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STUDENT PERSPECTIVES

A Case Study of a Parents' Self-advocacy Group in Malta. The Concepts of 'Inclusion, Exclusion and Disabling Barriers' are Analysed in the Relationship that Parents have with Professionals

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ABSTRACT *This paper attempts to develop a conceptual framework to understand how parents of a particular support and self-advocacy group in Malta, the **National Parents' Society for Persons with Disability**, experience difference and difficulty. The objective of this case study with the **Parents' Society** is to: (1) explore the historical and social context; (2) examine the concepts of inclusion and exclusion; (3) analyse the relationship between parents and professionals, from the former's point of view; (4) define whether the disabling barriers of parents are an issue of voice impediment.*

*Ultimately, the purpose of this paper is to reflect on the experience of parents in this group. The tools used to validate this paper are literature review, my own experiences and involvement with the **Parents' Society**, documentation review and a mail questionnaire.*

Prelude

My difficulty (as a mum) is not in the acceptance of my son's differences, but in accepting society's need to try and remould him into something within an 'acceptable norm' ... To discover the world in the way that is easiest/acceptable for him. He is a remarkable individual, and doesn't need changing. The forces outside of him apply so much pressure, and can be isolating (Dixon, 12-2-1999, E-mail).

Parents are increasingly dissatisfied with professionally regulated provision. Respondents in my research shared the negative experiences they had with professionals:

Family B: We were cheated into having to operate our daughter in a private clinic ...

Family F: Because my son was disabled I did not receive the appropriate medical attention ...

Family C: We pay a lot of money. Some doctors do not listen to what we have to say

Family G: Professionals do not keep to what we would have talked about.

This has increased pressure on the disabled community to put pressure on their organisations for control of the services on which they are compelled to rely on (Oliver & Barnes, 1998, p. 9). The Parents' Society has sought to counteract professional dominance consistently through its political activities.

Introduction

Organisations of disabled people and parents in Malta are refusing or carefully selecting *supporters* to help them run their organisations. Following the most recent Annual General Meeting of this Group, I wrote the following in my research diary:

Today we had the Parents' Society Annual General Meeting. Everything went on really well ... Following the AGM as I was going home, a parent accused me that what I said during the committee meetings was considered important whilst in her case she felt that she had to struggle to be understood. To say the truth I got rather upset at her comments, however, I kept asking myself whether somewhere along the way she was right. Maybe I was considered an ally to some and an adversary to others. (Azzopardi, 1999a)

Professionals consider most parents to be hostile. They are categorised as either parents who are able to get into a partnership 'with them', creating little to no resistance or parents that make life 'difficult' for professionals because they ask, expect answers and demand quality assurance.

Parents in this Group seem to feel pushed and pulled in different directions. They become resistant, perplexed and cynical about such ideas as representation and self-advocacy. They see themselves in a continuous power struggle with professionals. The oppressive discourse from professionals makes it difficult to keep open the possibility that these two polarities can form a partnership (Clare, 1990). Professional discourse is controlled through the use of language (Fulcher, 1999).

To function, this Group has developed its own ethos. What is exciting about this support group is their willingness and ability to develop their thinking, priorities and concepts (Gold, 1994, p. 451).

Self-advocacy needs to be seen as a process of societal adjustment to the requirements of the disabled minority and not *vice versa*. Membership to the community should not be conditioned by standards established by the majority but

a celebration of diversity. That is why the Parents' Society is compelled to be a 'self-advocacy' and a 'support' group.

Self-advocacy is a very important notion closely tied up to the mission of the Parents' Society. Fundamentally, this is a process with the objective of guaranteeing progress in life at an individual and group level. The principle which guides any self-advocacy group is the experience that members of the Group find themselves in "may be interpreted not as a personal misfortune but as a problem of Society's reactions to this group" (Finlay & Lyons, 1998, p. 39). So what brings the people together as support develops in self-advocacy to react proactively to issues that are precipitated by society. Although what defines 'self-advocacy' and 'support' are not identical, the underlying framework is common. Mitchell (1997, p. 46) says that activities of groups can,

"... include:

- speaking up for yourself;
- having options and making choices;
- being listened to and taken seriously;
- learning new skills;
- personal development;
- helping and representing others;
- getting information;
- not being treated as a child;
- rights and responsibilities;
- taking risks;
- influencing services;
- changing attitudes and labels;
- taking up specific issues;
- social contact and support ..."

