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THE EFFECTS OF DEINSTITUTIONALISATION ON THE LEISURE HABITS OF PEOPLE WITH AN INTELLECTUAL DISABILITY IN SOUTHLAND

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THE EFFECTS OF DEINSTITUTIONALISATION ON THE LEISURE HABITS OF PEOPLE WITH AN INTELLECTUAL DISABILITY IN SOUTHLAND

Michael Fallu

INTRODUCTION

This article discusses the findings from a research project investigating recreation and leisure participation among the intellectual disability community in Southland, New Zealand. The project draws on the original research conducted in 2004/2005 (Stanat, 2005) and was replicated in 2016. The purpose of the research was to assess the changes and constraints to leisure and recreation participation for individuals with an intellectual disability coming from long term institutionalism (deinstitutionalisation) to community mainstreaming. This research sought to identify the constraints to leisure participation, what has changed over the period between 2004 and 2016, and what this has meant for participants' quality of life (QoL). The original research project interviewed a range of individuals with disabilities including sensory, mobility, mental, and cognitive. For the purposes of this new research, only those with a cognitive disability or intellectual disability were interviewed. This was mainly because the original research was conducted by 12 interviewers, and the more recent research project by one interviewer.

BACKGROUND

The New Zealand Disability Strategy (NZDS) was implemented in 2001 and aimed to eliminate barriers wherever they existed (Ministry of Health, 2001). This strategy outlined 15 objectives that promote societal inclusion for people with disabilities. Objective nine, "support lifestyle choices, recreational and culture for disabled people" (Ministry of Disability Issues, 2001, p. 16), addresses the recreation needs of people with disabilities. This strategy was revised to produce the 2016–2026 NZDS, due to the recognition that, although some aspects had been improved, more work was "needed because disabled people remain worse off than non-disabled people across all social and economic outcomes" (Ministry for Disability Issues, 2016, p. 9).

Evidence from both local and international individuals and organisations reports numerous benefits (social, physical, and psychological) of leisure participation by people with a disability (Peterson & Stumbo, 2000; SPARC, 2004). Leisure has been found to have many social psychological benefits for people with disability such as cultivating friendships, developing life-long skills, acquiring social skills, and enhancing self-image (Palmer et al., 2011; Patterson & Fallu, 2004). Prompted by these findings, Dr Fran Stanat, manager of the Therapeutic Recreation Faculty at the Southern Institute of Technology (SIT), conducted a research project in 2005 to investigate the leisure participation of New Zealanders with a disability who live in the Southland region. Dr Stanat and 12 year three students conducted the original research which provided people with a disability the opportunity for their voices to be heard (Stanat, 2005). When the original research was conducted, one in five New Zealanders (743,000) were identified as disabled; according to a 2013 survey, that number has risen to 1.1 million, or one in four New Zealanders, which is the most recent data (Stats NZ, 2014).

The Disability Resource Centre (DRC), an Invercargill based information resource centre established in 1992, was involved in organising the original interviews. The Centre had had numerous clients with disabilities report that their recreational and leisure needs were not being met by existing facilities and organisations in Southland. Caregivers and advocates have also observed the lack of leisure and recreation opportunity for people with disabilities. The interviews were run at the DRC. While a survey of leisure needs (Southland Regional Development Strategy 2003) was undertaken in Southland just prior to the original research, it appeared that this research did not specifically address the wants and needs of people with disabilities. This strategy was later used to inform the *Southland Spaces and Places Strategy* (Sport New Zealand, 2023). Research was required to determine the leisure needs and wants of people with disabilities in Southland. It was hoped this research would enable future planning for the most appropriate recreational and leisure opportunities to ensure the participation of people with disabilities. It was further hoped planning in this fashion would enhance social inclusion opportunities in Southland.

LITERATURE REVIEW

Definitions

The following definitions are relevant to this research and the field of disability studies.

