination means having the possibility of being real protagonists, causal agents, of one's own existence and of having a decisive influence on the things that happen to us and that we experience.<sup>131</sup> Taking an active role as protagonists in one's own life is undeniably a fundamental pillar for enhancing the quality of life. Nevertheless, it is frequently observed that institutionalized individuals, like the ones in Estimia Residence, face a notable lack of self-

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<sup>127</sup> Paolucci, E. (2018). *Vivere in un istituto per disabili: la promozione della qualità di vita di disabili adulti istituzionalizzati* (Doctoral dissertation, Scuola Universitaria Professionale della Svizzera Italiana).

<sup>128</sup> Schalock, R. L., Bonham, G. S., & Verdugo, M. A. (2008). *The conceptualization and measurement of quality of life: implications for program planning and evaluation in the field of intellectual disabilities*. *Eval Program Plann*, 31(2), 181-190.

<sup>129</sup> *ibidem*

<sup>130</sup> *ibidem*

<sup>131</sup> Lepri C. (2016). *La persona al centro: Autodeterminazione, autonomia, adultità per le persone disabili*. Franco Angeli, Milano. pp.122-123

determination, abstaining from making decisions independently, and predominantly assuming a passive role.

To enhance the quality of life and foster self-determination, it is imperative to dispel certain misconceptions surrounding mental disabilities. "It is demonstrated in fact (...) that individuals with severe developmental disabilities and limited verbal abilities can learn, even as adults, to communicate and express their preferences, make decisions, and learn to implement problem-solving strategies."<sup>132</sup>

It is not enough to talk about self-determination without having illustrated the concept of *autonomy*. The definition offered by the dictionary is as follows: "being free to think and act, or even capable of providing for one's own needs."<sup>133</sup> We understand that in the "age of dependencies" we live in today, it represents a paradox.

Being autonomous does not mean living without relying on others. All human beings need to live in relation to others. The dichotomy of autonomy/dependence is well explained by Morin as follows: "Dependent autonomy is a concept that emphasizes the interdependence and interconnectedness of individuals rather than solely relying on asserting self-sufficiency. It involves being conscious of one's dependence on the surrounding context and other people. In this context, autonomy and dependency are not seen as opposing forces but as complementary aspects of an individual's life. As the complexity of our living environments grows, the development of autonomies and dependencies becomes even more intertwined and interdependent. Thus, the ability to navigate and adapt within these intricate contexts becomes essential for a fulfilling life."<sup>134</sup>

Autonomy, therefore, does not develop in empty spaces or does it exist independently; on the contrary, it is in relation to a series of dependencies that are to be considered essential conditions for its very existence: I am autonomous only when I am in relation, that is, when I am part of a broader and more complex system.<sup>135</sup>

Indeed, this perspective is particularly evident in discussions related to disability: in fact, disability is described in relation to a system of dependencies in which the person with a disability maintains their own capacity to exist, to identify themselves beyond their dependencies.<sup>136</sup>

The path outlined overturns the negative idea of help, support, and similar aspects, as these become the conditions around which the autonomy of everyone is built and exercised. This reversal requires

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<sup>132</sup> Lepri C. (2016). *La persona al centro: Autodeterminazione, autonomia, adultità per le persone disabili*. Franco Angeli, Milano. pp.122-123

<sup>133</sup> <https://www.garzantilinguistica.it/ricerca/?q=autonomia>

<sup>134</sup> Medeghini R., Messina M. *Come uscire dalla dicotomia autonomia/dipendenza?* Animazione sociale, dicembre 2007. p.13

<sup>135</sup> Medeghini R., Messina M. *Come uscire dalla dicotomia autonomia/dipendenza?* Animazione sociale, dicembre 2007. p. 3

<sup>136</sup> *ibidem*

educational settings and the experiences that take place within them to create contexts and situations that are rich in emotional, cognitive, and social support.<sup>137</sup>

Exactly, in this direction, the autonomy of a disabled individual develops around the possibility of being able to choose and make use of the best possible assistance in a way that transforms resources into vectors of ability and participation. This is where the essence of personalization in an educational project as well as the concept of inclusion lie.<sup>138</sup> By providing personalized support and accommodations, individuals with disabilities can maximize their potential and actively participate in educational and social activities, fostering their autonomy and overall development. In this context, inclusion refers to ensuring that individuals with disabilities are welcomed and integrated into all aspects of educational and social life, with the necessary support and resources to enable their active engagement and success.<sup>139</sup>

The third point is represented by the promotion of *social inclusion* which encompasses both self-determination and autonomy. A significant disadvantage of institutionalisation is the risk of social isolation and segregation. While living among peers can provide a sense of community, it may also result in limited exposure to the outside world and mainstream society. This isolation can hinder the social integration and inclusion of individuals with disabilities, potentially perpetuating stigmas, and barriers to their full participation in society.

In this context, the concept of inclusion speaks of an inherent right, regardless of abilities and individual circumstances. It emphasizes that these individuals have the right to exist, to make choices, to access opportunities, and to belong to the community they live in. Exercising this right is not an optional value, but an essential entitlement that should be sustained.<sup>140</sup>

For people with disabilities living in a residence, the principle of inclusion takes on special significance. It means recognizing and respecting their autonomy and agency, allowing them to participate in decisions that affect their lives, and fostering an environment where they can express their unique identities. It demands appropriate support and accommodations to ensure their full engagement in community life and promoting an atmosphere of acceptance, where diversity is celebrated.

To achieve and foster inclusive processes, protective and limiting attitudes do not always produce positive outcomes, as individuals need to interact with others to enhance their own potential. Azzolini and Milani, in the book "Un, due, tre... liberi tutti," emphasize that "in order to promote the emergence and development of the intelligences present in disabled individuals, another essential condition is to allow them to measure themselves with others in shared contexts." The role of the educator should be

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<sup>137</sup>Medeghini R., Messina M. *Come uscire dalla dicotomia autonomia/dipendenza?* Animazione sociale, dicembre 2007. p. 10

<sup>138</sup> ibidem

<sup>139</sup> ibidem

<sup>140</sup> Medeghini R., Vadalà G., Fornasa W., Nuzzo A. (2015). *Inclusione sociale e disabilità: Linee guida per l'autovalutazione della capacità inclusiva dei servizi*. Erickson, Trento. p. 109

to prepare the person they are assisting to face the various challenges of daily life, constantly promoting the individual's empowerment and emancipation.<sup>141</sup>

In institutions like Estimia, there is often a tendency to rely heavily on a protective model, which can unintentionally become confining for the residents. Therefore, it is vital to find a delicate balance between offering protection, stability, and comfort to the individuals while also empowering them to attain greater autonomy and self-determination. According to "Inclusione sociale e disabilità," individuals with disabilities and their families need educational institutions to offer services that go beyond a purely care and assistance-oriented approach.<sup>142</sup>

To effectively promote social inclusion, the educator must engage in supporting projects aimed at the external world. Unfortunately, there are instances where educators may limit their professional role to the care of the individual, without acknowledging the impact that the surrounding community can have on promoting growth and inclusion of the users.<sup>143</sup>

While it is indeed essential to recognize society's responsibilities towards individuals with disabilities, it is equally important to emphasize the crucial role that social institutions should play as the primary promoters of inclusive processes. Nuzzo contends that these institutions hold greater potential to initiate circuits of inclusive experiences. This means going beyond simply providing services to individuals and taking on a role of responsibility in fostering inclusive processes. The goal is to integrate the reality of disability as one of the many interacting realities within the broader context of society.<sup>144</sup>

## 2.6. CONCLUSION

In conclusion, this second chapter has explored the context and the definition/classification of disability, as well as the different approaches taken towards understanding and supporting individuals with disabilities. We have delved into the process of institutionalisation and its implications for people with disabilities, leading to the subsequent movement of de-institutionalisation.

Throughout this chapter, we have highlighted the importance of recognizing the rights and needs of individuals with disabilities, emphasizing self-determination, autonomy, social inclusion. These principles are essential in ensuring that individuals are active participants in society and have the opportunity to lead fulfilling lives.

The concept of quality of life has been central to our discussion, as it encompasses various aspects of well-being, including physical, emotional, social, and psychological dimensions.

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<sup>141</sup> Azzolini O., Milani L., (2004). *Un, due, tre...liberi tutti. Riflessioni e percorsi educativi tra disabilità e tempo libero*. Sei Frontiere, Torino.

<sup>142</sup> Medeghini R., Vadalà G., Fornasa W., Nuzzo A. (2015). *Inclusione sociale e disabilità: Linee guida per l'autovalutazione della capacità inclusiva dei servizi*. Erickson, Trento. P.75

<sup>143</sup> ibidem

<sup>144</sup> ibidem pp.78-79

As we transition into the next chapters focusing on my internship and the project with Music Therapy becomes evident that the principles explored here lay the foundation for an important connection with my project.

The connection between self-determination, autonomy, social inclusion, quality of life, and music therapy is, in fact, closely intertwined. Music therapy serves as a powerful means to empower individuals with disabilities, allowing them to express themselves creatively and make choices independently. By engaging in the therapeutic process, individuals experience a sense of control over their lives, which positively impacts their overall quality of life. Additionally, music therapy encourages social interactions and a sense of belonging, promoting social inclusion and fostering emotional well-being. The interplay of these principles makes music therapy a transformative and enriching experience, contributing to the well-being and empowerment of individuals with disabilities. Through this exploration, I seek to contribute to the growing understanding and appreciation of music therapy as a transformative tool.

## CHAPTER III

# THEORETICAL –METHODOLOGICAL AND ETHICAL FOUNDATION OF THE PROJECT

This chapter examines the methodological and theoretical decisions inherent in the internship process, particularly in relation to the context and my role within it. It proceeds to outline the distinct phases encompassing the internship experience. Furthermore, it describes and justifies the methodological options and techniques employed. The chapter delves into the ethical dimensions, highlighting the imperative of safeguarding the vulnerable population involved in the project.

### 3.1. JUSTIFICATION OF THE CHOICE

The idea of doing an internship has been significant since the beginning of my master's program. I have always believed in the value of practical experience to develop skills and gain a deeper understanding of my field. A volunteering experience, two years ago, further solidified this belief. Moreover, I felt a strong desire to expand my knowledge professionally, so I've chosen to pursue an internship.

I have chosen to work at a residence care for adults with disabilities because I've always been interested in special education and the social and educational aspects of disabilities. My prior experiences solidified even more this passion, fostering my comfort and confidence when working with this population. Furthermore, my decision to focus on the field of elderly individuals with disabilities result from its alignment with my future career aspirations.

During the second semester, I enrolled in the course “Questões Aprofundadas sobre Envelhecimento e Intervenção Socioeducativa” This class aimed to delve into the concepts of aging, community, development, and social change, as well as explore perspectives on democracy, human rights, citizenship, and participation. The goal was to equip students with critical and contextualized analytical frameworks encompassing theoretical, methodological, sociopolitical, and ethical dimensions. These frameworks were considered essential for addressing participatory research processes, socio-educational interventions, and the design and execution of projects related to aging.<sup>145</sup>

The learning outcomes and skills attained upon completing the course of “Questões Aprofundadas sobre Envelhecimento e Intervenção Socioeducativa” were as follows:<sup>146</sup>

1. Understanding and analysing various institutions involved in socio-educational and cultural intervention with the elderly.

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<sup>145</sup> FPCEUP - Questões Aprofundadas sobre Envelhecimento e Intervenção Socioeducativa:

[https://sigarra.up.pt/fpceup/pt/ucurr\\_geral.ficha\\_uc\\_view?pv\\_ocorrencia\\_id=477113](https://sigarra.up.pt/fpceup/pt/ucurr_geral.ficha_uc_view?pv_ocorrencia_id=477113)

<sup>146</sup> ibidem

2. Critically reflecting on educational, social, and community intervention programs, projects, and practices related to old age, while considering underlying conceptions of social change, participation, democracy, human rights, and citizenship.
3. Recognizing the integration of human rights and citizenship within communities, particularly concerning the elderly's rights and their social and community involvement.
4. Analyzing and problematizing different intervention processes, strategies, and sociocultural and educational animation logics and their implications for social change and work with the elderly.
5. Developing professional practices in socio-educational intervention with the elderly and designing training processes for professionals in this field.
6. Constructing a research project or internship framework incorporating socio-political dimensions.<sup>147</sup>

To practically apply the theories and develop those skills, I recognized that an internship in a residence for the elderly with disabilities was the ideal avenue. This environment offered the comfort needed to improve and apply the skills and knowledge gained. Simultaneously, my desire to step out of my comfort zone led me to pursue an Erasmus internship abroad, specifically in Barcelona.<sup>148</sup>

My primary aim was to immerse myself in a different educational approach within the disability field, further enhancing my skills and knowledge for future career prospects. Additionally, I craved for exposure to a different culture, and Barcelona's vibrant and artistic atmosphere perfectly matched this aspiration. The city's allure aligned harmoniously with my interest in music therapy, and I anticipated gaining fresh insights into diverse approaches to special education and disability care.

In summary, my choice to pursue an internship in Barcelona, specifically working with adults with disabilities, is driven by a passion for special education, a desire for professional growth, and an eagerness to embrace new experiences and cultures.

### **3.2. ENTRY INTO THE CONTEXT AND DIFFERENT MOMENTS**

My arrival at the institution was smooth and far from difficult or traumatic. On the contrary, as I describe in my field notes, I integrated very well from the very first day. The users welcomed me, showing genuine interest in learning about me. The fact that I wasn't a Spanish native intrigued them greatly. Despite not being fluent in Spanish, I managed reasonably well, engaging in meaningful and extensive conversations. Gradually, through shared moments, we got to know each other better.

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<sup>147</sup> FPCEUP - Questões Aprofundadas sobre Envelhecimento e Intervenção Socioeducativa (2022)  
[https://sigarra.up.pt/fpceup/pt/ucurr\\_geral.ficha\\_uc\\_view?pv\\_ocorrencia\\_id=477113](https://sigarra.up.pt/fpceup/pt/ucurr_geral.ficha_uc_view?pv_ocorrencia_id=477113)

I distinctly recall our initial conversations about travel and places we would like to visit. I progressively integrated further into the environment in the subsequent days and weeks. I observed and analysed situations without passing judgment. I gradually became familiar with my fellow educators and socio-sanitary operators, who explained the daily routines to me. I accompanied the users during activities and their daily routines.

The internship days followed a consistent pattern: I would arrive around 9 AM and assist them during breakfast and with completing personal care routines, such as grooming and facial cleansing. After breakfast and the morning routine, a period of tranquillity ensued, during which I engaged in conversations or played board games with them.

Around 11 AM, the planned activity of the day often took place. I would accompany them to the designated area where the activity was to occur and actively participate alongside them. At lunch time we returned to our designated area, and two assigned users prepared the table. When the food cart arrived, I distributed and served portions. I aided those who faced difficulties while eating, and later assisted with teeth cleaning and table cleanup. Once everything was tidied up, the individuals would rest, and we would assist those who needed help getting into bed. By 2 PM, it was time for me to conclude my day and head home.

The second phase was characterized by various changes. Firstly, after a few months, I can confidently state that I have become well-integrated within the institution and its rhythms and rules. Simultaneously, I managed to introduce myself a bit more to both the users and colleagues. As a result of this stability, another intern and I began to propose spontaneous activities for small groups. For instance, activities related to exploring the five senses, quizzes to stimulate memory, physical movement games, body care activities, and beauty routines. We attempted to do our best in making ourselves useful, learning to organize and implement activities, while also aiming to engage the users: as institutional life can sometimes become overly routine, a breath of fresh air and new faces can be quite beneficial.

During a subsequent phase, I noticed a growing recognition of my role as an intern, consistently participating in activities while projecting and implementing structured activities. Meanwhile, I gained insight into the distinct challenges and needs that the users faced. Consequently, I attempt to contemplate the most suitable interventions to address these requirements and problematics.

In this period, I faced a sense of apprehension as I found myself becoming more seated within the institution yet, I noticed a slightly reduced focus on my position as an educator.

Gradually, I came to realize that the residential setting did not allocate significant space or value to the educator's role. Among my colleagues, I appeared more as auxiliary support, aiding in the care-oriented aspect, an essential component, yet not my central focus. On the other hand, I acknowledged my responsibility in putting effort and designing interventions for the users.

Simultaneously, my participatory observation persisted, and I discovered a growing fascination with music therapy. I considered it as an exceptionally remarkable activity. I had previously not



comprehended the potency of music. Consequently, music therapy began to pique my interest more and more. Simultaneously, I recognized its pronounced appreciation among users connected with its benefits in alleviating the constraints imposed by institutional routines, which can sometimes be oppressive.

Considering these realizations, the third moment was characterized by concentrating my efforts on music therapy. I made the decision to accompany and support the therapist during all sessions, which not only deepened my immersion in the educational process but also significantly contributed to the holistic well-being of the users.

Every Wednesday, even after my internship ended, I attended and collaborated in the music therapy classes from 11 to 13, taking notes and closely observing the users' progress. Additionally, I engaged in numerous enriching conversations with the therapist and actively participated in the sessions, learning, and challenging myself each time.

The last phase coincides with the end of my internship and the beginning of my work at the Estimia institution. This transition has been gradual and well-received by the users, who were happy to see me stay. I started and concluded my internship on the 5th floor of the residence care, so, even if I had a lot of interaction with other users as well, I have developed a special connection with the users on the 5th floor. For this reason, it was decided that I should start working on a different floor to not disrupt myself and the users too much with a sudden change.

My internship does not have a clear ending but signifies a role and perspective change, marking the beginning of a new chapter. Starting to work has certainly opened my eyes to many things I could not access during my internship. However, this is another phase that is still ongoing.

### **3.3. THE DIMENSION OF THE INTERVENTION**

Through an internship, students are expected to engage in formative professional, social, and cultural learning activities. The internship also entails creating new opportunities for personal growth and enhancing prospects for future employment, in line with the current job market dynamics.<sup>149</sup>

Based on these premises, from the beginning, I attempted to establish clear objectives that would provide structure, definition, and planning to my internship experience. Firstly, my primary goal was to comprehensively understand the inner workings of the institutions involved. Secondly, I aimed to familiarize myself with the diverse range of users gradually. A deep understanding of both the contextual environment and the characteristics of the population being served is essential for developing a well-coordinated and effective intervention.

Furthermore, an additional aspiration of mine was to progressively integrate myself within the institution's framework. By actively engaging with users and colleagues, I looked to establish a meaningful presence and foster a sense of recognition. This multi-faceted approach facilitated a deeper

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<sup>149</sup> Ribeiro, A. D. S., & da Rosa Tolfo, S. (2011). *Estagiários, vínculos e comprometimento com as organizações concedentes de estágio*. Arquivos Brasileiros de Psicologia, 63, 15-25.

connection with those I was working with and enabled me to obtain insights from various perspectives, contributing to a more comprehensive and impactful internship experience.

As the months went by, I began to set more specific goals for myself. For instance, I started actively participating in and overseeing various activities to become a point of reference within that domain. For example, I ensured that all users registered for a particular activity were present at the scheduled time. A significant goal I later pursued was understanding the institution's challenges and proposing educational activities and interventions that would address users' needs and help alleviate problematic. However, achieving this last goal was not without its challenges. I pushed myself and experimented with several educational interventions that seemed suitable and engaging. I encountered multiple difficulties, and I myself wasn't initially as invested in these activities. After conducting a more profound analysis of the context, I ultimately decided to embark on the educational intervention of music therapy. In this attempt, I recognized the potential of music therapy for the well-being of residents. With careful consideration of the residents' backgrounds and preferences, I became aware that music therapy could foster emotional connection, alleviate stress, and create a positive atmosphere within the institution. This decision represented a turning point in my internship, as I not only addressed the users' needs more effectively but also reignited my own enthusiasm and commitment to the educational process. Through perseverance and adaptability, I was able to transform challenges into opportunities for growth and innovation, demonstrating the value of strategic thinking and a dedicated approach to my internship objectives.

### **3.4. METHODOLOGICAL OPTIONS AND TECHNIQUES EMPLOYED**

#### ▫ *Participant observation*

During my internship, I employed various techniques to carry out my investigation, and one of the primary ones was participant observation.

Participant observation (PO) is a research methodology where the researcher is immersed in the day-to-day activities of the participants. The objective is usually to record conduct under the widest range of possible settings. In this way, PO differs from naturalistic observation, because the latter does not involve interaction between the researcher and participants. PO was historically associated with a form of research in which the researcher resides for extended periods of time in a small community. Currently, PO is used in a wide variety of settings, and over varied periods of time, from single interactions to many years.<sup>150</sup>

Participatory observation often involves taking on the role of an observer-participant, where the researcher observes and actively participates to some extent in the activities or interactions being

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<sup>150</sup> Participant observation | Human Ethics Principles. (s. f.-b). <https://research.utoronto.ca/participant-observation>

studied. This participation helps establish rapport with participants, leading to more candid and authentic observations.

In the context of my internship project, participatory observation could offer a holistic view of the experiences, challenges, and interactions of individuals with disabilities. By immersing oneself in their environment and daily routines, it becomes possible to gain profound insights that inform a more comprehensive understanding of their lives and needs.

As Amado, in “Manual de Investigação Qualitativa em Educação” said, Participant observation is grounded in the principle that the researcher must maintain some level of interaction with the situation under study, influencing it while also being influenced by it. In this line of thought, the term 'participant' should be understood in at least two senses:<sup>151</sup>

- Firstly, the observer should 'participate' in the life of the 'observed', necessitating an extended stay at the location. The duration of this stay is determined by various criteria such as research objectives, the observer's availability and experience, and their acceptance by the observed group.
- Secondly, the observed individuals should 'participate' as 'informants' in the ongoing research. It is crucial that these 'native' informants, at some point in the process, recognize the reasons why it is important for them to collaborate in the research.<sup>152</sup>

In the context of participant observation, the researcher engages in a prolonged presence within the setting being studied. This immersive approach enables a deep understanding of the participants' perspectives, behaviours, and interactions, which might not be fully captured through other research methods. Additionally, involving the observed individuals as informants contributes to a more comprehensive and culturally sensitive interpretation of the data collected. This participatory approach fosters a collaborative and reciprocal relationship between the researcher and the participants, enriching the research process and outcomes.<sup>153</sup>

I connected deeply with this description of participant observation, especially during the initial month, which predominantly I focused on my integration into the environment. During this phase, I embraced an immersive approach by accompanying individuals in their daily routines. Simultaneously, I maintained a delicate balance, ensuring my presence did not disrupt their normalcy. This approach aimed to minimize any alteration to their daily lives while fostering a respectful coexistence within the context, to enrich my investigation.

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<sup>151</sup> Amado, João (2013). *Manual de Investigação Qualitativa em Educação*. Coimbra, Portugal: Imprensa da Universidade de Coimbra. p.156

<sup>152</sup> ibidem

<sup>153</sup> ibidem

□ Field notes

In ethnographic research, beyond the various data collection techniques utilized, it is essential to maintain a field notes where observations and other aspects, such as the researcher's impressions and emotions, initial interpretations and evolving hypotheses, recurrent expressions, and words, etc., are recorded. In this field journal, a range of skills and competencies are embodied, which are necessary to maintain a useful record.<sup>154</sup>

During my all internship I tried to write a note for every day to collect data and “food for thought” that would help me in the future to write my thesis. In the field notes in fact, I started to collect point of reflection about the institutionalization situation of the users.

A mix of descriptive, interpretive, and reflective writing styles is used in my field notes.

In descriptive notes, a description of what is observed is recorded. The details of the observations include the physical surroundings, participants' behaviors, and important events. Interpretive notes, delve into understanding the meaning of these observations, helping uncover cultural norms and patterns. Reflecting notes captured the researcher's thoughts, feelings, and evolving insights, shedding light on the subjective experience of being present in the field.

The researcher must strive for objectivity and also accept subjectivity. To ensure the reliability and accuracy of field notes, he should be careful of his own subjectivity. This involves being aware of personal biases, preconceptions, and emotions that could influence the interpretation of events.

In conclusion, field notes serve as a lifeline for investigators and researchers, helping capture the essence of real-world events, behaviours, and experiences. Their careful and detailed documentation is essential for preserving the authenticity and integrity of investigations and participant observation studies, contributing to a deeper understanding of the complex context we are involved.

□ Interviews

In terms of data collection, I employed the method of unstructured interviews with participants, creating moments of informal conversation during which I asked them to express how they felt about living in an institution, the frustrations and sensations they experienced throughout the day. Later, I would collect these conversations in my notes. These discussions proved to be very valuable in gaining their perspective on the issue of institutionalization. I also could consider their perspective about that thematic and many others. I could talk with them about their desires, challenges, goals, frustrations, internal conflicts, hopes, and thoughts.

Furthermore, I conducted two structured interviews to collect data. Firstly, to gather information about the institution, I conducted an interview with E., the professional responsible for organizing and planning activities as well as overseeing volunteer work and internships. The interview with her proved

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<sup>154</sup> Amado, João (2013). *Manual de Investigação Qualitativa em Educação*. Coimbra, Portugal: Imprensa da Universidade de Coimbra. p.160

to be highly productive. It provided me with the opportunity to gather a wealth of information regarding the residence, its rules, principles, history, hierarchy, and many other aspects that were previously unknown to me about Estimia Foundation. Additionally, I was able to gather insights and her perspective on the issue of institutionalization and all the surrounding facets of this phenomenon. It was extremely valuable to listen to her pragmatic viewpoint.

In the interview with E., I had two main objectives: firstly, to gather more information about the Estimia institution, and secondly, to understand her stance regarding the process of institutionalization experienced by the users. Indeed, there was a very interesting segment during the interview that touched upon this topic, she explained to me that, according to her, the best thing for a person with disabilities is obviously to live in their own home with their family. She then went on to explain the reasons why these individuals find themselves in care facilities. Firstly, there's a portion of them who don't have a family to rely on, but instead, they have an entity that takes care of them. These individuals are therefore obligated to stay in a residential setting, but they are also accustomed to it, likely having spent most of their lives there. Then there's the case of people with parents who are now elderly and don't have the energy to take care of their children anymore, or simply don't have homes adequately adapted. Finally, she reiterated how the care facility should be their home, and all the services of direct attention and more must be guaranteed to ensure a good quality of life for the users.

The second interview I conducted was equally interesting and instructive. I had the pleasure of interviewing the music therapy teacher with whom we have been carrying out the music therapy project together with the users since September. It was a very long and enriching conversation. We were able to analyse the lesson structure, the objectives it aims to achieve, the observed progress, the music therapy approach he follows, and many other specific aspects regarding the users and their advancements.

The most important recurring part of the interview is this phrase: "I make music." C. has indeed reiterated multiple times how his main goal is to make music with people, and consequently, all the benefits come naturally. I really liked his perspective. In the next chapter, we will analyse in more depth all the discussed aspects related to our music therapy intervention.

### **3.5. ETHICAL CONSIDERATIONS**

The research and investigative work require particular attention to ethical considerations, both during the internship and especially during the educational intervention project. In addition to this attention, in my case, we are dealing with individuals with disabilities, which means that their protection and consequently their rights must be a top priority when embarking on an investigative project. This population has fewer means to protect themselves and is more vulnerable from this standpoint. Therefore, it is our duty to take action to ensure that their rights are guaranteed and respected.

In this regard, Estimia has taken proactive steps by creating a Code of Conduct.

Estimia's Code of Conduct is a document that responds to the need to address new challenges in our sector. This code provides a series of guidelines for the behaviour of all those who collaborate with Estimia and is a fundamental part of the transparent, professional, and efficient management.

