

The Community Unit for Dual Diagnosis

Beit Issie Shapiro and Schneider Children's Medical Center of Israel

People with Intellectual Developmental Disabilities and Mental Disorders

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Beit Issie Shapiro (BIS) is Israel's leading non-profit organization furthering rights, opportunities and services for people with disabilities in all sectors of society, with an impact on some 500,000 people annually. It promotes social change though a three-pronged approach: development and provision of cutting edge services, changing attitudes in society and advocating for better legislation, and sharing knowledge throughout Israel, as well as internationally, through research, consultation and training.

As a 37-year-old social start-up in the field of disabilities, BIS's expertise is in scaling up its impactful solutions - developed, researched and validated on-site - enabling the organization to promote systemic change in the quality of life of people with disabilities in Israel and overseas.

BIS has had Special Consultative Status with the UN's Economic and Social Council (ECOSOC) since 2012.

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Background to the establishment of the Dual Diagnosis Unit

People with intellectual developmental disabilities are entitled, like everyone else, to receive all the services they need in the community, including mental health services.

In 1998 Israel's Knesset enacted the Equal Opportunities for People with Disabilities Act. The law is based on fundamental principles of equality and human dignity for all. "The rights of people with disabilities and the obligation of Israeli society toward these rights are founded upon recognition of the principle of equality, on man's worth - created in God's image - and on the principle of respect for all human beings." The law anchors the right of every person with disabilities to equal participation in community life. The concept of equal participation relates, among other things, to the right of people with disabilities to receive all the services they need in the community framework, appropriate to their special needs, in privacy and with respect, and in a manner that assures them opportunities for realization of their capabilities. The Equal Opportunities for People with Disabilities Act makes society responsible for finding ways to enable all people with disabilities to integrate in the community, and adapting the environment and the services to their needs.

In 2012 the State of Israel ratified the International Convention on the Rights of People with Disabilities. Article 3, which deals with the principles of the convention, sets out, among other things, the following three principles: Respect for difference and acceptance of persons with disabilities as part of human diversity and humanity (sub-article 4); Equality of opportunity (sub-article 5); and Accessibility (sub-article 6). These principles, which are in line with the approach of the Equal Opportunities Act, require the state to make determined efforts to implement them.

The increasing trend of care within the community and inclusion in society in Israel and around the world demands the development and adaptation of all the services provided in the community for people with various disabilities, including mental health services for people with intellectual disabilities. The mental health system is committed today to investing the necessary resources in making its services accessible and appropriate to this special population.

In 2006, in light of appeals by families and professionals complaining of great distress and the lack of appropriate response, Beit Issie Shapiro decided to take steps to promote an accessible response in the community adapted to this population, and to establish a unique service as a model for optimal services for people with Dual Diagnosis – intellectual disability and psychiatric / mental problems. In the first stage, we established professional contacts with people in Canada, Britain, and the United States providing services in this field. In the second stage, we raised funds to develop an appropriate model in Israel. Together with the Department of Psychological Medicine at Schneider Children's Medical Center, we set up the first ambulatory service of its kind in Israel – a community unit specializing in treating people with Dual Diagnosis. The unit has a multidisciplinary staff, and provides diagnostic and therapeutic services and guidance for people with disabilities, their families, and the people treating them in their everyday lives.

The unit, inaugurated in 2009 and funded by donations, acquired knowledge and expertise in the field and designed a working model that is unique in the make-up of its staff and in its work

processes. In July 2015, the unit was recognized by the Ministry of Health as a specialist medical service.

What is Dual Diagnosis?

People with intellectual disabilities are at increased risk of health problems in general, in particular in the area of mental health.

Dual Diagnosis is a complex concept that is interpreted in different ways around the world; in general, it always relates to a combination of two types of disability, with the disabilities included under this heading varying from place to place. In Israel, Dual Diagnosis relates to a combination of intellectual developmental disability (IDD) and psychiatric disorder. When intellectual disabilities and severe psychiatric disorders appear together, this has a critical and negative impact on the people themselves, their families, therapists, friends, and service providers.

The disorder may be manifested in a wide range of difficulties with adaptive functioning, the most noticeable of them being: aggressive behavior, verbal and physical violence, withdrawal as a result of depression, eating disorders – mainly not eating, severe difficulty with basic everyday functioning, and poor reality testing.

Psychiatric and mental disorders are more common among people with intellectual disabilities than in the general population (Schalock R.L., Buntinkx W., Brothwick-Duffy S., Luckasson R., Snell M., Tasse M.J., Wehmeyer M. 2007).

Dykens (2000) presents a number of studies that have found that relative to their peers, children and adolescents with intellectual deficiencies are at higher risk of psychopathology. These children have a broad spectrum of problems, including psychiatric problems (such as psychosis or depression), faulty behavior (such as attention disorder or hyperactivity), adaptive difficulties (such as anxiety or impulsiveness), and in addition, symptoms such as self-harm.