Social role valorisation (SRV) is a dynamic set of ideas useful for making positive change in the lives of people disadvantaged because of their status in society. SRV is utilised mainly in service to children and adults with impairments as well as elders, but it can be helpful to uplift the social situation of any person or group.

Intellectual disability is a condition of arrested or incomplete development of the mind, which is especially characterised by impairment of skills manifested during the developmental period, which contribute to the overall level of intelligence, in other words, cognitive, language, motor, and social abilities.

Leisure and quality of life

Leisure has been at least subtly involved in the development of social norms and practices. Arguably, when sitting around a fire in a leisure environment, primitive humans developed communication and eventually a civilisation (Mithen, 2005; Shivers & De Lisle, 1997). Rojek (2006) identifies civilisation as a complex blend of knowledge, beliefs, art, ethics, behaviour, and law; and, as Russell (2004) concludes, the major contributors to this knowledge and skills reservoir came from individuals when they were in a state of leisure. For Pieper (1952) leisure celebrates and affirms one's humanity (Kleiber, 1999, p. 8). This lends weight to the argument that therapeutically constructed leisure environments could be used to develop the necessary skills and knowledge associated with a new social paradigm. Duvdevany and Arar (2004) have made the point that simply living in a community does not assure friendship or quality of life.

Quality of life (QoL) is described by Brown et al. (1994) as "the discrepancy between a person's achieved and unmet needs and desires" (p. 41). This refers to the subjective, or perceived, and objective assessment of an individual's domain. The greater the discrepancy, the poorer the QoL. Smart (2001) argues QoL is both subjective and multidimensional incorporating, amongst other areas, freedom to function at one's highest possible level, physically, socially, and spiritually (p. 314). Smart (2001) also argues it is society's inability to accommodate the needs of people with a disability which most profoundly impacts on QoL. Quality of life includes the extent to which an individual increasingly controls aspects of their life regardless of the original baseline. Diodati (2017) has argued people with disabilities can experience constraints and barriers to leisure participation in these activities which negatively impacts their QoL. Since the 1970s, there has been a paradigm shift towards social inclusion instigated by the normalisation theory (Nirje, 1969) which has—among other social changes—provoked the deinstitutionalisation movement. As a result, new legislation has been instigated that has advocated for and

supported the rights of all individuals to be treated equally and to aspire to the highest possible quality of life. Not all individuals have had access to this QoL; for example, people with disabilities. Leisure and recreation are contributors to this high QoL. So, to understand participation in recreation, and any real or perceived constraints and barriers to leisure, is important data (Fallu, 2008).

Leisure and social inclusion

The problem of social exclusion and the need to develop a greater appreciation and acceptance of diversity are issues that have manifested in cultures throughout history (Murphy & Murtagh, 2004). For Sussmuth (1998), the inertia that contributes to the unwillingness of society to change is caused by fear and anxiety manifesting as complacency and self-satisfaction. Gaudiani (1998) argues that what has been acceptable in the past will have to change if societies of the future are to succeed, identifying “effective deployment of diverse human resources” as the key to success in the future. This is particularly relevant to the paradigm shift occurring in many Western countries in relation to deinstitutionalisation in general and that of people with an intellectual disability in particular (Bostock et al., 1996; DePoy & Gilson, 2004; Fallu, 2008). The impetus underpinning this deinstitutionalisation process stemmed from the theory of normalisation, developed by Bengt Nirje, Executive Director of the Swedish Association for Retarded Children. Nirje promoted the belief that all individuals should have access to as normal a lifestyle as possible (Grant, 2007; Nirje, 1999), with the process of deinstitutionalisation being a practical expression of Nirje’s altruistic theory. The need for this practical expression was already gaining momentum through works such as Erving Goffman’s (1961) *Asylums*, and Peter Townsend’s (1962) *The Last Refuge* (cited in Sennett, 2003). These authors and others like Michel Foucault (1978, 1988, 1997) paint a grim picture of what Goffman referred to as “total institutions.”

