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SUPPORTED LIVING AS A WAY OF SOCIAL INCLUSION OF DEAF-BLIND ADULT PERSONS

Abstract. The article deals with supported living as one of the modern perspective ways of socialization and social inclusion of a deaf-blind person. The study presents the basic principles of organization of supported living, its history and the modern state (content, organization and provision). The article considers the necessary conditions for satisfaction of the basic living needs of a deaf-blind person. The author describes successful experience of organization and implementation of supported living of deaf-blind persons in soviet times in Russia on the example of Zagorsk children's home for deaf-blind children. Much attention is paid in the article to the consideration of the problem of psychological and socio-cultural preparation of the deaf-blind person for transition from living in the family to supported living in a community; it is stressed that the corresponding preparation and the timely transition to the conditions of supported living are imperative. Organization of supported living of adult deaf-blind persons is a wide-spread kind of social assistance in many European countries, USA and Australia, whereas in modern Russia, this form of support of persons with a double sensory disorder is still in its infancy. In order to illustrate modern successful organization of supported living, the article provides a description of organization of activity of the communities "Our Village" and "Country Yard" in the vicinity of Fischbeck, near Hannover (Germany). The study highlights the goals, tasks, content and methods of support and stresses their individual character with relation to each concrete deaf-blind person. The article describes the organization of functioning of the communities, presents socio-cultural and other opportunities granted to deaf-blind persons, and comments on such a character of organization of the life of the communities that allows deaf-blind persons to be included in the society, to communicate and interact with various representatives of social environment and to satisfy various living needs without suffering from loneliness. The author also presents the experience of the work of the city day care center for adult deaf-blind persons, its goals, tasks, and content of activities.

The article also dwells on the experience of organization of supported living of deaf-blind persons in New Moscow sponsored by the charity foundation “So-edineniye” — “Quiet Home”, and the experience of “So-edineniye” in the realization of numerous social projects targeted at inclusion of deaf-blind persons in active social and cultural life. The purpose of the article is to propagate the experience of organization of supported living of adult deaf-blind persons in Russia.

Keywords: supported living; deaf-blind persons; social inclusion; independence; social activity; day centers; organization of supported living.

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An adult deaf-blind person needs organization of supported living which can help them solve their educational, socio-cultural and life problems corresponding to the period of adulthood: job (or employment), housing, spare time, material, family and partner relations, etc. The nature and the severity of sensory disorders laying significant limitations on the capacity for life call forth the need to provide *supported living* to an adult deaf-blind person by the social security services. The given article deals with urgent and potential opportunities of social inclusion of an adult deaf-blind person on the basis of adequate organization of their living conditions.

The support service relies on the following principles in the provision of supported living for adult deaf-blind persons:

- respect for the personality of the deaf-blind person supported and promotion of their self-development and identification;
- protection of the social rights and freedoms of the person supported;
- normalization of the life and social environments of the deaf-blind person supported;
- formation and preservation of partner relations with the person supported which presuppose mutual agreement and trust;
- purposive nature of assistance aimed at achievement of maximum feasible self-help;
- facilitation: there must be support exactly enough not to make the person supported used to excessive help and not to render them helpless in this way;
- guarantee of privacy and autonomy of life for the person supported;

– respect for the inner vision of the outer everyday life formed by the deaf-blind person in accordance with their interests, tastes and attachments.

Achievement of social adulthood and feasible independence depends on the living conditions of the adult deaf-blind person and the character of support organized for them. The achievement of the cultural level by the adult deaf-blind person directly depends on the place and quality of their dwelling. Life conditions have both objective and subjective characteristics.

The objective, or outer conditions, according to foreign specialists, are the following.

First of all, it is adequate, own and preferably constant living space equipped and adapted for the life of a deaf-blind person, in which they would feel themselves at home organizing it in accordance with their tastes and needs. This living space and its content should be the sacred property of the deaf-blind person treated with respect by the surrounding people including the members of their family.

Supported living should satisfy all vital needs of the deaf-blind person: economic protection and the corresponding living standard, medical assistance and service, education, employment, social inclusion and social activity, satisfaction of creative, communicative and aesthetic needs and hobbies, and recre-

ation and physical health promotion needs.