Estimia's values and principles of action are the followings<sup>155</sup>:

- *Respect for legality*: in Estimia, professional activities are carried out strictly always complying with the current legality and in every place where they are carried out.
- *Ethics and Integrity*: honest and ethical behaviour are maintained avoiding and rejecting without hesitation any form of corruption. Members of Estimia respect and promote the professional values of the organization.
- *Respect for individuals and cultures*: the main asset are people, and therefore they fully endorse the Universal Declaration of Human Rights adopted by the United Nations, as well as other conventions and treaties derived from that declaration.
- *Responsibility*: At Estimia, they assume their responsibilities and act, accordingly, directing all their efforts and commitment towards achieving their objectives.
- *Transparency*: Estimia operates in a highly regulated sector that is subject to government oversight. It is a fundamental objective of Estimia to disseminate appropriate, accurate, truthful, and verifiable information both internally and externally.
- *Commitment to quality and excellence*: Estimia offers the highest possible quality services to our students, residents, and their families.
- *Teamwork*: At Estimia, they believe that by working together as a team, they can accomplish more and experience a greater sense of professional fulfilment compared to working individually.
- *Innovation*: Estimia distinguishes itself as an organization focused on continuous improvement and constant innovation, leading the way in the application of cutting-edge systems.
- *Confidentiality*: At Estimia, the information of students, residents, and employees is treated with the highest level of discretion and privacy.
- *Leadership*: It is not merely a goal or objective, but a firm belief that guides Estimia's entire foundation activity in providing the best possible assistance.
- *User orientation*: All Estimia's activities are focused on exceeding the expectations of its students, residents, and families. The Foundation operates with the philosophy of offering services that represent the best option for assistance to all users.<sup>156</sup>

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<sup>155</sup> Estimia Fundacion (2021)Codigo de conducta [pdf file]

<sup>156</sup> ibidem

The Ethical Charter of Education Sciences from the Sociedade Portuguesa das Ciências da Educação states that:

Research in the field of Education Sciences should be guided by the respect for the well-being and integrity of all individuals involved, including the well-being and integrity of the researchers themselves. As such, research processes, as well as their outcomes, should be designed, conducted, and communicated in a way that avoids any situation that could pose a risk or threat to well-being and integrity. It is the responsibility of the researchers to promote an environment of mutual respect and healthy interaction among all parties involved.<sup>157</sup>

In relation to this and the Estimia's Code of Conduct, I have decided to utilize the Informed Consent for the music-therapy project. Informed consent is a fundamental ethical principle and legal requirement in various fields, including healthcare, research, and professional settings. It involves obtaining permission from an individual before initiating a specific activity or procedure that may have an impact on them. This process ensures that individuals are fully aware of the details, implications, and potential risks or benefits associated with the activity, allowing them to make an informed and voluntary decision to participate or proceed.

The Key components that I introduced in the Informed Consent include:

- *Disclosure of Information:* The individual must obtain clear and comprehensive information about the activity or procedure. This includes the meaning, nature, goals of the study; procedures applied, potential risks, advantages, and alternatives.
- *Understanding:* The person should have the cognitive capability to understand the information delivered. That's why it was important in my case to write it in Spanish. The complexity of the information should be adapted to the individual's level of comprehension.
- *Voluntariness:* The decision to participate or proceed must be entirely voluntary. There should be no coercion, intimidation, or manipulation to influence the individual's preference. They should be free to refuse or withdraw from the activity at any time without negative outcomes.
- *Competence:* The individual giving authorization should have the legal and mental capacity to do so. In some cases, such as involving minors or individuals with cognitive impairments, their legal caretakers may provide consent on their behalf. In the context I am involved in, for most participants, informed consent has been signed by their tutors or family members.
- *Opportunity to Ask Questions:* The individual should have the opportunity to ask questions and seek clarifications regarding any aspect of the activity. This helps guarantee that they fully understand the details and implications before deciding.

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<sup>157</sup> Sociedade Portuguesa das Ciências da Educação (2020). *Carta Ética das Ciências da Educação*. Porto. Sociedade Portuguesa das Ciências da Educação.

- *Documentation:* Informed consent is typically documented via a written consent form. This documentation serves as proof that the individual received the needed information and willingly agreed to participate.

In the context of Estimia, informed consent has been explained and introduced to the users and their families during a music therapy session where parents were present. Subsequently, the consent document was provided and signed by the family members. Through this process, I have ensured the protection of users' data while safeguarding and legitimizing my role as a researcher. This approach underscores my commitment to ethical considerations and my investigative work's secure conduct.

Another important aspect to address regarding the ethical issue is the end of my internship and the beginning of my work in the institution with a different role. In fact, it was agreed with the director that I would be moved to a different floor. Therefore, having mostly conducted my internship on the 5th floor, I started working on the 3rd floor. The rationale behind this relocation was not to disturb the users too much, considering my sudden change in role, and to prevent the emergence of toxic situations or dynamics that would be difficult to navigate. I would say that this approach was positive because, even though they saw me in a different capacity, they were able to gradually get accustomed to my new role, which undoubtedly helped both me and them adapt to my new position more smoothly.

Indeed, it is especially important to pay attention to these aspects of sudden detachment because users become attached quite quickly and they observe a lot. So, they get used to your presence and when you are not there, they notice, which can cause discomfort and deep sadness for them. I realized this quite early, so I always tried to notify in case I would not be there for a day or if I was running late. A very clear example of this process is documented in the field notes where I explain how the users noticed my absence after a period of illness.

During this week, I could not go to my internship because I had a fever, and I realized upon returning the following week how much they actually missed me. Everyone was asking me where I had been and how much they had missed me. (NT 32)

Lastly, but certainly not least, an important ethical matter that I deeply value is the ability to distinguish between one's professional role and that of a friend. In my work context, it is crucial to acknowledge that establishing a friendship between users and educators is not possible, even though this distinction can be intricate. I have often observed how friendship becomes intertwined with the professional role in my work environment, leading to highly problematic relational situations, which I have witnessed firsthand.

For instance, it is possible that a user might not respect the educator's professional role because they do not view them adequately due to a friendship-based relationship. Similarly, a user might develop an



excessive attachment to the educator, hoping the relationship continues beyond the professional setting. This blurred scenario can cause confusion and distress for both users and educators.

Thus, it is of primary importance from the beginning to establish a relationship between educators and users based on professional foundations, rather than attempting to build friendships. This separation is essential to ensure a healthy, balanced, and respectful environment where each party can fulfill their roles effectively without uncertainties or conflicts arising from inappropriately complicate relational dynamics.

In conclusion, ethics play a fundamental role in my internship, particularly within the field of disabilities. Sensitivity towards disabled users, their families, and staff necessitates an ethical and conscious approach. I have learned that even small actions, such as notifying them of absences, can greatly impact their emotional well-being. Building trust and respect is vital, especially when working with vulnerable individuals.

The gradual transition from internship to a distinct professional role demonstrated an ethically measured approach, helping users adapt more seamlessly to change. This underscores the importance of considering not only professional goals but also user well-being in the evolution of my role.

Lastly, within the sphere of disabilities, ethics become even more crucial, encompassing rights protection, autonomy promotion, and the creation of an inclusive environment. My internship experience emphasized that ethical consideration is not just obligatory but serves as a guide to provide meaningful and responsible support to individuals with disabilities. This contributes to enhancing their quality of life and interactions within society.

## CHAPTER IV

# INTERNSHIP JOURNEY: BUILDING IDENTITY, REFLECTIONS, AND INTERVENTIONS

In the following chapter, I will describe the essence of my internship, which can be summarized in four main themes: first, getting to know and integrating into a new context, different in terms of culture yet welcoming and within my comfort zone. The second theme revolves around my integration as an intern and my assimilation into the team of workers of Estimia. Furthermore, it's crucial to highlight the support I received from my supervisor in the Spanish institution and the assistance my tutor from the University of Porto provided. The third theme is getting to know the users, engaging in numerous informal conversations, and actively participating in various activities with them. Lastly, the fourth theme that characterized this internship was my educational intervention through music therapy, where I observed a significant improvement in the quality of life of the service users.

### 4.1. INTEGRATION INTO THE INSTITUTION

As I explained earlier, integration into the new context was relatively straightforward, but it came with challenges. Firstly, the language barrier. Since I wasn't proficient in Spanish initially, I had to resort to Portuguese and Italian. Consequently, I could communicate, but with various difficulties and misunderstandings. However, the language factor wasn't a significant limitation because, thanks to the enthusiasm of the individuals and my determination to learn a new language we soon established a close bond of trust with the users. I also believe that people with disabilities have a profound sensitivity and an exceptional ability to listen to others, which made our interactions more meaningful and rewarding. My status as a foreigner at the beginning made me feel somewhat "different" because I was the only non-Spanish native, on the other hand, it was also a strength. I was interesting for them: "the Italian in Barcelona." This sparked conversations and facilitated my approach to them. The genuine curiosity and interest they showed in my background broke the ice and made me feel welcomed and appreciated.

As for the context, it wasn't so different from what I had experienced in the past. My previous experience in a Residence for individuals with cerebral palsy in Lisbon had indeed greatly helped me. The population I interacted with was very similar to the one I had already worked with, so I felt very comfortable with them right from the start, which undoubtedly aided significantly in my integration into the context. This sense of familiarity allowed me to focus more on the unique needs and personalities of the users and tailor my approach to provide them with the best possible support and care.

## **4.2. THE TEAM: CHALLENGES AND LEARNING**

In the work context I joined, there are various professional roles, including healthcare operators, the activity coordinator, the director, the social worker, and other indirect care professions like the cook and cleaning staff, etc. In the first few months, I didn't feel very integrated. I had established a good connection with the volunteers and the other intern, however, with my colleagues, it wasn't initially easy. The healthcare operators are often very busy and don't have time for other things. They often see the role of an intern more as assistance in their caregiving work rather than as someone who can provide educational and formative input to the users. This is why I struggled initially to assert my role as an intern educator.

My goal was to accompany the people in their activities and, over time, develop my own activities. I also believed assisting with their daily care routines was essential, but I didn't want this to become my main focus within the residence.

Initially, I didn't find this context stimulating as an educator. However, over time, I tried to make the most of what this experience could offer. I gradually saw my role being recognized, becoming more and more useful and crucial to the success of the activities. Additionally, I started to independently develop more structured activities.

In this, I was often supported by my Spanish tutor, who always gave me the green light. She was always open to my ideas and never imposed or requested anything from me. Additionally, I received consistent support from my tutor in Portugal. Despite the geographical distance, he remained readily available to address my questions and provide guidance throughout this journey.

In summary, over time, I learned to value my role as an intern educator in an initially challenging context and tried to make the most of the opportunities to make a meaningful contribution to the well-being of the users.

## **4.3. INFORMAL CONVERSATIONS AND ACTIVITIES WITH USERS**

A crucial aspect of my internship was engaging in conversations with the users, which proved an effective way to get to know them and make myself known. Through verbal exchanges, I could gather valuable information about their interests, aspirations, and most importantly, the challenges they faced daily. Engaging in dialogue allowed me to identify their strengths and potential weaknesses.

In tandem with these conversations, I initially introduced spontaneous activities. For example, we started playing Connect 4, and it quickly became evident that there was a wide range of cognitive abilities among the users. I vividly recall a day when I engaged two users in playing the game of Dominoes, and I noticed that one of them had more difficulty concentrating than the other. In response, I implemented strategies to make her feel included and worked on enhancing her memory and concentration skills.

Later in the day, I decided to play a game of dominoes with V. and C., attempting to make the game more engaging for V. by actively involving her. I ensured she followed her turns, for example. Additionally, I constantly asked her about the numbers we needed to proceed. I didn't just ask during her turn but throughout the entire game to help her concentrate and develop her cognitive skills. So, at each turn, I would ask, "V. which numbers do I need?" She would look at the ends of the dominoes and tell me, for instance, "6 and 3." Sometimes she was quick and had the correct answer, while other times, I had to ask her to take a closer look, encouraging her to self-correct. It was both interesting and instructive for V., as well as enjoyable. I believe this is important because it allows her to actively participate, boosting her self-esteem and confidence. Unlike situations where she plays with fellow residents and isn't truly engaged in the game, leading others to move the game pieces for her without her understanding why. In that particular situation and context, I felt extremely helpful to her. (NT 19)

In a more advanced stage of my internship, I began to design and implement structured activities with specific objectives. One of these activities focused on the five senses, with the first session centered around the sense of touch. We used various materials and set up various activities to explore an aspect that people often take for granted the sensation and focus on the feelings that a surface can provide. We also had the opportunity to discuss with the participants what sensations they experienced when touching substances such as rice, soil, or flour. This activity was well-received by the participants, who responded very positively when asked if they enjoyed the activity and would like to repeat it.

Incorporating sensory exploration into activities for people with disabilities is enjoyable and essential for their overall well-being, communication, and development. It fosters inclusivity and ensures that individuals with disabilities can engage fully in enriching experiences that stimulate all of their senses. Through continuous investigation and participatory observation, I became aware that the residents often became its victims by living within the institution. They were subject to its rules and schedules, essentially becoming institutionalized individuals who spent most of their time inside the facility, adhering to its regulations, spaces, and timetables, as discussed extensively in Chapter 2. I realized that this was a significant issue for the residents.

Subsequently, I became more interested in the new activity of music therapy. I could sense the enthusiasm among the residents. Over time, I realized that a pathway towards enhancing the residence's quality of life could begin with that hour of music therapy.

## **4.4. MUSIC THERAPY INTERVENTION**

### **4.4.1. The Objectives and the Methodology of the Intervention**

Bruscia (1989) provides a comprehensive definition of music therapy as a methodical intervention process, wherein the therapist facilitates the client's journey towards improved health by employing the transformative power of musical experiences and the unique therapeutic relationship they cultivate. These musical encounters encompass a range of activities, such as singing, vocalizing, engaging with

various percussion and melodic instruments, and even passive listening to music. The music therapist actively participates in these interactions, utilizing musical elements to foster connection and engagement with the client.<sup>158</sup>

The general objectives of music therapy can be tailored to address diverse aspects of well-being, including cognitive development, emotional expression, social integration, enhancement of self-esteem, and motivation enhancement.<sup>159</sup>

It's fascinating to bridge theory with practice, and this becomes achievable through the interview I conducted with the music therapist C. In our conversation he emphasizes that the central focus is on making music, and as a result all the objectives are an integral part of it:

"My personal vision has always been to create music. I always bring this aspect into all my sessions as a music therapist. My goal is to make music. If you observe closely, I'm consistently and continuously engaged in making music with them. For example, if one of them strikes an object, I encourage them to strike it rhythmically to promote coordination and psychomotor skills. What I intend is for them to create music together with me. When they engage in music with me, it encompasses several objectives: coordination, psychomotor skills, group music, their relationship with me, and even more objectives at an emotional, cognitive, sensory, bodily awareness, self-confidence, and introspective level."(Interview Music Therapist)

A structured approach to music therapy can lead to alterations in an individual's musical behaviour, which may serve as markers for concurrent shifts in their psychological well-being and functioning.<sup>160</sup> The importance of a structured and consistent approach is well articulated by the music therapist, who, along with the group, creates two different sessions tailored to their specific needs. Both sessions have a more or less fixed structure that begins and ends with a ritual, which we consider to be a crucial tool for entering and exiting the musical context. We conclude each session with expressions of gratitude for making music together:

"The ritual is very important in every session because it marks a bit of a distinction between outside and inside. It's a musical introduction, followed by greetings. It's a matter of respect and esteem. And finally, I express gratitude to each one of them." (Interview Music Therapist)

Consequently, alterations in the dynamics and time, during spontaneous music improvisation may signify an enhanced capacity for self-regulation, improved social perception, and more effective expression of a range of emotions. These crucial components of music, including rhythm, melody,

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<sup>158</sup> Katušić, A., & Burić, K. (2021). *Music Therapy in Educating Children with Developmental Disabilities*. Croatian Journal Educational/Hrvatski Casopis za Odgoj I Obrazovanje, 23(1).

<sup>159</sup> ibidem

<sup>160</sup> ibidem

harmony, time, and dynamics, are intentionally employed in specific combinations and varying degrees of intensity to facilitate shifts in the client's overall functioning.<sup>161</sup>

In addition to music as a therapeutic modality, interpersonal relationships between the client and therapist play an equally vital role in facilitating change. For music to effectively serve as therapy, it must be administered by a qualified music therapist—an expert who possesses the necessary knowledge and skills to establish a professional therapeutic relationship with a client through musical experiences.<sup>162</sup>

Therapist C. emphasizes, first and foremost, the importance of having a background as a musician for this profession:

"First, to work as a music therapist, you need to complete a two-year master's program in music therapy, which is a postgraduate degree, essentially. But on a personal level, I highly value having studied music beforehand because, as you've seen, if I could only play three chords on the guitar, I wouldn't be able to achieve the same results. So, from my perspective, it's crucial that you have a background in music."  
(Interview Music Therapist)

Furthermore, C. delves into the importance of fostering an healthy and constructive therapist-client relationship:

"Here, I never take control. I'm always on the same level. I always appreciate their music, and I'm right there with them. In the second group, they always applaud me: 'Thank you, C., you're amazing in the way you play.' But no, we all make music together. I've told them, without all of you I'm nothing, because without a choir, there are no singers. I can't do anything on my own. So, it's about valuing what they do and meeting them at their level. I almost always use a chair, and that's not a coincidence. Then, I have great respect for them, I'm nobody to tell people what they should do." (Interview Music Therapist)

The music therapist's effort is to support the positive and productive behaviours that the person may experience in the music making process. It's crucial to emphasize that the therapist's approach is characterized by empathy and unconditional acceptance rather than judgment within the therapeutic relationship<sup>163</sup> as the professor of music therapy has emphasized:

"I try to teach a pedagogical approach to improve in the practice of the instrument, but I haven't told anyone that they are doing it wrong. What I will do is observe how each of them does what I have proposed

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<sup>161</sup> Katušić, A., & Burić, K. (2021). Music Therapy in Educating Children with Developmental Disabilities. *Croatian Journal Educational/Hrvatski Casopis za Odgoj I Obrazovanje*, 23(1).

<sup>162</sup> Rogers, C. (1961). *On becoming a person*. Houghton Mifflin.

<sup>163</sup> Katušić, A., & Burić, K. (2021). Music Therapy in Educating Children with Developmental Disabilities. *Croatian Journal Educational/Hrvatski Casopis za Odgoj I Obrazovanje*, 23(1).

and how I can help them to improve it. If they manage to follow my advice that's good. If not, that's fine too. In other words, I will tell them the same thing again next week if we were to repeat the same activity." (Interview Music Therapist)

By observing the client's expressions and assessing their confidence levels, the therapist gains valuable insights into both their musical and non-musical behaviours, allowing them to identify and address the person's unique needs. Central to music therapy intervention is the application of a client-centered therapy approach<sup>164</sup> as C. has enlightened in the interview:

“In the context of using music therapy, I find it crucial for me, as a therapist, to align my musical expression with the user's current energy level. When the user is experiencing low energy, I believe it's my responsibility to adjust my musical approach accordingly. My role as a therapist involves cleverly managing and manipulating the musical energy to meet specific therapeutic goals. This can mean either maintaining the current energy level or providing a boost, depending on the situation. I've observed that this approach places a strong emphasis on individualized attention, even in a group setting. Within such a setting, I tailor my music to suit the unique needs and energy levels of each participant.” (Interview Music Therapist)

Therapist C. draws a captivating metaphor by likening the therapist's role to the one of a doctor:

“You have to read and diagnose the situation every day, understanding what is happening. For instance, today, R. appears quite low on energy at the beginning of the session. So, it's essential to read and assess how R. is doing, just as a doctor would prescribe something specific.

Furthermore, it's crucial to continuously evaluate the situation in every moment. You evaluate and act based on how the individual responds, much like a doctor continuously assesses a patient's condition and adjusts the treatment accordingly.” (Interview Music Therapist)

The application of music therapy is transdisciplinary because it can simultaneously address various needs across different developmental areas. It is not confined to a particular area of functioning; instead, it is defined by specific activities centered around music that aim to bring change in non-musical domains.<sup>165</sup> For example, a music therapist has the capacity to enhance various aspects such as pronunciation, language development, attention, socio-emotional and interpersonal skills, as well as gross and fine motor skills, concept mastery, and problem-solving, among others. Songs, in this context, serve as effective mnemonic aids for memorizing sequences or categories, fostering associative learning

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<sup>164</sup> Katušić, A., & Burić, K. (2021). Music Therapy in Educating Children with Developmental Disabilities. *Croatian Journal Educational/Hrvatski Casopis za Odgoj i Obrazovanje*, 23(1).

<sup>165</sup> Pellitteri, J. (2000). Music therapy in the special education setting. *Journal of Educational and Psychological Consultation*, 11(3&4), 379-391.

by connecting sound to specific terms or body movements<sup>166</sup>. In addition to these important goals, C. believes that the lyrics of the songs are crucial, along with the message they convey, and explains it this way:

"While some of the songs are chosen by them, I've started to focus more on the lyrics and the message lately. I believe that the message conveyed by the songs is crucial. The songs I've selected all carry a meaningful message about life and the present moment. For instance, there's 'Happy Day,' which expresses gratitude." (Interview Music Therapist)

Models of music therapy that are based on improvisation and are commonly used in the educational process of people with disabilities are: free improvisation therapy, creative music therapy, known as the Nordoff-Robbins model, and Orff music therapy.<sup>167</sup>

The approach that we are been using in the session is Creative music therapy, which is based on having many resources, entering the session, and creating from what happens in the session, in the moment. It becomes very evident in group one. When something happens musically, but also when things occur or someone plays an instrument, the professor goes along with it, and together we create music.

Exploring again the advantages of music therapy: the creative process used in music intrinsically involves problem-solving, even more for individuals with disabilities who adapt their existing abilities to engage in music-making. The musical experience provides the motivation, stimulation of emotional state, and the structure that supports these cognitive processes.<sup>168</sup>

In conclusion, Music therapy is characterized as a clinical approach that centers around music as the primary activity. The inherent power of music can be employed effectively within various educational contexts for people with disabilities. This approach fosters an inclusive, integrative, and supportive environment, where the multi-sensory nature of musical experiences allows for self-expression and creativity.<sup>169</sup>

#### **4.4.2. Development of the Intervention**

In Estimia, music therapy sessions occur once a week, running from 11:00 AM to 1:00 PM. The first session for the initial group is from 11:00 AM to 12:00 PM, followed by the second session from 12:00 PM to 1:00 PM. The first group consists of 5 users who may face cognitive challenges, while the second group comprises 10 users with mild cognitive disabilities. This differentiation leads to the application of distinct approaches and objectives for each of the two sessions.

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<sup>166</sup> Katusić, A., & Burić, K. (2021). *Music Therapy in Educating Children with Developmental Disabilities*. Croatian Journal Educational/Hrvatski Casopis za Odgoj I Obrazovanje, 23(1).

<sup>167</sup> ibidem

<sup>168</sup> ibidem

<sup>169</sup> ibidem



In the first groups, there is a structured format. The sessions begin with a ritual, which is a good morning song addressed to each participant. Following this, there is a musical introduction to ease into the session. During these sessions, minimal verbal instructions are given, and participants are encouraged to express themselves freely.

The musical introduction is designed to create a gentle transition into the session. Percussion instruments are then distributed, allowing participants to engage actively in the session. During these moments, the therapist creates individual moments with each participant, encouraging collaborative creativity. This process is inherently creative as it is closely connected to what the participants do with the instruments, their voices, or their bodies. As I mentioned, the therapist's role is to attentively capture any stimulus that could be transformed into music. This phase of the session is marked by moments similar to the one described by the therapist in our interview:

“Suddenly today, J. began to drum. So, I moved in that direction, capturing that moment, synchronizing with him, incorporating what he was doing, and translating it into music. Because outside of the music therapy session, this is simply a beat. However, within our session, it's about converting this clack, clack, clack into music”. (Interview Music Therapist)

Furthermore, there is a relaxing segment featuring calming music and vibro-tactile instruments. The therapist and I collaborate with the participants, employing vibro-tactile instruments in unison. The objective is to allow them to experience the auditory aspect and tactile vibration, enhancing their connection to the music. These instruments produce natural and varied sounds, along with the tactile sensation of vibration.

The sessions conclude with another song led by the therapist, characterized by a rise in energy and intensity. Participants often join in, as they are familiar with the song and its lyrics.

At the end of each session, the therapist concludes the session with a traditional farewell song personally addressing each participant by name and expressing gratitude for their participation in the music-making experience.

The second group's session is conducted in a more flexible manner, and its structure has evolved over time.

It always starts with the ritual song, in which the therapist greets each participant individually and sings a song they are already familiar with. The participants enthusiastically respond to the therapist's good morning greetings and follow the ritual attentively. After that, the therapist usually begins with a calming song to ease into the session, and once again, the participants listen attentively and applaud the therapist. Later, the therapist and I introduce technique exercises that are used in this group as a form of introspection and sensory awareness. We focus on bodily awareness: being aware of the body, its parts, the breathing, and the part of the body where we make sound because we don't just make sound with

our tongue and lips. The exercises we propose have varied and evolved over time. For example, one exercise involves participants making sounds with their mouths and trying to listen to themselves by placing a hand in front of their mouth to hear themselves better. Another exercise involves participants massaging different parts of their body. These exercises are particularly essential for individuals with physical disabilities because being in a wheelchair can sometimes lead to a disconnect from one's own body. It's a way to reconnect with your body.

Then, there's a percussion segment where instruments are distributed, and participants often play along to a familiar song. Here, we work on rhythm, coordination, respect for others, listening skills, and more. Various exercises are introduced, such as the "ping pong" exercise, where the therapist initiates a beat on percussion, and each participant responds in turn, following the rhythm. This exercise has evolved, as participants now take the lead in coordinating it; they have become the protagonists of this activity. In this, active role, self-esteem, interpersonal dynamics, leadership, and more come into play.

Following the percussion segment, there's a part of the session where we combine repertoire from previous sessions with new songs. This mix is intended to make the session enjoyable, with participants singing songs they already know and like, alongside ones they have to learn. When it comes to learning new songs, the therapist often explains the lyrics and their meanings. Then, we let the music do its work. The session often transitions to another technique session where different tonalities are explored, and participants are asked to follow the therapist in changing key. This activity has evolved and become more complex as participants acquire new musical skills.

We conclude by singing two or three songs of their choice to enhance memory and create a carefree atmosphere.

Finally, we reach the ritual closing song in which the therapist expresses gratitude, bids farewell, and wishes everyone a great week.

The music therapy activity started in September 2022, and it is still going on, and I followed the activity till July 2023. I could observe all the progression that they have made and the benefits that music brought to them.

#### **4.4.3. Intervention Results**

We started music therapy activities with two groups who were initially quite inattentive and disoriented. Concerning the first group, the transformation has been remarkable. Initially, the participants were often lost in their own worlds, minimally engaged in the musical activities. They would talk and disrupt the session, seeking attention from their peers and displaying a lack of independence. Even though instruments were provided to them, they hardly touched them and sometimes let them fall. A few participants would cry and complain during the session, far from a relaxed state. Furthermore, they struggled to follow songs and rarely sang along. However, after a year of sessions, they have made extraordinary and distinct progress, each in their own unique way. I have meticulously recorded their

advancements, which, of course, represent just a portion of the magnificent work accomplished. Here are some noteworthy observations:

In addition to the week's notes, I'd like to highlight the progress made in the music therapy sessions by the first group, which comprises individuals who face cognitive challenges. It is truly impressive to witness how deeply engaged they are now during the music sessions, with each of them displaying significant progress. For instance, M., a lady who was initially rather hyperactive, has become considerably more focused compared to her early sessions. Whereas she used to constantly seek the hands of her peers for reassurance, she is now more independent and attentive to the activities. Moreover, she has started to actively use the instruments, something she never attempted before, and she follows the therapist in songs, even remembering the lyrics. It was heartwarming to see how the therapist managed to calm another participant, who is blind and is hypersensitive to sounds and smells. This individual would often become agitated and cry non-stop. The therapist began singing loudly, aligning with his crying, and the outcome was astonishing: after a few minutes, J. calmed down and even smiled. S. has also made substantial progress. Initially, she struggled to follow and seemed somewhat isolated in her own world. The music therapist succeeded in creating a moment of profound intimacy with her, once again aligning with her lamentations, which transformed into a shared song that S. actively participated in. It was truly captivating for me to witness these developments in each of them week after week. (NT 11)

These are just a few of the achievements reached midway through their journey. Currently, all of them are actively engaged. Some play the drum in rhythm, remember song lyrics perfectly, take the initiative to use the instruments, remain calm and relaxed, and, most importantly, as the therapist would put it, they are 'inside the music.' This last aspect is evident in how they recreate the therapist's musical note by talking or singing, indicating their deep involvement into the session.

