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Integration or Segregation? The same or different recreation and leisure facilities for people with learning disability

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Abstract

Despite the many policy changes that have occurred over the past decade, real and meaningful inclusion remains elusive for people with learning disability in Ireland. This paper critically analyses the accessibility of recreation and leisure facilities for people with a learning disability. Focusing on a particular area in County Cork, the research participants included thirty-five children and adolescents with learning disabilities. Their parents also contributed to the research by providing an insight into their daily lived experience and current opportunities for leisure and recreation. International, Irish and local policies are considered to determine the State's commitment to providing an inclusive society. Semi-structured interviews were conducted with people with learning disability and their parents to establish their level of impairment, additional supports required to access mainstream facilities and to determine the current availability of opportunities to access these facilities in the target area. The research found that people with learning disability do not have adequate support to access mainstream leisure and recreation facilities and they mostly access 'special' segregated services because of the additional support available there. As a result they are seen as 'different' because of their reliance on segregated facilities and as a result they are treated unequally.

Key Words: learning disability, inclusion, equal opportunities, recreation and leisure

Introduction

Many changes have taken place over the past twenty years for people with disability both intellectual and physical. Equality of opportunity has been promoted and some barriers to participation have been removed. Accessible mainstream education and community living have also become a reality for many people with intellectual and physical disability. It is evident however that making mainstream recreation and leisure services accessible to people with intellectual disability does not seem to receive the same amount of attention or urgency. Schalock believes that recreation and leisure activities contribute to a better quality of life for people and this fact is no less true for people with learning disability than it is for their peers of typical ability (1990). Participation within mainstream recreation and leisure ensures that people with learning disability are socially included, have an equal opportunity to integrate with their peers and improve their sense of worth. Hanson (2002) states that restrictive environments control access to social spaces, as a result it can easily be established who does and who does not 'belong'. Few studies have taken place in relation to recreation and leisure opportunities for those with a learning disability so the main purpose of this research is to establish if people with learning disability have equal opportunities for inclusion in mainstream leisure and recreation.

In the early 1990's parents of children with learning disability found that their children could not be accommodated within mainstream summer camps and recreation clubs that were already catering for children and adolescents of typical ability in a large town in County Cork. As a result their only option was to set up a Summer Camp especially for children with learning disability and this camp is still in existence today catering for children as young as five years old. This means that young people with learning disability living in the area remain segregated from their peers within the important area of recreation and leisure. People with learning disabilities have the same needs for recreation and leisure as people without learning disabilities; however they generally access more structured leisure activities within disability organisations and service providers, thereby reinforcing their segregation from community and friends.

Methodology

People have found that to be disabled means they are socially restricted by attitudinal and physical barriers despite all attempts to legislate them away. The theoretical perspective that underlined this research was Critical Theory, which assumes that certain groups in society are privileged over others, and oppression is reproduced when these groups accept their position as inevitable and natural or even necessary (Gall, Gall & Borg 1999). Oliver (1998) considers that critical theory sees the problems of people with disabilities as the result of an unequal society. Critical theorists believe the resolution lies in social action and change and agrees with the idea that people's lives are restricted more by discrimination and prejudice than they are by their impairment. Sarantakos affirms that the aim of critical research is to facilitate a critique of social reality thereby emancipating people and empowering them to change the social reality by suggesting possible solutions and as a result liberating them from oppressive and exploitative structures (2005).

Mike Oliver's emancipatory disability research was adopted as it is generally connected to qualitative data collection and this area of research calls for an input from disabled people themselves (1992). The everyday lived experience of disabled people could be understood and participants in this research had a sense of empowerment as they had been afforded an opportunity to contribute their comments and recommendations. Oliver finds emancipatory research must be located in the social model of disability, rejecting the individual or medical model view that impairment is the root cause of disabled people's problems (Ibid). The social model of disability was therefore adopted as the basis for producing this research in an effort to assess the real disabling barriers to inclusion for people with intellectual impairment. Eileen Kane believes that qualitative techniques can give a richness and depth that is not achievable through other methods (2005). It gave participants a voice and the researcher an opportunity to see the world through their eyes by seeking answers to questions to find the individual's interpretation of life.

