

## Recovery-oriented services for young people - what does it involve?

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### Introduction

Most mental health problems in life arise between the ages of 15 and 25. Between 1.5-3% of these children and adolescents are in contact with specialized mental health centers. Therefore, in the last decade, interventions for this population have become a priority worldwide.

Two experiences will be described in this article. The first, from Norway, is focused on support as the core of social and welfare services for young persons with mental health problems who are partly or wholly out of school and work. In recent years, a variety of models and initiatives have been developed to support young persons with mental health problems to regain or maintain their foothold in school and work. The second, from Italy, highlights how the DSM of Ferrara has addressed the challenge to engage adolescents and involve their families. This paper was developed from a presentation at the WAPR World Congress 2021.

### Support as Possibility – Lived experiences of support in the lives of young persons with mental health problems

Both at national and global level, several studies show an increase in young people struggling with mental health problems. Participation in working life is significantly lower among persons with mental health problems than the general population. Studies describe lower completion of upper secondary education among young people with mental health problems (Organisation for Economic Co-operation and Development (OECD), 2012). This raises concerns because not completing upper secondary education is one of the highest risk factors for permanently remaining out of the workforce (World Health Organization Regional Office for Europe, 2015). Most young people receiving social benefits in Nordic countries receive this due to mental health problems (Olsen, & Tägtström, 2013). Almost without exception, this leads to exclusion from social arenas such as school and work for the rest of their lives. The consequences of young people with mental health problems being left out of school and work are some of the biggest challenges for public welfare services in Nordic countries (Olsen, et al., 2016). Consequently, support for young people with mental health problems is an important social welfare priority.

Over the past three decades, a variety of initiatives and models aiming to support people with mental health problems have been developed and evaluated with the goal of helping them return and stay in school or work (Bond et al., 2008, 2012). These measures include evidence-based programs such as Supported Education, Supported Employment, Individual Placement and Support (IPS) and other models with similar elements of these programs. Despite a growing knowledge base about support, especially within recovery research, where support is such a frequently used term, we could not find research that systematically explored the existential meanings of support. There seemed to be a void in research asking, what is support as a genuine human experience, what is it like to experience support, or what qualities need to be present to make support supportive?

Based on the research literature and this seemingly unexplored area, a study was conducted, with the following overarching research question: *What are the lived experiences of support in the lives of young persons with mental health problems who are wholly or partly out of school and work?*

The purpose of the study was to contribute to a more nuanced, thoughtful, and in-depth understanding of support as lived experience. The aim was to increase the potential of supportive services to indeed be experienced as support by the young people.

Fourteen participants were included in the study: nine females and five males between the age of 18 and 25. They all had experiences with mental health problems (diagnosed or self-reported), experiences with being out of school or work, and experiences receiving services for their challenges. They were recruited through an interdisciplinary service in a small municipality in South- Eastern Norway.

Individual in-depth interviews were conducted, two interviews with each of the participants, totaling 28 interviews.

### Findings

The findings are nuanced and multifaceted, and can be organized into two main areas:

(1) *support as a subjective experience* and (2) *support as extended lived space*.

#### Support as a subjective experience

Participants described support as personally experienced. Support is only support when it is experienced as support, regardless of guidelines, systems, services, models, programs, initiatives, and professionals who intend to be supportive. Rather than support being something that can be guaranteed, we can say that the situation has a potential for support and that support is a possibility. The participants described situations that had a clear intention of being supportive but were not experienced as supportive.

Feeling alienated and not recognized as oneself by the other seemed to be an obstacle to experiencing support. Likewise, it can be offensive and alienating to be defined by others through standardized descriptions. The experience of alienation seemed to arise through a feeling of an absence of presence. The participants described situations when the person giving support was not truly present to them, despite being in the same room. They were listened to, but not really understood. The absence of presence can be so painful that one protects oneself by mentally leaving the situation.

Feeling seen and understood, feeling that the other is sincerely interested and really cares, was emphasized as inextricably linked to experiencing support. Thus, support as a subjective experience takes place and is practiced in relationships. It seems that some relationships have some qualities that are more supportive than others. Support is shown primarily in relationships that are nourishing, caring and authentic and that invite the young person into active involvement and cooperation.