I could go on listing the results achieved by the first group, but often such results are challenging to enumerate as they represent small, specific milestones for each individual. And that's the beauty of music therapy with this population.

Regarding the second group, there have been significant progress, especially in terms of musical technique. This group has grown tremendously, even in a collective sense. Initially, there were many conflicts due to the large number of participants. Often, rhythm wasn't maintained, and there was a lack of listening. However, after a year, the results are incredible. The group now plays in sync, with mutual listening and harmonious singing. Furthermore, there has been substantial improvement in personal awareness and self-esteem, among other aspects.

Based on the analysis of music therapy sessions and participant evaluations in both groups, it's evident that this intervention has yielded significant positive results, particularly in addressing the challenges related to institutionalization. Here are some key observations and findings:

- *Enhanced Emotional Expression and Connection:* Participants in both groups have shown enhanced emotional expression and a stronger sense of connection with others. The structured yet creative method of music therapy has provided a secure space for them to express their emotions, decreasing feelings of isolation frequently associated with institutionalization.
- *Improved Communication Skills:* Music therapy has contributed to developing better communication skills among participants. This is particularly notable in Group Two, where the therapist's focus on vocalization and rhythm has empowered individuals to express themselves more effectively.
- *Increased Self-Esteem and Confidence:* The participatory nature of the sessions, where participants actively engage with instruments and voice, has increased self-esteem and confidence. This is particularly beneficial for individuals with disabilities who may have experienced a lack of active role in other institutional settings.
- *Sensory Stimulation and Body Awareness:* The incorporation of vibro-tactile instruments and exercises aimed at enhancing sensory awareness has been highly effective. Participants have become more in touch with their bodies, a crucial aspect in addressing the challenges of institutionalization, especially for those with physical disabilities.
- *Social Interaction and Inclusion:* Music therapy has fostered a sense of social interaction and inclusion within the groups. Through collaborative activities like percussion ensembles and singing together, participants have built strong interpersonal bonds, mitigating conflicts often associated with institutional living.
- *Positive Impact on Memory and Cognitive Function:* The integration of songs and memorization exercises has contributed to memory improvement. The two groups experienced notable progress in this regard, which is essential for maintaining cognitive abilities over time.
- *Empowerment and Ownership:* The evolving structure of the sessions, where participants have taken on active roles, has resulted in a sense of empowerment and control of their musical experiences, becoming aware of one's ability to make music. This is a significant departure from institutionalized settings' passive routines.
- *Addressing the Institutionalization Problem:* Music therapy has effectively responded to the challenges of institutionalization by providing a creative and engaging platform for self-expression, skill growth, and social exchange. It offers a compensation to the depersonalization often associated with institutional care.

#### **4.4.4. Reflection on the Developed Intervention**

In the conversation with the participants following our music therapy sessions, their enthusiasm for the activity became increasingly evident. Throughout the week, they would frequently inquire about the next music therapy session, reflecting the tangible enthusiasm they experienced before, during, and after

each session. The professor and I take immense pride in these results. What is most exciting is that this activity continues to evolve, with significant potential for further improvement. The positive effect of music on the participants' quality of life seems limitless.

In conclusion, the analysis of music therapy sessions and participant evaluations underscores the profound positive impact of this intervention in addressing the challenges associated with institutionalization. It has enhanced the participants' well-being and fostered a more inclusive and vibrant atmosphere within the institutional setting. These results underscore the significance of incorporating creative therapies, such as music therapy, to promote holistic health and well-being in institutional contexts.

## CHAPTER V

### MUSIC THERAPY AND QUALITY OF LIFE: THE RESULTS

As we explore Chapter 5 and delve into the outcomes of the intervention, it's important to revisit our previous discussions in Chapter 2 about deinstitutionalization. In that chapter, we explored a contemporary perspective, highlighting the importance of viewing this process as a harmonious balance between the administrative commitment of the institution and the multifaceted elements of humanity, society, and education. This contrasts the earlier notion of simply moving away from institutional settings. We also discussed how educational action, to be effective, indeed requires an organized institutional apparatus. The planning of an educational intervention must be based on a collaborative relationship between the institution (formal organization) and the educator (the one proposing the educational action). We cannot consider educational action as a separate entity, autonomous and free from any administrative/bureaucratic constraint<sup>170</sup>.

The music therapy program that the teacher and I started in September had a specific goal for me. Such a broad and multidisciplinary activity like music therapy could, first and foremost, create an environment where users felt welcomed and protected.

Moreover, this intervention could lead to a process of deinstitutionalization, which, as we've discussed, doesn't mean breaking away from the institution but rather creating a space for sharing and co-constructing changes within the institutional framework.

The perspective was to cultivate a setting that improves the well-being of the users, in other words, their quality of life.

#### 5.1. MUSIC THERAPY AND THE PROCESS OF DE-INSTITUTIONALIZATION

During this year of intervention, I collected numerous conversations with the users and had the opportunity to observe them both during and after the activities. This has led me to draw several conclusions. I noticed that our work operated on various fronts. I realized that we disrupted certain dynamics and aspects inherent to the institutionalization process that tend to confine users within it.

The Music therapy activity, first of all, helped promote *Inclusivity*: Music therapy created an inclusive environment where individuals within the institution feel valued and included. This inclusivity fosters a sense of belonging and being part of something valuable. One manifestation of this positive influence was observed in the participants' behaviour. They not only engaged in the music therapy sessions but also continued to embrace the music's impact on their lives beyond the designated times. For instance, they frequently sang the songs played during the sessions also during communal moments like lunch or

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<sup>170</sup> Paolucci, E. (2018). *Vivere in un istituto per disabili: la promozione della qualità di vita di disabili adulti istituzionalizzati* (Doctoral dissertation, Scuola Universitaria Professionale della Svizzera Italiana). p.23

other group activities. This practice is an indicator of the positive influence of music therapy on their sense of inclusion and connection. During the session, I could also feel this sense of inclusivity becoming more and more significant. In the beginning, there was much individualism, typical of an institutional setting, and the users were not listening to each other's. Little by little, this dynamic changed, and you could see more respect between each other's.

Secondly, *Music Empowered the participants*: through music therapy, participants could actively engage in the creative process. This empowerment allows them to have a say in their own well-being and contributes to a shift from a passive recipient of care to an active participant in their own growth and development. This was particularly visible in some of the participants of the first group that from passive listeners became super active members. For example, as I explain, the transformation of J. was incredible. He was mainly stressed and annoyed in the session at the beginning, and he became relaxed and started to sing along many songs, also becoming aware of his capability of doing music. Furthermore, he often plays a passive role in the institution, but this is not typically the case in music therapy.

The activity helped the *Emotional Expression*, providing a safe outlet for expression of all kinds of emotions. Users could express their feelings and experiences through music, which can be therapeutic and cathartic. I often see more than one of the participants starting to cry due to the moment's intensity or the music's association with some memories. This emotional release contributed to a healthier emotional atmosphere within the institution than I had felt in the first place.

*Collaborative Decision-Making* had also improved during this time. By involving both users and staff in music therapy planning and execution, a collaborative decision-making process is established. This collaborative approach aligns with the principles of deinstitutionalization by giving individuals a say in the activities and services provided within the institution. Furthermore, they experience a sense of empowerment when they realize that their voices and choices are respected and considered in the decision-making process, which is quite different from what often occurs in the institutional setting.

Other results that we reached it is *empowerment and self-confidence*. Music therapy, in fact, focuses on individual strengths and abilities rather than deficits or limitations. This strengths-based approach shifts the perspective from a medical model often used in an institution setting to a holistic one, recognizing everyone's unique potential. As time passed, the participants gradually began to recognize their skills and their potential for improvement. The results were truly remarkable. For example, initially, A. displayed signs of distraction and low motivation, often expressing a desire to leave the sessions early. However, with the support of the therapist and the encouragement of fellow participants, he started to gain confidence, leading to a transformation in his level of engagement. By the end of the year, A. had not only grown musically but had also developed a consistently cheerful and proactive attitude. This transformation aligns perfectly with my goal: to enhance their overall quality of life.

## 5.2. MUSIC THERAPY AND QUALITY OF LIFE

Let's delve into the concept of Quality of Life, as previously introduced in the former chapter. I aim to elucidate this notion's profound interconnections with other vital concepts such as deinstitutionalization, integration, inclusion, freedom of choice, and empowerment.

I would like to reintroduce the meta-model originally proposed by Schalock and Verdugo Alonso, which provides a comprehensive framework for understanding Quality of Life. This model articulates eight distinct domains, each of which is crucial in shaping an individual's overall well-being.<sup>171</sup> Rather than simply listing these domains, I will highlight the relationships that exist between seven domains and the outcomes that result from music therapy interventions:

- *Physical well-being*: This domain focuses on an individual's general health and physical condition.<sup>172</sup> Music therapy positively impacts physical well-being by promoting relaxation, reducing stress, and even assisting in pain management. Music therapy improves physical health by reducing muscle tension and enhancing overall well-being through techniques like rhythmic entrainment and guided relaxation. After the music therapy session, the participants were very relaxed. They could let go of their stress and problems by using music. I remember talking to one person who said he was a bit stressed and frustrated but was happy to come to music therapy with me to try to feel better.
- *Emotional well-being* focuses on the ability to experience contentment with one's life, satisfaction with choices, and a positive self-image. The quality of the individual's interaction with the external world plays a crucial role in this dimension.<sup>173</sup> The music therapy sessions facilitated the improvement of emotional well-being by allowing participants to express their emotions in a safe and supportive environment. Through music, they could explore and process their feelings, which led to increased self-acceptance, greater emotional resilience, and an overall improvement in emotional well-being. As mentioned earlier, participants felt comfortable expressing their emotions during the sessions without fearing judgment. Additionally, they experienced an improved self-image as they witnessed progress in their skills, leading to a sense of pride and accomplishment.
- *Autonomy*: It means the capacity and satisfaction of making choices, expressing one's preferences according to individual capabilities and communication methods, and utilizing

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<sup>171</sup> Schalock, R. L., & M. A. Verdugo. (2002). *Handbook on quality of life for human service practitioners*. Washington, DC.

<sup>172</sup> Croce, L., & Lombardi, M. (2015). *Strumenti verso l'inclusione sociale: il disegno sperimentale della Ricerca. Progettare Qualità di Vita*, Report conclusivo e risultati progetto di Ricerca 'Strumenti verso l'inclusione sociale, matrici ecologiche e Progetto Individuale di Vita per Adulti con Disabilità Intellettive e/o Evolutive', ANFFAS Nazionale, Roma.

<sup>173</sup>ibidem



opportunities offered by the environment based on personal desires and intentions.<sup>174</sup> In the music therapy sessions, autonomy was fostered by encouraging participants to make choices related to the music they wanted to engage with, instruments they preferred to play, the direction of the session and finally having the opportunity to take control and lead exercises. This empowered them to exercise their autonomy, boosting their confidence in decision-making and enhancing their overall sense of control and independence.

- *Personal development*: The primary goal in this domain is to foster self-sufficiency, encompassing effective time management and the ability to organize oneself independently.<sup>175</sup> In our music therapy sessions, achieving personal development was facilitated by instilling a sense of responsibility. Participants were encouraged to arrive on time for the sessions, which helped them develop punctuality and time management skills. Furthermore, they actively engaged in planning and organizing their musical activities during the sessions, promoting autonomy in decision-making, and contributing to their personal development.
- *Interpersonal relationships*: This domain emphasizes the importance of building connections with individuals in one's environment.<sup>176</sup> In the music therapy sessions, we promoted interpersonal relationships through collaborative musical activities. Participants worked together to create music, fostering a sense of teamwork. Through music, they learned to listen to each other, respecting different perspectives and fostering empathy. Additionally, we incorporated exercises specifically designed to enhance active listening and encourage participants to engage with the person next to them, further strengthening their interpersonal skills and connections.
- *Social inclusion*: This dimension revolves around the sense of belonging to a specific group or community.<sup>177</sup> In the context of music therapy, social inclusion is facilitated through shared musical experiences. Participants come together to make music, creating a unique sense of belonging and community within the therapeutic setting. This shared activity transcends individual differences and disabilities, promoting a feeling of inclusion among participants. Additionally, the collaborative nature of music-making encourages interaction and connection, further contributing to social inclusion. The therapist strives to create this atmosphere, as he mentioned in the interview: he sits in a chair not by chance, but specifically to foster a relationship where what everyone does is valued, and no one is placed at a higher level than the others. As the therapist repeatedly emphasizes, "*I am nothing without your contribution*".

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<sup>174</sup>Croce, L., & Lombardi, M. (2015). *Strumenti verso l'inclusione sociale: il disegno sperimentale della Ricerca. Progettare Qualità di Vita*, Report conclusivo e risultati progetto di Ricerca 'Strumenti verso l'inclusione sociale, matrici ecologiche e Progetto Individuale di Vita per Adulti con Disabilità Intellettive e/o Evolutive', ANFFAS Nazionale, Roma.

<sup>175</sup> ibidem

<sup>176</sup> ibidem

<sup>177</sup> ibidem

- *Rights and Empowerment*: this dimension encompasses the feeling of being safeguarded and having the liberty to express one's thoughts openly.<sup>178</sup> In the context of music therapy, the achievement of rights and empowerment is evident through several aspects.

Firstly, there is a profound respect for each individual and their time. The therapist consistently begins sessions by personally greeting each participant, addressing them by name, and underscoring the person's importance in the therapeutic process.

Moreover, the therapy sessions provide an open, inclusive space where individuals are seen and genuinely listened to. Here, they have the freedom to articulate their thoughts, emotions, and experiences through music, creating a platform that respects their right to self-expression without fear of judgment.

Lastly, a strong sense of gratitude permeates the therapeutic environment. Both the therapist and me acknowledge and appreciate the privilege of being part of this musical journey together. This shared gratitude reinforces the sense of empowerment, emphasizing that everyone's contribution is valued and vital to the collaborative experience of making music.

### **5.3. PARTICIPANTS FEEDBACK**

As previously mentioned, I have been documenting various conversations with participants regarding our music therapy activity.

One of the participants is a proactive individual named I., residing on the fifth floor, who has been actively engaged in the second session of our program. Since the beginning of my internship, we had numerous conversations, as we both enjoy exchanging thoughts and opinions. When I asked I. about his impressions of the session, here is what he shared:

“I love going to music therapy, we are learning a lot about music, and I love our teacher, he is really good to do what he does, he also plays really well. I want to learn to play like him too one day. I also enjoy a lot when we sing the song that we like.” (NT 39)

Another conversation I collected was with a participant called M. She is a bit introvert but little by little she opens up more with me and we had the chance to speak about different topic in different moment. To her I asked how she was feeling after the session of music therapy:

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<sup>178</sup> Croce, L., & Lombardi, M. (2015). *Strumenti verso l'inclusione sociale: il disegno sperimentale della Ricerca. Progettare Qualità di Vita*, Report conclusivo e risultati progetto di Ricerca 'Strumenti verso l'inclusione sociale, matrici ecologiche e Progetto Individuale di Vita per Adulti con Disabilità Intellettive e/o Evolutive', ANFFAS Nazionale, Roma.

“I feel relaxed and joyful, the session leaves me with a sense of peace and serenity, I see the things around me with another light. Thank you, Maria, to be part of the project. Are you going to be the next time?” (NT 39)

I continued my interview with another participant of the first group that cannot talk but can communicate with us. Her name is S. and her journey in the session was really interesting because at the beginning she was always complaining and tired instead at the end she was super relaxed and active in the creation of the music. When I asked if she enjoyed attending music therapy S. answered me with a big smile. Another highly enthusiastic and cheerful participant is J., who looks forward to every session of the activity with excitement. When I asked J. about his preferences regarding the activity, he shared the following:

“I like when the therapist said the “Buen Dia” to everyone and we answer to him. Also, I love the moment when we play the drum because I think I am really good at it, and this make me happy.” (NT 39)

I briefly talked with a participant from the first group named R. His progress throughout the year has been remarkable. He can recall all the lyrics, frequently plays the drum in perfect rhythm, and often becomes deeply emotional during our sessions. His love for music in general has been a constant passion throughout his life. I had a short conversation with him since he has a limited vocabulary, asking if he like music therapy, and he answered me yes and he took my hand. Later, I started to sing a song of the activity and he started to sing along, smiling at me.

#### **5.4. CHALLENGES AND LIMITATIONS**

Even though I take immense pride in the intervention's accomplishments, I acknowledge that the intervention of music therapy faces certain challenges and limitations that require attention and resolution. Below, I outline some of these obstacles:

##### *1. Limited Access and Benefits for Some Participants:*

- **Inequality of Access:** One significant challenge is that not all residents of the institution have equal access to music therapy. This can result in a sense of unfairness or exclusion among those who are not able to participate. It may also hinder the program's ability to achieve its goal of de-institutionalization if some residents don't receive the same opportunities for personal growth and social integration.
- **Exclusionary Impact:** The restriction of benefits can lead to feelings of frustration and resentment among those who are left out, potentially affecting the overall atmosphere and harmony within the institution.

## *2. Cost and Affordability:*

- **Financial Barriers:** Music therapy, like any specialized therapeutic service, can have associated costs. Some participants and their families may struggle to afford these services, leading to disparities in access. This financial barrier could limit the program's inclusivity and effectiveness.
- **Resource Allocation:** Allocating financial resources for music therapy may compete with other essential needs within the institution, such as healthcare, education, or facility maintenance. Balancing these priorities can be challenging.

## **5.5. FUTURE POSSIBILITIES**

The music therapy program is continuing successfully at the Estimia institution because all participants from last year have re-enrolled, and additional users have joined. I am very proud that the project could continue because I truly believe in its effectiveness for the well-being of the users and for the institution. I hope that solutions can be found to include all institution users in the future or at least provide access without economic barriers creating discrimination. In the meantime, I hope the project carries on, and that users can make the most of it, improving themselves every day and further contribute to their overall well-being.

## **5.6. CONCLUSION**

In conclusion, the journey towards deinstitutionalization and the enhancement of quality of life for individuals with disabilities has been significantly influenced by the transformative power of music therapy. As evident in the outcomes listed above, music therapy has played a crucial role in breaking free from institutionalizing dynamics, offering participants a sense of empowerment, autonomy, and social inclusion. Moreover, it has created a safe and expressive space where their voices and choices are heard and valued in the decision-making process, a departure from the norm within institutional settings. In this way, music therapy has contributed to advancing the principles of deinstitutionalization and improving the overall quality of life for those it serves.

## CHAPTER VI

### FINAL CONSIDERATIONS

Upon reviewing my internship journey, including its characterization, theoretical-conceptual and methodological framework, internship experiences, interventions conducted, and intervention outcomes, it is time to engage in a reflective process. This reflection primarily revolves around my role as a person and as a specialist in the field of Education Sciences and later delves into my contributions to the institution.

This chapter will present a comprehensive overview of my enriching learning experience during the six-month internship at the Estimia institution. This period gave me a unique opportunity to immerse myself in the organization, and the insights I gained are truly valuable.

#### **6.1. LEARNING ACHIEVED AS A SPECIALIST IN THE FIELD OF EDUCATION**

##### **6.1.1. Personal and professional growth**

First and foremost, this journey has been a stimulus for my personal growth, significantly enhancing my skills, particularly in the realm of education. As an educator, I've expanded my knowledge and honed my abilities to engage with the users and promote their learning effectively.

I entered a new environment, adapting myself despite not knowing the language. However, the language barrier was easy to overcome, thanks to the welcoming attitude of the users. Right from the start, I didn't feel any embarrassment. I've grown significantly in my relationship with this population. It's not natural for everyone to interact with someone different from themselves. Over time, I've internalized the attitude of naturally engage with them without infantilizing them. These may seem like obvious principles from my perspective; however, as I encountered people outside the social context, I realized that relating respectfully and professionally to individuals with disabilities is not as straightforward as it may appear. Another aspect that has contributed to my personal growth and professional development as an educator is learning to separate my personal self from my role as an educator. In the context where I worked, distinguishing between these two roles is of paramount importance. Otherwise, toxic dynamics can develop, negatively affecting the user and educator. Setting boundaries and knowing how to uphold them is crucial.

##### **6.1.2. Growth through institutional experience**

Working in an institutional context has given me a great deal of insight, especially after my transition from being an intern to an employee. This time in the institution has allowed me to observe its strengths as well as its weaknesses, and I have been able to form my own opinion on these matters. As I have emphasized in the previous pages, I have often noticed that the Estimia institution, despite having a

broad range of activities, is often rooted in the traditional model where the user frequently plays a passive role and spends most of their time within the institution. My perspective is now directed towards a new institutional model.

A model in which services, such as day centers, occupational facilities, community housing, and residences, should be designed as "life gyms"<sup>179</sup>

A place where individuals can practice living in their own community, learn to navigate life "outside," and engage with the world beyond the institution. These places move away from the concept of being "containers where individuals with disabilities age together".<sup>180</sup>

Instead, they should enable individuals with disabilities to access levels of identity recognition and existential affirmation by allowing them to interact with the external community. This approach embraces the idea of the community as a place of opportunities, stimuli, and spaces that can contribute to the growth of individuals with disabilities, offering them the chance to take action in the real world, not just in protected environments.<sup>181</sup>

An invaluable lesson I gained while working in an institution is the awareness that educational theory can be difficult to harmonize with the institutional context. A concrete example is that of timing. Institutions operate under rules and schedules that frequently clash with the envisioned activities. Therefore, it was crucial for me to work within this context, immersing myself deeply to comprehend the various barriers or constraints educators face. Above all, it made me realize how important it is to understand a context thoroughly and its people before implementing an educational project.

During these months, and especially during the music therapy intervention, I aimed to bring about even small changes in the context where I worked, aspiring, even if only in a minimal way, to move towards the institution model presented earlier. Through my deliberate efforts, I learned a lot as an educator.

### **6.1.3. Music Therapy Project Insights: Discoveries and Lessons**

Thanks to music therapy, I have been able to learn and observe personally the numerous beneficial effects of music, which operate on countless levels in our lives. One of the positive outcomes is indeed the empowerment of individuals with disabilities. It is often the case that professionals tend to prioritize a perspective that focuses on the vulnerabilities that led individuals to seek services, rather than considering the person as a whole. Treating "vulnerability as a form of dependency legitimizes the tendency to view people as incapable and denies their agency"<sup>182</sup>. Through music therapy, participants could actively engage in the creative process. This empowerment allows them to have a say in their own well-being and contributes to a shift from a passive recipient of care to an active participant in their own

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<sup>179</sup> Branchesi, A. (2022). *La promozione dell'autodeterminazione e della partecipazione nelle persone con disabilità intellettiva*. Strumenti, approcci e metodologie nell'esperienza della Cooperativa Solidarietà Onlus.

<sup>180</sup> ibidem

<sup>181</sup> ibidem

<sup>182</sup> Dominelli, L., 2015, *Servizio sociale*, Erickson, Roma p.265

growth and development. Music therapy has helped me recognize the significance of self-determination, a capacity that was fostered during the intervention process. Currently, I regard it as one of the paramount objectives in an educator's intervention, closely intertwined with autonomy and empowerment.<sup>183</sup>

Moreover, my contributions as an educator have been multifaceted. I've actively participated in various projects and initiatives within the institution, offering innovative ideas and strategies to enhance the residents' educational experience. Another enrichment I gained during these months, thanks partly to my university courses, was designing and implementing an educational activity or project. During my internship, I had the chance to engage in various activities with the users, planning and executing projects through their different phases. I have gained more confidence in this aspect and feel more prepared for the future if I ever need to plan an educational activity or project in my work. This collaborative approach has not only enriched my own understanding but has also positively impacted the institution's educational landscape.

#### **6.1.4.Challenges of Ageing**

My experience has also enabled me to investigate and explore various issues and topics related to my curriculum unit and field of education: "Challenges of Ageing and Socio-educational Intervention".

First and foremost, in Estimia, there are several elderly users who no longer have the support of their families. As I mentioned earlier, this is a topic that is very close to my heart because users without family support are assisted only by an association that takes care of their various bureaucratic matters. In my view, the main problem is that these individuals, without family members visiting them, spend most of their time in the institution, leading to various negative and deteriorating consequences for them. There is, therefore, significant changes in aging as a disabled person. The institution and everything that is part of it becomes like family, so it is crucial for the residents to genuinely feel that the residence is their home.

Another important concept for disabled individuals is the aging of their parents. As their parents age, they often lack the energy and strength to care for a disabled person at home. This frequently leads them to choose the path of institutionalization, a decision that brings about a drastic change in their way of life, both positively and negatively. Entering an institution for disabled or elderly individuals can indeed be quite a drastic transition for the person. It may bring various challenges related to adapting to institutional life, loss of autonomy, and its impact on mental health.

Finally, the Music Therapy project has led me to consider how this therapy can be particularly effective for the elderly. It is indeed proven that the benefits of music therapy on these individuals' physical and mental health are numerous and lead to an improvement in their quality of life.

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<sup>183</sup> Fargion S., 2019, *Il metodo di servizio sociale*, Carocci, Roma p.49

## **6.2. CONTRIBUTIONS TO THE INSTITUTION**

I believe that my contributions to the institution impacted various levels. On a very practical level, I provided practical assistance in carrying out caregiving tasks, thus alleviating the workload of the healthcare workers.

I was also very helpful during educational outings, as having an extra person available to push a wheelchair is not something to be taken for granted. It means giving one more person the opportunity to participate in the outing. We sometimes had to leave some users at home because there wasn't enough staff to push the wheelchairs. It may seem like a simple and trivial contribution, but it is not at all. On the contrary, it is essential, and the institution greatly benefits from volunteers and interns. They are an integral part.

Another valuable contribution is related to the time I had available as an intern. This might sound simplistic, but as an intern, I had more time than the regular staff members. This extra time allowed me to dedicate myself to the users, listening to their needs and addressing various concerns at the moment. Moreover, having this surplus time at my disposal also enabled me to engage users in recreational or other activities with the goal of keeping their minds stimulated and active. Therefore, an additional, not-so-obvious contribution I made was the time I could offer.

I am also aware that during the music therapy intervention, I played a crucial supporting role for the music therapist, collaborating with him to create a positive and non-judgmental environment to enhance the users' quality of life. On several occasions, I received compliments and expressions of gratitude from both the music therapist and the users for being a part of this initiative, and I am very pleased about this. Lastly, I am confident that my presence, even if in a limited capacity, has played a role in elevating several aspects of the institution's dynamics. Through my active involvement in curriculum development, activities such as music therapy, and the creation of a supportive learning environment, I have contributed to the continuous improvement of Estimia Institution, just as this context has contributed to my own growth.



## CONCLUSION

In conclusion, my internship journey has been a profound and significant experience both professionally and personally. Throughout my internship, I had the chance to fully engage in the Estimia Institution's environment, allowing me to delve into intricate topics like enhancing the users' quality of life, considering all the associated aspects, and addressing the issue of institutionalization. Through my daily involvement and the use of music therapy as a key intervention, I aimed to positively contribute to the lives of the users.

By adopting a participant observation-based approach and implementing music therapy as a fundamental tool, I positively change the users' lives. This journey has provided a tangible lesson in the significance of embracing a person-centered and empowering approach, consistently considering the users' unique needs and emphasizing their strengths rather than their disabilities. The results highlighted in this report clearly demonstrate that music therapy significantly impacted their well-being, contributing tangibly to improving their emotional state and embarking on a process of deinstitutionalization.