Because of the paucity of research into the subject, the scale of the phenomenon is not known for certain; Werner S., Stawski M., Polakiewicz Y. & Levav I. (2013) found that people with IDD have double the risk of psychiatric illness compared with the regular population, and Bernard & Turk (2009) found that around one third of children and adolescents with slight intellectual disability or reduced cognitive ability also suffer from mental health problems.

The most common explanation for mental disorders among people with intellectual disabilities is based on two types of factor – those relating to the brain damage of people with IDD, and those relating to the range of emotional implications of being a person with IDD (Day & Dosen, 2002).

- The organic brain damage related to IDD indicates a damaged neurological infrastructure.
 This damage can be the basis for mental disorders.
- 2. IDD is often accompanied by motor and sensor disabilities, and communication problems. These problems can lead to psychiatric disorder.
- 3. The beginning of life of a person with IDD is undoubtedly accompanied by a family crisis that relates to coping with the diagnosis of a child with disabilities. In light of the importance of the first years of life in a person's emotional development, there is no doubt that this family crisis can have significant implications for the person's mental structure.

- 4. In the absence of sufficient cognitive tools, some people have difficulty coping with everyday pressures and understanding what is happening around them, a situation that creates stress, anxiety, and distress.
- 5. People with IDD are unfortunately more exposed to harm by carers and other entities. This harm in itself can lead to mental disorder.
- 6. The psychological impact of being different (particularly common among teenagers and young adults with slight intellectual disability).

In practice, when a person has a dual diagnosis it is difficult to determine one single factor behind the mental disorder. For the most part, it is the result of a number of factors that all contribute, one way or another, to creating the problem.

The need to make mental health services accessible and adapt them for people with Dual Diagnosis

Around 30,000 people with intellectual developmental disabilities live in Israel, and as noted above, this population is very vulnerable to mental illness. The mental health services existing today lack knowledge in the field of intellectual disability, and have never developed working models adapted to people with "Dual Diagnosis". Accordingly, today they are unable to provide these people, their families, and professionals in the community with fitting responses to improve their personal and social functioning.

In March 2007, Israel signed the United Nations Convention on the Rights of People with Disabilities, and in 2012 the convention was ratified in the Knesset. This convention defines the vision, and sets out international standards for the civil and social rights to which all people with disabilities are entitled. First and foremost, the convention anchors the general right to non-discrimination, accompanied by the active obligation of its signatories to promote equal opportunities for people with disabilities in all areas of life.

Treatment of mental illness among people with disabilities is a significant tool for enabling them to realize their hidden potential and live a full life.

Specialist therapeutic units in this field are important for a number of reasons:

- a. In the absence of fitting knowledge and treatment, some people with Dual Diagnosis receive inappropriate drug treatment.
- Sometimes treatment that has not been adapted can lead to extreme situations in which an individual may become a danger to himself or others.
- c. Because of the difficulty in coping with behavioral problems among this population, and in the absence of suitable treatment, patients become more vulnerable to neglect and abuse.
- d. Families raising a child or adult with Dual Diagnosis need an address that can provide them with support, advice, and accompaniment in coping with the behaviors and sensitive situations arising from the person's special condition.
- e. Professionals in the community who serve as the main and/or secondary carer of a child or person with Dual Diagnosis are also left in a state of distress, because they lack an advisory and therapeutic address to turn to for help.

All these have led us, in collaboration with the Department of Psychological Medicine at Schneider Children's Medical Center, to develop an ambulatory community unit specializing in treating people with Dual Diagnosis, with a multidisciplinary staff, providing diagnostic and therapeutic services and guidance for people with disabilities, their families, and the people treating them in their everyday lives.

The Community Unit for Dual Diagnosis at Beit Issie Shapiro, in collaboration with Schneider Children's Medical Center

The vision of the unit

All people with intellectual disabilities and psychiatric or mental problems will have access to adapted diagnostic and treatment services at the highest standard.

The Dual Diagnosis Unit at Beit Issie Shapiro, operated in partnership with Schneider Children's Medical Center, will be a model for countrywide distribution of accessible, adapted and superior community service for children and adults with Dual Diagnosis.

Areas of activity

- Developing a service in the community adapted to people with Dual Diagnosis
- Developing and disseminating knowledge with a multidisciplinary and multi-professional view, among decision-makers and service providers
- Changing policy with a view to recognizing these units as part of the basket of services in the field of mental health
- Promoting the establishment of additional community units for Dual Diagnosis in Israel

The objectives of the unit

Main objective

Improving the quality of life of people with Dual Diagnosis and their families, with the aim of maximizing their inclusion in all areas of life.

Objectives

Service

- Providing diagnostic, support, treatment, and guidance services in different spheres (medicinal, behavioral, emotional, and family), appropriate to the needs of children and adults with Dual Diagnosis
- Building the capacity of families and professionals taking care of people with Dual
 Diagnosis in their everyday lives. Capacity building is a process by which family members
 and professionals (from the public, private, and social sector) caring for people with
 mental disabilities acquire knowledge, skills, and tools with which to cope better with
 different situations (Linnel, 2003)
- Increasing the involvement of elements in the community in the process: psychiatrists, family practitioners, social workers.

