

- **Name of the study:** Shared reality under threat: the experience of staff members and aging people with intellectual developmental disabilities in the days of Corona
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- **Type of research:** research
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- **Authors:** Prof. Jacob Bachner, Prof. Tova Band Winterstein and Dr. Alon Zamir.
- **Research Authority:** Minerva Center for the Study of Marginalized Populations in Old Age, University of Haifa.

## Abstract

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With the increase in the life expectancy of people with intellectual disabilities (developmental intellectual disabilities), the issue of their aging in out-of-home housing settings has received attention in recent years in research and practice. This issue has been little studied in the context of out-of-home housing settings in emergency periods. The purpose of this study is to describe and to analyze the shared experience of the residents and the staff in the out-of-home housing frameworks for aging people with ALS, while comparing the supportive housing and housing in the community. The importance of this type of research is that it makes it possible to add and deepen the existing knowledge about dealing with emergency situations in the context of aging people with dementia.

This qualitative study was conducted at the end of and after the Corona period (the fourth wave and the fifth wave and "return to normality"). As part of it, 16 people with (mild to moderate) aging living in out-of-home housing (8 from community housing and 8 from supportive housing) were interviewed in in-depth interviews, and 17 different care workers working in these out-of-home housing settings (9 from community housing and 8 from the supportive housing) - a total of 33 interviews.

The participants in the study were selected using a purposive sample that ensured representation of participants with maximum variation. That is, we interviewed men and women with MS and treatment staff from different groups in the Israeli-Jewish population: secular, religious, ultra-Orthodox. The data collection for the study was done through semi-structured in-depth interviews in accordance with an interview guide according to the phenomenological tradition (when the interview was cognitively accessible to people aging with MS) E. The research procedure was carried out according to the rules of ethics and with the approval of the Ethics Committee of the Faculty of Health and Welfare, Haifa University and the Ethics

Committee of the Ministry of Welfare and Social Services. All interviews were transcribed and analyzed in accordance with the rules of qualitative research.

The findings show that the shared reality under the "threat of the corona virus" of the aging residents with ALS and the care staff in out-of-home housing is based on three main dimensions that are interrelated: the treatment challenges arising from the disability; the early aging process of the people with ALS and the characteristics of the care setting (community housing compared to supportive housing). These dimensions in their encounter with the Corona, which is in terms of a new and unexpected player, created a new life reality in out-of-home housing - "life under threat". This unique life reality is structured through three themes that describe, organize and analyze the experience and its meaning.

The first theme, "Everything we knew was no longer relevant": the corona virus as a new player in the housing frameworks for aging people with ASD. The beginning of this theme is the presentation of daily life in the various housing frameworks on the chronological time sequence while drawing three key turning points (sub-themes): The outbreak of the Corona epidemic; a new routine of life under the threat of the Corona virus and a return to normality after the Corona virus. In continuation, this topic describes the daily reality of life during the Corona period in out-of-home housing in the context of two major issues: A. Comparison of the nature of the routine of life in housing during the Corona period between housing in the community and supportive housing and B. Maintaining contact with the families during the Corona period in out-of-home housing.

The second topic, "It was real human rights, their lives are in my hands": the organization of the staff that cares for out-of-home housing settings for aging people with special needs. The first part of this topic shows how the corona virus shaped the nature of the daily work of the staff that cares for the various housing settings. In the context of two major personal-professional challenges: a. The corona virus as requiring a change to a strict cleaning routine and b. The corona virus as requiring a reduction in contact with the "outside world". The second part of the theme deals with the crucial importance of the formation and mutual support between the members of the therapeutic staff in the various housing settings while examining the experience of team support in community housing compared to supportive housing.

The third theme, "I think we are much smarter. In retrospect, I would have done things differently...": insights from the corona as a case in point. This topic deals with the corona epidemic as a case study for emergency situations where a stay in a limited space is required in the context of a population at maximum risk. The first part of the theme focuses on the challenges of mediating the threatening reality of life for the aging residents with MHA. The second part of the theme is structured as a table summarizing the many highlights, suggestions and insights that came up in the interviews with the aging residents with MHA and the care staff

on how to deal with crisis events that require hours prolonged in the housing frameworks. The last part is structured as a "recommended practical guide for dealing with the emotional aspect of "emergency situations" that require a prolonged stay in housing for people with intellectual developmental disabilities".

The discussion chapter deals with a comparison between housing in the community and supportive housing for aging people with disabilities in dealing with threatening and emergency situations that require organization and change. The research findings show that the supportive housing frameworks have advantages in dealing with emergency situations over community housing. This comparison deals with: "Experience The time in the out-of-home housing framework during the Corona period: a comparison between community housing and supportive housing"; and "Cohesion and belonging of the staff and residents: a comparison between community housing and supportive housing". The second part was presented as a theoretical - critical discussion on the issue of the lack of access to emergency situations for aging people with "E in out-of-home housing.

The implications of the research for practice and policy point to the corona virus as a case in point that enriches the knowledge regarding dealing with emergency situations in the context of people with dementia in old age. This knowledge will make it possible to develop guidelines for practice and policy in frameworks for people with dementia regarding dealing with aging tenants, while referring to tenants, staff members and the interaction between them. The product of the research includes practical recommendations and an emergency preparation guide, which includes organizational tools that will help the various housing frameworks deal with emergency situations. This guide will be available to all those involved in the field online.

This guide will address the threat perception of the research population, paying attention to maintaining the emotional and physical quality of life of the residents and striving to meet their specific needs; At the same time, they will refer to the conduct of the staff members in exceptional conditions while motivating to maintain a balance between the personal and the professional.

## **Keywords**

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developmental intellectual disability, old age, corona, emergency situations, out-of-home housing, Deinstitutionalization, intersectionality.

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