In addition to achieving practical skills in the field of educational work, particularly with individuals with disabilities, I have deeply internalized the value of empathy, understanding, and customizing educational interventions to adapt them to individual needs. This experience has shaped me, not only as a professional but also as an individual, and I am profoundly grateful for the learning opportunity granted to me and for the chance to make a positive contribution to the lives of the users.

It is essential to emphasize that this report represents just the beginning of a journey of exploration and contribution to the field of educational sciences. I sincerely hope that my research can serve as a starting point for further studies and investigations into optimizing the quality of life of individual with disabilities in institutional context. This experience has inspired me to continue growing professionally and constantly seeking new ways to contribute to the well-being of the people I've had the privilege of accompanying on this journey.

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## DOCUMENTS CONSULTED

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# **Appendix 1 – INFORMED CONSENT FOR FAMILY MEMEBERS AND PARTICIPANTS IN THE MUSIC THERAPHY PROJECT**

## **PROTOCOLO DE CONSENTIMIENTO PARA PARTICIPAR EN UN PROYECTO DE INVESTIGACIÓN:**

### ***Impacto de la musicoterapia en la calidad de vida de las personas con discapacidad***

Ha sido invitada a participar en un estudio dirigido por Maria Tezza, como parte de sus prácticas de Master en Ciencias de la Educación que se centra en el "Impacto de la musicoterapia en la calidad de vida de las personas con discapacidad". Su participación es voluntaria. Le rogamos que lea la información que figura a continuación antes de decidir si desea participar o no.

Si está de acuerdo, le pedimos que firme al final del documento.

### **Objetivo del estudio**

El objetivo principal del estudio es conocer los impactos reconocidos de la musicoterapia por los usuarios de la Fundación Estímia. La información recogida se utilizará exclusivamente para la realización de una tesis de master dentro de el Master en Ciencias de la Educación, Facultad de Psicología y Ciencias de la Educación, Universidad de Oporto.

### **Beneficios potenciales para la sociedad**

La investigación y el estudio son importantes por varias razones. En primer lugar, puede contribuir a mejorar la calidad de vida de las personas discapacitadas, identificando enfoques eficaces para apoyar su vida cotidiana y hacerles participar en actividades, promover su bienestar e independencia.

El estudio puede beneficiar a la institución al proporcionar estrategias eficaces y buenas prácticas para apoyar a las personas con discapacidad.

Al final puede contribuir a debates más amplios sobre la discapacidad y promover una mayor inclusión y accesibilidad en la sociedad.

### **Procedimientos**

Si desea participar como voluntario en el estudio, se le invitará el familiar a participar en un conjunto de sesiones de musicoterapia y a presentar y debatir sus ideas sobre estas sesiones y su impacto en el bienestar.

Las sesiones se grabarán, se harán fotografías y se tomarán notas por escrito. Las grabaciones se utilizarán únicamente para analizar las opiniones/percepciones de los participantes y servirán sólo

como material informativo sin hacer referencia a las respuestas de ninguna persona en concreto. El acceso a esta información será realizado exclusivamente por el investigador.

### **Tratamientos de datos**

El tratamiento de los datos obtenidos garantiza el anonimato de los participantes, no utilizándose nunca de forma que pueda revelar la identidad de los mismos. No se hará público ningún dato sin el consentimiento previo de los interesados.

El investigador asegura que cualquier publicación, incluida la publicación en Internet, ni directa ni indirecta, supondrá una violación del anonimato y la confidencialidad acordada.

La recogida y el análisis de los datos se integrarán en un informe de prácticas que será de acceso público en el Repositorio Científico de Acceso Abierto de Portugal. El Informe no contendrá ningún dato personal que pueda revelar directa o indirectamente la identidad de una persona física.

### **Confidencialidad**

Cualquier información obtenida como parte de este estudio que pueda identificarle será confidencial y no se divulgará sin su permiso previo.

Todos los datos recogidos serán almacenados de forma que permitan el cumplimiento de la legislación portuguesa y de la Unión Europea en materia de protección de datos y privacidad.

Todos los datos personales se almacenarán separados de los datos resultantes de la ejecución de las actividades del proyecto. Esto se garantizará mediante medidas técnicas y organizativas adecuadas.

Se adoptarán medidas para proteger los datos personales contra la destrucción accidental o ilícita o la pérdida accidental, la alteración, la difusión o el acceso no autorizados.

### **Supresión de datos personales**

Al final del proyecto, se borrarán todos los datos personales de los participantes.

### **Negativa a participar**

Usted es totalmente libre de participar o no en este estudio. Si se ofrece voluntario para participar en el estudio, es libre de retirarse en cualquier momento sin consecuencias de ningún tipo. También es libre de negarse a responder a cualquier pregunta o a participar en una actividad concreta.

### **Riesgos potenciales**

El estudio no entraña ningún riesgo potencial, ya sea social, jurídico o financiero.

### **Contexto del estudio**

Este estudio obtuvo el dictamen favorable del Comité Científico del Máster en Ciencias de la Educación de la FPCE de la Universidad de Oporto.

### **Identificación de los investigadores**

Si tiene alguna pregunta o duda sobre este estudio, puede ponerse en contacto con las siguientes personas:

- Maria Tezza - estudiante del Máster en Ciencias de la Educación,  
por correo electrónico: [tezzamaria97@gmail.com](mailto:tezzamaria97@gmail.com)
- João Caramelo - supervisor del estudiante que realiza el estudio,  
por correo electrónico: [caramelo@fpce.up.pt](mailto:caramelo@fpce.up.pt)

Entiendo los procedimientos descritos anteriormente. Se ha respondido satisfactoriamente a mis preguntas y acepto participar en este estudio. Se me ha entregado una copia de este protocolo.

Yo \_\_\_\_\_ como tutor de \_\_\_\_\_ autorizo la recogida

de los datos de lo familiar para el estudio

de imágenes de lo familiar para el estudio

Nombre: \_\_\_\_\_

Firma: \_\_\_\_\_

Fecha: \_\_\_\_\_



## **Appendix 2 – FIELD NOTES**

Fundació Discapacitat Estímia – Barcelona

Maria Tezza

### **NT 0 – 12.09.22**

Bello, primo giorno mi hanno accolta benissimo, nonostante non sia perfetta con la lingua spagnola non mi hanno mai fatto sentire in difetto. Abbiamo chiacchierato molto e mi hanno raccontato delle sue vite, dei viaggi che hanno fatto. Erano molto curiosi e interessati a conoscermi. Per ora inizierò con gli utenti del quinto piano della residenza. I ragazzi hanno capacità cognitive buone. Le conversazioni sono interessanti e io sono riuscita fin da subito a farmi apprezzare. Mi piacciono tanto e io gli piaccio. Sono attenti a tutto e molto responsabili. Vengono lasciati spesso senza supervisione. Si autoregolano molto bene. Hanno problematiche differenti che li hanno portati ad essere in carrozzina. La maggior parte però oltre ad una disabilità motoria ha anche una disabilità cognitiva. Il primo giorno sono stata pressoché a chiacchierare, a farmi conoscere e a conoscerli. Abbiamo giocato ad “uno” e ho potuto conoscere un altro signore I. che mi ricorda molto un mio ex utente, anche lui ha un sorriso stupendo ed affetto da paralisi cerebrale. Abbiamo giocato insieme con un'altra utente. Lui mi mostrava la carta che voleva tirare e io la lanciavo. Mi sono piuttosto divertita. Poi sono andata a partecipare ad un'attività di lettura in cui i due utenti hanno letto delle pagine di un libro proposto da una lavoratrice. Poi lo abbiamo discusso, è stato molto interessante e istruttivo. Troppo poco spesso chiediamo cosa ne pensano sull'attualità e in generale sulle cose.

### **NT 1 – 13.09.22**

Il secondo giorno invece mi sono messa un po' di più in gioco. Mi sono resa conto che non avevano nessuna attività pianificata così mi sono messa giocare con alcuni di loro a Forza 4. È stato molto interessante perché mi sono resa conto delle differenze in termini cognitivi tra alcuni di loro. La prima ragazza con cui mi sono “scontrata” era piuttosto “sveglia” e ho vinto, ma solo dopo alcuni minuti. Mentre V. affetta da un disturbo cognitivo più profondo mi ha lasciato vincere con facilità. Entrambe, comunque totalmente coscienti e in grado di svolgere una partita. Poi più tardi ho assistito a mezz'ora di fisioterapia di due utenti. Purtroppo, hanno solo mezz'ora alla settimana e se sentono il bisogno di un'altra mezz'ora, le famiglie devono pagare.

### **NT 2 – 14.09.22**

Mercoledì invece è stato un giorno interattivo perché ho partecipato con un piccolo gruppo all'attività di cucina. Abbiamo preparato un cocktail senza alcool ovviamente. Il gruppo era

composto da solo ragazze. Abbiamo seguito una ricetta e abbiamo fatto aggiungere i succhi a loro per poi dopo mescolare il tutto, aggiungere ghiaccio, fetta di limone e il cocktail era pronto. Erano tutte molto entusiaste del risultato, si sono e ci siamo divertite. Io sono sempre molto coinvolta e cerco di darmi da fare il più possibile. Quasi mai sto con le mani in mano a guardare. Poi siamo salite nei vari piani a distribuire il cocktail, il quale è stato molto apprezzato.

### **NT 3 – 15.09.22**

Giovedì, sono arrivata al centro e sono stata accolta come sempre con un grande calore da parte degli utenti. Erano sorpresi di vedermi la mattina invece che il pomeriggio. Dopo un'oretta, infatti, era programmata la spiaggia come attività e con un gruppo di tre persone, con il furgone siamo andati. Io ero abbastanza preparata su come ci si comporta nelle uscite in spiaggia con gli utenti avendo fatto la stessa cosa l'anno passato, però sono pur sempre utenti con esigenze diverse quindi nel momento del cambio ho pressoché osservato e quando mi sentivo abbastanza "confident" aiutavo pure io. Siamo entrati tutti insieme in acqua con loro. È stato molto emozionante. Loro hanno adorato l'acqua e si sono rilassati non poco. Siamo stati dentro pressoché un'ora. Poi siamo usciti li abbiamo messi sulle sdraio e ci siamo rilassati insieme. Tornata al centro abbiamo trovato tutti già in procinto di mangiare, ho aiutato e mi sono messa a raccontare della spiaggia con gli occhi di tutti addosso, forse anche un po' invidiosi. La prossima volta sarà il turno di qualcun altro ma per ora il fortunato era solo D.

### **NT 4 - 19.09.22**

Lunedì è stato un bel giorno, sono tornata dopo il weekend e mi hanno accolto con felicità. L'attività del giorno era notizie e ricorrenze del giorno, la ricorrenza era il giorno internazionale dell'aperitivo. Quindi l'operatrice ha portato patatine e bevande per fare aperitivo. Ovviamente erano tutti contenti. I partecipanti erano tanti! Abbiamo parlato della storia dell'aperitivo e successivamente delle notizie della settimana. Mi è piaciuto perché è stata una cosa congiunta! I ragazzi contribuivano a dire i fatti avvenuti. Sono molto informati, più di quanto pensassi. Me ne sono andata contenta.

### **NT 5 - 21.09.22**

Oggi tornata da un giorno di malattia. Mi hanno chiesto dove ero ieri, il che mi ha fatto ancora una volta piacere! Ricevo molti complimenti soprattutto da A., il quale continua a ricordarmi di quanto si sente fortunato ad avermi lì! Oggi l'attività è stata interessantissima, musico-terapia. Due gruppi hanno partecipato, il primo dalle 11. Il maestro era bravissimo! Il primo gruppo era formato da ragazzi e ragazze con capacità cognitive ridotte. Questo gruppo, quindi, inizialmente sembrava non potesse partecipare molto. Ma con il tempo il maestro attraverso il potere immenso della musica li ha fatti partecipare! Ero semplicemente ammaliata,

ammaliata da questa energia che si formava, questa scintilla. Il maestro si avvicinava cantando o suonando e l'utente iniziava a ridere inizialmente e poi partecipava e a volte si emozionava! Più avanti ha consegnato loro gli strumenti e pure lì inizialmente sembrava non contribuissero; invece, con calma e gentilezza il maestro avvicinandosi a loro cantano e suonando era in grado di coinvolgerli con una energia assurda che ammaliava chiunque

Il secondo gruppo è formato da ragazzi/e con capacità cognitive buone. I ragazzi pure qui hanno adorato, ovviamente molto partecipi e entusiasti nel partecipare cantando e usando gli strumenti. Qui gli obiettivi ovviamente erano altri: tra cui farli partecipare a tempo con la musica e rispettare le indicazioni del maestro ascoltando attentamente. Nel momento in cui ci fosse stata una disabilità fisica cercare di usare lo strumento nel modo più consono per loro! Molto molto interessante pure questa come esperienza! Ancora più interessante vedere la differenza dei due gruppi e degli obiettivi che il maestro si proponeva e la differenza di come la musica può essere usata per scopi differenti. Io sono rimasta sconvolta della forza terapeutica della musica!!

#### **NT 6 - 26.09.22 / 06.10.22**

Due settimane sono passate molto in fretta. Io mi sto ambientando sempre più, sto osservando molto e assorbendo il modo di lavorare nella fondazione. Sto osservando il modo di interazione tra gli utenti del mio piano. Andrò quindi per tematiche invece che andare giorno per giorno.

Il modo di gestire la routine diaria degli utenti. Io arrivo alle 9 e trovo gli utenti che stanno ultimando la colazione, una colazione mi sembra piuttosto equilibrata ma sicuramente non variata. Frutta, pane formaggio e prosciutto caffè, acqua. Poi i due utenti responsabili per la pulizia appena tutti hanno ultimato iniziano a sistemare e pulire, questo compito è preso con molta responsabilità. Successivamente c'è un po' di tranquillità in cui si chiacchera e si finisce di sistemare la camera. In seguito con alcuni utenti io e la ragazza volontaria facciamo una passeggiata fuori intorno al quartiere di Sarria. Questa attività è molto amata, gli utenti non passano tanto tempo fuori dalla residenza. Prendere aria è sempre un sollievo, mangiare un "donut" o bere un caffè per noi una cosa tanto scontata per loro non lo è affatto. Vedo la gioia nei loro occhi. Per esempio, una delle prime volte che sono uscita con una delle utenti: Lolli, mi ha detto che le avrebbe fatto immenso piacere mangiare un donut perché era un anno che non ne mangiava uno. La cosa mi ha lasciato un mix di tristezza e sconcerto, siamo andati in un bar per ordinare un donut che però sfortunatamente non avevano. Ci siamo comunque consolati con un croissant e un caffè.

Dopo la passeggiata si torna alla residenza per l'attività programmata del giorno la quale varia in relazione alla settimana e al giorno della settimana. I ragazzi, inoltre, una volta al mese si iscrivono alle attività che più gli aggrada, hanno quindi libertà di scelta cosa molto interessante e che confronto con l'esperienza di due anni fa a Lisbona. I ragazzi/e nella residenza a Lisbona erano obbligati/e a partecipare alle attività giornaliere. E rimproverati se non avevano voglia o

non gli piaceva l'attività proposta. Questa libertà di scelta è sicuramente un'arma a doppio taglio. Da una parte è positivo che gli utenti trattati da persone adulte abbiano possibilità di scelta dall'altra però questo porta molti utenti a non iscriversi a nessuna attività e passare le giornate a non fare praticamente nulla se non guardare la tv. Un'altra cosa che mi ha un po' scosso è il fatto che le famiglie devono pagare per le attività quindi in questo modo la libertà di scelta da parte degli utenti non c'è più, la scelta ricade sulle famiglie che decidono PER loro.

Le attività sono varie: leggere e discutere le notizie giornaliere, cucina, escursioni mattutine (zoo, spiaggia, parchi), attività manuali, pet-therapy, musica terapia e molte altre che variano rispetto alla disponibilità delle utenti e dei monitori/e.

Alle 13 si ritorna al quinto piano, piano dove dormono e svolgono tutte le attività di igiene. I due utenti responsabili per l'apparecchio preparano la tavola e puliscono. Arriva il carretto con il cibo e iniziamo a distribuire il primo, di seguito il secondo ed infine la frutta. Si distribuiscono le medicine, io aiuto nella distribuzione, nel sistemare e spesso aiuto Lolli a mangiare, la quale ha difficoltà nel movimento di inserire il cucchiaino e nella masticazione. Infine, ci si lava i denti e quattro utenti li lavano subito dopo il pranzo sulla stessa tavola dove hanno mangiato con l'aiuto di una bacinella e io li accompagno anche in questa mansione. Sono ormai le 14 e per me è ora di andare e per loro di riposare un po'.

#### **NT 7 - 17.10.22**

Lunedì abbiamo salutato la volontaria che ha concluso la sua permanenza nell'istituzione e poi mi sono messa a chiacchierare con loro, a volte mi piace anche solo stare con loro e passare il tempo parlando di tematiche interessanti o anche solo di come stanno, come si sentono, come stanno i loro parenti. Penso sia molto importante questa parte, ti permette di connetterti a loro e conoscerli e farti conoscere. Più tardi abbiamo giocato a "mimica" ed è stato interessante vedere a cosa pensano, le azioni che propongono e che gli passano per la mente sono la realtà che vivono. L'attività del lunedì è diario, ossia le notizie della settimana e i ragazzi/e sono sempre molto contenti di prenderne parte. E penso che sia molto importante per loro sapere cosa accade nel mondo e in Spagna.

#### **NT 8 - 18.10.22**

Oggi non è stato un giorno facile per me ma mi sono sforzata e sono andata comunque. È stato comunque molto interessante e istruttivo poiché ho appreso quanto le professioni in cui hai a che fare con le persone ti mettano alla prova. Ero particolarmente nervosa, infatti, e qualsiasi cosa mi infastidiva. Ovviamente sapevo che non era colpa loro e mi sono sforzata per fare il mio lavoro e essere disponibile e aperta all'ascolto. Il giorno è finito senza troppi problemi però mi sono messa

realmente alla prova. E ho seriamente riflettuto sull'alto rischio di Bornout nelle professioni sociosanitarie.

#### **NT 9 - 19.10.22**

Giornata decisamente migliore: la mattina mi sono messa ad aiutare ed a osservarli ancora, e ho avuto una realizzazione. Quella è la loro casa, e la loro vita. Mi sono sempre imposta di proporre attività e cose da fare. Mi dava pena vederli fare niente o guardare la tv. Poi però mi sono immedesimata in loro e ho pensato, se io fossi in casa mia vorrei poter oziare quanto mi pare, ovviamente la cosa intervallata da attività ricreative ma tutto nel giusto equilibrio. Quindi perché no. Pure loro hanno tutto il diritto di oziare e non fare nulla. Poi ci sarà pure il tempo per l'attività. Ma la loro vita casalinga non deve essere a tutti i costi riempita di attività "ricreative". Hanno tutto il diritto di non fare nulla. Come faremo noi a casa nostra.

Più tardi ho proposto un gioco a carte con due ragazze. Mi è piaciuto molto perché V. ha problemi con i numeri e colori e quel gioco penso le sia servito molto a migliorare le sue abilità.

Più tardi musicoterapia che come sempre mi ammalia. Una delle attività più interessanti e complete che propongono ad Estimia. Il gruppo si sta ampliando quindi a volte sorgono delle discussioni. Del tutto normalissimo visto che sono una grande comunità e passando 24 su 24 insieme. C'è chi si piace e chi non si sopporta. Non deve essere facile vivere in comunità così grandi.

Finita l'attività pranzo, e tempo di salutarli, mi salutano sempre con molto affetto e me ne vado sempre con il cuore pieno.

#### **NT 10 - 20.10.22**

Oggi escursione allo zoo con nuovi utenti. Erano tutti molti entusiasti di andare. Tra loro c'era anche D. B. un usuario un po' burbero a cui non piacciono le persone nuove. Fin dal principio, infatti, non mi calcolava e salutava anzi mi insultava e commentava il mio spagnolo parlato male con un forte accento italiano / portoghese. Io non ci davo molto caso poiché cosciente che era una sua abitudine comportarsi in questo modo con le persone nuove. Oggi però allo zoo ha iniziato a parlarmi e chiedermi cose sulla mia provenienza e sulla mia casa a Barcellona. La cosa mi ha stupito molto e mi ha fatto ovviamente piacere. L'escursione allo zoo è andata come sempre molto bene. Tornati al centro D. si è messo a pranzare con gli altri e subito mi sono accorta che qualcosa è cambiato, mi ha iniziato a chiedere dei favori, cosa mai fatta prima da lui. Io semplicemente non esisteva. Mi ignorava. Per la prima volta ieri mi ha coinvolto e mi ha "accettato". Quel piccolo gesto di chiedermi un favore era come dire "okay ti accetto, sei la benvenuta qui con noi". Mentre con gli altri utenti mi sono sentita fin da subito accettata con D. è stato un processo un po' sudato ma che ha portato ad una grande soddisfazione. Ora sono cosciente che la sua fiducia va costruita piano piano. Non posso credere di essere già parte della famiglia da un giorno all'altro ma con

calma un giorno alla volta, una chiacchiera alla volta sarò capace di farmi apprezzare e capire pure da lui.

#### **NT 11 - 24.10.22 / 27.10.22**

La settimana si è svolta più o meno seguendo lo stesso schema di attività delle precedenti. Mi sto integrando sempre di più nell'istituzione e sono di fondamentale supporto nella gestione delle attività quotidiane. La mattina, per esempio, aiuto spesso l'operatore/operatrice socio-sanitario a sistemare le camere e a ultimare la colazione con gli utenti. Accompagno l'operatore o operatrice nelle attività di routine mattutina degli utenti come per esempio la doccia, vestirsi, pettinarsi, pulire la faccia etc. Durante la mattina svolgiamo attività di vario tipo e poi verso le 11,30 si svolge l'attività principale e io li accompagno al piano dove si svolgerà la medesima e poi rimango con loro a seguire l'attività proposta. Infine, il pranzo alle 13.00. come ho già spiegato io sono di importante contributo nella gestione della distribuzione del pranzo e questo mi soddisfa. Ho però una riflessione rispetto a questa settimana. Mi rendo conto di aiutare molto nell'ambito della pulizia e igiene affiancando l'operatore o operatrice e mi rendo conto che lavorando in questo ambito è totalmente normale perché come educatrice devi essere flessibile e per conoscerli ed entrare realmente in connessione con loro sicuramente devi saper svolgere anche le attività di routine diaria. Cosciente che questa formazione sia importantissima per me sento che non sono abbastanza attiva nel mio ruolo di educatrice, ossia non sono abbastanza proattiva, per ora mi limito a intrattenerli con giochi in scatola o chiacchierare e ovviamente accompagnarli durante le attività ricreative. Io però non ho ancora proposto nessuna attività e questo mi fa sentire un po' da meno. Mi sento un po' in difficoltà perché ormai li conosco abbastanza e dovrei iniziare a pensare un'attività da poter implementare con loro, ma al momento non ho troppe idee. In conseguenza a questo mio sentimento inizierò così nelle prossime settimane a documentarmi, leggere e successivamente confrontarmi con la tecnica della residenza E. per vedere se insieme possiamo pensare un progetto o semplice attività da proporre.

Un' ulteriore postilla riguardo alla settimana riguarda l'attività di musico-terapia. Gli utenti del primo gruppo con capacità cognitive ridotte hanno fatto enormi progressi. È impressionante vedere quanto sono coinvolti ora nell'ora di musica e in ognuno di loro è visibile un progresso non indifferente. M., una signora piuttosto iperattiva è molto più concentrata rispetto le prime volte e mentre inizialmente cercava sempre la mano dei suoi compagni per avere un senso di rassicurazione ora è molto più indipendente e attenta a seguire l'attività. Inoltre, inizia a usare gli strumenti cosa che prima nemmeno toccava e segue il maestro nella canzone ricordandosi le parole. È stato molto bello vedere come il maestro è riuscito a calmare un altro utente non vedente, il quale ha alte difficoltà cognitive e non vedendo è ipersensibile a suoni e odori. Capita che egli si agiti e inizi a piangere senza smettere. Il maestro si è messo a cantare forte assecondando il suo pianto e il risultato è stato incredibile dopo qualche minuto il ragazzo si è calmato e ha sorriso.

Anche S. ha fatto enormi progressi, inizialmente non seguiva e restava un po' isolata nel suo mondo. Il maestro di musica è riuscito a creare un momento con lei di totale intimità dove ancora una volta ha assecondato i suoi lamenti e la cosa dopo qualche minuto si è trasformata in un canto a cui pure S. ha preso parte. È stato estremamente interessante per me assistere a queste evoluzioni in ognuno di loro settimana dopo settimana.

#### **NT 12 – 07.11.22**

Oggi è stata una giornata produttiva, ho aiutato a sistemare i letti e a concludere la routine mattutina poi ho deciso di andare a salutare gli altri utenti. Sono andata al terzo piano e lo c'era M. che mi aspettava e ricordava il mio nome come avevo provato a insegnarle, iniziamo a chiacchierare ma qualcosa la preoccupava ed era distratta. Poi mi sono messa a parlare con C., una anziana signora che ama sentire le cose appoggiando la bocca. Così prende spesso la mia mano e la appoggia alla sua bocca. Poi siamo andate alla sala multisensoriale con lei. È stato molto interessante, la sala cerca di stimolare i vari sensi. C'è un materasso di acqua, delle luci speciali, un diffusore di profumo, la sala è scura e ci sono vari strumenti che puoi utilizzare per far provare sensazioni diverse e esercitare gli altri sensi. O per J. per esempio che non vede costruire un'esperienza realmente significativa per lui. Non vedendo ha sicuramente altri sensi più evoluti così per lui questa sala è realmente utile e importante.

Poi siamo andati con due utenti a fare una passeggiata fuori in un parco. È interessante perché abbiamo noi stagiste/volontarie molta autonomia, non capita spesso che nelle istituzioni ti lascino questa responsabilità. Sono contenta ma allo stesso tempo so di dover stare realmente attenta. La passeggiata fa sempre bene a loro. Sono spesso tutto il giorno dentro è un po' di aria fresca e luce solare non può che fargli bene. Sia S. che I. erano contentissimi. Tornata per pranzo ho aiutato come sempre a servire.

#### **NT 13 – 09.11.22**

Oggi giornata più tranquilla ma sempre interessante, noto che Lolli spesso mi chiede favori e credo perché sa che io la aiuterò. Mi domando spesso dove sta il limite tra essere disponibile ad aiutarli e essere a loro servizio. Se non la aiuto mi sento in colpa però aiutarla sempre e non ponere dei paletti penso che non vada bene, devono sapere che non ci sono solo loro ma bensì altri 9/ 10 utenti e che, se ognuno di loro avesse tutte queste richieste non se ne uscirebbe più. Cercherò quindi con gentilezza di mettere dei paletti.

In ogni caso oggi c'era musica, oggi sessione più tranquilla per quanto riguarda il primo gruppo. Mentre per il secondo ci sono stati dei progressi non da poco. Quasi tutti andavano a ritmo e rispettavano le indicazioni del maestro rispettandosi anche vicendevolmente.

Un aspetto che mi ha particolarmente stupito è stato a pranzo: M. stava evidente male o era di malumore, subito gli altri suoi compagni hanno cercato di sapere che avesse per aiutarla e farla

stare meglio. Lei non voleva parlare e loro hanno compreso. Ho comunque percepito una coesione è reciproco affetto non indifferente. Mi ha realmente stupito quanto siano attenti l'un l'altro anche se da fuori può sembrare che siano spesso per conto loro.

## NT 14 – 13.12.22

### ATTIVITA' I 5 SENSI: IL TATTO

In questa giornata io e Dalma abbiamo organizzato la prima sessione di stimolazione sensoriale relativa al Tatto.