Leisure participation has been identified as one of the most important aspects of encouraging community adjustment (Rynders & Schlein, 1988) and this has helped to reduce society’s negative impressions of those people with an intellectual disability. This has been identified as an essential step in achieving total social inclusion in accordance with the social model (Oliver, 1990). Iso-Ahola and St Clair (2000) discuss how the acquisition of leisure knowledge affects the individual’s values, attitudes, motivations and perceived constraints. Access to knowledge in a leisure environment has great potential for promoting positive attitudes and values (Iso-Ahola & Mannell, 2004). People with disabilities given the opportunity to participate in leisure education programmes have a greater likelihood of developing the necessary social skills to form satisfying social relationships. In their research, Duvdevany and Arar (2004) found a strong correlation between social contacts and participation in leisure activities. Devine & Dattilo (2001) found that individuals with disabilities who perceived they were accepted socially by their non-disabled peers participated more in leisure activities and experienced a higher degree of leisure satisfaction in inclusive leisure environments. Therefore, leisure contexts may provide insight for understanding society’s norms, attitudes, beliefs, and values (Devine, 2004). According to Patterson and Pegg, “in the past, western societies have tended to devalue people with disabilities, and as a consequence they were less likely to have valued social roles through paid work” (2009, p. 1).

Like Minds, an initiative established in 1997 by the New Zealand Government, was one of the first comprehensive national campaigns in the world designed to counter stigma and discrimination associated with mental illness and increase social inclusion (Ministry of Health, 2014, para. 1). When considering the objectives of Like Minds, Godbey (2006) observed that over eighty percent of what contributes to a state of health exists within the realm of what could be described as individual leisure domains. These leisure domains have great potential to contribute to the reduction of stigmas and discrimination. These realms include our environment and our relationships, including our position within a society and our perception of self. Leisure experiences can provide a powerful tool for the elimination of negative labels associated with disabilities, as leisure brings these individuals into contact with mainstream society, and this interaction can help replace negative stereotypes and myths with the reality of the individual. At the same time, leisure helps to increase the skill level of the individual which, in turn, elevates self-esteem and the likelihood of success in the community (Hutchinson & McGill, 1992; Patterson & Pegg, 1995).

Social role valorisation and study rationale

It is difficult to discuss disability, leisure, and social inclusion without understanding the theory of social role valorisation (SRV) which was developed by Wolf Wolfensberger (1983) as a refinement of Nirje's (1969; 1999) normalisation theory. SRV now represents a complex social theory. It is an empirically based social theory that addresses the social devaluation of individuals and groups. Due to this devaluation some individuals and groups are accorded low social value. The consequences of social devaluation can be described and the factors that contribute to social devaluation can be understood and countered to some extent (Cocks, 2011, p. 13). Connaughton and Cline (2021, p. 1) have argued that individuals with a moderate intellectual disability leaving school are excluded from the "good things of life" which SRV affords many nondisabled individuals, such as having a job, meeting friends, and going on to higher education. These friends, jobs, and education all contribute to having a valued social role.

This research was conducted to document the changes that have occurred since the first interviews by Dr Stanat (2005). The same questions were asked around leisure, fun, and barriers to inclusion, and the responses were compared to the original responses. The aim was to give a voice to individuals and groups not always involved in the planning of their lives (Stanat, 2005).

METHODS

Community-based agencies (PACT and IDEA) that focus on providing support for people with disabilities in the Invercargill area of Southland New Zealand were approached by the researcher to provide access to any suitable clients that they knew of who participate in leisure activities and were willing to be interviewed for the purposes of the study. The relevant support organisations were approached and provided with an information sheet, consent form, and the interview questions. Through the relevant organisations a convenient time was arranged, and the interview was conducted at a day care/activity centre. Ethics approval was granted by the Human Research Ethics Committee at SIT on 23 September 2016.