It is essential to provide a possibility to spend spare time independently, to communicate, make friends, choose occupation according to one's interests, and to make conclusions about realization of personal far-reaching and everyday plans. Supported living also presupposes guarantee of further education encompassing all areas vitally and socially significant for a deaf-blind person. This means the provision of all individual and social opportunities for further development of an adult person, satisfaction of the needs and aspirations which would facilitate the development and self-realization of their personality: professional education or employment, equipment and maintenance of dwelling, spending spare time, partnership, communication, interests and hobbies, acquisition of self-provision and self-protection skills, and many other things.

Subjective or inner conditions, and specifically the feelings of well-being, stability, reliability, belonging to the social group significant for the person, and assurance of one's own identity seem to be especially important.

Supported living is still quite a new and rare phenomenon of special assistance for people with disabilities for our country. Foreign countries have a longer and richer experience in this field.

In Soviet times, considerable experience of organization of supported living of adult deaf-blind persons was accumulated while transferring the graduates of Zagorsk children's home for deaf-blind children to the place of work at the Industrial Practice Enterprise of the All-Russian Association of the Blind (IPE VOS) and organizing their accommodation at the IPE hostel. The deaf-blind young people got considerable independence in the organization of their everyday life, meals, apartment furnishing, and independent movement around the city (often aided by their partially sighted friends or IPE workers). A specially appointed tutor provided support for ten young deaf-blind persons. If the deaf-blind persons decided to get married, they were given a separate apartment in the hostel. The hostel was in constant communication both with city organizations and with all hostel apartments; both day and night duty of a social worker ready to come to one's aid and answer any urgent questions was organized in the hostel. Many everyday life problems were solved by the deaf-blind persons independently via mutual help, the formation of which was paid much attention to in the Zagorsk children's home. After moving to the hostel, the communication with the children's home was not terminated: the deaf-blind young people often and with pleasure visited their

former school, pupils and pedagogues, took part in events and holidays, and rendered voluntary help.

Nevertheless, far from all deaf-blind persons passed on to live in the hostel after finishing Zagorsk boarding school. If there was any chance to live in the family, the school leaver moved to live with the family and got a job either at the IPE VOS or used other employment opportunities. The life of a young deaf-blind person in the family incurred a number of problems for the family members (absence of specialized social support service, aging of family members, material problems, etc.). On losing working capacity or on the death of the family members capable of caring for an adult deaf-blind relative, if the family was not ready and unable to take care of a senior deaf-blind relative, the question of the disabled person's moving to a boarding house for adults with disabilities was inevitably raised. The social security character of these institutions and the organization of life on the principles of medical establishments limited to providing treatment and care, brought about fast degradation and aging of these people as a result of seclusion, absence of rehabilitation programs, educational and recreational aspects of everyday life, and opportunities for social inclusion of the boarding school inmates in the surrounding world.

As early as in the 70s and 80s of the 20th century, social-educational support structures for the families caring for persons with severe and multiple developmental disorders limiting or totally preventing employment were created abroad. Those were the so-called *day care centers* where the family could bring their adult child with a disability and take them back home at night after work. At such day care centers, young persons with sensory disorders (and, possibly, with other disorders) get meals, care, qualified help, and psycho-pedagogical support. It includes recommended rehabilitation classes, feasible labor, communication and social interaction, participation in recreation activities, physical exercises, satisfaction of creative needs, etc. These centers develop and improve communicative skills, expand the understanding of models and situations of social behavior, form behavioral norms of partner contacts between genders, widen the sphere of involvement in what is going on in real life – individual and social events, holidays, etc. The family and the close adults can be sure that their family member in need of supported living has a busy day and develops both personally and socially. Day care centers make it possible for the employed members of the family to return to their job, to be socially and personally needed, and to live a holistic life.

The problem of supported living of a deaf-blind person in the family is complex and ambivalent. It should be regarded and solved in the context of complexity of the whole life of the person and his family, as well as from the point of view of the change of educational tasks, socialization, and alteration of the individual needs and aspirations depending on the person's age. If in early and preschool childhood, the developing family environment and the closest adult relatives are more comfortable for the deaf-blind child, closer to the school age, the educational, developing and socializing environment of the education institution gradually takes the lead. The return to the family after finishing school sharply limits the already formed needs for constant social contact and communication with a wide range of acquaintances, friends and pedagogues. Limitations are also laid on the personal activity and independence; the socially significant stimuli deteriorate. Long life of the deaf-blind person in the family is associated with the inevitable aging of their parents and creates ever greater burden for them. The parents' death, especially if there are no other relatives ready to care for the deaf-blind person, will not only produce an unfavorable effect on their no longer young child but will make it absolutely inevitable for the deaf-blind adult to leave the par-

ents' house and move to the place where they can get assistance and support in everyday life.