- **Prima attività:** viene domandato ad ognuno di loro: come ti senti? Al quale potranno rispondere usando un piatto con della sabbia e disegnare una faccina: contenta☺ - okay☺ - triste☹
- **Seconda attività:** toccare i diversi materiali con le mani ed esprimere cosa si sente in risposta alle nostre domande.
  - *Materiali:* sabbia, riso, sale, zucchero, terra
  - Domande: come ti senti? Ti piace come sensazione? È freddo o caldo? È molle o duro? Fino o grosso? Ti ricorda qualche esperienza passata?
  - In concomitanza abbiamo anche deciso di fargli indovinare uno alla volta quale materiale fosse facendogli chiudere loro gli occhi.
- **Terza attività:** comparazione tra materiali  
Uno ad uno li abbiamo posti con due diversi materiali di fronte a loro e con occhi chiusi dovevano descrivere le differenti sensazioni e se avevano voglia provare ad indovinare quale fosse il tipo di materiale
- **Quarta attività:** scoprire l'oggetto nascosto nella borsa senza guardare ma toccando. Gli oggetti: palla, cerchio, penna, spugna, contenitore, pietra, bambola.
- **Valutazione:** abbiamo chiesto loro di giudicare l'attività con lo stesso metodo iniziale: se mi è piaciuto☺ - è stato okay☺ - Non mi è piaciuto☹

### Considerazioni

- **Prima attività:** Abbiamo disposto i ragazzi/ ragazze intorno ad un tavolo rettangolare. 5 partecipanti. Dopo aver spiegato l'attività abbiamo passato il piattino con la sabbia e uno ad uno hanno disegnato una faccia rispetto a come si sentivano. È stato interessante vedere le differenti maniere in cui hanno espresso come si sentivano. Anche nel modo di disegnare si può indagare e capire molto. Per esempio, alcuni di loro hanno disegnato la faccia felice senza pensarci troppo, in modo molto impulsivo mentre altri si sono presi il loro tempo dopodiché hanno disegnato una faccia sorridente ma molto simile ad una faccina 'regular': ☺ quasi tutti comunque erano parzialmente felici, molto partecipativi e



collaborativi nello spiegare come si sentivano e il perché della faccina, se ne avevano voglia.

- **Seconda attività:** Questa attività ha subito un cambiamento. Inizialmente volevamo far provare con occhi chiusi un materiale ad ognuno ma poi ci siamo resi conto che durante il processo i ragazzi /e aprivano gli occhi e i tempi sarebbero stati troppo dilatati quindi ho preso in mano la situazione e ho deciso di apporre un cambiamento. Tutti ad occhi chiusi e rapidamente io e Dalma passavamo a fargli immergere la mano della ciotola con il materiale scelto (es: riso). È stato interessante vedere come L e V. non eseguissero le nostre indicazioni ma aprissero gli occhi. Piano piano mi sono adattata capendo che V. non era capace di mantenere gli occhi chiusi a lungo penso per un problema di 'iperattività' e fatica a restare concentrata. Quindi cercavamo di dare il tempo a ognuno di loro di sperimentare con le mani il materiale dopo di che davamo l'indicazione di aprire gli occhi, nascondevamo il materiale che avevano toccato e gli utenti dovevano per gioco indovinare che materiale avessero toccato. Quasi sempre sono riusciti ad andarci molto vicino. Io cercavo di guidarli facendo le domande scritte sopra ed era molto bello vedere che erano molto coscienti di quello che avevano sentito e se gli avesse dato piacere o no. Mi è piaciuto molto guidarli e renderli coscienti che per esempio il materiale che avevano sentito era molto umido e fino rispetto magari a quello che avevano sperimentato precedentemente, il quale era grossolano e secco.

- **Terza attività:** Questa attività è stata molto più apprezzata delle altre! Uno ad uno abbiamo posto davanti a loro due ciotole con diversi materiali e a occhi chiusi dovevano cercare di sperimentare la differenza tra i due, provare a descrivere le differenti sensazioni e mettere quindi in pratica ciò che avevano appreso prima. Tutti quanti, infatti, sapevano il gruppo di materiali e i relativi nomi. Io li ho sempre guidati anche in questa attività con varie domande: ti piace come sensazione? Quale sensazione ti piace di più? Quale è più secco? Quale è più ruvido? Quale è più fino? Etc.

Per poi giungere a indovinare i rispettivi materiali che stavano toccando. Sono quasi sempre riusciti a indovinarli, confusione tra sale e zucchero. Tutti si sono sentiti molto coinvolti e aperti ad esprimere che stessero provando.

Un'ulteriore domanda è stata: "cosa ti fa ricordare questo materiale?".

L'intervento che più mi ha colpito è stato quello di A. che toccando il riso, ha detto che gli ricordava la spiaggia dove andava da piccolo e faceva molti castelli. È stato toccante. J. anche ha fatto interventi super interessanti, spesso rispondeva che gli ricoprava la felicità, poter toccare un determinato materiale è più di una volta domandando di descrivere un materiale ha detto che gli sembrava giallo. Molto molto interessante il paragone che c'è tra l'olfatto e i colori. È studiato che ci sia infatti una relazione forte.

- **Quarta attività:** Nell' ultima attività dovevano indovinare uno ad uno gli oggetti dentro una borsa, è stato interessante vedere come quasi tutti hanno indovinato facilmente. Ho provato ancora una volta a farli riflettere sulle superfici differenti che stavano toccando. È rotondo? È duro? È chiuso? aperto? È spigoloso? È soffice? Ti piace come sensazione. Per poi giungere sempre alla domanda che cosa ti sembra. È piaciuto molto anche questo gioco.
- **Valutazione:** Abbiamo ripetuto la stessa prima attività, la domanda era in questo caso: “vi è piaciuta l'attività?” usando lo stesso metodo delle faccine. Molto interessante perché due ragazze sono state molto sincere e hanno fatto la faccia regular ☹. Mentre il resto degli utenti sono stati tutti contenti. Penso che sia molto importante questa attività perché ci permette di migliorare e capire cosa è andato storto. Inoltre, abbiamo chiesto quale attività gli è piaciuta di più e hanno risposto quasi tutti: il confronto tra materiali. Potremmo quindi basare le nostre attività future su giochi simili. Un altro fattore che ci ha fatto capire che gli è piaciuto è stato il fatto che ci è stato chiesto se avremmo ripetuto l'attività e quando sarebbe stata la prossima volta.

Finita l'attività io e Dalma ci siamo confrontate. Abbiamo trovato dei problemi. Uno di questi sicuramente il fatto che era troppo lungo il tutto. Poi forse la mal comunicazione tra di noi e il fatto che io più volte avevo preso in mano la situazione senza troppo discutere con lei. E inoltre che l'uso di una bandana per coprire gli occhi avrebbe facilitato l'attività e la sua riuscita.

Mia valutazione: molto positiva, migliorabile ma molto positiva.

Se mi vengono in mente altre osservazioni le scriverò più avanti

**NT15 – 15.12.22**

## **MUSICOTERAPIA**

Oggi è stato super interessante!

Il maestro ci ha spiegato che si è accorto che i ragazzi/e erano coinvolti nell'attività poiché mentre suonava la chitarra e cantava con la tonalità RE si è accorto che stessero cantando/parlando usando la stessa tonalità da lui scelta. Impressionante. Mi ha colpito moltissimo questa cosa.

È stupendo e mi sento estremamente grata di poter partecipare alle sue lezioni.

I ragazzi stanno facendo enormi progressi. Sono infatti ora evidentemente coinvolti e partecipi anche se da fuori potrebbe non sembrare. La musica mi affascina e il suo potere ancora di più

**NT16 – 23.01.23**

### **ATTIVITA' CULTURALE**

Oggi era in programma l'attività del Diario, in cui i ragazzi/e insieme alla operatrice parlano delle notizie del giorno e in generale di attualità.

L'operatrice però non c'era, quindi ho pensato di organizzare un'attività altrettanto informativa come quella del "Diario". Io e Dalma abbiamo così fatto una minipresentazione riguardo Verona e riguardo Budapest. Una volta finita la presentazione Dalma ha suggerito di organizzare un quiz, abbiamo così pensato ad alcune domande al quale dovevano capire se la cosa esposta appartenesse all'Ungheria o all'Italia. Sembrava molto semplice e invece è stato interessante vedere come ci fosse della confusione su alcune domande. Mi è piaciuto mettermi alla prova in un'attività pensata ed effettuata in modo molto spontaneo ma riuscita molto bene. Gli utenti erano molto soddisfatti e grati, e noi a loro per aver voluto partecipare.

Questa giornata mi ha fatto riflettere sull'importanza del team work nella strutturazione di un progetto educativo. Io ho avuto l'idea della presentazione su cui Dalma non era molto convinta poiché non parla bene spagnolo, poi quando si è convinta ha invece dato un forte apporto all'attività pensando di introdurre un quiz, un'idea estremamente interessante perché rende interattiva e dinamica l'attività e sviluppa le capacità cognitive dei ragazzi. Inoltre, gli fa conoscere e imparare qualcosa di nuovo, cosa sempre importante e su cui a volte non poniamo abbastanza importanza. Anche solo il fatto di imparare qualcosa di nuovo è una ricchezza

**NT17 24.01.23**

### **SALA MULTISENSORIALE**

Oggi siamo state con tre utenti con disabilità gravi sia motorie che psichiche nella sala multisensoriale. Abbiamo provato vari stimoli in relazione al soggetto e a cosa gli aggrada di più. È stato estremamente interessante vedere le reazioni di felicità, rilassamento o semplicemente lavorare su alcuni sensi che gli utenti non esercitano abbastanza. Essendo disabili gravi per esempio Joan, il quale non vede, ha bisogno di più stimoli sonori, tattili o olfattivi. Vedere J. commuoversi infatti è stato il momento più intenso per me oggi. Di seguito lascio le varie attività estremamente schematizzate che abbiamo eseguito con loro.

Utente 1 S.L.

- Materasso con acqua che le è piaciuto molto
- Luci spente
- Abbiamo acceso delle luci colorate
- Riprodotto una canzone iniziale (che S. già conosce) che funge da rituale.
- Riprodotto una Musica per bambini che a Sara piace molto.

- Abbiamo provato a farle ascoltare anche musica rilassante
- Rispondeva a stimoli muovendo la testa in segno di no se lo stimolo non le aggradava.

#### Utente 2 J.

- Seduto sulla sedia non sul materasso
- Piangeva molto prima che arrivassimo nella sala, poi si è calmato
- Spente le luci si è rilassato ancora di più
- Abbiamo iniziato a giocare con il fascio di fibre ottiche (il quale stimola la percezione visiva e tattile, la capacità attentiva e promuove un senso di rilassamento) e lo abbiamo contornato con quelle e successivamente lo abbiamo massaggiato con le luci
- Lui è stato molto contento della cosa, Era visibilmente felice e si muoveva eccitato, sembrava provasse emozioni forti, quasi arrivando al pianto
- Poi abbiamo massaggiato la testa con uno strumento specifico, che gli è piaciuto molto
- Con la musica avvicinando e allontanando il cellulare per vedere se riuscisse a percepire che il suono prima era vicino e poi lontano
- Infine, con le luci proiettate (J. non vede) abbiamo creato di cambiare la posizione sul muro per vedere se le seguisse.
- E anche se per poco, ha voltato la testa in direzione delle luci, segno che alcune luci/ombre le ha percepite
- Inoltre, quando muovevamo le fibre ottiche era estremamente esaltato, sicuramente sono molto più visibili e essendo uno stimolo nuovo lo incuriosisce e ammalia

#### Utente 3 S.P.

- Distesa nel materasso con acqua
- Abbiamo riprodotto una prima canzone come rituale
- Successivamente una canzone rilassante
- S. sembra stare bene e non si lamenta come al solitamente fa.
- Abbiamo riposto le fibre ottiche attorno a lei
- Reagisce male al massaggio alla testa, ci fermiamo.
- Proiettiamo delle luci al muro con il proiettore
- S. fissa queste luci e si calma
- Infine, canzone di rituale finale per concludere la sessione

## NT 18 – 25.01.23

### MUSICOTERAPIA

#### *Gruppo 1 – disabilità grave*

- J. oggi è nervoso e piange molto
- Maestro suona una melodia calma e i ragazzi/e si rilassano
- Canzone rituale cantata dal maestro: “Bom dia ad ognuno”
- Maestro pone gli strumenti al polso, i quali sono ben ricevuti dai ragazzi/e
- Inizia a suonare il tamburo con M. e R., il maestro inizia a suonare il tamburo affinché lo imitino.
- M. infatti, ha capito come fare e lo segue suonando il tamburo a ritmo
- C. è attratta sempre dalle superfici, tocca il tamburo e batte un po’
- J. continua a piangere, il maestro inizia a suonare e cantare e J. risponde molto positivamente, sorride e scalpita
- Canzone con ritmo cantata dal maestro che gli utenti già conoscono e hanno cantato in passato: R. canta a tono e si emoziona
- C. attratta dalla chitarra allunga la mano e accompagna il maestro nel suonare la chitarra.
- M. inizia a cantare con parole e versi.
- S. viene accompagnata dal maestro nel suonare il tamburo, il quale le accompagna le mani verso il tamburo
- Maestro fa vibrare il tamburo suonano sulla mano di J. il quale ride e si emoziona
- M. suona il tamburo a tempo!!
- Riproduciamo una musica rilassante e passiamo vicino ai ragazzi/e a suonare tre strumenti rilassanti a fianco di ognuno di loro.
- R. vuole prenderli in mano e suonarli, ceci pure prende il tamburo, M. prende il tamburo e lo suona cercando l’approvazione del maestro
- Ora il maestro suona la chitarra e si affianca ad ognuno di loro cercano di creare un momento intimo con ognuno di loro.
- Canzone “adeu” come rituale (molto importante): R. ha cantato e si è emozionato di nuovo
- Maestro ringrazia ognuno di loro chiamandoli per nome.

#### *Gruppo 2 – disabilità lieve*

- Musica rilassante suonata alla chitarra dal maestro passando vicino ad ognuno di loro
- Canzone del *Bom dia*: come rito, tutti rispondono al Bom dia
- Canzone che conoscono cantata da tutti: a diversi livelli di tonalità: bassa, media, alta
- Altro esercizio: cantare i versi: *ma ma ma ma* alzando il livello della voce e fermarsi quando il maestro dice stop.
- Esercizio parlare a ritmo sillabando le parole suonando il tamburo.

- Ping-pong con il tamburo: prima il batte un tocco il maestro poi l'utente a tempo batte il secondo tocco, in cerchio è il turno di ognuno.
- Inviare il suono alla persona che si sceglie, come un Ping-pong senza fermarsi, obiettivo: riuscita molto bene
- Canzone conosciuta dagli utenti, battere il tamburo solo alla sillaba *du* nelle strofe della canzone.
- Momento relax: ognuno ha uno strumento rilassante e lo suona
- Canzoni da cantare che già conoscono, le stanno imparando sempre meglio.
- Canzone di Addio, come rituale finale

### **NT 19 – 26.01.23**

#### **GIOCARE A DOMINO**

Giornata piuttosto tranquilla, ho aiutato come sempre la mattina a riordinare e accompagnare gli utenti nelle attività diurne.

Più tardi mi sono messa a giocare a domino con V. e C. e ho provato a rendere il gioco più stimolante facendo partecipare V. attivamente, facendole rispettare il suo turno per esempio. Inoltre, le chiedevo sempre quali erano i numeri di cui avevamo bisogno per poter procedere. Non lo chiedevo solo durante il suo turno ma durante l'intero gioco affinché si concentrasse e potesse sviluppare le sue abilità cognitive. Così ad ogni turno le chiedevo: “quali numeri mi servono V.” lei guardava le estremità e mi diceva per esempio “6 e 3”. A volte era veloce e aveva la risposta corretta altre volte dovevo chiederle di guardare meglio, affinché si correggesse da sola. È stato molto interessante e istruttivo per V. nonché divertente. Penso sia importante anche perché in questo modo si sente di partecipare attivamente e sviluppa la sua autostima e confidence. Mentre più volte quando gioca con i compagni di residenza non è realmente presente e attiva nel gioco, fattore che porta i giocatori a giocare e muovere le pedine per lei, senza che lei capisca realmente il perché. Mi sono quindi sentita estremamente utile per lei in quella situazione e contesto specifico.

### **NT 20 – 30.01.23**

#### **DIARIO: GIORNATA MONDIALE DEL CROISSANT**

Attività di oggi come sempre è il diario, ossia discutere sulle ricorrenze del giorno e su quello che sta passando nel mondo in generale. Il 30 gennaio è il giorno del croissant, così l'operatrice sociosanitaria ha portato per tutti dei croissant. Successivamente abbiamo mostrato un video sulla preparazione dei croissant parigini. Infine, abbiamo discusso insieme su altre ricorrenze come, per esempio, l'ultimo concerto dei Beatles. È sempre molto interessante sia per me che per i residenti. Penso sia fondamentale che stiano informati e tengano la mente in funzione, costantemente consci di quello che gli sta attorno. A volte può essere facile alienarsi dal mondo,

essendo che vivono un po' in un mondo parallelo. Con queste notizie li rendi parte di un mondo di cui fanno parte e devono sentirsi di far parte.

### **NT 21 – 31.01.23**

#### **MAKE UP**

Io e Dalma oggi abbiamo pensato di realizzare un'attività di make-up. Ci siamo organizzate un giorno prima per portare qualche trucco. Così abbiamo simulato un centro estetico e abbiamo accolto i clienti, chiedendo loro cosa desiderassero da questa seduta. Proprio come se fossero davvero in un centro estetico. Abbiamo truccato alcune di loro, pitturato e tagliato le unghie, posto la crema sulle mani etc. gli utenti sono stati felici di potersi concedere quel momento di relax per sé stessi/e.

### **NT 22 – 01.02.23**

#### **MUSICOTERAPIA**

Oggi musicoterapia come sempre. L'attività di oggi è stata straordinaria. R., M. e J. stavano cantando in una maniera piuttosto esplicita, non più con versi o parlando. Ma era evidente che seguivano e cantavano a ritmo. R. assieme al maestro suonava il tamburo e ha iniziato a ridere di gusto fino a piangere con una risata contagiosissima che ha reso tutti allegri. M. anche ha suonato il tamburo, è stata anche a tempo con il ritmo. Impressionante vedere come migliorano in fretta e come la musica abbia in effetti un impatto molto positivo!

### **NT 23 – 02.02.23**

#### **VISITA AL MUSEO DEL BARCA**

Visita al museo del Barca, è stato carino perché siamo usciti e penso sia sempre interessante per i ragazzi avere qualcosa di nuovo e diverso da fare. I ragazzi infatti erano molto eccitati di andare anche i giorni precedenti. La gita è stata carina per alcuni per altri meno ma pur sempre istruttiva in qualche modo.

### **NT 24 – 06.02.23**

#### **DIARIO**

Oggi attività del diario: sempre molto istruttiva e interessante per i ragazzi i quali sono sempre molto partecipi e interessati nel conoscere cosa succede nel mondo e quali sono le ricorrenze del giorno. Oggi ho giocato per un'ora a *Parcisi* (un gioco da tavolo) con i ragazzi e le ragazze. Ho cercato di accompagnare il più possibile V. cercando di renderla partecipe. Cercavo di renderla conscia di quando fosse il suo turno, in questo modo la spronavo a seguire il gioco e a porgli

attenzione. Doveva imparare che dopo C. era il suo turno, e piano piano lo ha inteso e non doveva essere richiamata all'attenzione.

**NT 25 – 08.02.23**

MUSICOTERAPIA

*Gruppo 1*

- Maestro suona una canzone con vibrazioni forti
- R. danzava e ballava a tempo con la musica
- Il maestro usa degli strumenti con suono rilassante e una struttura ruvida. Li fa toccare a M. e R. ai quali sembra piacere molto la sensazione.
- R. inizia a toccare lo strumento o usarlo battendo sulla mia gamba
- Maestro pone lo strumento ruvido sulla pelle di J. (non vedente)
- E più tardi lo posa sulla pelle di S. che non si muove e sembrerebbe non essere partecipe.
- Maestro tenta di assecondare il pianto di J. con la chitarra e cantando: J. si calma
- M. e il ritmo con il tamburo: si prepara già con la mano sa cosa deve fare, sta estremamente a ritmo
- Iniziano a cantare una canzone conosciuta già dagli utenti
- R. usa pure il tamburo e canta
- J. canta o piange (obbiettivo è che si renda conto che con la sua voce possa creare un suono e quindi cantare)
- R. batte le mani, J. si calma dopo la chitarra
- R. batte a tempo il tamburo con la canzone e canta finendo le parole della canzone iniziata dal maestro (Idem montse)
- J. riconosce canzone già cantata in passato e inizia a ridere
- Canzone rilassante, passiamo tra gli utenti con strumenti rilassanti
- Canzone cantata in inglese: R. si emoziona e canta un poco
- Canzone di *adeu*: rituale

*Gruppo 2*

- Rituale: Canzone Olá/bom dia
- Alzare di tono della frase cantata seguendo il maestro
- Abbassare di tono seguendo il maestro
- “Oh happy day” musica cantata a ritmo dagli utenti
- Vengono ripassate altre canzoni che già conoscono e che vanno perfezionate
- Rituale: canzone di adeu



### **NT 26 – 09.02.23**

#### **GITA MONASTERO**

Come ogni giovedì siamo andati a fare un'escursione. Oggi è stata al monastero di Pedralves. Una giornata estremamente interessante in cui una guida con sindrome di Asperger ci ha accompagnato all'interno del monastero spiegandoci la storia e le curiosità della vita delle monache che hanno abitato nel monastero.

Estremamente interessante il progetto: persone con sindrome di Asperger che fanno da guida al monastero:<https://beteve.cat/societat/persones-amb-asperger-fan-de-guies-al-monestir-de-pedralbes/>

Per i ragazzi/e è stato altrettanto interessante e istruttivo. Sono sempre stati attenti alla guida e rispettosi dello spazio. Si sono divertiti e hanno potuto conoscere una nuova realtà nonché un progetto interessantissimo. A cui faremo sicuramente di nuovo ricorso.

### **NT 27 – 13.02.23**

#### **DIARIO**

Il lunedì è stata una giornata tranquilla. Solita attività di Diario ma comunque sempre stimolante sia per me che per i ragazzi/e. I quali sono sempre felicissimi di partecipare a questa attività estremamente fondamentale.

Mi sono anche dilettata a pitturare le unghie a due miei ragazzi/e a tagliargli le unghie. Loro sono sempre molto sollevati, non c'è una cura molto attenta alla pulizia della persona. Purtroppo, ci sono due operatori per piano e non c'è veramente tempo. Io da tirocinante avendo più tempo mi rendo conto di molte cose: gli occhiali sporchi, la bocca sporca, le unghie lunghe, le orecchie sporche etc. purtroppo, questo è un sistema difficile da cambiare e mancano i soldi.

### **NT 28 – 14.02.23**

#### **SAN VALENTINO**

Martedì molto interessante: oggi giorno di San Valentino. Il giorno prima L. mi aveva chiesto di accompagnarla fuori a bere un caffè con I. (suo ragazzo) per l'occasione. Così io ho chiesto a E. la quale ha acconsentito. Così oggi io L., I. (con la sedia elettrica) e C. accompagnata da Dalma siamo andate a berci una birra analcolica in un bar e prendere un po' di sole. È stato molto bello e rilassante per loro immagino. Sembravano felici di poter lasciare la residenza anche solo per un'ora e mezza.

### **NT 29 – 15.02.23**

#### **GITA AL CENTRO CIVICO**

Oggi è stata una giornata differente, infatti ho accompagnato i ragazzi/e del Taller (il centro occupazionale) ad un'escursione in un centro civico nei paraggi della residenza. Un centro con

uno spazio molto bello all'esterno e dei bei tavoli al sole. Abbiamo fatto un giro per il quartiere tranquillo e adattato per i disabili. Barcellona è in effetti una città parecchio avanti da questo punto di vista. Spesso andiamo in giro per i quartieri e ci sono sempre delle vie adattate alle carrozzine. La gita alla fine consisteva nel fare una passeggiata per poi nella terrazza mangiare un croissant e una bibita. Sono importantissimi anche i momenti come questi. Che come sempre dico, noi diamo per scontato ma non lo sono affatto. Una cosa mi ha fatto molto riflettere. Uno dei ragazzi, molto giovane e piuttosto autonomo continuava a ripetere: “non voglio più tornarci al Taller, raccontiamo alla presidente che ci siamo fatti male e siamo all'ospedale. Dai non torniamo più, stiamo via per sempre, io non ci torno” Queste frasi scherzose fanno piuttosto riflettere su quanto siano istituzionalizzati. Infatti, si discuteva sul fatto che le escursioni sono rare. Ognuno di loro esce una volta al mese. Proprio come accade nella residenza. La gita comunque è andata molto bene! Ci siamo rilassati e abbiamo mangiato bene. Poi dopo un altro giro siamo tornati con il pullman al centro per pranzare.

### **NT 30 – 16.02.23**

#### **QUIZ**

Il giovedì è normalmente il giorno della uscita. Io non ero stata informata e mi ero preparata per la gita. Una volta arrivata ho capito che non vi era escursione così io e il mio collega abbiamo pensato di fare un Quiz di cultura generale e proporlo agli utenti. Mi sono messa prevalentemente io a farlo poiché Jose era impegnato in altre cose. Abbiamo pensato a delle domande interessanti non troppo semplici né troppo difficili. Poiché i ragazzi e le ragazze del quinto piano sono piuttosto informati e consci di quello che gli sta attorno, quindi è bene trattarli con rispetto riguardo alle loro capacità. Abbiamo diviso il gruppo in due squadre e iniziato. Lo scopo era rispondere per primo e il primo a rispondere avrebbe preso il punto. Dopo le prime domande purtroppo sono iniziati dei battibecchi tra due di loro, A. e D., i quali sostenevano che non si rispettasse le regole. Abbiamo dovuto interrompere il gioco e dividerli. Poi siamo andati avanti con più calma ma D. ha deciso di lasciare il gioco. È stato molto triste perché sono stata io a convincerlo a prendere parte al gioco e il mio esperimento di inclusione è fallito miseramente. L'Attività nel complesso è piaciuta molto e i Residenti si sono divertiti. Erano ovviamente più che preparati a rispondere. Siccome il gioco è finito relativamente presto abbiamo proposto un altro quiz di cultura generale preso da YouTube. In questa seconda attività è stato interessante vedere come due residenti che inizialmente non volevano partecipare hanno partecipato molto attivamente alla seconda. Forse perché si sono ricreduti o solo per far vedere che sapevano rispondere. Non lo so. Però ho percepito una bella partecipazione per la durata di ben 30 domande. Spero di aver alleggerito e reso interessante almeno un po' la loro giornata troppo spesso rutinaria. Verso ora di pranzo V. ha iniziato ad essere nervosa. ultimante succede spesso perché ha iniziato ad avere la dieta con masticazione facilitata, così deve bere l'acqua con una sostanza che rende

l'acqua più densa e il cibo tagliato e pezzi più piccoli. V. purtroppo capisce molte cose e pensa di essere molto più indipendente di quello che è realmente. E quando si accorge che viene aiutata o trattata come 'stupida' se ne accorge e ci sta molto male. Rifiuta di mangiare alza la voce e inizia a piangere. Non è bello perché lei non vuole essere trattata come bambina o come disabile e purtroppo alcuni colleghi e compagni di piano la trattano in questo modo.

### **NT 31 – 20.02.23**

#### **GITA AL MUSEO DEL BARÇA E STADIO**

Oggi gita al museo del BARÇA per la seconda volta, io non ero troppo motivata il calcio proprio non mi piace. Invece L. e D. erano molto felici di poter andare! Erano estremamente eccitati e felici. E il solo fatto di vederli contenti mi bastava per essere a mia volta contenta. Il museo era veramente pieno di persone. La cosa non rendeva facile l'accesso. Ti rendi conto solo in questi momenti di quanto realmente ogni spazio aperto o pubblico non è realmente accessibile ai disabili.