Purposive sampling was used to target specific members of a disability group in and around the County Cork town because of their relevance to the research. A

questionnaire was distributed to parents of thirty five people with learning disability for completion in order to obtain their perspective. There were eighteen responses to the survey and five parents were then selected to take part in an in-depth telephone interview. Consultation on research ethics was conducted with the participants before the interviews took place and the ethical standards adopted by the National Disability Authority and Federation of Voluntary Bodies informed the research. The interviews were semi-structured and each interview was recorded in writing by the interviewer. Young people with intellectual disability were interviewed with parents' permission while relaxing after taking part in their social club and parents were also present. Secondary materials were used to gain an insight into research already undertaken to determine the importance of recreation and leisure in the lives of people with a learning disability. Secondary research was also considered and is highlighted in the literature review.

Literature Review

While accessing secondary research in the area of learning disability I came to realise that there is a distinct lack of study in the area of accessible mainstream leisure and recreation and research is generally to be found focusing on community care, education, behaviour modification, treatment and therapy issues, which are synonymous with the medical model of disability. Disability language is based on the Social and Medical Model. The medical model describes the person's disability in relation to their medical condition and considers that the person must be 'fixed' to fit into society. On the other hand, the social model considers that the person is disabled by societal barriers. There is a general agreement among disabled people that the social model best describes their situation.

The Social Model arms people with the tools to tackle inequalities they experience and it encourages a demand for a change within society as well as policy. Thomas (2004) finds disability was uncovered as a type of social oppression and as a result, people were likely to be disadvantaged and excluded. This has proved true in the area of education as in the past people were consigned to segregated special educational services, away from their peers of typical ability as well as their communities and

often their own families. Today in Ireland the Education for persons with Special Education Needs Act (2005) has ensured that mainstream education for people with disabilities is a reality. Mainstreaming, however, does not need to end with education. The inclusion of people with disabilities in leisure situations is inevitable as a result of their continued inclusion in everyday life (Devine 2004). A study undertaken by the Thomas Coram Research Unit found that children with disabilities experience social exclusion out of school and during holidays while also experiencing negative attitudes while using leisure and play facilities (Petrie et al. 2007)

Although the historical attitudes to disability are deeply ingrained in the psyche of society it is envisioned that total integration will bring about the changes that are needed in order for people with a disability to be fully accepted and people with learning disabilities will have real opportunity to experience aspects of life many people take for granted in the 21st century (Gates 2003). It has been found by Carr (2004) that environmental, cultural and economic factors limit disabled peoples opportunities to exercise choice in accessing leisure activities, resulting in the emergence of many segregated facilities.

Leisure presents the most enjoyable activities to all regardless of ability. In research carried out by the Cope Foundation to enhance service provision to people with learning disability, it was found that the majority of students depended greatly on family members and engaged in passive and solitary activities (Buttimer & Tierney: 2005). The importance of having friends and engaging in social relationships is a necessary element to ensure social integration as was found by Mahon, et al (2000). In research undertaken by a UK based organisation, 'Contact a Family', it was found that of parents surveyed, 52% believed their children would be better off within segregated services as the problems associated with mainstream opportunities relate to lack of training and transport, public attitudes and rigid rules. On the other hand, the situation in Ireland is quite the opposite, following the Quality of Life of People with Disabilities in Ireland Survey it was found that specialist services support people with disabilities in segregated settings only despite the fact that the majority of people with learning disability live at home (2007). This resulted in a call for more integrated

services to be developed to allow people remain in their communities rather than be placed within segregated service.

The limited availability of secondary research in accessible leisure activities for people with learning disability highlights the lack of attention this very valuable facet in the life of the person has received. Many people with learning disability continue to socialise as a homogenous group apart from their peers thereby ensuring their isolation and lack of a sense of self and identity. True change can only come about when effective policy is developed.

