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Occupational Therapy and Intellectual and Developmental Disability Throughout the Life Cycle: Position Paper

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# **Occupational Therapy and Intellectual and Developmental Disability Throughout the Life Cycle:**

## **Position Paper**<sup>1</sup>

Yalon-Chamovitz, S., Selanikyo, E., Artzi, N., Prigal, Y., and Fishman, R.<sup>2</sup>

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Occupational therapy is an educational and practice-oriented health profession concerned with rehabilitation. The main role of occupational therapists is to promote individual's participation in self-defined significant occupations, thus enabling meaningful participation in the tapestry of life. Occupations enable people to participate in various contexts to enhance health, well-being and quality of life.

The academic training process for occupational therapy incorporates knowledge from occupational, medical, social and behavioral sciences. This training includes attaining expertise in a variety of assessment, evaluation and treatment methods in the different areas of human function. One of the areas of specialization in occupational therapy is the area of intellectual and developmental disability (previously referred to as "mental retardation").

Intellectual and developmental disability is defined by significant limitations in intellectual function and adaptive behavior as expressed through perceptual, social and practical adaptive skills. These limitations appear before the age of 18 (Luckasson et al., 2002). A gradual change has occurred over the last few years, concurrent with the transition from the medical to the social model in health professions, in which the term 'mental retardation' has been replaced with the term 'intellectual and developmental disability'. Accordingly, classification of this disability has changed from defining the population according to levels of delay, to defining it according to the intensity of required supports. The assessment of mental retardation in Israel is legally entrusted to an evaluation and placement committee in the Ministry of Welfare and Social

<sup>1</sup> This position paper was written based on guidelines provided by the High Israeli Occupational Therapy Board and is partly based on previously published position papers in various areas

<sup>2</sup> This position paper was initiated by the Israeli Forum on Occupational Therapy for People with Intellectual Disabilities, and is partly based on forum discussions

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Affairs. The incidence of intellectual and developmental disability is estimated to be 2-3% of the overall population, dependent on the definition used (Ronen, 2005). Legally, each individual with an intellectual and developmental disability is entitled to occupational therapy services throughout his/her life (National Health Law, 1994; Special Education Law, 1988; Rehabilitation Day Centers Law, 2000).

The population of people with intellectual and developmental disabilities is diverse and complex. Throughout their life cycle, individuals with intellectual and developmental disabilities manifest varying levels of function with respect to skills of daily living, as well as varying cognitive, intellectual, social, physical, emotional and behavioral capabilities. The etiological factors leading to these disabilities include genetic, dietary and metabolic factors, infections and poisoning, traumatic brain injury during and following birth, as well as social and environmental factors (Ronen, 2005). The intellectual limitations experienced by these individuals frequently co-present with other limitations, such as cerebral palsy, pervasive developmental disorder (PDD) and autism, hearing and visual deficits, epilepsy and other physical or emotional deficits.

As the population of people with intellectual and developmental disabilities is heterogeneous and present a complex set of needs, a multidisciplinary staff is essential to the support system available to people "within this population". In a multidisciplinary team, each discipline contributes its unique knowledge. However, since the intervention process focuses to a large part on a functional-occupational perspective, occupational therapists have a significant role in treating this population.

## Occupational Therapy Evaluation and Intervention among Persons with Intellectual Disability

Client/family-centered practice represents the overall perspective that guides professional activity in occupational therapy. In accordance with this perspective, the evaluation and intervention processes are accomplished through dialogue, listening to and cooperating with the client, his/her family, and with other significant people in his/her environment. The unique contribution of occupational therapy to this population is in its ability to provide professional solutions to the functional limitations they experience as a result of the intellectual disability. These limitations may present in all human occupational areas such as activities of daily living, learning, work, play, leisure and social participation.

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## The Assessment Process

In occupational therapy, the assessment process provides the baseline for intervention and often focuses on identifying and defining an individual's priorities and the factors that enable or limit his/her occupational performance. The assessment process among people with intellectual disabilities is ongoing, and usually takes place in the client's natural environment (e.g. residential, educational, occupational or recreational facility). Bonding with the client is an integral part of the process, as is collecting routine information from family members and other professionals. In addition to the information gathered from these people, the assessment is also based on information derived through observation, questionnaires, and appropriate standardized and often dynamic evaluations. Observation plays a major part in the evaluation of this population, and is sometimes the primary way in which necessary information is obtained. This process is based upon observing actual performance in various occupational areas. As the occupational therapist observes the client's performance, the therapist attends primarily to aspects of performance skills, such as motor skills (position, stability or mobility), process skills (attention, initiative, choice or organization in time and space), and communications skills (establishing eye contact, cooperation or methods of expression that are utilized). Occupational performance analyses, together with the remainder of the assessment data collected, are used to determine the focal points of the intervention.

## The Intervention Process

Similar to the assessment process, occupational therapy intervention for people with intellectual disability is also an ongoing process that is both gradual and dynamic. Treatment is provided throughout the life cycle in accordance with the client's changing needs, desires and preferences in all areas of occupation. The intervention often requires repeated drills and practice to achieve internalization and learning, and performance in a variety of contexts to enable generalization. As is the case with respect to assessment, the intervention is preferably carried out in the client's various daily environments. This enables and encourages the client's participation in the many contexts of his/her life.