The fundamental target of the Parents' Society is to support from birth, disabled children and their families by helping, supporting and educating parents, thus enabling them to overcome the challenges and pressures that society imposes on them. The Parent's Society acts as a medium between disabled people, parents and the official authorities and professionals (National Parents' Society for Persons with Disability, 1999, p. 1; Barton & Armstrong, 1999).

Stigma towards parents is the result of society at large and professionals' attitude specifically. It is clear from the outcomes of my research that professionals have a 'detached and clinical' understanding of disability, encouraging disabling barriers rather than providing parents with the right type of support.

The professional dominance in such organisations is still evident. The scope of this Group at the time was to develop special education provisions. As Armstrong says

History is contested not only in the struggles that are recorded but also in the voices that are represented in its telling ... 'otherness' and exclusion have been created through the system of categorisation that has developed (Barton & Armstrong, 1999, p. 9).

Parents have moved from encouraging and advocating for segregation to integration, from normalisation to inclusion, continually finding ways how to interpret the needs in the particular historical context.

The Social Context of the Group

The Parents' Society has always seen professionals as 'active accomodators' to attach and encourage parents to be 'actively receptive' to a 'dominant discourse'. In a social context, professionalism takes on the character of "language intermediary" (Corbett, 1998, p. 59). The social context can be explored twofold:

- (1) 'the internal concept' which members of the Parents' Society 'have of their own capacities and their' experiences 'of how they fit into the social world',
- (2) 'the social context in which they are acting out their' expectations from those 'not labelled as *other*'.

Families need to speak up for themselves. They need to see the urgency of their situation. They are required to realise that discourse is to be developed by them. Self-advocacy has the objective of enabling and equipping politically the individual. Self-advocacy is an end in itself, where people find themselves more equipped to take their own decisions, thus 'gaining autonomy' (Mitchell, 1997, p. 44).

Parents are often too tired, exhausted and cynical to be concerned about self-advocacy (Mitchell, 1997). My research (Azzopardi, 1999b) shows that 31 respondents (or 63%) joined the Parents' Society "to be able to voice our thoughts to the authorities" and 35 respondents (or 71%) joined to "fight for the rights of our son/daughter". Family T., in 'other comments' said: "Each member of the group will strengthen the group. The stronger the group the higher the chance to raise public awareness ..."

My Involvement with the Parents' Society

Since the onset of my involvement with this Group, I have questioned the issue of 'power' and the role I am to assume in this organisation. The Group gave me the responsibility to be their Advisor.

Oliver (1990) has very clear ideas about professionalisation that is taking place in groups. He believes that professionals are oriented towards rehabilitating the individual to normality. Goodley (1997) goes on to challenge an important aspect of the professional discourse. Professionals seem to be rooted in an oppressive routine.

Having a vigorous self-advocate involvement is crucial. The role I assume is a very complex one. I realise that I am an *outsider* and that my only right for involvement is determined and conditioned by this minority itself. However, the roles I find myself assuming are "collaborator", "advocate", "emotional support", "education" and "resource person" (Singer *et al.*, 1996, p. 97)

But what are parents expecting from professionals? In the January 1993 Newsletter, the Parents' Society considered the professionals' role as an informative and a formative one. They are there to 'offer' a diagnosis and provide parents with the support necessary to develop programmes, which can enhance their children's life style.

Gillman *et al.* (1997, p. 675) discussed in depth the professional discourse. Certain disciplines emanating from the medical field, psychology realm and social work seem to condition the value of truth. Their dominant discourses lead to 'individualism, meritocracy and consumerism'. It seems that people are considered 'clients' and the relationship is processed through conceptual and academic frameworks. This process in itself destabilises the power relation and creates a struggle between professionals and parents both working hard to claim territory, recognition and control. Conceptual frameworks initiate professionals and parents often lose their *voice* due to the lack of dialogue and interpersonal relationships (Booth & Ainscow, 1998, p. 48).

