

ETHICAL CONFLICTS IN WORK WITH PERSONS AFFECTED BY SEVERE MENTAL DISORDER AND INTELLECTUAL DISABILITY

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Abstract

The changes that have occurred in recent decades in society have led to the emergence of new ethical dilemmas in socio-educative work. The concern here is the principle of self-determination of persons with severe mental disorder and intellectual disability. From the fields of Social Education and Social Work, it is necessary to approach such dilemmas with the implementation of effective and integrative practices that respect the fundamental freedoms established by the Convention on the Rights of Persons with Disabilities. For this purpose, we present two methodologies (supervision and ethical reflection space) used to solve two cases occurred in real intervention contexts.

Keywords

Convention on the Rights of Persons with Disabilities, ethical reflection space, supervision, self-determination, ethical conflict.

Résumé

Les changements apportés au cours des dernières décennies dans la société ont conduit à l'émergence de nouveaux conflits éthiques dans le domaine de l'intervention sociale. Parmi ceux-ci, celui qui nous occupe dans cet article est lié au principe de l'autodétermination des personnes atteintes de troubles mentaux graves et de déficiences intellectuelles. Dans le domaine de l'éducation sociale et du travail social, il est nécessaire de prendre en charge ces conflits en mettant en œuvre des pratiques efficaces et inclusives respectant les libertés fondamentales établies dans la Convention relative aux droits des personnes handicapées. En ce sens, deux méthodologies sont exposées (la

supervision et de la réflexion éthique) utilisées pour résoudre deux cas survenus dans des contextes d'intervention réels.

Mots-clès:

Convention relative aux droits des personnes handicapées, espace de réflexion éthique, de supervision, d'autodétermination, de conflit éthique.

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Introduction

We are witnessing a paradigm shift regarding the decisions that persons with severe mental disorder (SMD) and intellectual disability (ID) can make. This change means we should listen to the voices of those affected and consider, not only their ability to make decisions, but help them to discern and provide the necessary support for them to make those choices.

This shift of paradigm has been caused, among other things, by the emergence of the Other, the different, with their own claims regarding their rights. One of the changes that the end of the century has brought is the still ongoing emergence of the “others”, the evidence that others different to us exist and they are willing to claim their otherness, their differences, and their right to live their lives with those differences, to enjoy their rights to the full (Canimas, 2010).

The new paradigm has been institutionally confirmed by the Convention on the Rights of Persons with Disabilities, passed in 2006 by the General Assembly of the United Nations and ratified by Spain in 2008. Article 12 of the Convention describes the conditions required to guarantee persons with disabilities the right to equality before the law, without distinctions between physical or intellectual disability.

The implementation of the Convention brings about complex and difficult situations in residential care centres working with persons with SMD and ID, because it can cause anxiety feelings in the families as well as contradictions among the professionals.

To understand these difficulties, it is important to take into account the evolution of the assistance and care of persons with SMD and ID in Spain. The first care services for persons with ID were only created in the decade of the 1980s, thanks to the efforts of the families. Until then, there was not any established social care for them, other than the hospitalization in psychiatric hospitals.

The parents did a very significant task, giving visibility and dignity to a situation that had been hidden until then. It became essential to rescue these persons from ignorance and neglect and, in this regard, a protecting and well-intentioned paternalism was occasionally exercised.

Nowadays the residential centres make an effort to respect the right of persons with SMD and ID to self-determination on their own lives. These efforts are laudable but managing the difficult situations they bring causes anxiety among professionals.

Methods of intervention and cases

We expose below two methodologies to approach such ethical conflicts and seek solutions that arise from the working team. Both of them have been implemented by the authors in real intervention contexts. In each of these methods we show a concrete situation, its development and final approach, following the principles of narrative ethics. This method emphasises three dimensions: personality, relationships and community (Banks & Nohr, 2014).

Supervision

The first case exposed took place in a residence in which 30 persons with SMD were living. The residence was managed by an interdisciplinary team formed by social educators, psychologist, social worker, occupational therapist and assistants. The centre provides home, food and psychosocial assistance to the residents. Admissions are normally due to aging or decease of the residents' parents or due to a lack of conditions that ensure the cohabitation with their family. As long as it is possible, and if the residents show the needed conditions, they live in a supervised apartment, with more autonomy than the residence.