Le persone pensano al loro percorso e non sono per nulla attente al prossimo, non siamo abituati a doverci preoccupare per il prossimo, viviamo in una società molto individualista. Quindi anche una semplice visita ad uno stadio risulta molto difficile se non impossibile per una persona in carrozzina. Deve essere sempre accompagnata da un tutor e anche in quel caso sarà tutto rallentato dalla massa di persone che non curanti passano avanti e non ti lasciano passare.

Ovviamente la parte più interessante del museo (quella dove vi erano le coppe i palloni d'oro e le scarpe d'oro di Messi etc) era inaccessibile per noi, poiché era veramente piena di persone e ci sarebbe stato impossibile farci strada tra la massa. Quindi spesso la parola accessibile per disabili è realmente molto complessa. Un luogo per essere realmente accessibile deve tenere in considerazione moltissimi aspetti, non solo il fatto che ci sia una rampa, ma anche che sia per esempio grande abbastanza affinché una carrozzina possa passare facilmente senza doversi fare strada tra la massa di persone che non curanti bloccano il passaggio. Questa la mia riflessione del giorno su cui si potrebbe fare una ricerca approfondita, esistono luoghi realmente accessibili al giorno d'oggi? È questa una società attenta alla disabilità? Le nostre città sono inclusive?

### **NT 32 - 27.02.23 / 31.02.23**

#### **ASSENZA**

Durante questa settimana non sono potuta andare a tirocinio perché ho avuto la febbre e mi sono accorta tornando la settimana dopo di quanto in effetti abbiano sentito la mia mancanza. Tutti che mi chiedessero che fine avessi fatto e che gli ero mancata molto.

Spesso penso di non fare una grande differenza e mi sento a volte anche inutile. Ma questi momenti mi fanno capire che in realtà la mia presenza ha un effetto positivo, potrà essere anche minimo ma sicuro non sono indifferente e questo mi gratifica e mi dà la forza per impegnarmi di più e la volontà per non arrendermi anche nei momenti in cui tutto sembra un po' piatto e rutinario.

**NT 33 - 01/03/23**

## MUSICOTERAPIA

Primo gruppo:

- C. nervosa
- Canzone rilassante
- Canzone Olá: tutti reagiscono al bom dia con espressioni di felicità, versi o parole
- C. graffia la sedia: maestro tenta di creare una melodia con lei è un ritmo (parte dal presente)
- M.: inizia a toccare la chitarra così il maestro la lascia toccare è imposta le note per lei (forse per fargli capire che può suonare pure lei -costruzione confidence?)
- Avvicina la chitarra a J. per fare sentire le vibrazioni: J. apprezza
- Ceci prova diverse superfici su cui grattare
- Il maestro le avvicina la cassa e lei prova a grattare la cassa
- Canzone “adeu” rituale

Secondo gruppo:

- Canzone rituale
- Ping-pong del ritmo
- canzone che già conoscono per praticare utilizzo di strumenti

Discussione con Maestro di musicoterapia:

gli ho chiesto perché quando M. tocca la chitarra lui imposta le note con la mano e lui mi ha risposto che lo scopo è sempre quello di fare musica. Inoltre, quello di fargli svolgere un ruolo attivo poiché la maggior parte del loro tempo nella residenza lo svolgono avendo un ruolo passivo. Quindi lavora su due piani: il piano di ricezione, il maestro canta e suona e loro ricevono il positivo della musica e le sue vibrazioni e il piano più attivo in cui loro in primis fanno musica e si rendono conto di esserne capaci, il quale ovviamente va a lavorare sull'autostima e sul sentirsi di avere un ruolo attivo.

Abbiamo commentato come anche lui avesse un metodo di improvvisazione ossia che parte dagli stimoli dei ragazzi e dalla situazione presente per poi elaborare e costruire un'attività attorno ad essi. Per esempio, come ho descritto prima C. era nervosa e grattava la sedia così lui si è messo a creare una canzone attorno a quel ritmo dandogli uno strumento sul quale potesse grattare. Poi abbiamo cercato anche di usare delle tecniche per calmarla che sono servite ma non del tutto.

### **NT 34 – 06.03.23**

#### **ATTIVITÀ AL TALLER**

Lunedì mi è stato chiesto di recarmi la mattina al taller, ossia il centro occupazionale dove vari ragazzi e ragazze vanno per svolgere attività e vari laboratori. È stato estremamente interessante vedere le diverse attività svolte dai ragazzi, ognuno aveva un compito diverso in relazione sia alle capacità sia a propri interessi. La cosa che più ho trovato interessante è stata una ragazza totalmente paraplegica che con l'aiuto di una strumentazione particolare riusciva a scrivere frasi solo battendo le palpebre. L'ho trovato bellissimo e importantissimo. Questa persona non ha modo di comunicare se non con sì e no e attraverso questa nuova tecnologia non si comunica ma può persino articolare pensieri molto profondi e complicati.

### **NT 35 – 07.03.23**

#### **MOVIMENTO**

Oggi è stata una giornata apparentemente calma ma in realtà molto intensa e movimentata. Ho aiutato a sistemare l'armadio di una mia utente e successivamente ci siamo trasferiti tutti quanti al piano 2 poiché le operatrici erano in riunione. Quando c'è una riunione, infatti, ci sono delle persone che possono restare sole e altre che devono sempre essere vigilate, poiché non hanno il consenso dei genitori o dei tutori di poter rimanere da soli. Quindi nel momento in cui ci siano meno operatori disponibili ci si sposta tutti al piano 2 e una o due operatrici restano a vigilare.

Ci siamo messi a guardare un film e altre persone giocavano a domino con il volontario. Poi successivamente io ho avuto una piccola riunione con la direttrice poiché inizierò a lavorare, la quale mi ha spiegato quali saranno i miei orari e varie altre cose pratiche.

Da domani probabilmente accompagnerò più da vicino la pulizia e l'igiene dei ragazzi/e dovendo iniziare a lavorare a breve.

### **NT 36 – 12.04.23**

#### **MUSICOTERAPIA**

##### *Primo gruppo:*

- Canzone di ola iniziale: R. canta con la stessa nota
- R. Risponde alla canzone e canta a tono e seguendo una specie di ritmo
- Maestro intona una canzone e R. canta con foga e inizia a battere la mano sulla gamba
- Con il tamburo avvicinandolo al corpo e muovendo per loro la mano a tempo
- M. e R. suonano insieme il tamburo a tempo
- M. Vuole spesso l'approvazione di R. E lo cerca piano piano diventa indipendente
- Passa con la cassa e musica relax vicino ad ognuno di loro
- Poi passiamo con gli strumenti
- R. e M. Esplorando la chitarra

- R. si emoziona con la canzone di saluto
- C. pure esplora la chitarra rispondendo a silenzi voluto del professore

*Secondo gruppo*

- sentire un sapore e fare suono “miam” con la bocca e sentirne la vibrazione sulla testa e petto
- Cam Pam con la bocca e alzare il tono (toni che vibrano) a e m vibrano in modo differente
- A e i o u provare le diverse vibrazioni
- Cantare una canzone con diverse tonalità
- Cantare canzoni già conosciute da ripassare

**NT 37 – 19.04.23**

**MUSICOTERAPIA**

*Primo gruppo*

- Intona una canzone con testo molto difficile e R. Si ricorda le lettere
- si sviluppa anche la memoria
- Con J. Fa lo stesso, il quale non sembra molto presente
- M. si avvicina allo strumento del mare in una maniera diversa non battendo (come suggerisce la forma di tamburo) ma accarezzandolo
- M. Suona la chitarra
- R. Anche e intona una canzone con toni bassi come la canzone (usa le mani che spesso non fa) prende possesso delle sue abilità
- M. Pure intona una canzone con le parole che conosce
- J. sembra pure cantare
- C. aiutata usa la chitarra
- Maestro intona una canzone con una parola inventata da M.: cocon
- Canzone adeu, R. continuava il testo

*Secondo gruppo*

- Ha iniziato un ritmo e tutti lo hanno seguito
- Ping-pong migliorato moltissimo/ tutti sono sincronizzati
- In più ora il maestro canta e suona e loro non si distraggono — prima non poteva cantare durante il ritmo
- Poi ora divisi in due gruppi e entrambi sono quasi sincronizzati
- Pensare un sapore
- Mama ma ma alzando il tono tutto insieme e poi singoli
- Inizia una canzone e loro continuano il testo senza nessuna indicazione

- Canta frase e chiede di essere ripetuta da un piccolo gruppo segnato da lui

### **NT 38 – 10.05.23**

#### **MUSICOTERAPIA**

##### *Primo gruppo*

- R. canta tantissimo e partecipa
- M concentrata
- I ragazzi/e sono calmi e rilassati
- Momento strumenti relax
- Farglieli toccare e suonare ma solo una parte affi
- R. suona il tamburo

##### *Secondo gruppo*

Mi hanno vista e sono stati sorpresi e felici di vedermi è come se vedessero in altra Maria quando sono qui a musicoterapia

Una Maria che può ascoltarli e passare del tempo con loro di qualità

Erano nervosi e agitati e stavano litigando tra di loro

Musica rilassante presentazione di un nuovo strumento

Autoascolto con mano a conca sull'orecchia

Modo adattato di usare lo strumento, ognuno trova il suo modo per tenerlo e poterlo suonare (Ping-pong)

Maestro ha dato delle direttive/ canta di più o canta meno, ti voglio sentire di più etc

Fine molto positiva con musica molto positiva

### **NT 39 – 31.05.23**

#### **MUSICOTERAPIA**

Oggi ho voluto intraprendere delle piccole interviste per raggruppare i feedback dei ragazzi/e :

- Prima intervista a I: "Me encanta ir a musicoterapia, estamos aprendiendo mucho sobre música, y me encanta nuestro profesor, es muy bueno haciendo lo que hace, además toca muy bien. Yo también quiero aprender a tocar como él algún día. También disfruto mucho cuando cantamos la canción que nos gusta."
- Seconda a M. : "Me siento relajada y alegre, la sesión me deja una sensación de paz y serenidad, veo las cosas a mi alrededor con otra luz. Gracias, María, por formar parte del proyecto. ¿Estarás la próxima vez?"
- Terza a J: "Me gusta cuando el terapeuta dice el "Buen Día" a todos y nosotros le respondemos. También me encanta el momento en que tocamos el tambor porque creo que se me da muy bien y eso me hace feliz".

## **NT 40 – 07.06.23**

### MUSICOTERAPIA

- Porte aperte famiglie
- Salutarsi attraverso la música
- Parte coscienza corporale ( vedere se vibra etc ) dentro di noi (sapori etc)
- Parte attiva
- Ogni musica tiene un messaggio (testo molto importante)
- Conversa con maestro: lasciare il tempo che rispondano agli stimoli che gli ho dato, Perché non sai in che modo stanno processando quindi devi rispettare i loro tempi
- Ognuno di loro, infatti, ha risposto nel suo modo specifico grazie allo stimolo dato dal maestro diverso per ognuno di loro

## **NT 41 – 28.06.23**

### MUSICOTERAPIA

- S. non fa versi di sofferenza
- E muove le mani e i piedi per mettersi meglio
- Mani poste in una
- maniera differente

## **NT 42 - 05.07.23**

### MUSICOTERAPIA

#### *Primo gruppo*

- Musica rilassante per connettere con loro
- Hola a todos canzone
- Canzone freedom conosciuta da loro
- (M e J reagiscono positivamente)
- Maestro fa toccare con la mano la chitarra a J che non vede
- Suono rilassante emesso dal tamburo avvicinato a joan e mosso affinché senta le vibrazioni con al Mano (si entusiasma)
- Sarà mette la mano sul tamburo
- Avvicina tamburo a ceci intonando canzone conosciuta: ceci lo sfiora
- M. Suona e canta a ritmo con il tamburo
- R. Sta a tempo e suona il tamburo senza volersi staccare cantando a momenti
- J. È contento non piange e sembra essere molto entusiasta e estasiato di poter battere il tamburo con l'aiuto del maestro, può fare musica anche lui
- Maestro riprendo suono rilassante con tamburo strofinandolo



- Passiamo vicino a loro con strumenti che rilassano / facciamo sì che tocchino gli strumenti e li suonino o semplicemente sperimentano anche il senso del tatto
- Ora si avvicina ad ognuno di loro con una canzone solo strumentale e parla con ognuno di loro un po' intonando delle note
- Inizia canzone conosciuta e r. Inizia a battere le mani da solo a ritmo
- M. Anche inizia a stare a ritmo
- Diamo a loro un tamburo e iniziano entrambi a suonare poi si prendono le mani e le muovono a ritmo
- Canzone adeu atmosfera molto più rilassata
- Sessione molto molto intensa io e educatore abbiamo parlato pochissimo

### *Secondo gruppo*

- Melodia rilassante solo instrumental
- I ragazzi chiedono dove le ha conosciute queste canzoni e che canta molto bene
- Esercizio con la bocca di mmmmm (toccando la mandibola con la mano)
- Miam con la bocca e sentire la vibrazione che fa
- Sentire la vibrazione del petto mentre facciamo ma ma ma
- Papapa sentire la vibrazione del cranio
- A gruppi: manuma ue manuma alzando e abbassando il livello
- Ping pong con il tamburo a ritmo a gruppi, tutti hanno eseguito molto bene
- + musica cantata
- Ora canzone tue tue conosciuta
- (Iniziata da un usuario cantata da solo)
- Poi tutti hanno accompagnato
- Canzone conosciuta da tutti e con spiegazione del significato
- La la la la a toni differenti
- Prima maestro e devono rispettare il momento esatto (il segnale) per fare loro
- Canzone conosciuta e cantata insieme happy days in catalan
- Intona una frase e la fa ripetere a loro con la stessa intonazione
- Canzone cantata tutto insieme con testo già conosciuto: chissà chissà chissà
- Altra canzone
- Canzone rito finale

## **Appendix 3 – INTERVIEW GUIDE TO THE MUSIC THERAPIST**

### **Definición de Trabajo**

- ¿Qué estudios y trabajos ha realizado?
- ¿Qué es para usted la musicoterapia?
- ¿Puede definir un poco el público con el que trabaja?
- ¿Puede definir un poco cómo estructura sus clases? (1ª y 2ª gr)
- ¿Las preparas en casa, te marcas objetivos diarios o no?
- Siempre tenéis un ritual (música bom día/adeu) ¿qué importancia tiene este ritual?

### **Proceso sistemático**

- Objetivo claros: ¿cuáles? (diagnóstico, descriptivo, prescriptivo, evaluativo)
- ¿Cómo están organizadas las sesiones en los dos grupos? ¿Qué diferencias hay?
- ¿Puede describir los objetivos que tiene para el primer grupo y los del segundo?
- Método?:
  - diagnóstico (objetivos)
  - tratamiento (dirección general del trabajo) (que tipo de experiencia: improvisación, re-creación, composición, escuchar)
  - evaluación: cambio de las condiciones del cliente

### **Proceso**

- La musicoterapia es un proceso que se desarrolla en el tiempo (¿hay fecha de fin del proceso terapéutico en este caso o no?)
- ¿Tipo de proceso? (evolutivo, educativo, interpersonal, artístico, creativo, científico)

### **Intervención**

- Música como terapia (M. Medio principal) o Música en la terapia (M. no es el único agente terapéutico)?

### **El terapeuta**

- ¿Cómo se establece una relación terapeuta-cliente sana y constructiva? (ética profesional)
- ¿Puedes explicar un poco cómo estableces las sesiones individuales en el primer grupo? (porque noto que tienes un enfoque diferente para cada una y por lo tanto también objetivos diferentes)

### **Ayudas**

- Modelos de ayudas: ¿Cómo quieres ayudar a los clientes? (empatía, oportunidades de autoexpresión, etc.)

### **El cliente**

- ¿En qué medida influye el contexto en las clases de musicoterapia?

### **Usar la Música**

- ¿Es importante no emitir juicios de valor? Explique lo que piensa
- ¿Cuáles son las implicaciones multisensoriales de la música? (La música incorpora todos los sentidos) cómo lo incorporas a tus clases?

### **Niveles de la experiencia musical**

- Qué tipo de experiencia musical quieres que tengan los usuarios (premusical/musical/extramusical/paramusical)

### **Los 4 métodos principales de la musicoterapia**

- Qué método utilizas (experiencia de improvisación/ recreativa/ composición/receptiva)

### **Relaciones**

- ¿Qué función tienen para ti las relaciones (agente terapéutico) que surgen de la musicoterapia?

### **Fuerzas dinámicas**

- ¿Qué tipo de experiencia quieres que tengan los usuarios? objetiva, subjetiva, energética, colectiva, estética, transpersonal

### **Cambio**

- ¿Qué cambios observas en el usuario después de estos meses de musicoterapia?
- ¿Qué valoración haces de este proyecto?

## **Appendix 4 – INTERVIEW GUIDE TO THE ACTIVITIES COORDINATOR**

### **Introducción**

- Formación/educación
- Carrera profesional
- Dimensión profesional en la institución :Papel, funciones y responsabilidades dentro de la institución
- Cómo entró a formar parte de la institución y cuál ha sido su evolución desde entonces

### **La institución**

- Cómo nació: breve historia
- Tipo de entidad
- Cuáles son los objetivos, la misión y las metas
- Cómo ha cambiado
- A nivel de actividad, cómo ha cambiado
- Cuál es la finalidad educativa y formativa de las propuestas educativas
- ¿Cuál es la perspectiva/principio socioeducativo utilizado y promovido en esta institución para garantizar la calidad de vida de este tipo de población?
- ¿Por qué se adopta esta perspectiva y no otra? ¿Por qué se promueven este tipo de actividades y no otras? (hay varias perspectivas teóricas)
- ¿Qué evaluación puede hacerse de esta lógica de trabajo? ¿Existen límites en su opinión? ¿Cómo la perciben los usuarios?
- Los desafíos de la residencia
- Recursos humanos que trabajan en la institución: cuántas personas componen, lista y funciones (cómo han cambiado las figuras profesionales a lo largo del tiempo)

### **Educación**

- Opinión sobre: Desventajas y ventajas de la vida institucionalizada. ¿Por elección o por obligación?
- Discutir el tema: la persona discapacitada se hace mayor y el cuidador es demasiado mayor o ha fallecido: consecuencia vivir en Residencia
- Existe una organización semanal planificada de las actividades ¿De dónde surgió la idea de un horario fijo y por qué?
- Qué actividades son de pago y cuáles no
- La fisioterapia es accesible a todos, ¿está incluida en el coste que pagan (cuánto?)

- ¿La institución es privada o pública?
- ¿Pagan una cuota mensual? ¿Qué incluye esta cuota? ¿Qué actividades?
- ¿Las sillas de ruedas, etc. corren a cargo de las familias o del Estado?
- ¿Cuánto reciben los usuarios en concepto de ingresos por discapacidad?
- ¿Qué se puede mejorar para favorecer la calidad de vida de los usuarios?

### **Usuarios**

- ¿Más jóvenes y más mayores?
- ¿Cómo entran los usuarios en la residencia? ¿Existe una graduatoria?
- ¿Cuál es la situación en España en materia de alojamiento y atención a discapacitados?
- ¿Cómo funcionan las reuniones entre usuarios?
- ¿Existe una jerarquía entre los usuarios?
- ¿Cómo es el flujo de información de los usuarios a la dirección, etc.?
- Relación familia-usuario (Explicar cómo funciona el papel de el Referente y de Laila)

### **Cuestiones Éticas**

- Principios y valores éticos de Estimia
- Cuestión de privacidad: ¿cómo se gestionan las fotos y vídeos de los usuarios cómo se protege su privacidad?
- Cada usuario tiene un tutor o fundación tutelar: ¿me puedes explicar cómo funciona esto en términos prácticos?
- ¿Siempre debe haber consentimiento para todo o La residencia tiene un tipo de independencia?

## Appendix 5 – TRANSCRIPT INTERVIEW TO THE MUSIC THERAPIST

### Legend

**YELLOW:** Making music for making music: positive results will follow

**GREEN:** The positive outcomes of music therapy

**BLUE:** The structure of the activity

**GREY:** Methodology

**PURPLE:** Relationship Clients and music-therapist

**Speaker 1:** Maria

**Speaker 2:** Musicoterapeuta

**Maria** [00:00:01] Ciao Benvenuto a esta entrevista.

**Musicoterapeuta** [00:00:10] Grazie Mille

**Maria** [00:00:10] Bueno, en principio te pregunto un poco que estudio ha hecho y el trabajo que ha realizado.

**Musicoterapeuta** [00:00:28] Bueno, en primer lugar, para trabajar como musicoterapeuta tienes que estudiar un máster de dos años en musicoterapia, en principio sólo eso. Pero a nivel personal, yo valoro mucho que has estudiado música antes porque tu lo has visto, Si yo supiera tocar tres acordes con la guitarra, no puedes conseguir lo mismo. Entonces es muy importante, desde mi punto de vista, que hayas estudiado música o que estudies música.

**Maria** [00:01:05] Si, tener una base.

**Musicoterapeuta** [00:01:08] A nivel personal estudié filología.

**Maria** [00:01:12] Está bien interesante. Te puede ayudar.

**Maria** [00:01:17] Que significa para ti la musicoterapia?

**Musicoterapeuta** [00:01:23] Que significa para mí? Bueno, para mí es un es un campo que yo he descubierto. Yo me he puesto a estudiar musicoterapia, sencillamente por curiosidad. Yo soy

muy curioso, me gusta aprender y empecé a estudiar musicoterapia y después he descubierto que es fascinante entrar en el mundo de la discapacidad. También trabajo en un hospital de personas que son un poco más vulnerables en situaciones difíciles y poder ofrecer música en estos contextos me encanta. Entonces, para mí es muy importante, porque en realidad yo lo único que hago es es música, como cualquier músico, pero me he especializado con hacerlo con personas con discapacidad o en situaciones difíciles, vulnerables.

**Maria** [00:02:31] Pero no es solo musica, es música con una finalidad un poco terapéutica. No crees?

**Musicoterapeuta** [00:02:38] Sí, pero mi visión personal siempre es hacer música. Yo entro siempre en todas mis sesiones: en el hospital, en la escuela donde trabajo como musicoterapeuta, aquí en la residencia y mi objetivo es hacer música. Si te fijas, siempre, siempre estoy haciendo música con ellos y no estoy intentando, por ejemplo, si una de ellas golpea, pues no intento que golpe para hacer una coordinación de psicomotricidad. Lo que yo pretendo es que hagan música conmigo y cuando hacen música conmigo eso lleva implícito pues la coordinación, la psicomotricidad, la música en grupo, la relación conmigo y a nivel emocional, a nivel cognitivo, por ejemplo, uno de nuestros usuarios canta o repite alguna de las canciones. En el grupo dos por ejemplo, alguien que tras sesión empieza ya a cantar, se siente partícipe de un grupo. Lo importante no es que cante muy bien ni qué canciones cante, pero yo de entrada lo que pretendo es hacer música con él y el resto va de consecuencia

**Maria** [00:03:59] Se puede explicarme un poco la estructura de la clases. Ha una estructura no? Muy diferente del primer y segundo grupo. Se puede explicarme como la subdivide, se la piensa antes etc.

**Musicoterapeuta** [00:04:31] Mi especialización o el campo de la musicoterapia que me interesa a mí es la musicoterapia creativa. La musicoterapia creativa se basa en tu tener muchos recursos, entrar en sesión y a partir de lo que acontece en sesión tú vas creando al instante. Se ve muy claro en el grupo uno, cuando pasa algo a nivel musical sobre todo, pero cuando pasan cosas o alguien percute un instrumento.

**Maria** [00:05:06] Hoy por ejemplo con J.

**Musicoterapeuta** [00:05:07] Por ejemplo. Con J, pero también con R. De golpe se ha puesto a golpear, hacia allí, a aprovechar este momento, a sincronizar con él, a incluir eso que está haciendo él, a convertirlo en musical. Porque si yo no estoy aquí, esto es solo un golpe: clac, clac, clac. No,

En cambio se trata de convertir este clac clac, clac en música. Sí, si. J. hace lo mismo en el piso de abajo quizás está gritando.

**Maria** [00:05:41] Sí.

**Musicoterapeuta** [00:05:42] Sí, lo hace. Aquí hace música.

**Maria** [00:05:43] Piensa que canta J.?

**Musicoterapeuta** [00:05:47] Uno de mis objetivos, como te decía, mi objetivo es hacer música. Pero luego yo me propongo otras cosas. Y una que me he propuesto es que él sea consciente de que la voz también la puede utilizar para cantar, no sólo para comunicarse, quejarse, sino también para hacer música. Entonces, yo creo que a veces él es consciente que estamos en el mismo nivel, es decir, que yo hago lo mismo que él. Lo interesante de este trabajo es que yo me pongo a su nivel, yo voy a él siempre, no espero que ellos vengan a mi normalmente. Entonces yo voy a J., J. hace un sonido, yo voy a ese sonido, yo hago música con ese sonido. Y yo creo que J. tiene que percibir que este tío está haciendo lo que hago yo pero esto es música. Entonces un objetivo a largo plazo es que el haga sonido con intención musical.

**Maria** [00:06:51] Sí, pero ya está procediendo. Se ve un poco más.

**Musicoterapeuta** [00:06:58] El primer paso es ser consciente de eso que te comento. Ser consciente de que yo puedo hacer sonido igual que haciendo yo.

**Maria** [00:07:05] Sí.

**Musicoterapeuta** [00:07:06] Porque yo hago las mismas vocales, las mismas notas que él.

**Maria** [00:07:11] Y to vè que él se vocaliza con la misma nota o todavía no?.

**Musicoterapeuta** [00:07:16] Con la misma nota que yo estoy tocando? Siempre.

**Maria** [00:07:21] Sí?

**Musicoterapeuta** [00:07:24] Siempre, J. siempre. Incluso hoy he puesto una pieza de piano, un audio de piano que está en DO sostenido, que simple no es. Y hemos empezado en la escala de LA porque J. ha hecho LA. Entonces yo he aprovechado el LA y hemos empezado a jugar con la



escala de LA. Cuando hemos puesto la pista de piano esta en DO sostenido y el sonido que he hecho después de la audición estaba en la escala de DO sostenido, que son las teclas negras del piano, no las blancas. Vale.

**Maria** [00:08:05] Eso no lo sabía.

**Musicoterapeuta** [00:08:07] Que estaba súper dentro de la música. Sí, sí, sí, sí.

**Maria** [00:08:12] Sí. Entontes la estructura la tienes, pero después flue

**Musicoterapeuta** [00:08:19] Pero si te fijas, Siempre tengo una estructura muy fija en los dos grupos. En el grupo uno siempre hago una introducción musical para entrar con música. Si te fijas y utilizo muy pocas palabras durante mis sesiones. En la primera casi no uso palabras, no doy consignas verbales, no digo lo que tienen que hacer, lo que tienen que dejar de hacer. Introducción musical, algo muy suave para entrar, luego algo de percusión para que tengan un papel activo y a continuación, esto puede llevar a si alguien hace algo, enlazar con lo que ellos hacen. Y después hay un momento de audio con los instrumentos vibro táctiles, que quiero que ellos sientan la vibración además del sonido, que son sonidos más o menos naturales, la vibración. Y luego acaba con otra canción por mi parte y ya con un con una subida de energía y de intensidad, etcétera Y luego al final, al culminar la despedida.

**Maria** [00:09:37] Eso me he fijado mucho, que tiene siempre un ritual.

**Musicoterapeuta** [00:09:45] De entrada y de salida

**Maria** [00:09:46] Que dicen un buen día y un adeu, qué importancia tiene este ritual para ti?

**Musicoterapeuta** [00:09:53] Es muy importante en toda sesión porque marcas un poco la diferencia entre fuera y dentro. Introducción musical. Luego saludo. Es una cuestión de respeto, de estima. Y fíjate que a cada uno de ellos les agradezco , sobre todo al final doy gracias a todos.

