

## YOUNG DISABLED PEOPLE

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### Speaking Up For Yourself

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In this chapter we are examining the realisation of identity, by young disabled people, not just as adults, but as disabled adults. Mason expresses this as follows:

*“My disability is a fundamental factor in the being that is “me”. I do not want to deny this by calling myself “a person with special needs” or any other euphemism, nor do I want to deny the collective identity we have achieved ourselves. Therefore I am a disabled person, and proud of it.” (1992, 22)*

The realisation of adult status is recognised in our society through criteria such as physical maturity, personal autonomy, employment and leaving the parental home.

‘Disabled adulthood’ is realised through identity with disabled

people as an oppressed minority whose adult rights of full citizenship are denied.

The social and historical context for exploring the way that young disabled people have in their lives can be looked at broadly, particularly in terms of relevant legislation such as the Children's Act, but also more specifically in terms of the growth of the Disability Movement. Taking a broader view first, the dominant ideology emphasises the rights of the 'consumer', 'client' or 'service user' to have choice. The market orientation and minimalist intervention of state policies put the onus on individuals in terms of rights, and of course responsibilities, to compete for their share of scarce resources and services. It is in this context that such terms as 'self-advocacy' and 'empowerment' have gained easy currency. As Garner and Sandow (1995) state, "the political system itself generates advocacy and self-advocacy" (p 6). This individual model of voice in decision making has been easily incorporated into and reinforced by the individual models of disability which are readily apparent in the terminology of 'assessing needs' and 'individual programmes'. In the broader social and historical context,

the voice of the individual young disabled person may be recognised, but it competes against all the barriers he or she faces being both young and disabled.

The past 20 years or so, however, have also seen the growth of the collective voice of disabled people in this country and internationally. There are many ways of understanding this 'disability movement'. In organisational terms the movement has been established through the growth of many small organisations, throughout the world, run and controlled by disabled people themselves. Umbrella organisations have been founded in more recent years, including the British Council of Organisations of Disabled People and the Disabled People's International, both in 1981 (French, 1994). In ideological terms, the movement has developed and promoted a social model, in which disability is understood as a social rather than an individual condition. Disabled people have shifted the focus to the barriers faced in a society geared by and for non-disabled people: barriers which exclude disabled people from full active citizenship. The barriers pervade every aspect of the physical and social environment: attitudes, institutions, language and culture,

organisation and delivery of support services, and the power relations and structures of which society is constituted (Swain et.al., 1993). In activity terms, the movement is diverse, but has included campaigns for anti-discrimination in Britain.

Concentrating on education, Whitney states:

*Children have few rights at school. They have no right to see their personal files until they are 16 and even then few schools seem to make the facility available, so they have little opportunity to challenge what others have said about them. (1993)*

Young people under 18 are even banned by law (section 15 of the 1986 Education Act) from participation on governing bodies and are thus excluded from formal participation in educational decision making. The exclusion faced by young people generally is reinforced for young disabled people by the dominance of individual models of disability. Young disabled people, suggests Oliver:

*“see themselves as pitiful because they are socialised into accepting disability as a tragedy personal to them. This occurs because teachers like other professionals also hold to this view of disability, curriculum materials portray disabled people (if they appear at all) as pathetic victim or arch villains.” (1990, 92)*

The contrast of individual and collective voices is particularly apparent in ideas and practices relating to the integration of young disabled people in mainstream schools. A say for an individual young disabled person would, in theory, involve inclusion in placement decisions and in determining the necessary support and facilities for integration. A say for the collective voice of disabled people, however, would involve the recognition of disability culture, the inclusion of the representative voice of disabled people in formal educational decision making, and the promotion of a social model of disability as integral to the processes, relationships and content of education.

## Supporting The Voices Of Young Disabled People

The context for supporting the voice of young disabled people, then, is one of considerable barriers, but is also, in the wake of the burgeoning disability movement, a context for developing strategies and possibilities. There have been many developments in this direction, often under the umbrella terms of “empowerment” and “partnership”. Williams conveys this ‘new foundation for professional practice’ as follows:

*For professionals who have trained for many years to acquire a body of expert knowledge and entry to the profession, to challenge the pre-eminence of their professional knowledge base constitutes a grave threat. It removes power from them and hands it over to the client; and locates their base of power with their clients rather than with their professional body. (1993: 12)*

This shift of power can be seen, at least in principle, in ‘alternative approaches’ (Greasley, 1995) to individual planning with people with learning difficulties. These approaches, including Shared Action Planning (Brechin and

Swain, 1987) and Personal Futures Planning (O'Brien and Lovett, 1992), place greater emphasis on the principles of self-advocacy and a greater role being played by the person in planning their own futures. A social model is espoused:

*From the individual's perspective the problem is not so much the difficulties with learning, the struggles to acquire social skills, or the medical explanations for their problems. The problems they see are the difficulties and obstacles people put in their way; the experiences, opportunities (or lack of them), attitudes and conditions of society they have to face as a result of being labelled 'mentally handicapped'.*

(1987: 84)

Personal Futures Planning has a similar orientation and also emphasises the importance of informal support from 'non-service providers'. There are also a number of practical examples of pupil involvement in the organisation of learning and school organisation (Garner and Sandow, 1995).

Sweeney (1995), for instance, uses drama in an empowering approach drawing on non-verbal communication and the development of self-expression through empathy.

The notion of 'empowerment' is, however, deeply problematic. A damning critique comes from Gomm:

*Those people who say that they are in the business of empowering rarely seem to be giving up their own power; they are usually giving up someone else's and they may actually be increasing their own.*

(1993: 137)

In the above examples of supporting the voice of young disabled people, empowerment is seen largely as an individual rather than a collective process. Oliver (1993) argues that, for disabled people, it is more realistic to see empowerment as a collective process. Examples of strategies to support the collective voice of young disabled people are more difficult to find.

*Moving On* is a series of courses and follow-up days in the early 90s for young people with learning difficulties and with physical impairments, run by *Skills for People*, a self-advocacy organisation in Newcastle upon Tyne. The courses have been planned, presented and evaluated by young people themselves in teams drawn from schools and colleges in the area. The overall aim has been to help young

people to speak up for themselves, and topics covered have included “rights and responsibilities”, “making choices” and “listening”.

The recorded evaluations of the planning teams emphasize the importance of collective identity and voice.

*“It gives students a chance to get together.”*

*“Planning it ourselves is important. It is our own and the teachers do not plan it for us.”*

*“We made our own rules. We sorted out our own problems . . . instead of getting someone to do it for us, like in school.”*

This has provided the context for personal empowerment.

*“I know now that we all have our opinions and decisions that we have to make. That is why speaking up for yourself is important.”*

*“There was one time when I would not have been able to go into the office and ask for my money, but I do now.”*

Ultimately it has to be asked whether would-be supporters of the voice of young disabled people, notwithstanding their good intentions, prepare young disabled people for life as

disabled adults who are conscious of their identity as disabled people, and of the struggle for full participative citizenship in our society. Though it is questionable whether the collective voice of disabled people is supported by individualised strategies, it would seem that individual young disabled people are empowered by experience of contributing to, and articulating their own views within, a collective voice.

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