Every resident has a reference professional who looks out for his/her global vital situation. There are regular supervision sessions involving the entire team (15 professionals), plus the supervisor, who is an external professional. Supervision allows professionals to describe, understand and develop ethical conflicts that generate difficulties in the team. The aim is to interpret and seek appropriate interventions.

The case we expose presents a situation where the fears of the professionals and the recognition of self-determination as a right are the main axes. A dilemma arose when a couple of residents, who had started a romantic relationship, requested to share a room. The reaction of the families of the residents influenced the approach to the situation.

The couple is formed by Simón and Raquel. Simón is 50 years old and has been living in the residence for 7 years, with occasional admissions at the psychiatric hospital. He suffers from schizophrenia, which is relatively well controlled, but affects his ability to lead an independent life. His parents have deceased. Raquel has a borderline personality disorder and she has difficult relations with the other members of the residence due to her explosive personality. She has lived in the residence for 3 years, she is legally incapacitated and her legal guardian is her sister.

They have been in a sentimental and affective relationship for 6 years. There was already an occasion when the team suggested the possibility of the couple living more independently in an apartment, but it was not possible due to a relapse of Simón and the strong opposition of Raquel's sister.

There are single and double rooms in the residence, segregated by sex. Simón and Raquel ask to share a room as a couple. Although the team had already discussed the possibility of a room for couples, this discussion always took place in abstract terms. It is now, with a specific couple asking for it explicitly, where the fears appear: *"This couple is explosive"*.

During the supervision session, the debate revolves around the contradiction between respecting the self-determination of the residents and at the same time protecting them from situations that the professionals define as stressing. The fears that rise up among the professionals are:

- Fear of a relapse due to stress, especially of Simón.
- Conflicts within the couple (they fight very often). Pressures from Raquel's sister.
- Isolation and hostility to the rest of the residents.

These fears lead part of the team to propose certain conditions to access the room, based in the peaceful cohabitation with the rest of the residents. It is at this point where an interesting debate arises about the room as a right or the room as a reward associated to certain behaviours.

The case is finally contemplated as a possibility to approach Raquel from the understanding of her frustration for not fulfilling her plans of living independently as a couple.

From the awareness and development of all these fears, the team decides to give access to the room as a right, with no additional conditions than for any other member of the residence. The team establishes a family work plan to make Raquel's sister aware of the importance of her support.

Ethical reflection space

The Committee of Social Services Ethics of the Generalitat de Catalunya (Catalan regional government) (2011) promotes the creation of Ethical Reflection Spaces in Social Intervention Services (ERESS). Their main aim is to incorporate this perspective in the daily professional practice.

The ERESS are created to analyse and provide guidance on the resolution of ethical problems that may arise during the intervention, and their final goal is to improve the quality of the assistance of the service users, the promotion of ethical values and the good practices in the care provided.

The ERESS are created voluntarily and by agreement of the decision-making bodies of the centres where they are implemented. They have an interdisciplinary character and are at the service of its participants.

The participants need a basic training in ethics or the commitment of acquiring it in a reasonable period of time. They also commit to preserve the confidentiality of the information they access for being members of the ERESS.

The second case we present takes place in an institution for persons with intellectual disability. This centre provides services to take care of all vital aspects: residence, labour integration, rehabilitation, leisure, etc. It is located in a small town of 15.000 inhabitants.

It is important to note that the institution was created in 1975 thanks to the initiative of parents of persons suffering from ID. They maintain nowadays an active role within the organization and its functioning. It is worth noting as well that the organization's culture is strongly based in the protection and paternalism in all aspects of the daily life. The institution counts currently with a staff of more than 120 employees.

The Ethical Reflection Space was created approximately 5 years ago, and counts with the participation of professionals belonging to all the positions in the centre (therefore, families are also represented), and with the persons who present the problematic situation. They are coordinated by an external advisor trained in ethics. Meetings are held regularly every three months, and can be held exceptionally if needed.