A key aspect of experienced support is that support is experienced in diverse contexts, both in informal and formal relationships and all the complex contexts a human being is part of. Experienced support cannot be detached from everyday life and context of the young person. When those who offer support do not include the young person's context, there is a risk that the intended support is not experienced as supportive.

#### Support as extended lived space

The second main finding was support as extended lived space. Lived space is understood as room to maneuver; the space in which we can move and act, as free and responsible human beings. In experienced support, there is a sense that the lived space is expanding and gives direction and hope for a good life with future perspectives. It stands in contrast to a feeling of being stuck, without the possibility of movement, and is related to having a direction for life and the future.

Experienced support had the potential to set young persons in motion and to open and expand the

otherwise narrow personal and interpersonal space with opportunities to be who they want to be and to move towards a desired future.

A friendly push by a person who cares was sometimes what helped young people in this study to get out of situations in which they felt stuck. Support that is experienced as supportive diminishes or eliminates the hopelessness that many of the young participants experienced in a situation that felt stuck and despairing. The experience of extended lived space, which sets the lives of young people in motion and offers hope for the future, seems to be inseparably linked to the lived experience of support.

### Concluding remarks

The study's findings document that support, as a phenomenon, is personally experienced and associated with an experience of extended lived space.

The findings question the increasing confidence expressed that outcome measurements give us the solution to what works at both the population level and the individual level. Standardization and model fidelity may be good for certain purposes, but it can also lead us to believe that we know what support is. And, moreover, the belief in evidence-based models may exclude young people who do not benefit from the standardized treatment they are offered. One consequence of this is the thinking that when the support does not yield the desired benefit and effect, it is the young person and not the approach or system which is at fault. This study's findings contribute to the understanding that perceived support is most likely to be realized in collaborative relationships where young persons are invited into joint exploration of what support is for them in the context of their everyday life (Sommer, 2019; Sundet et al., 2016). This encourages professionals and others who offer support to young people with mental health problems not to oversimplify by attributing the lack of desired program outcomes to the absence of the young person's motivation or availability. One should instead consider some alternative ways for exploring, beyond pre-planned and standardized treatment pathways or measures and, together with young persons, focus on their own experiences of what support is or can be for them.

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### **Adolescents and mental health services: the challenge of establishing a working and lasting relationship**

In Italy, in the last 10 years, the number of users in care of Child and Adolescent Neuropsychiatry Services (NPIA) has doubled. In no other area of medicine or adolescence social and welfare services there has been such a significant increase in accessing services, without increasing the staff and without being able to guarantee appropriate responses to users.

Even before the pandemic, 200 out of 1000 Italian children and young people had mental health problems that affected them in social, psychological, and functional domains. Of those 60 children and young people, only 60 were able to access Child and Adolescent Neuropsychiatry Services and only 30 had appropriate therapeutic-rehabilitative responses. Of the total number of children and young people who had mental health problems, only 0.7% accessed the emergency room for a psychiatric disorder, 0.5% were hospitalized for a neurological or psychiatric disorder, only 20% were hospitalized in an NPIA ward, translating to 80% hospitalized in inappropriate wards, of which, in the case of the latter, 25% ended up in adult psychiatric wards. Between 2017 and 2018 (the latest data available), hospitalizations for psychiatric disorders increased by 22%. Of the 43,863 hospitalizations in 2019, only 13,757 occurred in the NPIA ward and therefore received the assistance they needed. Many adolescents in severe need did not receive any response and were discharged from the Emergency Room, and other had to turn to private services. For many others, hospitalization has become unavoidable where symptoms worsen, which is as a result of the lack of the adequate intensity of care in the community.

Such a dire situation requires increased efforts by mental health services for adolescents by supplementing resources and developing professional skills. With regards to the latter point, particular attention should be paid to how to “hook” and “retain” adolescents with psychiatric disorders in therapeutic relationships.

