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Independent Living in the Community: Are people with intellectual disabilities reaching their full potential?

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Abstract

This aim of this study is to provide qualitative information regarding the quality of life of adults with intellectual disabilities living in community settings, or in supported independent living accommodation in the Limerick region. Schalock (2004) identifies eight quality of life domains which this research considers. In this study these headings were further broken down into five categories which are based around the five levels of Maslow's Hierarchy of Needs (1943) and were informed by guidelines on how questions can be simplified (Prosser and Bromely 1998). The study indicates that the lower levels of the participant's needs are being met however; the research suggested that participants had low expectations in regards to meeting their needs. The research indicated that the participants had the basic skills required to live in the community. It also revealed in order to reach their full potential through community living a more holistic service user assessment could be performed based on the principles of Maslow's Hierarchy of Needs.

Keywords: Intellectual disability; community living; quality of life; hierarchy of needs; normalisation.

Introduction

The accommodation trends for people with intellectual disabilities have experienced significant change over the past twenty-five years. This shift was not only in social, but in professional attitudes which supported the idea that large institutions were not able to facilitate the needs of those with disabilities and the recognition that people with the most challenging needs could live successfully in the community (Castellani in Mansell and Ericsson 1996: 209-224). Moves away from institutional care to community based settings was brought about not only to reduce the cost of care but were in response to the demands for better quality of life for those with intellectual disability (Walker, 1993: 204-206). However, as Schalock (2001) highlights, the agenda for the closure of large institutions was more process oriented than outcome oriented and failed to provide a clearly articulated goal to those involved.

Quality of Life (QoL) became a central issue in the field of rehabilitation in the 1990s (Schalock, 1990). A recent analysis of the international quality of life literature Schalock (2004) has confirmed the multidimensional structure of QoL. The work of Schalock will be considered in defining quality of life domains. Schalock identifies eight factors which need to be considered.

1. Physical wellbeing.
2. Material wellbeing.
3. Interpersonal relationships.
4. Social inclusion.
5. Personal development.
6. Self determination.
7. Emotional wellbeing.
8. Rights. (Schalock 2004: 369 -384)

Learning Disability

The term 'disability' is a highly contested one and is not easily defined. The World Health Organisation has defined disability as 'having severe problems of functioning stemming from capacity, ability and/or opportunity to function' (p.1). 'Capacity to function' is understood to have emerged from body function and the limitations this

imposes on the individual. 'Ability to function' concerns the difficulties around completing tasks that result from reduced capacity. 'Opportunity to function' or to participate in society, involves accessibility to buildings and resources. It also includes economic participation and supports in the community (WHO, 2001).

Medical Model of Disability

The medical model of disability has its focus on the lack of capacity to function. This emphasises impairment in physiological and psychological body functions and anatomical or biological structures. This definition views people with intellectual disabilities in terms of being incompetent, or impaired (Oliver, 1996: 30-43). Any intervention is approached from a medical perspective, with outcomes focused on health and illness. Although the medical model has a contribution to make in the field of intellectual disabilities for individuals with higher support needs, it can also restrict others from being involved in everyday activities and social interaction. This may deny them the opportunity for creativity and self-expression and for reaching any potential they may have.

Social Model of Disability

A social model of disability is associated with improving the quality of life of people who face barriers in everyday living which prevent them from participating as full members of society (Oliver, 1996). If we apply this concept to Maslow's hierarchy of needs theory, which is often represented as a pyramid to illustrate different levels of needs with basic needs at the lower level and the need for self-actualization at the top, we discover that society can often block individuals from reaching their full potential. Maslow infers that, the main reason people do not reach their full potential, or self-actualize is because of hindrances placed in their way by society (Simons et al 1987).