**Maria** [00:10:22] Y también me he fijado que tú tienes gracias y el nombre también de ellos, como diría el tipo bueno, estoy para ti, te doy importancia.

**Musicoterapeuta** [00:10:33] Porque quizás algunos de ellos que quizás no haya participado ese día o algo. No María, gracias por haber tocado hoy y siempre les digo gracias por tu música, no por mi música, no por la música que yo he hecho, porque la música, la idea es que la hacemos

todos, entonces gracias, cada uno de vosotros entonces es una entrada en contexto. Ahora estamos en sesión de musicoterapia y por eso ese hola siempre es la misma canción que ya conocen. Y la última también es muy importante porque ahora vais a salir de aquí y ya es otro contexto y vais a encontrar otras personas, otro ambiente, otros compañeros y se trata de de crear un poco de fuera dentro.

**Maria** [00:11:20] Ok, interesante. Perdona, y en el segundo grupo? La estructura es más fija. No?

**Musicoterapeuta** [00:11:32] Se ha ido creando. Es que cuando llegué aquí no sabía que acabaría creando un tipo de coro. No lo sabía. No tenía ni idea. Pero he visto que con los recursos que tengo, porque con los instrumentos que tengo, no podemos hacer muchas cosas, porque no tengo muchos instrumentos. Tengo percusión para cada uno de ellos. Pues percusión. Si tuviera placa haríamos placa. También tenemos voz y percusión, pues se ha creado esta estructura.

Entonces de abrir siempre es introducción musical, bienvenida individual. Y luego empiezo con una canción para entrar, para calentar un poco y luego un poco de técnica. La técnica yo la utilizo en grupo dos como una manera de introspección, de sensación.

**Musicoterapeuta** [00:12:39] Se llama **La plena conciencia**. Es la conciencia llena de de tu cuerpo, tus partes de tu cuerpo, de tu respiración, de como respiras, de la parte donde sonamos. No sonamos la lengua, los labios.

**Maria** [00:12:57] Corporal.

**Musicoterapeuta** [00:12:58] Sí. Conciencia corporal. Sé un poco de conciencia corporal y siempre, por tanto, porque es musicoterapia, no pretendo que sepan técnica. Creo que en su caso es muy interesante porque no sé si trabajan mucho en lo que es la conciencia corporal, tú que estás más con ellos?

**Maria** [00:13:20] hacen Reiki, sabes? Pero entonces esto le da un poco de introspección, pero poco, no me parece, pero bueno.

**Musicoterapeuta** [00:13:37] Si hay alguna otra pueden ser pocas a la semana no? Y pienso que en su caso es muy interesante porque el estar sentado en una silla siempre, es posible que pierdas un poco de contacto con tu cuerpo y eso es un poco **reconectar con con tu cuerpo**. Luego hago una parte de percusión y luego el ritmo

**Maria** [00:14:05] Un poco saber respetar el turno?

**Musicoterapeuta** [00:14:06] Sí. Y ahora, si te fijas, ya lo estoy dando a iniciativa cada uno de ellos. Antes yo era el director que creaba el turno con cada uno de ellos y ahora ellos ya son protagonistas de esta actividad. Es posible que algún día ya no sea necesario, sea uno más de ellos. Y después ya hay una parte del repertorio combinado con temas nuevos, con otros que ya saben, para que no sea todo un trabajo, sino cantar canciones que sabes y que ya te gustan, que no piensas y otras que tienes que aprender.

**Maria** [00:14:41] El texto también hay una importancia, ¿cómo escoge las canciones?

**Musicoterapeuta** [00:14:46] Algunas de las canciones creo interesante que las escojan ellos porque son sus canciones, pero las otras Últimamente yo intento fijarme en el texto, en el mensaje, porque creo que es muy importante el mensaje de las canciones. Y las que he escogido tienen un mensaje "top en la vida" que habla de la vida, del momento. Y de la otra por ejemplo, es Happy Day, que es una canción de agradecimiento. Nos ha salido también. Aleluya! Pero intento que tienen un mensaje y según que mensaje no lo cantaré. En la radio está lleno de canciones que si nos fijamos el mensaje es nocivo.

**Maria** [00:15:39] Si, si. Pero también yo pienso que no es solo el texto, también la melodía. Tal vez un texto un poco así. No tiene nada más de la melodía te conecta con algo de tu pasado.

**Musicoterapeuta** [00:15:56] Eso es totalmente cierto. Pero, dime algo malo. Dime algo malo, una frase. Dime algo.

**Maria** [00:16:06] Malo?

**Musicoterapeuta** [00:16:07] Y yo qué sé si un pensamiento malo o negativo. Y en ese.

**Musicoterapeuta** [00:16:18] La vida es aburrida, La vida es aburrida. Que si yo vengo cada semana y canta una canción que dice la vida es aburrida y yo creo que esto lo absorbes.

**Maria** [00:16:40] yo me escucho un montón de canciones tristes.

**Musicoterapeuta** [00:16:44] Bueno. Si, pero van de acuerdo a tu estado de ánimo. Tu manera de ser. Escuchamos más canciones tristes que alegres normalmente creo. vale, pero si que es verdad que hay que tener cuidado con con qué mensaje es la tristeza. Si hoy en día son muchas canciones de amor que: "sin ti no soy nada".

**Maria** [00:17:15] Si, si, si.

**Musicoterapeuta** [00:17:20] En español hay una canción que se llama sin ti no soy nada.

**Maria** [00:17:22] muy tóxica.

**Musicoterapeuta** [00:17:23] Si tu cantas, sin ti no soy nada eres cantando yo no soy nada, yo no soy nada, yo no soy nada. Por lo tanto el mensaje es muy importante. En cambio, si cantas a tope en la vida.

**Maria** [00:17:34] Si te da una energía diferente.

**Musicoterapeuta** [00:17:38] Por tanto el mensaje si que es muy importante.

**Maria** [00:17:42] Bueno, hay uno hay objetivos claros y un trabajo y hay mas objetivos diagnóstico, descriptivo, prescriptivo o evaluativo? Tu te enfocas mas en una tipología?

**Musicoterapeuta** [00:18:20] Yo creo que esto no sería en objetivos, sino que esto es un proceso. El diagnóstico sería cuando tu llegas en sesión.

**Maria** [00:18:30] A Okay.

**Musicoterapeuta** [00:18:31] Tu tienes que saber leer cada día lo que diagnosticar, que es lo que pasa. Por ejemplo hoy R. al principio de la sesión esta bastante apagado. tienes que saber leer como esta S.? Como esta C aquel día si,si esta más activas y si M. va a responder o no va a responder.

**Maria** [00:18:54] También C. estaba un poco apagada.

**Musicoterapeuta** [00:19:00] Entonces no creo que esto sean prescriptiva, sería prescribir. Lo que hace el médico.

**Maria** [00:19:09] Prescribir algo.

**Musicoterapeuta** [00:19:11] Y evaluar es al final como evaluar lo haces cada instante. Evalúas como responde según como responde, tu actua.

**Maria** [00:19:24] Bueno como metodo tu utiliza mas la improvisación, la composición, recreación ..?

**Musicoterapeuta** [00:19:39] La composición seria si nosotros creamos una canción en el grupo dos ok, por ejemplo vamos a hacer nuestra canción.

Recreación, en el grupo dos recreamos porque las canciones no son nuestras, las recreamos, es decir, canciones que ya existen, las reproducimos. Esto es reproducir una melodía o una canción. En el Grupo uno Escuchamos, por ejemplo. En el grupo dos también escuchan as veces si yo canto. Y luego trabajo la improvisación, sobre todo en el grupo, bueno, no tanto en el dos. Lo que hemos hecho hoy, en el grupo dos, es improvisación.

**Musicoterapeuta** [00:20:32] Vale, son diferentes métodos que tenemos en musicoterapia, que son estos cuatro. Que uno no significa que no puedes utilizar el otro y a veces los puedes mezclar, puedes estar recreando y poner un poco de improvisación.

**Maria** [00:20:55] En la musicoterapia está descrito que es un proceso que se desarrolla en el tiempo y tú piensa que hay una fecha de fin? Exemplo cuando tú vas en terapia normalmente hay un inicio y una fin. Aquí con esto tipo de poblacion piensa que se pudiera continuar.

**Musicoterapeuta** [00:21:19] Es cierto que una terapia se acaba cuando vas a terapia. Lo que pasa es que en el contexto en el que yo trabajo, por ejemplo aquí, cuando pondrías fin al grupo uno?.

**Maria** [00:21:37] Esto me lo preguntava.

**Musicoterapeuta** [00:21:40] Entonces yo no creo que ellos vengan a terapia para llegar a una situación de confortabilidad, de salud. Porque ese estado es el estado que tienen y no va a modificarse.

**Musicoterapeuta** [00:22:01] Entonces yo lo vivo más como vivir una experiencia musical. Vamos a vivir la música juntos, no? Y entonces, claro, esto no tiene fin.

**Maria** [00:22:15] Pero puede ayudar más al Bienestar. La musicoterapia viene tener direntes finalidades en correspondencia con el cliente y donde sea el cliente. con esa poblacion pienso que más hay con una finalidad de hacer música para el bienestar. Pero pienso que puede ayudar un poco a nivel cognitivo, etc..

**Musicoterapeuta** [00:22:52] Pero es lo que te decía, yo hago música y luego si R. pues le trabajamos lo que es la memoria con él, pues es fantástico. Otra opción sería venir a trabajar con R. y empezar a trabajar a nivel cognitivo para trabajar la memoria, pero esto no es mi manera de trabajar, pero podría hacerlo. Por ejemplo, en centros de rehabilitación, en sitios Goodman que conoces, que son para enfermos neurológicos, accidentes, ictus, pues hay una función de recuperación, y una vez llegan, supongo, al nivel máximo de recuperación posible, se acaba la terapia.

**Maria** [00:23:38] Ok.

**Musicoterapeuta** [00:23:39] En este caso se dice y si veo que no hay aprovechamiento también daría de alta.

**Maria** [00:23:59] No es el caso.

**Maria** [00:24:04] Bueno, el tipo de procesos aquí es más evolutivo, educativo, interpersonal, artístico y creativo o científico?

**Musicoterapeuta** [00:24:26] Bueno, hay un poco de todo. Yo creo.

**Maria** [00:24:29] Imagino. Sí.

**Musicoterapeuta** [00:24:30] Incluso el interpersonal para mí es muy importante.

**Maria** [00:24:32] Este si te quería preguntar también,

**Musicoterapeuta** [00:24:35] En realidad tenemos que interpretarlo como una actividad social, entre personas, de interactuar juntos. Entonces yo ofrezco música, tú haces la música conmigo y yo lo hago contigo. Es un acto interpersonal.

**Maria** [00:25:00] Entre tú y yo, entre ellos en el grupo, no? Que función piensa que tienes la relaciones que surgen en la terapia, que surgen entre ellos también?

**Musicoterapeuta** [00:25:09] La música trabaja el ser humano en todos los niveles. A nivel emocional. Emociones. A nivel espiritual. Cantamos el aleluya a alguien lo puedes cantar y sentir de una determinada manera. A nivel cognitivo, trabajamos la memoria, la atención, a nivel físico, coordinación, psicomotricidad, a nivel fisiológico, hormonas y a nivel social. Por lo tanto, por eso

te digo, yo vengo, hago música y todo eso lo estamos haciendo a la vez. Entonces a veces yo puedo poner más el punto en, por ejemplo, coordinación: físico, la actividad que hacemos del ping pong el grupo dos, coordinación.

**Maria** [00:26:10] Respetar el tiempo.

**Musicoterapeuta** [00:26:12] Pero es interpersonal, es social porque hay una escucha, hay un respeto del compañero, hay un silencio en trabajar juntos en el grupo dos.

En alguna vez si tú estabas ha habido un poco de contestas un poco fuera de lugar y por lo tanto dentro de ese espacio he gestionado esto. y cuando haces música juntos, creo que puede ayudar a mejorar las relaciones.

**Maria** [00:26:40] tú hace música como terapia o en la terapia? porque la música, el medio principal o no es el único agente terapéutico?

**Musicoterapeuta** [00:26:54] Música como terapia, es decir, música en terapia. Sería yo hago la terapia y pongo música.

**Maria** [00:27:08] Ok.

**Musicoterapeuta** [00:27:09] Lo utilizo para crear un ambiente. Para esto. Esto sería música en terapia. Pero música como terapia es cuando la música es el agente. quien provoca los cambios es la música, yo no hago nada.

**Musicoterapeuta** [00:27:23] es que hay una paradoja muy interesante que es, que todo lo hace la música. Yo no hago nada.

**Maria** [00:27:36] Tu eres el Trámite.

**Musicoterapeuta** [00:27:36] yo soy el gestor, quien gestiona, quien produce la música.

**Maria** [00:27:42] No hay musicoterapia sin musicoterapeuta.

**Musicoterapeuta** [00:27:44] Pero claro, es una paradoja. Y es una paradoja porque yo no hago nada. Si el efecto para J. es de la música, del sonido.

**Maria** [00:27:53] Sí, sí, sí, es verdad.

**Musicoterapeuta** [00:27:54] Pero el sonido lo hago yo, vale, pero yo sin sonido no soy nada. Por lo tanto, esto es música como terapia

**Musicoterapeuta** [00:28:05] Porque es la música la que hace todo esto.

**Maria** [00:28:08] Y cómo establece la relación terapeuta-cliente, sana y constructiva? Porque también he visto que tu también utiliza un modo muy específico de relacionarse con ellos però tu has podido establecer una relación bastante profesional y constructiva.

**Musicoterapeuta** [00:28:37] Sí te diré que he visto y tratado con pocos profesionales de aquí de centro, pero a veces sí que dan un poco de instrucciones, no? Quizás porque es su trabajo y fuera de este espacio tienes que dar instrucciones. Pero fíjese que aquí yo no, no mando nada nunca, pero nada.

**Maria** [00:29:00] Pero te respetan

**Musicoterapeuta** [00:29:02] No?, pues es una manera de ser. Y en este caso también siempre estoy al mismo nivel. Agradecer siempre su músicas y yo estoy a su nivel. En el grupo dos siempre me dejan por las nubes. Gracias Carlas, eres súper como tocas. No, no, no, no, la música la hacemos todos. Ya les he dicho, yo sin vosotros no soy nada, porque si no hay coro, no hay cantantes, yo no puedo hacer nada. Entonces se trata una una relación de valorar lo que ellos hacen, de ponerte a su nivel. Casi siempre utilizo la silla y no es casualidad.

**Maria** [00:29:44] Porque?

**Musicoterapeuta** [00:29:48] Igual que ellos, yo no estoy de pie primer, a la altura de los ojos. Porque sí que es verdad que si estás sentado y miras así, es distinto de miran así. Entonces sí, se esto pasa mucho rato, que cada día de tu vida, lo tienes de alguna manera un mundo distinto. Yo estoy a tu nivel, contigo, en el mismo nivel, vale? Y luego, con mucho respeto, no soy nadie para decirle a la gente qué es lo que tiene que hacer. Y doy muy pocas consignas.

**Maria** [00:30:29] As veces complicado con J. que continua, pero tu mantiene la calma.

**Musicoterapeuta** [00:30:51] Y fíjate incluso que casi nunca les digo ni cuándo tienen que tocar. El segundo grupo puede ser un poco más dirigido, si te fijas, nunca cojo o pocas veces, perdón, agarro la mano de alguien para que toque.



**Maria** [00:31:11] Sí, sí.

**Musicoterapeuta** [00:31:12] Es la música que lo hace. Si veo que pueden tener intención pero no son capaces de hacerlo, les acompaño, les ayudo para que puedan. Pero de entrada, si quieres tocar el tambor bien si no, no.

**Maria** [00:31:33] Bueno, las **sesiones individuales** del primer grupo no, que tú te pones muy individualmente y noto que tienes un enfoque diferente para cada uno y portanto también objetivo. Pienso diferente.

**Musicoterapeuta** [00:31:51] Sí, porque cuando estás en terapia, una de las cosas que te enseñan en terapia es el principio de ISO.

**Maria** [00:32:03] ISO ?

**Musicoterapeuta** [00:32:06] El **principio de ISO** es que: tu, en este caso la música, tienes que ponerte en el mismo estado que el usuario.

Es decir, si yo estoy bajo de energía, yo no te voy a decir venga va, energía. No, no, es decir, yo me pondré a un nivel musical con energía baja, vale? Y luego yo como terapeuta voy a gestionar esa energía con un objetivo. o mantenerla o voy a darte más energía para que sí. Entonces, si te fijas, como has dicho muy bien en la sesión, una atención más individualizada en el grupo uno, incluso dentro de la misma canción, la toco distinto dependiendo a quién me dirijo.

**Maria** [00:33:04] No es una sabia.

**Musicoterapeuta** [00:33:06] Es decir, M. puede ser muy enérgica. Sabes? Pero S. no, C. Menos entonces hago algo más delicado con outro tono de voz.

**Maria** [00:33:28] Si. Si.

**Musicoterapeuta** [00:33:29] Vale. O por ejemplo. Si. Si R. se pone a llorar alguna vez yo tengo que ir en el estado este para llegar a él, acompañarlo y luego hacer lo que yo considere. quedarme ahí o más cosas.

**Maria** [00:33:46] Yo también veo que un bueno con M. y R. trabaja y a un nivel más de percusiones que le dan más papel activo. Y con S. y C. más de tal vez escuchar y cantar.

**Musicoterapeuta** [00:34:05] SI ,Pero no olvidemos que M. al principio no hacía nada. Aunque parezca ahora que es imposible. nadie movió un brazo aquí.

**Maria** [00:34:18] Me he olvidado.

**Musicoterapeuta** [00:34:20] Vale. Es decir, parece que M. siempre hubiera actuado así. Y no, no, no, al principio nada de nada. Un golpe, tras, retirada. Y ahora hemos cantado toda una canción. Ella llevando el ritmo de la canción.

**Maria** [00:34:37] Sí, sí.

**Musicoterapeuta** [00:34:38] Iba adaptando la canción a su ritmo. No espero que ella venga a mí ritmo. vale, porque estamos haciendo la música juntos, entonces. C. y S. también tienes un papel activo.

**Musicoterapeuta** [00:34:53] S., Le acerco un instrumento y mueve la mano para llegar a él. Todos los instrumentos, la cortina, la percusión. Y los hace sonar un poco. Si antes era absolutamente nada. Y C. también depende del día se pone a rascar la guitarra. Hoy ha habido un momento que ya ha puesto la mano en el mástil de la guitarra. Pero yo sigo tocando.

**Maria** [00:35:28] También las cosas que hace las notas. Cuando M. toca a tu toca también las notas. También el objetivo es imagino de un **papel activo**, que hagan música.

**Musicoterapeuta** [00:35:47] Claro. Es decir, tú quieres tocar la guitarra pero no sabes tocar la guitarra. yo sé tocar la guitarra. Entonces yo voy a hacer que tu tocas la guitarra. Entonces tu sabes rascar, sabes deslizar la mano izquierda de arriba abajo. Perfecto. No sabes hacer la otra mano en el mástil? Pues ya lo hago yo. Y entonces es hacer música juntos. Yo creo que tienes la sensación de que tú estás tocando la canción con la guitarra, si yo voy cambiando de acorde.

**Maria** [00:36:17] Y eso trabaja también en **la autoestima**. Pienso mucho en autoestima.

**Musicoterapeuta** [00:36:21] Yo este aspecto lo considero muy importante.

**Maria** [00:36:24] Si de sentirse capaz de hacer.

**Maria** [00:36:31] Y bueno, el modelo de ayuda cuál es? Cómo quieres ayudarlos? donde?.

**Musicoterapeuta** [00:36:57] Lo que entiendo es que hablen de modelos de ayudas. Pero yo no, no utilizaría esta palabra. No? Porque si te fijas, es como. Venga, el miércoles vengo a ayudaros.

**Maria** [00:37:14] Si yo pienso que esto, el problema de este libro, que se pone: yo te ayudo y yo su terapeuta, me pongo a ayudarte. Entonces al final ellos son pasivos porque si yo te ayudo Se crea una dinámica de niveles.

**Musicoterapeuta** [00:37:37] Yo cuando entro por la puerta no pienso voy a ayudaros, voy a ayudaros a hacer música, voy a ayudaros a cantar. Voy a ayudaros a tocar el tambor. No! Es decir, no, como te he dicho antes, yo entro y vamos a hacer música juntos.

**Maria** [00:37:58] Enfocarnos sobre que sabe hacer. No que no sabe hacer.

**Musicoterapeuta** [00:38:02] Sobre sus capacidades o no sobre su discapacidad.

**Maria** [00:38:05] Exacto, Gracias.

**Maria** [00:38:06] Es muy interesante. en qué medida influye el contexto en la clase de musicoterapia? tipo eso es un contexto de una residencia, cerrado etc.. Cómo esto influye ?

**Musicoterapeuta** [00:38:30] Claro, es que yo trabajo en distintos contextos. En este caso soy yo que vengo a su casa, digamos. Hacemos música semanalmente. Es una actividad más del centro. Es distinto, por ejemplo, el trabajo en un hospital. El contexto es distinto. La lectura de la sesión es distinta, la dinámica de la sesión es distinta. Si trabajásemos en una escuela también es distinto. Yo trabajo en la escuela y a veces el pensamiento es más de pedagógico. Vale. Sí, supongo que sí que tiene, que influye el contexto, pero mi visión es la misma. Hago música donde haga. vengo aquí hago música con el grupo uno, con el grupo dos me voy al hospital, hago música en la habitación 513, voy al colegio, a la escuela y hago música.

**Musicoterapeuta** [00:39:39] La protagonista ès la musica!

**Maria** [00:39:40] Sisi

**Maria** [00:39:41] Y bueno, es importante no emitir un juicio de valor, se puede explicar un poco lo que piensa sobre esto.

**Musicoterapeuta** [00:39:58] Juicio de de valor. Sí.

**Musicoterapeuta** [00:40:08] Sí. Aquí te puedo comentar dos cosas. Si te fijas, creo que he expresado alguna vez en sesiones que no existe el bien y el mal en sesión. Nunca les he dicho yo sí.

**Maria** [00:40:26] para mí es muy muy complicado, por ejemplo hoy I. lo estaba haciendo mal y yo le he dicho que se hace en este modo no en esto.

**Musicoterapeuta** [00:40:41] Yo también lo hago. Fíjate que les he dicho vamos a coger, vamos a hacer la pinza. Intento enseñaron una visión pedagógica para mejorar en la práctica del instrumento. Sí, pero a nadie le he dicho no lo haces mal, no? Entonces yo lo que haré será ver cómo cada uno de ellos hace lo que yo he propuesto y cómo puedo ayudarles para mejorarlo. Si consiguen seguir mis consignas, mis consejos, pues está bien. Si no, pues también. Es decir, y la semana que viene se lo volveré a decir. Si volviéramos a repetir la misma actividad.

**Maria** [00:41:30] con A. esto proceso funcionó. El nunca seguía el ritmo y ahora espera siempre su turno.

**Musicoterapeuta** [00:41:51] SISI! A., yo estoy contentísimo con este caso, en el sentido de que parece que no está, pero su evolución ha sido mucho mayor que como han evolucionado de otros, porque era de nada. Y ahora su cara está súper relajada. Sonríe muchas veces, comenta, comparte, participa y empieza a cantar.

**Maria** [00:42:19] Sí, sí, impresionante. Y el resultado? Muy directo. No sé cómo explicarlo, que esto metodo funciona: no hace falta que le digas noo antonio lo estas haciendo mal. poco a poco acompañándolo y dándole instrucciones al final lo intiendo.

**Musicoterapeuta** [00:42:41] A veces sí que doy alguna consigna de Del bien y el mal. Sí que sí quiero mejorar. Por ejemplo, esta frase no la cantáis bien, vamos, o lo tendríamos que cantar de otra manera. Estas frases son con estas notas o con esta melodía. No con esta otra melodía. Así que hago este trabajo para intentar mejorar. Vale, pues les digo, vamos a intentar escucharnos siempre en positivo.

**Maria** [00:43:10] Sí, sí, sí.

**Musicoterapeuta** [00:43:11] Pero sí que hay un trabajo de mejorar estéticamente también.

**Maria** [00:43:16] Sí, sí.

**Musicoterapeuta** [00:43:17] Te has fijado en el grupo dos? Hay veces que hemos cantado algo y luego dejo el silencio. Y ellos saben cuando aquello suena bien. Sí, ha sonado como un churro. También lo sabes. Eso tengo que decirles, pero cuando he sonado muy bien, te llega y se quedan todos si plabras.

**Maria** [00:43:42] Si te ha quedado sin palabras, eh? Y después el J. que quebra el silencio, ahahah. Bueno, hay también implicaciones multisensorial de la música ?

**Musicoterapeuta** [00:44:08] Si, si. Sin duda. Sin duda. Fíjate que he hecho algún ejercicio para trabajar. No sé si lo has visto alguna vez de escucharse.

**Maria** [00:44:17] Si,si.

**Musicoterapeuta** [00:44:21] Si trabajamos el oído en este caso. Vale. Luego trabajamos un poco el que es el gusto para sentir la lengua. porque hay una teoría que es que según sientas cada uno de estos sentidos, vas a emitir la voz de una manera u otra. Luego también he trabajado un poco el tacto a nivel sensorial.

**Maria** [00:44:57] Si en el principio, verdad.

**Musicoterapeuta** [00:45:00] Lo que he visto que esto es bastante lento. Muchos no llegan. Se lo tengo que hacer yo, que como somos nueve, si lo quiero hacer bien me llevo media sesión y tampoco es el objetivo, pero sí trabajo a nivel sensorial y los instrumentos que utilizas tú del palo de Lluvia, tambien son a nivel sensorial.

**Maria** [00:45:26] Sentir también las vibraciones. Los metodos?

**Musicoterapeuta** [00:46:10] Receptivo sería solo musicoterapia receptiva es cuando solo tienes una actitud receptiva que no pasiva, que es distinto, sino que tú recibes la música que hace el terapeuta. Y luego hay la musicoterapia activa en que tú tienes parte. La Creativa sería pues lo que creas también.

**Maria** [00:46:45] Si la experiencia que quieres que tenga los usuarios. Más objetiva, subjetiva, energética, colectiva, estética o transpersonal o todas?

**Musicoterapeuta** [00:47:18] Como te he dicho antes, yo siempre me propongo hacer música y el resto que venga solo, así que puedo acentuar un aspecto, otro aspecto, como os he dicho. Pero por ejemplo, cuando yo canto Aleluya alguien lo puede hacer a un nivel más espiritual, otros ponen los acentos en la parte más estética o para gestionar la energía del momento.

**Maria** [00:47:39] Sí. Que qué cambios has observado en el usuarios después de meses de musicoterapia? Bueno, un montón y a cada uno tienes lo suyo.

**Musicoterapeuta** [00:48:28] Yo estoy muy contento porque tampoco te tengo que decir que yo nunca había trabajado con había hecho música, musicoterapia, en esto contexto.

**Maria** [00:48:41] Con discapacitados nunca? No, no me lo creo. Bueno, lo hace muy bien.

**Musicoterapeuta** [00:48:48] Bueno. Entonces yo llegué aquí y me pusieron con C., con J., con M. y con R.

**Maria** [00:48:59] Y ya tiene experiencia, pero con discapacitados? no? te salió muy bien. Bueno, que tal vez las personas no sabe como relacionarse con ellos

**Musicoterapeuta** [00:49:12] Es decir. Me propusieron esto. Llegué el primer día y me dicen vas a hacer música, musicoterapia, que en realidad es música, con cuatro personas que no hablan, movilidad: algunos no tienen y los que la tienen la tienen parcial o reducida, pero tienes que hacer música con ellos. Es un reto, no? Sí, y estoy muy contento y muy orgulloso de como ha ido. Pero tienes que confiar, lo que te he dicho. Yo lo he dejado todo en manos de la música. Ya sé encargar a la música, no? Y entonces fue un verdadero reto. Y tengo que añadir entre paréntesis que a mi lado estaba la persona que me había contratado.