Policy Review

International policy in the shape of the United Nations Convention on the rights of Persons with Disabilities was considered for its contribution to enhancing young people's rights concerning recreation, leisure and play. European policies and strategies were also explored for their value in delivering accessibility and inclusion for people with intellectual disabilities. Finally national and local policies were also considered for their contribution to mainstream inclusion.

The United Nations Standard Rules on the Equalisation of Opportunities for Persons with Disabilities was adopted in 1993 resulting in over fifty countries adopting disability rights legislation. Article 11 of the Agreement focused on the physical accessibility of sporting organisations and disabled persons organizations; little emphasis was placed on participatory recreation and leisure for persons with disability (UN, 2008). The UN Convention on the Rights of Persons with Disabilities was adopted by the General Assembly in 2006 and in March 2007 the Irish Government signed up to it. An Optional Protocol allows for people with disabilities to lodge complaints to the new UN Committee which will be established to assess progress made by states that have ratified the treaty. Article 30 of the Convention is expected to influence policy so as to ensure that people with disabilities will be guaranteed the right to equal participation in cultural life, recreation, leisure time and sports without experiencing discrimination. Even though it does not give new rights it does explain how the existing rights might be encouraged and protected. All European Countries

have declared their willingness to ratify the Convention. To date Ireland has not ratified it (DFA: 2009).

In the European Union, the Barcelona Declaration of 1995 encouraged local government to address the inclusion of people with a disability by developing a plan of action which would include consultation with persons with a disability. The Amsterdam Treaty (1997) also called for actions to tackle disability related discrimination. There were directives calling for member states to introduce anti-discrimination legislation; this particularly concerned discrimination in the area of employment. There was little evidence of any commitment towards mainstream participation or integration. The Council of Europe Disability Action Plan 2006-2015 is expected to become a roadmap for member states as policymakers and will carry the objectives of the Council of Europe in relation to human rights, equal opportunities, citizenship, non-discrimination and participation for persons with a disability (CEDAP, 2006). For people with intellectual disability accessing rights, integration and participation in mainstream services requires additional supports and; without funding for these supports then strategies and policies will have little effect. Despite the many policy recommendations by Europe and the UN, Ireland has been slow to deliver rights based legislation for people with disabilities.

In 1993 the Irish Government set up the Commission on the Status of People with Disabilities with the aim of consulting with people with disabilities and their families and to advise the Government on measures that would ensure people with a disability could access their rights to participate in economic, cultural and social life. Its report 'A Strategy for Equality' was delivered in 1996. Following the report, the National Disability Authority was set up with a remit to advise the Government on disability policy and practice. The Employment Equality Act 1998 and the Equal Status Act 2000 were delivered as a result but they only addressed employment discrimination and accessing the built environment. The same was true for the Programme for Prosperity and Fairness (Government of Ireland, 2000) when a commitment was made to making public services accessible.

The Disability Act which was finally passed into law in 2005 which also addressed the accessibility of public buildings and services as well as making a provision for a Centre for Excellence in Universal Design under the aegis of the National Disability Authority. The Centre is expected to enable people in Ireland with a disability to participate as equal citizens within a society that is accepting of human difference (Social Inclusion Report: 2007). Once again the Act overlooked the social and cultural needs of people with intellectual disability. The Office of the Minister for Children produced a policy document called 'Teenspace' which acknowledges that people with disabilities experience difficulties in accessing recreation and this needs to be taken into account in developing opportunities for recreation for young people (2007). Within this document, structural barriers are once again to the fore and generally determine if people with specific disabilities will access mainstream provision; there is little evidence to show that the additional needs of people with intellectual impairment will be addressed.

Within the geographical area of research the Town Council in their Development Plan boasts the largest number of clubs and organisations of any town in the country (2004). Once again physical accessibility is called for within this Plan as well as within the Cork County Development Plan 2003-2009. The mission of the 'County Cork Local Sports Partnership' is to increase the number of people participating in sport, exercise and physical activity and in particular, people with a disability (2000). A new sporting initiative has taken place specifically for disabled people within the town, however, no effort has been made to integrate disabled people into mainstream sporting organisations resulting in their continued segregated from peers taking part in mainstream clubs and organisations.