Inclusion and Exclusion

The Parents' Society perceive 'inclusion' as a fundamental principle to social understanding and respect. It is about a community for all, a society that is ready to groom away its disrespect, where the individual (against individualism) is seen as a whole. Inclusion as Barton and Armstrong (1999, p. 29) say is not an abstract concept but a 'policy discourse' that has different interpretations depending on the 'historical context' it reads. The Parents' Society seems to interpret inclusion as a 'socio-political oppression' and struggle. The Parents' Society interprets inclusion and exclusion as being two opposing polarities.

To opt for 'inclusion' is to swim against the tide (Rouse & Florian, 1997). Discourse is the fundamental tool for effective dialogue and evolution of thinking. It determines how situations are analysed. Extensive debate has been going on regards the issue of 'inclusion'. We have a wealth of theories, concepts and definitions (Corbett, 1998, p. 52).

Fulcher (1999) considers four meaningful debates on inclusion: "medical, lay, charity and rights, all of which are relevant to the discourse on inclusion". Inclusion values difference and creates a climate of tolerance and social equity where individual qualities are given resonance. Probably one of the main features that reinforce and strengthen 'inclusion' as opposed to 'exclusion' is 'information'.

Services have often assumed disapproving roles, especially at the time of early stages when parents are informed about the new reality that they are going to experience. It seems that parents are given little information and are left in the dark. Parents often pass through phases in their life where they have to plan their day in minute detail. The 'rigid schedules' to get their duties completed deposits a lot of pressure on them. Domestic tasks, parental duties and self-directed activities make their days long and stressful (Todd & Shearn, 1996, p. 385). Inclusion is a decision to overthrow exclusion, to choose equity against excellence and choice against planning (Rouse & Florian, 1997).

Conclusion

The Parents' Society needs to develop its political lobby and remain in continuous dialogue with parents. One way of doing this is by being organised in smaller

issue-focused committees (Sherman Heyl, 1998, p. 694; Jaeger & Jaeger, 1988, p. 166).

Parents find themselves having to squeeze their life in a time frame that is conditioned by day and family support services (Todd & Shearn, 1996, p. 390). The time frame offered to parents is hardly convenient and meets the needs of the service agencies rather than the requirements of parents.

This case study of the Parents' Society was a representation of the importance of the historical and social context when developing a conceptual understanding of a support group. Inclusion and exclusion are the foundation of the discourse on *voice* in relation to parent-professional relationships and how these can develop or obliterate disabling barriers. The Parents' Society is clearly indicating a need for family-focused services, where professionals exercise a more supportive and informative role, whilst parents take on a directive role. In other words parents are looking more at 'collaborative relationships'. The Parents' Society members' still experience barriers, limited resources and are restricted in their ability to control aspects of their lives (Singer *et al.*, 1996). Altering the power relationship between professionals and the parents is probably the biggest challenge that this support group has.

Summary

The principle outcomes of this paper are:

- parents of disabled children provide each other with support within the Group;
- all families interviewed recognise the essential and necessary role of professionals in their life;
- professionals are still highly involved in the life, function, administration of the Group;
- professionals can and do play a very important role. They offer encouragement, support and practical assistance, such as the means of contacting other parents, liaison with the medical system, provision of meeting space and willingness to act as a technical advisers, especially when medical, legal or social advice is needed by parents;
- the Parent's Society is not an impaired-based group even though the great majority of families have disabled members with learning difficulties;
- what started as a support group moved towards meeting diverse requirements. It is now extensively involved in self-advocacy and is starting an activist approach to issues (Wilson, 1988; Drake, 1999).

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* Over 3,000 sheets of documents of the Parents' Society were analysed. This documentation included minutes, correspondence and circulars/newsletters.

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