**Musicoterapeuta** [00:50:07] Aquí conmigo estaba la persona que me había contratado, E. observando, mirando.

**Musicoterapeuta** [00:50:21] Por ejemplo. Vale, pero yo agradezco también, lo veo como una muestra de interés. Es decir, quiero ver qué he contratado y si me interesa o no?

**Maria** [00:50:37] Si.

**Musicoterapeuta** [00:50:43] pero sí que esa primera sesión fue un reto, porque como hace música, alguien que no canta, alguien que nos toca, no? Y quieres hacer música con ellos. Entonces es lo que te he dicho. Se trata de estar muy atento, ver. Y del grupo, no? Bueno, es que J al principio sólo lloraba, no sé si te acuerdas. Ahora casi nunca llora, no?

**Maria** [00:51:07] Y Está super contento también.

**Musicoterapeuta** [00:51:09] J. como abre los ojos, M. tiene súper interiorizado lo que hacemos. R. también. S. Son muy pequeños pasos, pero son pasos.

**Maria** [00:51:22] Sí, sí. Se puede hablar con Sara. Le pregunte si le gusta la musicoterapia y me dijo que sí a su manera

**Musicoterapeuta** [00:51:29] Sí, sí, Siempre me dice el bom dia y cuando la saludo, sólo verme una sonrisa, los ojos así. Sí. Y el grupo dos también ha mejorado mucho.

**Maria** [00:51:44] También. Sí. A nivel de técnica también. Ellos impresionantes.

**Musicoterapeuta** [00:51:48] A nivel de técnica. Sí, sí, a nivel de voz, de escucharse. Antes eran un grupo un poco descompensado y ahora.

**Maria** [00:51:58] Bueno, entonces que valoración hace de este proyecto. Muy positiva, no?

**Musicoterapeuta** [00:52:03] Sí, estoy muy contento, estoy muy contenta. Es un placer venir a trabajar aquí con ellos porque es un trabajo. Yo digo que no puedes trabajar muchas horas al día de esto.

**Maria** [00:52:14] Te saca muy energía, eh?

**Musicoterapeuta** [00:52:19] Sí, sí, porque hay una inversión de energía tuya bastante. Sí, Es un trabajo que tú das mucho. Sí, das.

**Maria** [00:52:29] Pero eso tú continúa bien a decir: es la música que hace, es que no. Perdona, pero precisa de un terapeuta que lo hace bien. Porque hay persona que la música la sabes, pero no sabe trabajar bien. entonces tu tienes que también valorizarte, ok yo soy la primera que no se valoriza. Pero felicidades porque un proyecto que he acompañado desde el principio y me gusta y pensando en ellos lo veo muy contentos, y eso es lo importante en fin.

**Musicoterapeuta** [00:53:00] Muchas gracias! También Valoro mucho tú, tu interés, tu la manera de participar, la manera de observar. Porque para mí también es muy positivo. Es distinto tener una persona así o alguien que está mirando el mobil, porque todos estamos aquí. Es decir, es la energía ya cambia. Vale? Y bueno, ya te he puesto un reto de tocar dos instrumentos a la vez.

**Maria** [00:53:30] Y esto como ha ido?

**Musicoterapeuta** [00:53:31] Muy bien. No? Sí. Y cuando estaba tocando, pensaba. Qué guay. Porque cuando necesito. Necesito mucha energía sonora. Y no lo puede hacer solo.

**Maria** [00:53:43] Preguntar no más. Puedo intentar, si se precisa, más instrumentos, para la canción. Lo voy a intentar.

**Musicoterapeuta** [00:53:55] Y también es interesante para ti que ya que estás aquí, que puedas participar activamente también.

**Maria** [00:54:00] Sí, pero también, no sólo yo la participante tipo puedo, te ayudo, pero no me gusta ponerme muy activa.

**Musicoterapeuta** [00:54:07] Ah, no, no. Muchas veces no os digo nada.

**Maria** [00:54:11] Porque eso sí, exactamente.

**Maria** [00:54:14] Bueno, Muchas Gracias Carlos!

**Musicoterapeuta** [00:54:14] Muchas gracias a ti Maria.



## **Appendix 6 – TRANSCRIPT INTERVIEW TO ACTIVITIES COORDINATOR**

**Speaker 1:** Maria

**Speaker 2:** Activities coordinator

### ***FIRST PART***

**Maria** [00:00:00] Bueno en principio un poco sobre ti, sobre la tu formación, educación, carrera.

**Activities coordinator** [00:00:11] hice psicología, vale en la Universidad pública de Cataluña y entonces empecé a trabajar aquí, pero trabajaba en planta como cuidadora y después salió la oportunidad de la plaza, de coger la plaza de Técnico de Actividades y Voluntariado y nada, aquí estoy llevo en en la residencia desde hace 9 años.

**Maria** [00:00:38] Trabajando como cuidadora.

**Activities coordinator** [00:00:39] Exacto, y hace tres años como tecnica.

**Maria** [00:00:44] Cuáles son tus funciones? Tu papel y responsabilidades dentro de la institución?

**Activities coordinator** [00:00:51] Vale. Además de mi responsabilidad en la residencia, es como técnica de actividades y un poco supervisión de la atención directa. Sí, técnica de actividades que decir que marco todos el tema de las actividades que hacen los chicos. Hacemos un plan de actividades. Si lo marcamos en el horario, se ajusta a los tiempos. Y entonces, claro, tiene que ver muy directamente con la atención directa, porque tú has de saber como funciona cada planta y los horarios de cuidado de los chicos cuando se levantan, cuando desayunan, cuando se duchan para saber como podemos encajar las actividades en el día a día de los chicos. Y eso ya lo sabes todo. Atención directa: nos reunimos periódicamente, hablamos sobre posibilidades de mejora, modificaciones en cosas que quizá vemos que no acaban de ir bien. Valoramos con el equipo.

**Maria** [00:01:49] Y también eres tecnica de la práctica y de voluntariado.

**Activities coordinator** [00:01:53] Exacto. Por otro lado llevo todo el tema de prácticas en la residencia y todo el tema de prácticas. En la Fundación también soy técnico de voluntariado de los tres servicios que gestionamos. La Fundación tiene tres servicios una escuela de educación

especial, un centro ocupacional y la residencia. Entonces todo el equipo de voluntariado también lo gestiono yo.

**Maria** [00:02:32] también de las escuela. Eso no sabía. Interesante! Muchas cosas.

**Activities coordinator** [00:02:36] Demasiadas.

**Maria** [00:02:40] Sí, entonces ya me explicaste tu evolución dentro de la institución, antes como cuidadora, después como tecnica. Además, ahora sobre la institución un poco, pero en breve, porque ya tenemos documentos. ¿Cómo cómo nació la institución Estimia?

**Activities coordinator** [00:03:07] Esto mejor sacarlo de la web. Estima tiene muchos años porque empezó siendo Auxilia, después se cambió el nombre etc.. el colegio va a hacer 50 años ahora, este año, O sea, si tenemos 50 años, sí.

**Maria** [00:03:27] Y después se separa.

**Activities coordinator** [00:03:28] A Sí, exacto. Primero fue Auxilia, luego se separó y se ha quedado Estimia

**Activities coordinator** [00:03:35] Mejor sacarlo de la web.

**Maria** [00:03:36] Y la identidad es privada o pública. Que tipo de identidad es?

**Activities coordinator** [00:03:51] Es concertada. Qué quiere decir? Que la mayoría de su presupuesto es público. O sea que decir no es público del todo, porque la gente que trabaja, que no son funcionarios, pero si que es verdad que el Departamento de Servicios Sociales, en el caso de la residencia, es el que decide el coste de cada chico según sus ingresos.

**Maria** [00:04:27] Los chicos pagan una cuota mensual?

**Activities coordinator** [00:04:31] Depende de sus ingresos en la residencia.

**Maria** [00:04:34] Que significa?

**Activities coordinator** [00:04:36] Y de lo que ganan, del dinero que tengan, de sus bienes. De eso.

**Maria** [00:04:43] Ok, bueno, también dime un poco sobre la misión, los Objetivos...

**Activities coordinator** [00:04:52] De la Fundación? Eso lo tienes en la web. Seguro. ahí está todo.

**Maria** [00:05:01] Y a nivel de actividades, Cómo es que ha cambiado aquí?

**Activities coordinator** [00:05:07] En la residencia?

**Maria** [00:05:08] Sí, sí, había siempre este tipo de programa y ese tipo de actividades?

**Activities coordinator** [00:05:14] Al principio, cuando se creó la residencia, bueno, se priorizó sobre todo lo que es la atención directa, el cuidado del chico. Una vez empezó a rodar la residencia, se empezaron a hacer alguna actividad, hasta que se creó la figura del técnico de actividades. Claro, cuando empiezas una residencia hay unas prioridades que primero es el cuidado, la atención directa y la parte asistencial, no?

**Maria** [00:05:45] Sí, sí, es lo básico.

**Activities coordinator** [00:05:47] Esto es lo básico, es una vez esto funciona y funciona muy bien, pues viene la parte de las actividades que primero se empezaron haciendo. Bueno, se iban encajando los horarios. Hasta que salió se creó la figura esta del técnico de actividades, que sí, que ahora es verdad que es la persona, en este caso soy yo, que que que gestiona todo el tema de las actividades.

**Maria** [00:06:09] Sí, sí se. Interesante. Cuál es la finalidad educativa y formativa de las propuestas educativas que nos proponemos. Si hay una finalidad específica. Si hay más que una etc..?

**Activities coordinator** [00:06:31] ¿Hay objetivos? Claro, claro. Sí, sí. Sobre todo es la estimulación, el mantenimiento cognitivo al máximo posible, la movilidad. Aquí la mayoría de chicos, como sabéis, es discapacidad física. Todo, aunque cognitivamente también algunos están afectados. Entonces, dentro de cada nivel lo que intentamos es sobre todo mantener el nivel cognitivo. Sí, mantener la movilidad. Y lo que se hace en general es intentar mantener la memoria a largo plazo.

**Maria** [00:07:14] Sí, exacto.

**Activities coordinator** [00:07:17] Trabajar sobre como vivir la vida comunicaria, las relaciones sociales.

**Maria** [00:07:23] Pero también los papeles de vida cotidiana.

**Activities coordinator** [00:07:26] Exacto. Las tareas. Porque esto es una residencia. Todos y cada uno tiene su tarea diaria, no? Todo esto nos ayuda a que sepan lo que es una tarea. ya que es su casa han de participar activamente en el mantenimiento de la casa. Entonces los que pueden hacen sus tareas. Esto forma parte del día a día y de la rutina. La rutina en este caso es muy buena porque da seguridad y a la vez estamos reforzando el movimiento manual, como doblar una toalla, doblar un pitet. Tengo que bajar a cocina. Todo esto hace que se muevan, que tengan que acordarse, que tengan que repartir la ropa. En realidad todo va como ligado un poco.

**Maria** [00:08:10] Y también precisa de tiempo.

**Activities coordinator** [00:08:15] Claro. Y todo esto es tiempo.

**Maria** [00:08:17] Sí. todo conectado. otra pregunta que pensé: cuales son las perspectiva y principios educativos utilizado y promovido para garantizar la calidad de vida de ese tipo de poblacion? todo lo que hemos comentado significa garartzizar la calidad de vida?

**Activities coordinator** [00:08:48] Garantizar Calidad de vida. Exacto.

**Maria** [00:08:50] Y tiene una perspectiva educativa adelante de esto?.

**Activities coordinator** [00:08:57] Hay un plan educativo detrás de todo esto.

**Maria** [00:09:03] Se puede buscar?

**Activities coordinator** [00:09:07] Sí. Lo tengo, lo tengo.

**Maria** [00:10:17] En vuestra perspectiva, las actividades, este programa educativo que tenemos. Cree que hay límites en el plan educativo y si se podría mejorar.

**Activities coordinator** [00:10:38] Seguro que se podría hacer mejor. Claro, siempre.

**Activities coordinator** [00:10:48] Pero si es decir, no encajo la palabra límites con el plan educativo.

**Maria** [00:10:59] Los desafíos de la Residencia. Y también de la lógica del programa de actividades. Si hay desafíos.

**Activities coordinator** [00:11:27] Que no se pueden conseguir? Si podrían haber. Lo que pasa que todo está basado en criterios. En realidad se hace por criterios alcanzables. O sea, lo que no nos podemos proponer es que durante el curso que viene, todos los chicos de la residencia van a escribir perfectamente.

**Maria** [00:11:52] No.

**Activities coordinator** [00:11:52] Esto es inalcanzable. No nos podemos poner estos objetivos. Todos van a utilizar el ordenador y el Word.

**Maria** [00:12:00] No, no era esto. Era más se hay desafíos.

**Activities coordinator** [00:12:33] Claro, claro. En fin. Un desafío a nivel usuario personal que te desafía?

**Maria** [00:12:39] No, no al nivel de estructura, de actividades, de planos, de actividades que vosotros han conseguido hacer, O que sí hay límites que tú está consciente?

**Activities coordinator** [00:12:53] Sí, claro. Los límites a nivel actividades, sí. Horarios, límites, horarios. Por ejemplo, viviendo en una residencia hay un límite horario en las actividades, números de chicos por actividades. Eso también es un límite.

**Maria** [00:13:14] Pienso que todo debe integrarse con la práctica

**Activities coordinator** [00:13:17] Exacto.

**Maria** [00:13:19] Cuando entré a trabajar aquí cambié mi perspectiva y el modo de ver las cosas. Antes, como educadora en practica, tiene un plano más idealizado y abstracto. Pero después ponerlo en la realidad (que es clave en tu trabajo también) es mas complicado. La residencia tienes horario, tienes reglas etc..

**Activities coordinator** [00:13:48] Entonces por eso es muy bonito desde los técnicos vamos a hacer esto etc.. Pero cuando estás arriba (como cuidadora) y lo ves y dices: No puede ser.

**Maria** [00:13:57]. Creo que tu cambio de rol te ayudó a entender.

**Activities coordinator** [00:14:04] Claro, claro, si no lo ves todo de una manera mucho más fácil.

**Activities coordinator** [00:14:12] Por qué no pueden estar a las diez todos preparados para hacer una actividad? Hasta empezamos a las diez. No.

**Maria** [00:14:20] Esto es los límites de una institución. Bueno, pienso que ellos lo necesitan estar en una institución porque te da una calidad de vida al nivel de la vida cotidiana. Pero después tal vez están institucionalizados. Como tiene que estar al ritmo de la Istitucion.

**Activities coordinator** [00:14:41] Exacto. Claro.

**Maria** [00:14:42] Esto tiene sus limites.

**Activities coordinator** [00:14:44] Sí. No, yo creo que tú puedes aportar muchas cosas de tu vivencia, de lo que has visto.

## ***SECOND PART***

**Maria** [00:00:00] Vamos a hacer más rapido. Puedes dar una opinión sobra la desventajas y la ventaja de la vida Institucionalizadas. Los chicos en final están aquí por obligación.

**Activities coordinator** [00:00:20] Claro, claro. O sea, lo mejor que le puede pasar a una persona es estar en su casa con su familia. Sí. Vale, entonces aquí tenemos dos perfiles. Partimos de esa base que lo mejor es que una persona esté en su casa con su familia. Que nos encontramos en la residencia: Primero personas tuteladas, que son personas que no tienen familia, entonces tienes entidades que las tutelan, por lo cual han de vivir en residencias. Están muy acostumbrados también a vivir en residencias, con lo cual son personas que en su casa por diferentes motivos no pueden vivir o bien porque no tienen la casa adaptada, o bien porque tienes padres muy mayores y físicamente no pueden hacer movilizaciones. Pues sí que tenemos todos los servicios de atención directa garantizados, higiene, comida, un cuidado extremo, no? Pero en casa a lo mejor también lo tienes. Todo esto que yo parto de la base de que pienso que lo mejor es que una persona esté es en su casa.

**Maria** [00:01:27] Bueno, creo no estan adaptada.

**Activities coordinator** [00:01:29] Exacto. Cuando no tiene la Infraestructura. Cuando unos padres son mayores o gente que no tiene familia, evidentemente han de venir a una residencia. Entonces aquí se les da lo mejor. El objetivo y prioridad en la residencia es que el residente se sienta como en su casa, esto es su casa, con lo cual hay que hacer lo máximo para que se sienta tu casa.

**Maria** [00:01:55] Sí, también. Estaba pensando en estas cosas sobre las actividad. Lo usuarios no tiene que estar siempre haciendo algo. Me salía mal cuando lo veía, a descansar/ver la televisión. Pero al final en tu casa no hay que estar siempre activo.

**Activities coordinator** [00:02:12] Exacto. También a veces este conflicto pasa. Hay un usuario que es más mayor. Hai veces que quiere ver la novela por la tarde. Pues claro, si tiene 70 años, que hace la gente de 70 años? ver la novela por la tarde tocarse en el sofá. Entonces aquí, sí que es verdad que es bueno, porque siempre hay actividades y están muy, muy estimulados, no? Pero también es verdad que hay momentos en que uno puede estar sin hacer nada y viendo la televisión.

**Maria** [00:02:40] Sí, sí, que de fuera como chica de práctica te parece que tienes que hacer halgo.

**Activities coordinator** [00:02:46] Si hacer algo.

**Maria** [00:02:47] Algo así. A ver, a mí me pasó en principio.

**Activities coordinator** [00:02:50] Claro, claro, claro.

**Maria** [00:02:52] Hiciste una organización semanal planificada de actividades. De dónde surgió la idea del horario fijo y por qué?

**Activities coordinator** [00:03:06] Es que no se puede. Sería una anarquía. O sea, cuando estás institucionalizado ha de haber un horario, de levantarse, de desayunar, de actividades, de comer, porque es mucha gente. Sólo en este caso son 30 usuarios. Entonces el orden es necesario.

**Maria** [00:03:22] ¿Cuáles son las actividades a pagar y cuáles no?

**Activities coordinator** [00:03:31] Valen, por ejemplo, músicas de pago, terapia de perros que se hacen los miércoles por la tarde también de pago, las salidas con el autocar también son de pago.

**Maria** [00:03:44] Y la familia decide se sujetar a los usuarios a las actividades o no.

**Activities coordinator** [00:03:46] Exacto, exacto.

**Maria** [00:03:47] Ok, se distribuye una hoja?

**Activities coordinator** [00:03:49] En principio a primero de cursos es a papel. Mira, tenemos las cunas en Barcelona que son las salidas estas en los jueves, tenemos musicoterapia, tenemos terapia asistida con animales, tenemos también fisioterapia, que es lo que hace A. a nivel particular. Cada familia apunta sus familiares a lo que quieren y luego son las actividades internas que hacen los mismos cuidadores. Es lo que hace J. por la tarde también. La diferencia entre la tarde y la mañana es que en la tarde hay mucha actividad, cada tarde hay actividades. El tiempo está repartido de otra manera.

**Maria** [00:04:26] Más tiempo.

**Activities coordinator** [00:04:27] Entonces son actividades abiertas. Ya creamos dos grupos de chicos que van a hacer cada actividad.

**Maria** [00:04:33] Y el tema de la fisioterapia, está incluida en el coste que pagan o no?

**Activities coordinator** [00:04:41] Una algunas horas de fisioterapia que sí están incluidas, otras que no. Esto pregúnteselo a A.

**Maria** [00:04:53] Y si quiere hacer más hay que pagar una session privada

**Activities coordinator** [00:04:57] Exacto, privada.

**Maria** [00:04:58] Es. Y bueno, ellos pagan una cuota mensual, no? Y que incluye la cuota?

**Activities coordinator** [00:05:07] Todo, O sea, la cuota mensual que paga cada usuario incluye todo el cuidado, la comida, todo el gasto que pueda suponer.

**Maria** [00:05:29] la cuota más la actividades?



**Activities coordinator** [00:05:33] Exacto.

**Maria** [00:05:34] Y la silla de ruedas y esas cosas son a cargo del estado o de la Familia?

**Activities coordinator** [00:05:40] Sisi

**Activities coordinator** [00:05:54] Te la da cada tres años creo. Pero esto si no se lo pregunta a A., que cada tres años te da una silla nueva gratuita.

**Maria** [00:06:03] Interesante. Los usuarios, los más jóvenes y los más mayores ?

**Activities coordinator** [00:06:12] Yo creo que J.

**Maria** [00:06:13] Que tienes?

**Activities coordinator** [00:06:14] 25/ 26 más o menos, que si no esto lo puedes mirar tú en el web. Y el más mayor creo que es L.

**Maria** [00:06:25] bueno, existe una graduatoria? cómo es que entran los usuarios aqui?

**Activities coordinator** [00:06:33] A través del departamento de Servicios Sociales. Nos los derivan y si no les podemos decir mira, tenemos una demanda de un chico usuario del taller, que tal? Y ellos te dicen vale, pues sí o no.

**Activities coordinator** [00:06:50] Es del Gobierno de la Generalitat de Cataluña y diferentes departamentos, Departament de Educació, Departament de Bienestar Social de este departamento son los que deciden.

**Maria** [00:07:12] Sabes un poco como es la situación de España en materia de atención a los discapacitados?

**Activities coordinator** [00:07:30] Bueno, está bien, pero podría ser mejor. La ciudad más adaptada de Europa es Barcelona.

**Maria** [00:07:37] serio?

**Activities coordinator** [00:07:38] Adaptada en cuanto a ir por la calle, a Barcelona, a los centros comerciales.

**Maria** [00:07:45] Sí, sí, Italia es fatal.

**Activities coordinator** [00:07:48] Pero a nivel español, no sé, supongo que más o menos es igual.

**Maria** [00:07:53] Si en Barcelona también el Ayuntamiento es muy proactivo.

**Activities coordinator** [00:07:57] Sí, sí, en este aspecto sí.

**Maria** [00:07:59] E Una cosa muy interesante: cómo funciona la reunión entre los usuarios?

**Activities coordinator** [00:08:07] Las asambleas?

**Maria** [00:08:07] Sí, la asambleas

**Activities coordinator** [00:08:09] Cada dos meses hacemos una asamblea por planta y dos veces al año hacemos una asamblea general. Entonces en las asambleas tratamos el día a día, las tareas, los problemas que puedan tener entre ellos, las demandas que puedan tener de cualquier tipo de cosas, si la comida no es buena, si las actividades están bien etc.. entonces cada dos meses se hace por planta y dos veces al año todos los chicos en general.

**Maria** [00:08:37] quien participa?

**Activities coordinator** [00:08:39] Solo los chicos.

**Maria** [00:08:40] Ok, cada planta?

**Activities coordinator** [00:08:41] Sí.

**Maria** [00:08:42] Ok. Interesante. Sí, y hay un referente para estas asamblea?

**Activities coordinator** [00:08:48] Bueno, en este caso, este año hemos implementado las delegadas de planta, que en este caso son tres de la planta porque había más problemas así como de convivencia y entonces hemos implantado esto de los delegados de planta, que son los que hacen un registro de cuando hay algún conflicto entre estas cosas.

**Maria** [00:09:10] No está un delegado a cada planta?

**Activities coordinator** [00:09:14] Sólo en la tercera lo se ha implementado ahora me lo inventé yo el otro día. Sí, porque medio quería ver cómo funciona, si funciona en la planta 5 igual también lo hacemos.

**Maria** [00:09:22] Ah, interesante. Me puede explicar el papel de P.?

**Activities coordinator** [00:09:45] Ella forma parte del Consell de Participación. y creo que está el A. y el I., que forman parte de un grupo que se reúne una vez al año en el cual están dirección, gerencia, representantes del Ayuntamiento, representantes de la Generalitat, representantes de los trabajadores, representantes de familia y representantes de los usuarios.

**Maria** [00:10:14] Y se reúne?

**Activities coordinator** [00:10:16] Una vez al año.

**Maria** [00:10:21] Pero se pasa un problema, cuando por ejemplo aquí el passillo no estaba bien adaptado....?

**Activities coordinator** [00:10:27] Ejemplo es apto, que lo puede hacer la P. si quieres y puede hacer una carta y enviarla como miembro del Consell de participación, pero porque la P. es más proactiva. El A. le da igual, pero ya sabes como es la P.

**Maria** [00:10:41] Sí, sí. y El flujo de información entre el usuario y la dirección?

**Activities coordinator** [00:10:53] Pueden bajar, pero normalmente están o el referente de planta que es el cuidador o el referente del chico. Luego está el referente de familiar, que en este caso son los técnicos. Pero ellos tienen acceso totalmente a dirección cuando quieren.

**Maria** [00:11:08] Sí, sí. También me puede explicar el papel de el referente. Exacto tipo yo soy referente, por ejemplo de I., que cuál es mi papel?

**Activities coordinator** [00:11:23] El papel del referente es la persona, que tiene un vínculo directo con el usuario. lo tenemos descrito. O sea, el referente es el encargado, como la persona a

la que el usuario le tiene que hacer todas las demandas. De cualquier demanda que tenga un usuario, se la hace a su referente.

**Maria** [00:12:04] Demandas de que tipo?.

**Activities coordinator** [00:12:07] “que me gustaría ir el sábado a misa, que hoy el J. me ha echo no sé....”

**Maria** [00:12:16] O “Me siento un poco mal” ?

**Activities coordinator** [00:12:20] Vale. Desde estas cosas hasta el control de su ropa, sus objetos personales, los cambios de armario, desde la cosa más práctica hasta la cosa más emocional. Depende del usuario que tengas, tienes más tarea a nivel emocional o menos. No es igual tener a L. por ejemplo, que a J.

J. es una tarea más de orden porque al final no te va a preguntar nada. cuando hay un conflicto con un usuario, salirá el referente de este usuario.

**Maria** [00:13:03] Sabes cuántos cada cuidador?

**Activities coordinator** [00:13:06] Depende. Puede tener tres o cuatro. Y depende del usuario.

**Maria** [00:13:12] Si normal. Si, se va bilanciando

**Maria** [00:13:15] Y ok. Puede explicarme también la función de la trabajadora social?

**Activities coordinator** [00:13:19] L. es la trabajadora social de la fundación.

**Maria** [00:13:24] También la función y sus los papeles. Cuál es?

**Activities coordinator** [00:13:28] Si, es relaciones :Familia-escuela, familia- taller. familia-residencia, becas de la escuela, todo este tipo de cosas.

**Maria** [00:13:43] Los principios y valores ético de Estimia?.

**Activities coordinator** [00:13:49] Los valores, la misión, los objetivos: Esto lo encuentra en la web.

**Activities coordinator** [00:13:55] Porque te voy a meter un rollo, pero estará mejor explicado en la web.

**Maria** [00:13:58] Y también la Cuestión de privacidad cómo se gestionan las fotos y vídeos de los usuarios cómo se protege su privacidad ?

**Activities coordinator** [00:14:03] Como dice todo esto hay. Por cierto, tengo un papel para ti. Nada, todo esto son las familias las que han de dar el ok.

**Maria** [00:14:12] Ok.

**Activities coordinator** [00:14:12] Está muy protegido.

**Maria** [00:14:13] Pero dentro actividades todo han dado el consenso para hacer fotos con el móvil de la actividade?

**Activities coordinator** [00:14:26] exacto.

**Maria** [00:14:27] puede dar o no dar el consenso ?

**Activities coordinator** [00:14:32] Ok, si, si, una familia no quiere no.

**Maria** [00:14:36] Pero aquí todos han dado.

**Activities coordinator** [00:14:38] No? S. según qué días te dice que sí, según que dice que no y como decide por ella y A. lo mismo. Hay veces que dice que sí o veces que te dice.

**Maria** [00:14:48] Muchas Gracias Erena por tu tiempo!

**Activities coordinator** [00:14:49] A ti! Buena sorte!