There are few opportunities for young people with intellectual disability to socialise with their peers of typical ability because of a lack of awareness of people's needs by policymakers and a lack of commitment by service providers. This has been shown to be true at the European Study 'Specific Risks of Discrimination against Persons in Situations of Major Dependence' which reported that there is an increasing awareness

of the need for participation in mainstream activities in leisure and recreation:- however no European country shows a satisfying degree of inclusion (2008).

Data Analysis

The social model of disability and its use in understanding the lived experience for people with learning disability was considered in the literature review. Social acceptance is also a prerequisite to equality for all regardless of difference of ability. Recreation and leisure activities afford an opportunity whereby social acceptance may be gained. Analysing segregation and integration was also considered valuable in the review and to this end research within the area of education was considered in lieu of limited research in the specific area of inaccessible recreation and leisure facilities.

Research Findings

The research considered the level of impairment of young people, the additional supports they require for inclusion, their current opportunities to access recreation and leisure facilities, sourcing these facilities and views of the young people with intellectual disability. Of the eighteen respondents three had autism spectrum disorder, two had intellectual and physical disabilities, six had Downs Syndrome and seven had a general intellectual disability. Within each category of disability there were also variations in the levels of disability from mild to moderate. Some children were young and quite active and required a lot of attention while others required less supervision.

All respondents considered that a greater level of support through additional staffing as well as additional training is the most important prerequisite to enable people with learning disability to access mainstream recreation and leisure. For both respondents whose children presented with physical and intellectual disability, appropriate equipment was deemed to be an important requirement. 'Kind' and 'caring staff' were considered to be important qualities and a 'safe environment' was required to ensure parents are confident when handing over responsibility for their child.

The more severe a disability is the less opportunity for mainstream recreation and leisure inclusion as supports needed will be greater and service providers will be more apprehensive due to their lack of knowledge of the disability. As found in an Inclusion Europe study people with severe disabilities experience major discrimination relating to their opportunities for choice of leisure activities and as a result, their leisure time opportunities are almost exclusively within disability services (2008). Not all young people with learning disability require support to partake in leisure and recreation activities. As one parent of an eleven year old found, young people with more severe impairments may not have an opportunity for inclusion if support is not at hand. 'Sally enjoys playing with friends from her mainstream school but, for health and safety reasons she could not be accommodated in the mainstream summer camp as she would need a carer or Special Needs Assistant (SNA). This made the Summer Camp too expensive so she was accepted in a Special Needs Summer Camp where all the children had learning disability. The level of care was high but she didn't *'know anyone here and she really missed her friends'*.

All of the young people within the study primarily access disability specific recreation and leisure facilities, therapy based leisure within their service providers and through services provided by voluntary disability support groups. This confirms Sutcliffe's findings that people with learning disability spent most of their time outside of their home with other people with a disability (1989). To be included in one's community means having links that will lead to meaningful friendships and familiarity. As a consequence of having a valued social role people will receive more community acceptance and as a result experience greater inclusion. The presence of people with learning disability living and contributing to their community conveys an image of belonging and value for that person.

One third of respondents did not approach mainstream recreation providers and one parent believed her child's disabilities would prevent him from being accepted. *'I didn't know of any other children with disabilities going to the club so I was afraid they would turn him down as they wouldn't be able to cater for his needs'* (Parent of 8yr. old male)

On requesting inclusion for their children parents are often easily put off accessing the service when the provider cites health and safety reasons or staff shortage. Generally parents see this for what it is, a lack of commitment to include young people with a learning disability. One parent approached a mainstream provider to enroll her now sixteen year old son: *'I tried to get him doing gymnastics when he was younger on recommendation from his teacher...she had her own children doing the classes... when I tried to enroll him and they were informed of his needs they refused to take him'*.