Dissemination of knowledge

- Documenting the knowledge developed in the Dual Diagnosis Unit and translating it into a working model
- Planning and holding seminars and training sessions for professionals and families
- Establishing and operating a countrywide information and knowledge center on the subject

- Periodic meetings intended for developing a model, work processes, and tools for future dissemination
- Knowledge research and dissemination (articles, conferences, training sessions)

Policy

- Working with government ministries and health funds to achieve recognition of the importance of an accessible and adapted mental health service specializing in treating people with Dual Diagnosis
- Professional accompaniment of the establishment and operation of additional community units for treating people with Dual Diagnosis in different parts of the country.

Working principles

The Dual Diagnosis Unit has a number of guiding working principles:

- System-wide view because of the complexity of the population of people with Dual Diagnosis, it is not sufficient to relate only to the patients themselves, and it is also necessary to look at the circles of their life: family, educational / sheltered occupation staff, housing frameworks, therapeutic and medical entities, welfare entities, and any other relevant entity.
- Partnership with the family and entities in the community following on from the
 system-wide view, there is a partnership among all the relevant entities in the
 treatment itself. This partnership will be manifested at all stages of intervention, from
 intake and Diagnosis, through the treatment stage, until the case is closed with
 recommendations for the future.
- Working with a multi-professional team Dual Diagnosis, by its very definition, relates
 to at least two professional disciplines mental health and developmental disabilities. It
 is therefore necessary to have a multi-professional view by the two disciplines, in which
 each staff member contributes the unique viewpoint of his or her area of expertise. The
 staff works and learns together in order to create an integrated picture of the person
 and his or her needs.
- Short-term intervention and long-term recommendations because of the characteristics of the population, the starting assumption is that it is not possible to change the nature of the problem, but rather the way of dealing with it. Therefore, intervention in the unit is for a short period of time, aimed at assessing the person's function, providing a focused and time-limited intervention, and forming recommendations for the long-term aimed at returning treatment to the entities treating the person in the community.
- <u>The capacity building approach</u> further to the explanation given above, building the capacity of the entities treating the person increases the ability to cope with the complexity of Dual Diagnosis within that person's life support systems.
- <u>Learning organization</u> the team work is carried out according to Peter Senge's principles of the learning organization (1991):

- Learning from cases at staff meetings, and generalizing the knowledge for additional cases
- Study and enrichment meetings held every 6 to 8 weeks with the aim of enriching the theoretical knowledge of the staff
- Visits and consultations with experts from abroad
- Personal training by external experts
- o Contact with other units in the country involved in treating this population

The target population – the service recipients

The community diagnostic unit provides diagnostic and treatment services for children and adults with intellectual developmental disability who also have a psychiatric disorder. The service recipients meet the following criteria:

1. Children and adults with intellectual developmental disability

- A person diagnosed with intellectual disability or where there is a suspicion of intellectual disability
- A child learning in a special education framework for children with intellectual disabilities, or learning in a small class in a regular school

2. Significant behavioral difficulties and/or emotional distress

For example:

- Violent behavior (towards themselves or others)
- Sleep problems
- Anxiety
- Withdrawal and introversion

(In cases where there is a doubt or question with regard to meeting these criteria, a consultation is held between the director, the psychiatrist and the social worker of the unit, in order to determine whether to accept the person for treatment.)

The unit staff

The staff numbers six permanent positions:

- Psychiatrist
- 2. Social worker
- 3. Psychologist
- 4. Behavioral analyst
- 5. Occupational therapist
- 6. Unit director

(Additional professionals, such as a speech therapist, may be involved as necessary.)

The trans-disciplinary teamwork approach

The trans-disciplinary approach involves all members of the team contributing their professional knowledge, learning from the professional knowledge of their colleagues, and together obtaining a broader and more complex picture of the explanation of the individual's situation. This explanation makes it possible to build an optimal, comprehensive treatment and intervention program.

Stages of the treatment process in the unit

Evaluation stage	Receiving an enquiry and initial screening
	2. <u>Intake</u> Meetings and collecting information, explanation to the family
	Meeting of the therapeutic staff Presenting the intake and determining the process of multi- disciplinary evaluation
	Multi-professional evaluation meeting Evaluation meeting with the patient, family, and unit staff
	5. <u>Observation</u> Observation in the patient's natural environment
	6. <u>Therapeutic staff meeting</u> Summary of the evaluation process and recommendations on the basis of the information collected
	7. Presentation of the evaluation findings and recommendations Two staff members present the family with the conclusions from the process, and recommendations for the future – intervention or closing the file
Intervention stage	8. <u>Implementation of the intervention</u> With follow up and consultation in the multi-professional staff
	9. <u>Summing up the process</u> Summary of the intervention process and evaluation of the results, presentation of the intervention and its results, and recommendations for the future, closing the file and summing up in writing

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