Hierarchy of Needs

Many ideas in humanistic psychology derive from a theory proposed by humanist psychologist Abraham Maslow in 1943. Maslow's work involved 'self-actualisation' and reaching 'human potential'. Maslow's work centres on feelings of fulfilment and attempts to attain fulfilment through achieving higher levels of needs. Maslow (1943)

envisioned people's 'motivational strivings' on a pyramid that he referred to as the 'hierarchy of needs'. According to Maslow this pyramid is made up of five different levels, at the bottom were basic physical survival needs, such as food, sleep and water; on the second level were security needs, such as protection against danger; at the next level were social needs, such as affection and belonging; at the next level were self-respect, the respect of others and esteem; and finally at the top of the pyramid were needs for 'self-actualization' (Wade and Tavis 1998: 447). Maslow maintained basic needs must be realized or satisfied, to some degree, before other higher needs may be met (Taylor and Devine 1993).

Maslow argued that people can 'behave badly' if their lower needs are frustrated (Wade and Tavis 1998: 448). Research has indicated that deinstitutionalization has resulted in improvements in functioning and behaviours for people with intellectual disabilities (Felse, Dekock and Repp 1986). This is attributed to the opportunities available in the community for people to meet their needs. For example, being able to choose what food they want to eat, (which also provides the opportunity for self expression) and when they want to eat it.

Schalock (2004) also recognised that a person's quality of life can be determined by satisfying their needs. He identified eight factors which he associated with quality of life. These are clearly reflected in Maslow's Hierarchy of Needs theory. These include physical wellbeing, which Maslow (1943) considers a basic need, interpersonal relationships, and social inclusion. These are echoed in level three of the Maslow's pyramid which he refers to as social needs. Finally Schalock (2004) talks about self determination, emotional wellbeing and rights and how Maslow considers these elements to be an integral part of what he refers to as self-actualization.

Normalisation-Community

The term normalisation emerged in the area of intellectual disability because of the move from institutional to 'normal' community living where a person could live a normal life. The primary goal of normalisation is the, 'community integration of the

handicapped individual and the development and maintenance of as normal a lifestyle as possible given the potential of each individual' (Leane, 1991:19). From this definition the term normalisation recognises that people with disabilities have the potential to live in the community. However, Leane also highlights that the success of the normalisation process depends on individuals acquiring the necessary skills to live in the community especially social and interpersonal skills.

Quality of Life the Social Context

According to the literature the term 'Quality of life' has various definitions for example, 'a sensitizing notion' that gives an individual a point of reference and a form of guidance from their own perspective, focusing on the individual and their own social setting (Lindstrom 1992: 301-306). It also has been referred to as a 'systematic framework' this views quality of life as a measuring tool that is used from a 'systems perspective' in other words that it measures aspects of life from various social settings. Examples of this are the family, the community, the neighbourhood (Keith and Schalock, 2000, Schalock and Verdugo-Alonso, 2002). Although these definitions are helpful in trying to understand the concept of quality of life in general, the definition that may be most appropriate for the purpose of this research is the idea that quality of life:

is a social construct that is used as an overriding principle to evaluate person-referenced outcomes and to improve and to enhance a person's life. In that regard the concept is affecting programme development, service delivery, management strategies, and evaluation activities in the areas of education, disabilities, mental health, and ageing. (Schalock, 2001: 187)

Schalock (1990) has contributed enormously to the debate on quality of life for people with intellectual disabilities and is one of the major researchers in this area. He asserts that, people who fulfil basic needs in community settings in ways satisfactory to themselves and others experience a high degree of quality of life. This refers to areas such as meeting responsibilities in regards to ones family and in doing so being accepted by ones family which may result in improved levels of self-esteem.

In reviewing the literature it would appear that there is a clear link between a person meeting their needs and their quality of life. If we are to apply the principles of Maslow's hierarchy of needs (1943) to Schalock's research it would suggest that quality of life is underpinned by meeting one's needs in order to be satisfied. It is evident from Schalock's work that being accepted by one's family or community contributes positively to one's quality of life. According to Maslow's hierarchy of needs theory, being accepted is also core to satisfying a person's need for self-esteem and self-respect.