At such moments, when the habitual course of life is suddenly disintegrated (statement of impossibility of getting further support in the family, progression of visual and/or auditory disorder, and realization of imminent deaf-blindness), it is utterly important to get a qualified consultation of the specialist who can help to find an acceptable way out of the critical situation. With this end in view, specialized counseling centers are created abroad (at public organizations or associations for the deaf and/or the blind, at education institutions for the deaf-blind, at rehabilitation centers and other organizations and institutions) the aim of which is to provide counseling for deaf-blind (or partially deaf-blind) adult persons in a difficult life situation using the whole range of opportunities (variants of further supported living: at home or moving to a community; provision of an assistant; taking a course of supported education – study of the means and methods of communication of deaf-blind persons, teaching mobility, use of computer technologies under the conditions of deaf-blindness, etc.).

Foreign specialists believe that if the family does not get supporting assistance from the mobile support services, it is most feasible to organize supported living of the adult

deaf-blind member of the family in groups and communities based on the principles of co-residence. In the community, each member is allotted permanent apartment furnished as they wish and can use it for life. All inmates are involved in the life of the community and in the activity of its social services. The community may be located in all kinds of places. It may be situated both in the city (for example, a specially equipped section of a large block of flats) and out of the city in the form of cottage settlement or village also equipped to meet the needs of deaf-blind persons. The organization of living is based on a rational combination of privacy and life autonomy of each person and their personal inclusion in the life of the community. Such organization of supported living of an adult deaf-blind person is not simply provision of dwelling. They find here such life conditions, under which they are protected, treated with respect, employed, engaged, and can live a holistic social and spiritual life. It is the world they live in; it is their second birthplace.

Preparation for such transition should be gradual. It should begin in school, but must take place not later than 23-25 years of age. It is necessary to handle the questions of moving the deaf-blind person from one place to another, because the suddenness of this event may become a cause of a deep psychologi-

cal trauma. It is good if several deaf-blind persons who know each other and are in friendly relations – for example, leavers of one and the same school – are moved to the community.

Foreign experience shows that such communities should not be large: the workers of small open institutions of community type are more often satisfied with their work than their colleagues in large boarding houses. And the community members also feel more comfortable and confident.

Today, organization of supported living of adult deaf-blind persons is a wide-spread kind of social assistance in many European countries, USA and Australia.

On the example of activity of one of such institutions – the Hanover Center for the Deaf-Blind – we will describe in detail the content and organization of supported living of adult deaf-blind persons with partial visual and auditory impairment in two communities: “Our Village” and “Country Yard”, organized in the vicinity of Fischbeck, near Hannover (Germany).

The communities are sponsored by the German Federation of the Blind and Partially Sighted and the Association of the Blind and Partially Sighted in Lower Saxony. “Our Village” was opened in 1990, and “Country Yard” – in 2011.

The main goal of activity of these institutions is to create a worthy

life full of meaning and satisfaction based on the realization of the individual abilities and skills for the community members.

The key tasks of the supported living in the communities include:

- overcoming of isolation caused by sensory disorders;
- assistance in the formation, development and support for communication systems;
- formation and support for social contacts;
- assistance in participation in the life of the local community on the basis of all-round help and support;
- acquisition of new knowledge and skills and development of abilities; activation and support for the aspirations to learn new things;
- formation and support for mobility and orientation skills;
- help with overcoming fears and uncertainty;
- medical support, counseling and treatment taking all necessary measures;
- creation of conditions revealing creative abilities and DIY skills; organization of useful and interesting kinds of activity in workshops, support groups or daily routine events.

The institutions organize their work around the principle of all-round support for the inmates under the conditions of safe and friendly atmosphere, personnel competence, trustful and hearty relations between the personnel and the com-

munity members, and unconditional recognition of the value of the personality of each individual.

The aims, tasks, content and methods of support for each patient are individual and correspond to their personal situation.

Both communities organize supported living for the total of 127 people – adult deaf-blind persons with considerable multiple impairment of vision and hearing (partially deaf-blind). They are subdivided into 17 groups with 7 places of accommodation and 2 groups with 4 places of accommodation in each. Each group occupies its own cottage and is provided with 24 hour support (by a team of 6-7 people). Each of the 19 groups has one-room flats for individual residence(or, if they wish, for co-residence), one bathroom for every two rooms, common living room, kitchen, sanitary facilities, terrace or balcony, utility room, and a room for the support team personnel. The personnel provide situational assistance and support for all kinds of activity and events, including assistance in spending spare time. They also help to establish contacts with families and outer organizations (for example, visiting a doctor, consulting a lawyer, etc.).