A qualitative, interview-based research approach was adopted, using the same questions as the previous study. In the original research two interviewers were involved with one asking the questions and one acting as a scribe. For this new research the researcher working alone recorded the interview on a digital device. A group interview was arranged at the above-mentioned day care/activity centre. The participants were given consent forms and the researcher explained the purpose for the interview after which the consent forms were signed. The group were asked if they were comfortable with the interview being recorded, and they were. Only a small number (17) of the total group at the day care/activity centres were involved in this interview mainly due to the level of their disability, as many lacked the cognitive linguistic skills necessary to be effectively interviewed. Two support staff also participated in the interview. They were helpful in giving prompts when necessary; for example, when the group ran out of ideas, or clarifying what was being asked. Consideration for participant understanding was used to modify questions; for example, the word "fun" was used as an umbrella term incorporating all possible definitions of recreation, leisure, sport, and play.

Research questions

1. What do you do for fun?
2. What does having fun mean to you?
3. How satisfied are you with what you do for fun?
4. How much time do you participate in activities that are fun, when do you do it and why?
5. What places do you go for fun?

6. What are the barriers to your having fun?
7. If there were no barriers, what would you do for fun?
8. What would be the perfect fun activities?
9. Anything else which should be considered about having fun?

FINDINGS

Seventeen participants plus two support staff were interviewed for the study. An overarching theme among participants from both old and new data sets was as expressed by “Alex” as a desire to participate in an inclusive fashion with non-judgemental people, or people who “treat me like a person and not just like a person with a disability.”

Using debriefing techniques, the researcher discovered emerging themes for each question. The results are presented for each question.

What do you do for fun?

Activities for both the original and new interviews ranged from passive and solitary to active with the heaviest emphasis being on socialisation activities. Examples of socialisation activities included going to a mall, going to the activity centre, bocce, ten-pin bowling, talking with mates on the phone, and shopping. Both old and new data were similar, with the new data identifying more activities. One of the new activities mentioned was Tai Chi; this may be due to the researcher teaching some of the respondents Tai Chi as part of a vocational training programme which started after the first research study.

Structured and organised activities were viewed as highly desirable for two reasons. First, structured activities usually ensured that there was someone available to provide assistance. Assistance could be as simple as help in the locker room at Splash Palace, or more complex, such as providing safety in an unfamiliar environment to enable confidence. Respondents were especially concerned about safety issues related to acceptance by others.

A second reason that organised activities were preferred was because many felt it was difficult to always ask family or friends for help. One participant (“Trish”) said they would “put things on hold” rather than ask for assistance all the time. Some participants stated that they participated in agency activities because support was provided. Some participants were quick to point out that the availability of planned activities was diminishing.

A theme of the role of employment also emerged from the discussions. Members of this group considered their employment a fun activity along with the more traditional recreation and leisure pursuits.

What does having fun mean to you?

Respondent group members appeared to find this question difficult but, as discussion ensued, several interesting comments and themes emerged. Many emphasised that friends had a lot to do with participation in fun activities. One participant (“Todd”) from the original research reported, “These things make me feel normal.” Another (“Jane”) talked about “getting comfortable” and “being included.” A respondent from the new research (“Beck”) stated simply that fun meant “being happy” and “not being bugged by others.”

Themes emerging included the notion that having fun is being normal; being included and part of the community; being with friends; being in control and able to make choices; laughing, and an opportunity to enhance one’s abilities and find meaning in life.

How satisfied are you with what you do for fun?

This question did not generate much discussion. Respondents agreed that time, money, and the severity of the disability were all factors that limit satisfaction. There were many comments that were extensions of earlier discussions about a need for structured or organised activities. Specifically, many felt that satisfaction was dependent on supportive and accessible venues. The opportunity to try out new activities with the proper assistance was desired. Both old and new respondents needed prompting, and there appeared to be a general dissatisfaction regarding access to resources with responses like “okay or “not bad.” One individual from the new research stated that they wanted “more fun.”