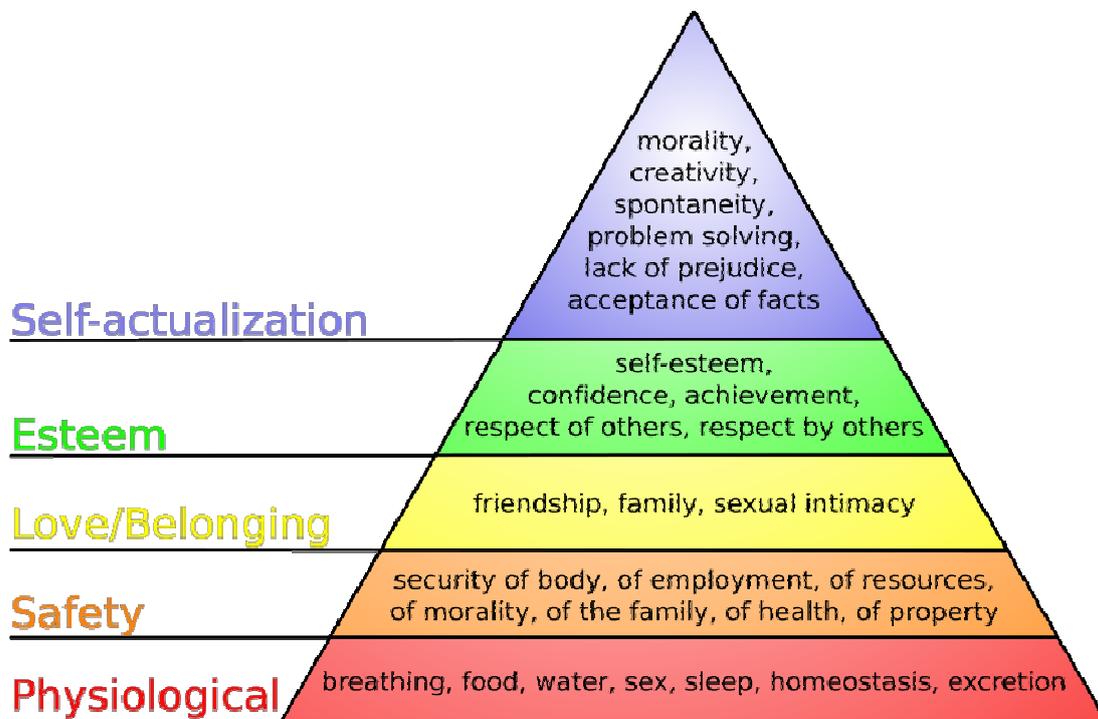
Methodology

The research is composed of qualitative research using semi-structured interviews, in order to determine how satisfied people with intellectual disabilities are living independently in the community and are they reaching their potential. A purposive sample of 4 men and 3 women with mild to moderate intellectual disabilities participated in this phenomenological study. Six lived in various community houses in the Limerick region with an average of 5 residence per-house before moving to independent living. One moved from a family home. Inclusion criteria were (a) mild to moderate intellectual disability, (b) service-user had moved to independent or semi-independent living in the community, (c) service-user had good verbal skills. Research has indicated that quality of life is positively correlated with personal satisfaction, which addresses the subjective nature of quality of life, generally by asking people how satisfied they are with different aspects of their lives (Schalock, 2004: 261-279). This involves hearing the voice of a group of marginalised participants and attempting to interpret the meaning they put on their life and in the process highlighting their needs. In other words the question is trying to establish if the participants are satisfied with their lives in the community by exploring their lived experiences in this setting.

Question Design

The questions were designed around the five levels of Maslow's hierarchy of needs and were informed by guidelines set down by Prosser and Bromely (1998). This work

is concerned with researching people with intellectual disabilities by designing appropriate questioning styles. These ideas proved practical and valuable in the design and execution of the study. Generally the questions were subjective with a view to seeking the respondents' opinions. The questions were broken into five categories. The categories were, (1) Physical Wellbeing, (2) Safety Needs, (3) Belongingness-needs of Love and Affection, (4) Self Esteem, (5) Self-actualization. The five levels are further broken down by quality of life indicators espoused by Schalock (2004). Although the question design is complex it provides for a flexible research instrument that theoretically allows for information to be gathered which facilitate the key objectives of the study.