The support personnel includes specially trained assistants, social workers, typhlo-surdo-pedagogues, special psychologists and medical staff (doctors and qualified paramedical workers).

Workshops with 63 specially equipped work places are organized for the community members without significant working capacity limitations. These are 51 places for crafts and work in the hothouse and 12 work places for the persons with significant developmental disorders who are in need of enhanced support.

The community premises also have rooms for rehabilitation work, gyms for physical exercises, halls for holidays and staff in-service training (advanced training), swimming pool, internet café, health path (a path equipped for walks), bike track, stable and riding arena for therapeutic horseback riding, and aviaries for dogs and poultry. There is also a big kitchen and a laundry.

In the hothouse, the community members grow flower seedlings and flowers, and preference is given to fragrant plants. In the workshops, decorative objects and toys and souvenirs for Christmas, Easter and New Year holidays are made. The work in the workshops is differentiated according to the difficulty and the working capacity of those who take part in it. These can be the simplest operations in the form of sorting or putting things in boxes for those who need considerable support; work connected with assembling, carpentry or metalwork, making things from wood, clay, metal, plastic, plant or other materials – for low vision persons and

those with individual capability for such work.

The communities have their own shops attached to the workshops where they sell things they produce (seedlings and flowers, decorative objects, souvenirs). Deaf-blind persons act as shop assistants as well. The money gained is used for the community needs.

A wide range of rehabilitation classes that meet the needs of the inmates are conducted in the communities. They encompass work and occupational therapy, therapeutic horseback riding, canistherapy and interaction with domestic animals and poultry (hens), lessons on stimulation and development of communication, mobility trainings, everyday life and self-service skills training, basal stimulation, perception development based on safe analyzers, physical training and motor activity (including the swimming pool), music therapy, cooking, kinesiotherapy, massage, hydrotherapy, etc.

The community members are not deprived of the opportunity to take part in the religious life corresponding to their denomination.

More than 5 years ago, a day care center for the deaf-blind was opened and has been functioning ever since for people with multiple disorders of vision and hearing in Hannover near which the center for the deaf-blind is situated. It is visited by about 40 persons living in the

family outside the community. As a rule, they cannot work in the workshops due to age and character of disorder, and they often feel lonely at home. At the day care center, they get support and a chance to develop their everyday life and self service skills, and they find here their circle of communication and opportunities for interesting pastime. The stepping stone of all kinds of activity offered by the day care center is the chance to make those who attend it happy, and to feel pleased with their own activity and communication with a friendly environment. The center grants an opportunity of doing physical fitness and motor activity exercises, helps to reinforce and develop the skills of cooking, elements of creative activity (molding, pastry cooking, handcrafts, etc.), playing activity (for example, table games), organizes visits to a café or tea parties for the center patients with the pastry made by themselves, during which they gladly communicate with each other. The activity of such center is highly praised by those who attend it.

Thus, supported living of an adult deaf-blind person is not just provision of assistance in solving vital everyday life problems. It encompasses various methods of inclusion of such people in the surrounding social world and creation of conditions for holistic meaningful life not differing much from the

life of typical persons. This work is done not only by the state and the social services affiliated to it. In foreign countries, this work is carried out by charitable and public organizations and associations; a serious contribution is made by volunteers. It is they who raise funds for realization of the programs of inclusion of deaf-blind persons in social life. These programs are extremely different. They may take the form of a weekend summer camp where the participants can have various opportunities for communication and pleasant and interesting pastime, various kinds of recreation and entertainment: horseback riding, boating, car driving, bike riding, playing golf or darts, surfing, wall climbing, computer games, drawing or painting, active games, amateur theater performances, and many other things.

Charitable programs may presuppose package visits to a café or restaurant by a group of deaf-blind persons who know each other, where they can pick up and order the dishes by themselves and spend time over pleasant communication while eating.

An important area in the activity of public organizations and volunteers is dedicated to work on detection of deaf-blind persons in need of supported living, work with government structures aimed at improvement of legislation, financing and provision for the support for

adults with multiple sensory disorders with the view of creation of conditions facilitating early detection and early diagnostics of visual and auditory impairments in aging population beginning with 45 years of age.