How much time do you participate in activities that are fun, when do you do it and why?

Some answers were typical of what would be expected for most people. Those who did not work preferred morning and afternoon activities while those who were employed preferred evening and weekend activities. Generally, responders did not understand the question in both old and new data sets and tended to restate things they liked or would like to do.

What places do you go for fun?

Both old and new interviewees reported typical leisure and recreation agencies associated with the activities they described in question one. A major barrier for many people with disabilities is that many of the venues are overwhelming in terms of noise, activity level, people, and the attitudes they perceive. A person with a disability can often feel intimidated by the general public. The group identified their respective activity centres as safe places for them.

What are the barriers to you having fun?

The specific barriers addressed in this question were money, transport, adaptive devices, access, attitudes, people, support, and any other impediment to participating in leisure. The interviewees in the old and new interviews agreed that money was a barrier. Money, or lack thereof, created many of the other barriers (for example, no money for transport, access memberships, or adapted devices). General community attitudes emerged as a major barrier also in both sets of data.

Transportation was also identified as a barrier. Concerns were expressed about the number of buses available, the times that the buses operate, the need for assistance or support when riding the bus or in a taxi (drivers unwilling or not prepared to help), the cost of transportation, insufficient wheelchair taxis, and the limited number of rides to which a person was entitled from the Transit Mobility service.

Barriers experienced by people with an intellectual disability had not changed in the period between the two interviews. There was agreement that societal attitudes continue to pose a limitation to their ability to freely participate. Respondents believed that many people are uninformed about disabilities and are either unwilling or afraid (or both) to ask questions. One of the respondents (“Narmer”) in the new data set stated: “People assume I can’t do things, even if they don’t know me.” The respondents spoke of feeling unwelcome, discriminated against, not viewed as a real person, and disrespected.

Lack of support was another concern that was consistently discussed throughout all the responses to the questions. The groups felt that, with support, they could overcome many of the barriers to participation in leisure and recreation including the attitudinal barriers. Many said that if they had support, they would be able to be involved in inclusive opportunities.

If there were no barriers, what would you do for fun?

Participants were asked to address the question of barrier-free leisure participation relative to the activities in which they would like to participate, the resources required, the time and location for participation, the cost or funding for programmes, the people with whom they would like to participate, and any other comments about the leisure and recreation opportunities. Participants in both data sets did not initially understand the question. It was then rephrased as, "If you could have three wishes for leisure, what would you do?" The main difference between the old and new data was that in the old data there was a general happiness with what the respondents had access to. However, in the new set of data, many new skills and opportunities were identified; for instance, learning to play a musical instrument and more freedom to do more of the things they enjoyed such as socialising with friends.

Emerging themes

Generally, participants in both the old and new interviews were interested in learning new activities. There was also interest in just having a place to "hang out"; a safe place where participants could go to socialise. All agreed that resources were available in Invercargill, but that assistance was often needed to access and utilise many of the facilities to their fullest extent. There was discussion of having qualified people available to teach and provide support, in part to ensure a sense of safety. The need for transportation was also reinforced. All participants agreed the location of resources or a place to just "hang out" should be in the central city (and therefore easy to get to). Costs should be minimal. Suggestions included providing community-funded resources, with participants paying a small fee to cover cost of materials and memberships.

DISCUSSION

There was little to distinguish between the old and new data sets. Several themes emerged throughout all the questions and in both the old and new data sets. These themes related to reasons for participating; the need for structured and organised activities; public attitudes towards people with disabilities; the desire to try new activities, and "a place to hang." Each of these themes will be discussed and recommendations offered.

The reasons the group members cited for participating in leisure were typical of those cited in classic leisure studies research (Pieper, 1952/1998; Russell, 2004). Socialisation was a major reason for participation in leisure and recreation activities. Other reasons included "to be in control," "to be able to make decisions," to "stay motivated," "being included," and to "be with friends." One response not cited in the research literature as a motivation for participating in leisure and recreation was that participating in leisure and recreation was equated with "feeling normal."