Abraham Maslow – Hierarchy of Needs - A Theory of Human Motivation (1943),
Image from <http://www.wiserearth.org>.

Data Analysis

The procedure of data collection was similar for each participant. The data for this study was analysed using Colaizzi's (1978) phenomenological framework. In employing this method the participants interview transcripts are read a number of times and from this several sentences or themes are identified. Moustakas (1994)

refers to this step as ‘horizontalization’. This allows for common themes to emerge relating to the phenomenon. Meanings are then constructed from these themes which emerge. The themes are then used to understand how the participants experienced the phenomenon. Finally, the researcher creates clusters of meanings from these sentences or statements. These are then used to provide a description of what the participants experienced.

This was executed under five headings and considers how these may affect the respondents quality of life in the following areas, (1) Physical Well-Being. (2) Safety Needs. (3) Belongingness, Love and Affection. (4) Esteem Needs. (5) Self - Actualization.

Findings

(1) Physical Well-Being

The key aim in addressing issues associated with physical well-being was to determine whether these needs were being met by the sample group and to determine their level of satisfaction in this area. Under this section the researcher asked thirteen questions. All of the questions were answered by the respondents.

Overall, there were high levels of reported satisfaction concerning physical well-being. All of the respondents indicated that they were satisfied with their apartments and observed that since moving to independent living they had greater autonomy. This especially pertained to areas such as, choosing the food they could eat and when they could eat it. All of the respondents reported to doing their own shopping and meeting various dietary needs that they had. One respondent stated that ‘I feel sick if I eat spicy food and would never buy that in shopping’. While another said ‘I can’t eat hard biscuits because of my teeth; I would only buy marshmallows when I go shopping’. He also reported that ‘when I lived in the community house I never had soft biscuits’. The questions sought where possible to compile information on how the basic needs of the sample group were being met. In this respect this section of the study indicated that all the basic needs of the respondents were being met. There was no significant difference between the seven respondents’ answers or between genders.

The percentage of interviewees expressing positive levels of satisfaction was 100% in this section of the study. This is a significant finding as it suggests that the sample group indicate that they have a good quality of life at this level and didn't identify any needs that were not being met.

(2) Safety Needs

The questions in this section were to establish if the safety needs of the sample group were being met and to ascertain how satisfied the group were with the welfare and safety measures in place in the apartments and the local community. In this section the research asked four questions. All of the questions were answered by the sample group. Among the seven individuals interviewed five expressed satisfaction regarding their safety in their apartments. These five people also indicated that they were satisfied with where their apartments were situated. Two felt safe in their apartments, but suggested that they needed someone to look after it when they were away, as they thought they might be broken in to. One respondent observed that the workshop she was attending had been recently broken into, this made her feel unsafe when she was outside the apartment as she said, 'they were never caught they could be around,' but said she felt her apartment was safe. Another individual reported that he needed to come back and check his apartment a number of times if he goes away and recognised that any place can be broken into, 'very hard to find a safe place now'. However, overall the findings in this section indicated that the group felt safe in their apartments and the community, with five out of the seven interviewed reporting no safety concerns. Of particular note in this section was that two of the respondents that felt unsafe in the community related this back to a burglary at their workshop.

