

# Self Determination for Adults with Intellectual Disabilities

## Living in Residential Settings

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### Abstract

*Services for people with intellectual disability have brought people out of institutions and into the community. The purpose of this project is to assess progress made toward the good things of life as they enter a more normalized community. A sample of convenience allowed the project to observe staff and the people they serve. Do the settings of residential living and the relationships between staff and people served have an impact that is positive and self-determining? The qualitative coding revealed themes carried from institutionalization. Recommendations for community service improvement are developed with attention to meeting the most pressing needs of individuals served*

### Introduction

In the past 40 years, the shift for services provided to people with intellectual disabilities has moved from institutions to the community. Services like respite, residential housing, behavioral support, day programs, and supported employment were designed to help people with disabilities remain in the community and stay out of the institutions. But the quality of these services and programs can be very different and they are not federally legislated. Social Role Valorization is a response to conditions prevalent in institutions (Wolfensberger 2013). According to Kumar (2015) the blueprint for supporting people as they left institutions was created in 1969 based on the Principles of Normalization. Most statewide

regulations focus more on funding rather than program quality. People with intellectual disability often spend their lives in well-funded and poorly operated services. (Friedman, 2021). The major factor that is impacting the lives of people with disabilities is the type of support available (Reid et al., 2001). This research project focuses on residential service quality of care and the impact on individual self-determination for people with intellectual disability.

### Method

Convenience sampling was used in two residential group homes. Seven participants receiving support from a local agency were chosen as a sampling of

convenience. Direct observation for two weeks, without intervention, produced the project data. Participants were observed while receiving direct care and support. In addition to observation, six participants engaged in the Self-Determination Inventory (SDI) (Hagiwara et al., 2021). Observations were documented and open coding produced themes.

## **Results**

The results indicated that a significant level of support and services were received. Emerging themes suggest the services and supports received were often determined by staff more than the person being supported. People who are self-determined know what they want and how to get what they want (Shogren et al 2018).

Initial findings indicated an impact on self-determination, institutionalization, and social exclusion. People, who are self-determined, choose goals and work toward acquisition. People with intellectual disability recording high SDI scores tend to, with support, be self-advocates, become involved in solving problems, and have decision-making skills (Hagiwara et al., 2021). Each individual influences life patterns that can improve the quality of their life (Shogren et al 2018).

The themes developed from the data indicate services are often prescribed by well-meaning professionals and tend to reflect a culturally narrow mindset of social acceptability. In the setting observed, the majority of support staff demonstrate a highly nurturing model that can result in protection over skill acquisition as a foundational objective. This tendency of protection overgrowth was demonstrated in the observational data and may have impacted performance on the SDI. Internal strength, referred to as self-determination, is developed by processes of individual

discovery. The data in this study indicates a significant disconnect between supports provided and the individual's most pressing needs.

Another emergent theme supported in the data and the work of Dr. Wolfensberger (2013), is the approach based on an unconscious mindset of infantilization. This approach produces a disabling effect on the person, further depriving them of self-determining an individual path toward the good things of life. Rather than acquiring highly valued social roles in society (Wolfensberger 2013), people are experiencing unintended, service-related loss of self-determined valued roles.

## **Discussion**

The themes from this research project suggest that the "high nurturing model" of service may result in not only a loss of roles but the gaining of negative social roles. This circularity of loss of role resulting in prescribed protection can be significantly limiting interpersonal relationships. In other words, an impact of institutionalization. Most support and services tend to be done, organized, directed, and prepared without individual authentic involvement and participation. Meanwhile, loneliness and systemic control are shutting down the inner self. Observations revealed that employees are also struggling. Staff are often trying to make it through days of long shifts without adequate support and guidance, in a permanent and agonizing surviving mode. The result seems to cause a reliance on policies, procedures, and activity that chart completion over life sustaining experiences. Often the researcher observed this being rationalized for billing purposes. The person, in this instance, may become fodder for organizational operation rather than the person to connect with. The codes indicated that direct support staff may have personal

wounding experiences and have pressing needs for support for quality of life and relational richness.

### **Recommendations**

To address the plethora of challenges discovered, the organization must improve and alter how they are organized and what they are organized around. This research suggests continuous improvement is based on clarifying and understanding who each person is, what they need, and how to serve that need (Wolfensberger 2013). The shift in the recommended process is critical to support people as they become owners of their life.

This project and themes developed indicate the following residential service improvements:

- From a management standpoint level, support professionals, family members, or any members of the circle of support to foster an environment that helps people to increase their independence and autonomy in their choices and decisions.
- Find a balance between person-centered services and regulatory processes.
- Support people to have and hear their own voice, to become active members, and to become the owners of their lives.

- Democratize the services and have people receiving support to be part of any decisions that are influencing and impacting their lives.

- Just being in the community doesn't necessarily mean being included and integrated and just being physically located doesn't mean being home.

- Focus on helping people to develop and maintain unpaid relationships that can help them feel they have worth, and they are not invisible and trapped. This is more effective and has a bigger impact than any teaching or behavioral support plans.

- Loneliness is a subtle form of abandonment, exclusion, and control that is generating multiple other vulnerabilities, especially for people with disabilities.

- The community always has a better response than we imagine or expect.

- Being productive and having the opportunities to do things for others is powerful

- The support professionals also require support to be able to grow in their roles, develop their unique competencies, and sense of autonomy.

- Focus on possibilities and respect people's rights to take risks and grow.

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