In modern Russia, this form of support of persons with a double sensory disorder is still in its infancy. A series of initiatives of public organizations, firms and deaf-blind persons themselves which would change the life of a deaf-blind adult expanding the feasible spheres in the surrounding world are being implemented today.

In November 2016, a new officially adopted profession of typhlo-surdo-interpreter based on a state educational standard appeared in Russia. Surdo-interpreters now help deaf-blind people when they visit offices and institutions and assist in interpersonal communication. The typhlo-surdo-interpreter figures out the optimal route of travel with the deaf-blind person under support, proofreads the text of the typhlo-surdo-commentary, translates the oral, written and gesture speech of the surrounding people into tactile speech. All this expands the capacity of the deaf-blind person to establish and keep up social contacts – business, friendly, and the like, making their life busy and interesting, and turning them into independent self-sufficient persons. Such support allows deaf-blind per-

sons to conduct negotiations, manage their finance, visit shops, various personal and domestic services, medical and cultural institutions, and so on. Special training of guide dogs has begun, and the first experience of their application proves to be positive.

In order to expand the scope of communication of the deaf-blind with the surrounding people, the telecommunications operator Beeline together with the charity foundation "So-edineniye" opened a special mobile phone tariff for them. All deaf-blind persons who took part in the census and declared that they used mobile telecommunication services were sent a letter with a SIM card enclosed in it. The tariff provides 10 Gb of Internet traffic and 1000 SMS messages, thus satisfying the deaf-blind person's communication needs.

The charity foundation "So-edineniye" initiated work on establishing cooperation with trading companies in creation of accessible environment for deaf-blind persons at retail outlets.

Deaf-blind persons, just like all other people, can and like traveling. Public organizations and resource centers opened at the initiative and under support of the foundation "So-edineniye" organize tourist travels for the deaf-blind and summer camps for the families caring for children with visual and auditory disorders.

Involvement of deaf-blind persons in the cultural life and introduction to the cultural values play a big role in their social inclusion. And this is not limited to visiting museums and exhibitions. This means dance and drawing therapy, creation of a tactile and fragrant garden (Moscow) and its visits by blind, partially sighted and deaf-blind persons. The foundation "So-edineniye" possesses many initiatives in creation and realization of continuing cultural projects: master classes of world famous specialists of inclusive theater, functioning of inclusive theater school and theater performances at the Moscow Art Theatre Studio School, in which deaf-blind actors play alongside professional ones (performances "Touchable", "Marriage: An Absolutely Incredible Event", "Carmen", action-performance "Seagull: Fragments", sensory performance "The Tea Party in the Magical Wood" and others. These also include exhibitions of works by deaf-blind painters, celebration of the International Day of Deaf-Blind People (it is also a birthday of Helen Keller – June 27) in the museum interiors, and many other events.

The foundation "So-edineniye" develops and implements such socially useful activity popular with the deaf-blind people as a cooking holiday. Master classes, competitions of deaf-blind cooks, and folklore festivals including cooking

dishes of the Russian traditional cuisine are held. Some activities are held by resource centers; not infrequently, the participants are invited to take part in the corresponding TV shows. The common dinner that follows these events served with the dishes cooked by the deaf-blind persons themselves is a good opportunity for the deaf-blind participants to communicate between themselves and with other people.

As it was mentioned above, in 2016, the foundation “So-edine-niye” sponsored the opening of the boarding house “Quiet Home” in New Moscow for supported living of adult deaf-blind persons. It is the first institution in Russia for supported co-residence of deaf-blind people. The dwellers of the “Quiet Home” have a typhlo-surdo-interpreter at their service and try to live an independent life. They can earn their living, plan their budget, and pay their expenses for meals, household services and cultural leisure activities. They do many chores independently, for example, clean the house, cook, gather fruit and vegetables, look after seedlings, read, play chess, work with computer, knit socks, and walk outside with the aid of sensory cues. Before holidays, the dwellers of the “Quiet Home” are busy making Christmas and New Year gifts. On Sundays, they visit the local church. Excursions and visits to medical specialists are organized for them.

Other Russian cities have experience of preparation of young people with developmental disorders for independent and self-sufficient life. For example, significant experience has been amassed in Vladimir, where the Vladimir public organization “Association of the Parents of Children with Disabilities ‘Svet’” initiated the creation of the so-called “learning (or training)” flats where young people with disabilities learn to be independent in living and self-serving under the conditions of home environment.

With each year, these initiatives involve more and more regions of Russia helping deaf-blind persons to live a maximum independent and holistic life.

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