### **Factors of disengagement of adolescents**

In the past decades, the number of adolescents with mental health problems that need integrated, multidimensional and interprofessional treatment has increased dramatically. There is an ever-greater need of going beyond services that work each on their own (failure of parallel model as well as sequential model) toward an approach in which the medical, social and welfare services work together with the aim of providing a comprehensive array of service to young people aged 14 to 25, using an Assertive Outreach Model. In this context, the core is the person and their treatment plan and not services or professionals. Different competencies are involved based on the different needs of people, and not because practitioners belong to a specific unit or service. This model implies building an interprofessional team, constituted of Childhood and Adolescence Services, Social and Welfare Services. If, in addition, the parents have mental health problems, Adult Mental Health Services are also included. The model implies periodical meetings between all practitioners involved with the aim to review the treatment plan.

Using a normalizing framework is the most appropriate way to help the young person and their family understand and come to terms with their mental health problems. This approach also promotes an expectation that young people can lead ordinary lives within their communities. Other agencies involved in the multidisciplinary treatment approach for adolescents are the judiciary, the pediatrician, the general practitioner, as well as teachers, to avoid as much as possible interruption to the study path of the adolescent.

One of the first complications, that may appear, in the process of trying to find ways of engaging adolescents and their parents, is a gradual emergence of negative feelings toward the appropriateness of the treatment, the therapeutic relationship, and the requests requirements posed by the treatment itself. Initially full of hope, some adolescents and their parents begin to experience negative feelings, such as disappointments and criticisms, about the treatment itself. Parents may also disengage from the treatment because of negative feelings about its adequacy. The attitude of the therapist, such as silence and the absence of reactions, may be perceived as acts of hostility, lack of interest, or even rejection, and produce negative feelings towards the clinician.

However, it can be difficult to find ways to help adolescents with mental health and social problems for a variety of reasons. One of the main challenges can be that they do not always reveal their negative feelings toward their therapist, giving a false impression that everything is going well. As a result, the will to disengage sometimes remains obscured to clinicians. The third source of emotional activation may be a growing aversion to treatment requests, such as having to maintain a regular frequency of sessions or talking about painful topics.

The activation of feelings that are hard to bear, like guilt, anger, frustration, shame, sense of inadequacy, fear to be labeled with a psychiatric diagnosis, hopelessness, and helplessness may give way to behaviors, that are indicators of disengagement: irregular presence, treatment becoming more a formality than a real commitment, self-treatment, and concealment of information (i.e. changing the dosage of drugs, dealing with difficulties with friends, instead of the therapist, completely hiding a problem) and refusal of help.

### **Factors that promote the engagement of adolescents: skills and attitudes of the staff**

Adolescents seem to appreciate and value a friendly and welcoming attitude, tailored to young people's situations, and motivation of providers, that should have the following characteristics (Ambresin et al., 2013; WHO, 2002): motivated, honest, passionate, enthusiastic, offering support, relating easily, being respectful, having an evolutionary approach and learning about the multiple changes in the lives of adolescents, providing information to adolescents, so that they can choose freely and informedly, believing that teenagers have a promising future and transferring this belief to them, being sensitive to hierarchical differences, avoiding an "us versus them" attitude and not treating adolescents in a disqualifying way.

### **Motivational strategies**

#### *Shared decision-making*

As stated in the United Nations Convention on the Rights of the Child (UNCRC) (1989), adolescents have the right to take part in all decisions that affect them. Therefore, practitioners must learn to involve adolescents in defining therapeutic goals and choosing suitable interventions. Unfortunately, it is not always possible to reach a common agreement. A typical example is when hospitalization is inevitable for safety reasons and the adolescent does not agree.