People employed within the mainstream leisure services, as Russell points out, believe that any needs of people with learning disability should be provided for by special services (1995). Generally, it was found that there was no level of support within mainstream groups and parents would be concerned for their children within such a setting. One-to-one support was found by parents to be important for their children to avail of mainstream facilities but sufficient resources would not be available. For those who were accepted in mainstream sports clubs, it was found that their children were soon left behind as the competition for success was too great. One mother was asked to take her child home as he was spoiling the camp for other children. Another child was refused swimming instruction. Some of the parents of children with physical disability gave up swimming as the only place for changing was in the office and lifting equipment was inadequate.

The success rate of parents in securing inclusive mainstream recreation and leisure facilities was 11% but they found that when their children reached ten to twelve years old they began to be left behind so they had no alternative but to look for alternative facilities with children of similar ability. No respondent currently accesses mainstream recreation or leisure activities and as a result, they feel excluded and isolated. Gates finds that sourcing special recreation and leisure opportunities for people with learning disability serves to segregate them from society (2003).

All of the respondents avail of separate recreation and leisure for their young people through one of the five groups that have been developed specifically for people with a

disability in the County Cork town. Knowledge and skills are important factors for people who work with people with intellectual disability and as some of the groups are organised and run by parents then they are deemed to have an understanding of the needs of people with intellectual disability. From the in-depth interviews, it emerged that parents felt more secure using separate recreation and leisure facilities for their children and were reluctant to approach mainstream providers. Russell believes that the attitudes of able-bodied people are the greatest challenges to developing leisure activities for people with learning disability, (1995) and this is borne out by the findings of his research.

All young people like to socialise with their peers and young people with intellectual disability are no different. Tony (not his real name) did not want his parents to attend the club with him and liked the company of his peers of typical ability who came to help out at the club. From the views of young people with intellectual disability it was found that few have friends in their own communities outside of their families. Most of the young people currently socialise with their parents. Young people who rely on the support of their family to socialise are often obliged to accept the parents' taste in entertainment; they are often unable to pursue their own interests if family members are unable to be present for supervision. Young people who have a learning disability are generally unaware that they are excluded, they seldom question why they cannot join a club or take part in various activities, but this does not mean that their needs should be ignored by the providers of such services, the people who fund them or even the policymakers.

Challenges within the Research

Many of the target group had poor or in some cases no communication necessitating parental interviews. The young people who were interviewed dictated the duration of the interview as their concentration span was quite short. Some parents present with their child for the duration of the interview attempted to prompt the child which did not give a true reflection of the child's experience. A small number of respondents appeared to have felt inhibited by the presence of their parents at the interview and were reluctant to give their own independent answer. As the young people within the

study were members of a Special Needs Activity Group all of their social activities occurred within that group. Any further research in this area would require a broader sample selection with consideration given to targeting research subjects through mainstream education.

Recommendations

For people with learning disability to lead fulfilling and meaningful lives they must be supported and encouraged to become mainstream participants in recreation and leisure activities. More opportunities must be provided for young people with intellectual disability to access mainstream leisure and recreational activities. Increased opportunities for participation should be encouraged and practical help available to ensure people can avail of the service. There is also a great need for inclusiveness training for recreation and leisure providers as it seems a lack of knowledge exists which discourages providers from accepting young people with learning disability.

It is the function of the Local Authorities in Ireland to provide recreation and leisure activities and they also grant aid many of these services. All grants to recreation and leisure services should come with a provision to accommodate the needs of people with intellectual disability and to be responsive to their interests so they can have real choice. It would be good to think that leisure providers would have the interests of people with intellectual disability at heart but this is not always the case and in Ireland today families gather the support of family and friends to facilitate the social integration of the person with learning disability. This gives a certain amount of independence from family and an opportunity to use ordinary leisure facilities in the community while making new friends. Removing the socially constructed disabling barriers within recreation and leisure will advance opportunities for people with intellectual disability and allow them to improve their life chances, give them a better quality of life and create a more inclusive society.

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