In every meeting a team presents (at their own request) a situation that poses an ethic conflict. The problematic situation is analysed jointly and in a deliberative way. Possible approaches to its resolution are raised. Actions undertaken are evaluated at subsequent meetings.

The case hereby presented poses a situation where persuasion without manipulation allows the application of the principle of self-determination. It is the refusal of a resident with ID to be hospitalized to go through medical tests.

The person of this case is Pedro. Pedro is 48 years old and has a moderate intellectual disability. He lives alone since the decease of his mother two years ago. He does not have siblings and his only family bond is a very old uncle who communicates with him occasionally. Since her mother died, his hygiene and care conditions have worsened notably. He has debts and is not able to manage his economy. His aspect is not healthy and he has experienced a very important weight loss. Due to the difficulties to find an ordinary job, he finally seeks assistance at the working centre of the institution, where he starts a job.

At a certain point, Pedro takes a medical examination and is diagnosed a diabetes that needs to be treated at the hospital. The doctor points out the gravity of the situation. Pedro refuses to be admitted to the hospital claiming he has very bad memories in there because it is where her

mother died. He also explains that he fears for the security of his house when he is not at home. The family doctor does not consider appropriate that he works at the centre because he may suffer fainting, and therefore processes a sickness leave. However, Pedro keeps going to work, because the workshop is his only source of social relationships.

Pedro is offered help and support for the hospitalization, but he keeps refusing it. Being afraid that his situation worsens, the professional team asks for an evaluation for his incapacitation, which could force his admission to the hospital. Nevertheless, the team is uncomfortable with this decision because they do not think it is the appropriate solution. Therefore, they are stuck in this situation.

The team of the special work centre presents the situation at the ERESS with the following questions:

- In legal terms they are acting correctly but, is their decision ethically correct?
- What to do when a person does not want to accept help but there are concerns that he/she is aware of the seriousness of the situation?
- How to manage a situation where respecting the autonomy can mean respecting the right to make the wrong choices?

The ERESS starts a deliberation posing the dilemmas associated to this case: how to respect without abandoning and how to help making decisions without manipulating. It is obvious that Pedro needs support to make a decision; it must be ensured that he has all the information needed, true and adapted to his cognitive capacity to be able to make his choice consequently.

Therefore, the dilemma is not between doing something or not, but rather within the possibilities of intervention, which one can be more correct? Pedro's voice is added to the reflection space in order to understand his refusal to the hospital. His mother was hospitalized there and died, and this frightens him strongly. On the other hand, he is integrated in the centre, he feels supported, he really likes it there and he is afraid of losing a situation that he considers positive. And finally, he has an irrational fear to lose his house if he stays too long at the hospital. Pedro has cognitive difficulties to understand the consequences that not taking the medical tests can have for his life.

With all these circumstances, the team tries to approach him from a healthier aspect, rather than threatening or manipulating him. There is a supervisor at the institution, Olivia, who has a very good relationship with Pedro. She knows him since they were kids because they were neighbours, and Pedro holds her in high esteem. So far there have been several professionals intervening in the case, and now the team suggests centralizing in Olivia all the information, so she can be the one to take

care of the counselling. With this decision they try to avoid the pressure feeling that Pedro is currently experiencing.

The evolution of the case was that Olivia was implied in the situation, she offered Pedro counselling and listening without judgement. She provided true and appropriate information and persistently offered her support and the institution's for the hospitalization. In approximately one month, Pedro accepted to be admitted to the hospital and he was correctly diagnosed. The centre supported the hospitalization with care and hospital visits and nowadays Pedro follows his treatment correctly.

Conclusions

The professionals of social intervention find ourselves in a transition process in our practices and our manners of relation with the people we assist. We come from a paradigm where we made decisions about them, and we move forward to a different one, where we make decisions with them. This change poses new conflicts and dilemmas which have to be approached with deliberative and reflexive methodologies. This is the way it has been approached in the two cases presented. In the first one, the supervision brought to light the appropriateness of respecting a legitimate decision when the affected persons have the capacity to understand it, even when that can bring an unstable scenario for the professionals. In the second case, the ethical reflection space made it possible to call off a coercive practice such as the incapacitation and to start a persuasive intervention that allowed sorting out the risky situation the person was facing.

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