It is very important to remember that children and adolescents have the same general human rights as adults as well as specific rights that recognize their special needs. Children are neither the property of their parents nor are they helpless objects of charity. They are human beings and are the subject of their own rights. The UNCRC (1989) sets out the rights that must be realized for children to develop to their full potential and offers a vision of the child as an individual and as a member of a family and community, with rights and

responsibilities appropriate to his or her age and stage of development. By recognizing children's rights in this way, the Convention firmly sets the focus on the whole child and affirms the fundamental human dignity of all children and the urgency of ensuring their well-being and development. It makes clear the idea that a basic quality of life should be the right of all children, rather than a privilege enjoyed by a few. The UNCRC (1989) comprises four main pillars - the right to survival, the right to protection, the right to development and the right to participation. These rights are based on the non-discrimination principle and all actions must be in line with the best interest of children.

### **Parental involvement**

Parents are usually key partners for young people. Providers should inform and engage parents as soon and as often as possible. At the beginning of therapy, this is one of the first issues to discuss with adolescents. The goal is to achieve a good balance between respecting the privacy of adolescents and involving the family. In fact, family members – especially parents – who live with a teenager with mental health disorders often experience problems (Vermeulen, et al., 2015). Sometimes there are dysfunctional relationships in the family environment. Therefore, supporting the adolescent's family is crucial, even when the adolescent does not want to involve the parents. The review by Kaslow, et al. (2012) offers a review of family-level prevention programs, psychotherapies, and effective psycho-educational interventions. Research confirms that it is needed to involve the family (Young & Fristad, 2015).

### **Organizational factors influencing the engagement of adolescents**

Services more congenial to young people are those that reduce barriers to adolescents' access to appropriate services, convenient opening hours, access without parental permission, low-cost or free services, reduced waiting times, convenient location near public transport stops, availability of e-health tools, pleasant and welcoming environments, discreet entrances, and a positive image.

The transition from mental health services (SSM) for adolescents to those for adults  
Some adolescents may need to continue their care in adult mental health services because the journey of living with mental health problems may last for many years. In this transition phase, young people and their families may feel lost, because the quality of care may be poor (Singh et al., 2010). The main obstacles that disrupt a smooth transition are system fragmentation, lack of leadership, poor communication, lack of common transfer protocols, and lack of information about services. The transition may also fail because adolescents often refuse to be transferred to services for adults. The interruption of care in the transition phase has a negative impact on the mental health and well-being of adolescents and therefore represents an important issue that needs to be addressed.

The TRACK study (Singh et al., 2010) offers some recommendations, aimed at improving care in the transition phase. Firstly, adolescents must be supported in the context of leaving their therapists in adolescents' services and being introduced to professionals in adults' services. Secondly, an adolescent should enter adult mental health services when their psychological situation is stable. Thirdly, adolescent and adult services must work closely together and adult services must be actively involved before adolescent services sign off on patients. Finally, services must be able to easily transfer users' data from one service to another. The collaborative practices between the person, family, and professionals, in ways of understanding the problems and situation and how to be helpful and supportive, often differ radically between adult services and adolescent services. So, it is very important to give the family clear information on the organization of the adult service, so that the families may have a good understanding of how the new service will work, in collaboration with the person and their relatives.

The criteria to evaluate the steps in this transition is the evidence of continuity of care, the number of transfer planning meetings, and the frequency of transfer of information.

### Continuity, integration, and coordination of care

Continuity of care is defined as the quality of care over time (Gulliford, et al., 2006). It includes both longitudinal continuity (uninterrupted series of long-term contacts) and transversal continuity (coherency of interventions between different service providers) (Thornicroft & Tansella, 1999). Young people have multiple needs (developmental, medical, social, and educational) and require a series of services, provided by different workprovidersers, who often work in different services. This organizational model, founded on teambuilding and teamwork, has several advantages: it reduces fragmentation and overlapping of the interventions; it is a response to the need for multidimensional and inter-professional integrated treatments; it facilitates communication processes and promotes network work; it enhances the specific knowledge and skills of the practitioners; it allows for more easily identifying the most appropriate and effective type of intervention in shorter times and with a lower expenditure of energy; it stresses the interaction between social and biological factors in health promotion; it recommends the need to work in close cooperation between all social and health agencies; it enhances shared knowledge with other disciplines and the skills of users, carers and the whole community; and, lastly, it does not burden the patient and his family members to seek the most appropriate treatment or to have to link two or more services or professionals.

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