Occupational therapy interventions for people with intellectual disabilities are specifically adapted to the client with respect to the degree and type of support needed as well as the context. Interventions may include direct treatment as well as environmental adaptations, guidance, monitoring and counseling (including of the family, the educational staff, the clinical staff, employers and others).

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### **Examples of Occupational Therapy Intervention:**

**Activities of daily living:** including activities directed to the person's care of his/her bodily needs (ADL) such as personal hygiene, eating, dressing, and instrumental activities of daily life (IADL) such as preparing a meal or managing finances. This area represents a central focus of intervention in occupational therapy for this population. For example, with respect to activities related to eating, the intervention can range from adapting the feeding environment, choosing preferred food or bringing the food to one's mouth, to teaching more advanced skills such as organizing shopping, and meal preparation.

**Learning/Studies:** These are activities necessary to be a student and to participate in a learning environment, including academic and non-academic activities. Intervention in this area covers a variety of educational settings such as day care centers for very young children, kindergartens and special education schools (ages 3-21 years), regular school settings and professional training facilities. The intervention is varied and may focus on gaining basic learning-skills, such as understanding cause and effect processes and object permanence, or on more complicated skills, such as preparation for learning and writing, organization in time, in space and with accessories, adaptation to different learning environments, the use of information technologies and computers and gaining learning strategies. In addition, the intervention can include adapting various learning environments.

**Work:** These are productive activities, whether for remuneration or not, that include preparing for work, producing a product and providing services. Intervention in this area covers a variety of work settings including: special educational settings in which students receive training to enter the work force, youth rehabilitation centers, adult sheltered-work facilities, an array of protected supportive community work systems, and placement-services for gaining open market positions. Intervention varies and may include basic work skills training (behavior norms, work routines), developing and practicing basic cognitive abilities, practicing motor skills, exposure to varied work opportunities, support and advice for developing areas of interest, identifying abilities and choosing suitable occupations, analyzing occupations and adapting them as needed, as well as supporting and assisting placement in various work sights in the community.

**Play:** These are activities that are generally internally motivated and provide pleasure, entertainment and learning. Play-intervention, as an occupational therapy goal in this population, is directed towards the most basic experiencing of play as a source of pleasure, as well as providing the client with an opportunity to participate in play activities. The intervention includes

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drills in basic skills such as the use of equipment, recognizing rules and agreed-upon behavior patterns, or choosing suitable play activities. In addition, play represents a treatment method for learning and practicing a variety of social, motor and functional skills.

**Leisure:** These are non-obligatory activities that are internally motivated and are performed at times that are not devoted to work, studies, self-care or sleep. Research reveals that people within this population have a relatively large amount of time to devote to leisure, whereas their participation in leisure activities is minimal (Buttimer & Teirney, 2005). Therefore, coping with leisure within this population is a central topic. Intervention in this area may focus on exposure to varied leisure opportunities, identification and choice of areas of interest, planning leisure time and participation in activities that lead to a perception of capability, pleasure, control and satisfaction.

**Social participation:** These are activities related to agreed-upon behavior patterns expected of an individual within a given social system (e.g. community, family or with friends). The intervention within occupational therapy encourages the person to gain skills in the various areas of occupation and thus supports and strengthens social participation. For this population, an emphasis is placed upon understanding acceptable social norms and as well as learning and practicing activities that lead to satisfactory social interactions.

**Accessibility and Environmental Modification:** Occupational therapy practice relates to the person, the occupation and the environment. The occupational therapist's broad knowledge base in the areas of function and limitation enables him/her to identify, through performance analysis in the different areas of occupation, environments and/or tasks that should be modified. The various limitations that characterize the population of people with intellectual disabilities require both general and client-specific environmental modifications to ensure accessibility. The characteristic difficulty in problem-solving, initiative and coping with unfamiliar situations, amplifies the need for accessibility modifications for this population. These accessibility modifications include changes in the environment (as in widening passageways, modifying playgrounds or adding symbol signs), in the equipment (such as adapting seating systems or adapting feeding aids), or of the task (such as changing the complexity of instructions or dividing a task into sub-stages).

**Assistive technology** is one of the methods used to adapt the environment and includes modifications of hardware, software and various combinations thereof (such as a virtual keyboard, a touch screen, a motorized wheelchair, switch systems, computer programs and internet sites, adapted content amount, or voice output devices). Thus, for example, a switch can be modified to be activated through the person's head or hand. Other modifications of the switch may include size, color, texture, or sensitivity (such as speed or pressure-

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response). Assistive technology promotes a variety of functions related to the individual, the occupation and the environment. In addition, it allows for the modification of an individual's environment in the manner in which his/her requires, by relating to his personal abilities, wants, areas of interest and specific limitations and difficulties.

Environmental modification is likely to significantly improve a person's ability to participate in all areas of occupation, his or her level of independence and the degree of supports required.

In summary, the occupational therapist, as part of a therapeutic, rehabilitative and educational profession play a central role within the support system available to people with intellectual and developmental disabilities, throughout the life cycle. As such, occupational therapists hold key positions as leaders in this area. Working with people with intellectual and developmental disabilities requires consideration of function, independence and participation in the various areas of occupation, which enables the occupational therapist to utilize all the areas of knowledge and expertise included in the practice of occupational therapy.

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