There was considerable concern expressed about the need for structured and organised activities. The concept of structured and organised was often interchangeable with the notion of support and assistance. Activities that are structured and organised, and/or supported and assisted, were viewed as safe, secure, and within the participants' "comfort zone." Group members were fairly comfortable with the idea of receiving this type of support in an inclusive venue. However, the primary emphasis was not on inclusion. Rather, it was on safety and security.

Attitudes of the public were often seen as a barrier to participating in leisure and recreation. The public can be defined as other participants in an activity or as infrastructure personnel (for example, taxi drivers, service personnel, or managers).

The participants indicated that they would like to try new and varied activities if support was available. Some group members thought of their work as leisure and would like to learn new skills that would enhance their work options.

The notion of a “place to hang” ran throughout all responses to all questions. Some participants were quite keen to have a centre just for people with disabilities. Most, however, were looking for a place where they could access the support they needed to participate in leisure and recreation fully. There was general agreement that Invercargill had the resources and venues available, but that access was limited for a variety of reasons. The primary reasons were that support needed to participate was not available and that attitudes of people at the venue caused discomfort or fear.

RECOMMENDATIONS

Based on focus group data from the original study and supported by the new research, it was and remains recommended that a community-based leisure/recreation assistance centre should be developed to provide support and to enable people with disabilities to participate in leisure and recreation. While this centre would focus on meeting the needs of Southlanders with disabilities, it should be open to all community members. The parameters and functions of the centre might include, based on both the old and new research:

- Being a drop-in centre where people can get the information, advice, or the support they need to be able to participate in leisure and recreation in the community. This drop-in centre could also be a place where people can come to socialise.
- Collecting and distributing information about leisure and recreation in the community.
- Delivering leisure education and community (re)integration classes.
- Providing support services for people who need assistance to participate in leisure and recreation.
- Providing actual activity programmes. The centre could seek to help people to become involved in Invercargill and Southland leisure and recreation programmes and services.
- Offering training and consultation to providers of leisure and recreation services in Invercargill and Southland to ensure that their programmes are accessible and safe for users with disabilities.
- Recommending and providing training to leisure and recreation service providers for introducing new activity opportunities for Southlanders with disabilities.
- Developing and implementing a system to enable agencies to work together to deliver leisure and recreation services to Southlanders in the least restrictive environment.
- Developing and delivering disability awareness programmes to leisure and recreation service providers and other personnel who may have an impact on delivery (for example, taxi drivers, wait staff, store clerks, and so on).
- Developing and delivering disability awareness programmes to the general public, perhaps starting with speaking engagements at clubs.

All these services should be provided in a safe, inclusive environment.

When the original research was conducted in 2004–2005, there seemed to be a growing awareness of and enthusiasm for developing recreation for people with disabilities. This awareness and enthusiasm would seem to have dissipated. This perspective is also supported by the new interview data and the lack of support for recreation and leisure as an important enabler for QoL in the lives of people with a disability.

The main concerns to arise from the new data were that nothing has changed for the better in the decade-plus since the original research. In fact, there seemed to be less awareness of the importance of leisure in general and specifically for those with an intellectual disability.

Limitations

Only a small percentage of the total number of individuals with an intellectual disability were involved due to limitations such as lack of understanding in relation to the questions or lack of verbal ability to express their ideas. The participants in this interview would be classified as at the mild to moderate end of the intellectual disability continuum.

CONCLUSION

This research replicated a research project conducted in 2004. The purpose was to investigate what if anything had changed since the original research had been conducted. The same methodology was adopted using the same questions. The findings were very similar; however, a community-based support provider which was involved in organising the original interviews, when approached, declined saying they had no interest in recreation. As with the original research, the new data also highlighted the need for greater awareness and education for the general community and the provision of safe leisure environments.

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