(3) Belongingness - Needs of Love and Affection

The objective of this section was to discover to what degree the above needs were being met. This involved asking questions regarding friendships and to determine if the respondents felt they were part of the community, or belonged there. There were twelve questions in this section which addressed a number of sensitive issues. All of the questions were answered by the respondents. From analysing the data, there was a clear need for friendship and to be connected to family members. However, overall

there was no community involvement, although all the respondents suggested that they felt they were part of the community, this was not correlated in the findings. There appeared to be no social networks outside of family or the workshop where the group worked. None of the group were involved in any club or society outside of the workshop and had no friends apart from those at work. The sample group cited staff members as being their friends, 'I'd have a drink with them if I met them out; they are my friends'. All of the group attended mass at least twice per-week and talked about enjoying the music in the church and the sense of occasion. The group also reported that they would like to live with someone, 'someday I'd like to settle down and meet someone someday'. Overall the findings suggest that many of these needs are not being met. With 100% of the group not being part of any club in the community, or living with someone. This suggests that under this section many of the quality of life indicators are not being met and indicates that even though the group are living in the community they are not a part of it.

(4) Needs For Esteem

This section was concerned with investigating issues around individual's esteem. There were eleven questions that set out to determine whether respondents had acquired a satisfactory level of esteem. There was 100% response rate. This section highlighted the fact that many of the respondents had a low level of self-esteem. This was evident in regards to the decision making process. In general, decisions were made for the sample group concerning areas such as, going on holidays and day trips. 'They (staff) pick where we go, we just go along' ... this was also the case regarding who they went with on a day trip, 'they just take everyone and we go as well'. Five out of the seven participants reported that they would not tell the staff where they would like to go for a day trip. The same number also indicated that they would not talk to the shopkeeper when they were doing their shopping, 'I get the stuff and go'. In analysing this data it appears that the majority of needs for self-esteem are not being met by the sample group.

(5) Self-Actualization

This section had six questions. Many of the questions are concerned with determining whether an individual has reached their full potential. Although it can be a challenge to recognise what people want when there is a need for self-actualization. There was 100% response rate to this section. This section of the study revealed that in general the respondents have not reached their full potential, the reasons for this will be addressed in the discussion section of this study. Although 100% of the group reported that they cooked to some degree, they also suggested that it was very basic. One respondent answered, 'I cook potatoes every day' while another indicated that they would like to be able to cook, but answered, 'I wouldn't know what to put in to the food'. Others suggested that they eat at the workshop because the food is nicer than what they could cook. When it came to reaching peoples' potential in areas such as art and music the findings were similar. One of the respondents said that he would like to be able to play the keyboard, but none of the group could play a musical instrument or participated in painting or drawing. One respondent reported 'we don't do that in the workshop'. While another said 'I might draw if my sister's kids visited me'. However, the four women in the study outlined an interest in dressing up and wearing different clothes, this provided them with the opportunity to express themselves and to be creative. However, respondents reported that staff did not encourage this. Overall the needs for self-actualization were not met by the sample group. With 100% of respondents reporting that they cannot play a musical instrument; never paint or draw, or experiment with food even though all of the group could cook to some degree.

Conclusion and Recommendations

From using Maslow's framework to analyse the data it provides a very clear picture of what needs are being met and how this reflects on the quality of life of the participants. If we consider the data in section one, it indicates that all the basic needs of the sample group are being met. Section two suggests similar findings. However, section three suggested that many of the needs for belonging and love were not met. An interesting theme emerged in this section when participants identified their need for sharing their life with someone, or having a partner which none of the group had. Under section four which considers the need for self-esteem, it is evident from the data that these needs

were not met. Finally the data would suggest that none of the group has reached level five. Overall the sample group appear to meet their basic needs but this trend seems to dissipate as the levels increase.

This study has revealed a paucity of research evidence at a national level regarding the needs of people with intellectual disabilities living independently in the community. This especially pertains to needs such as, belongingness and love. The study suggests that the lower levels of the participants' needs are being met, but there was also a strong suggestion that the participants had low expectations. Subjective evidence of this was identified during the interview process. This is also linked into to staff expectations of service users and staff perception of service users' ability and potential to learn skills. The study suggested that the participants had the adequate and basic skills required to live in the community. However, in order to reach their full potential a more holistic service user assessment could be performed based on the principles of Maslow's hierarchy of needs. Individualised training programmes could be designed and facilitated to provide the opportunity for service users to achieve this.

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