Learning disabilities: Socio-cultural context and inclusion. A comparative study between Greece and Wales.

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Learning Disabilities:

Socio-Cultural Context and Inclusion

A comparative study between Greece and Wales

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Sylvia van Maastricht

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Summary:

This study looks at learning disabilities in socio-cultural context. It does so by comparing the experiences of two small groups of people that each attend a day centre for adults locally considered as having learning disabilities. One of these centres is on the Greek island of Aniksi, the other in the small Welsh town of Ffynnon. It considers what goes on in these centres, the processes of classification that have lead to admission to the service, the experiences of the people that attend them and their parents. By examining the lives of individual people in local context, in particular in the area of work, socio-cultural elements have been identified that contribute to or act as barriers to their inclusion. I hope that this research will further understanding of their lives and the forces that shape them.

INDEX

CHAPTER THREE: TWO CENTRES

CHAPTER FOUR: THE PARENTS' STORIES

Part A: Aniksi

Part B: Ffynnon

CHAPTER SEVEN: INDIVIDUAL LIVES

CHAPTER EIGHT: SUMMARY AND DISCUSSION

intellectual disabilities, were cared for by their families or by charitable patrons (Whyte 1995: 269). Individuals with a mental handicap who posed no threat to society were treated as "les enfants de bon dieu" and allowed to roam the streets of Europe unharmed, sometimes posing as jesters or acting the fool. What happened to those who where perceived as dangerous is not clear. People with intellectual disabilities did not appear to have any social function or identity as a distinct group (Whyte 1995: 269).

In early modern Europe, impairment and infirmity became objects for more extended scientific and medical discourse. Special institutions for disabled people were established, for example the Hotel Des Invalides in Paris for invalid soldiers in 1674 (Whyte1995: 269). Lack of sufficient evidence makes it impossible to draw extensive conclusions on the prevalence and treatment of people with intellectual disabilities up until this time in history. It appears that 'intellectual' disability was recognised in some form or other across different societies but I have found no evidence of widespread classification and treatment of this as a separate category.

At the start of the 18th Century, most people with motor and/or intellectual disabilities in Europe were cared for by their families. Only if they were unable to do so were people handed over to institutions (Whyte 1995: 270). Institutional care initially meant care in the sense of 'looking after' and/or 'protecting society'. Scientific attention focussed on the symptoms, causes and classification of various conditions that up until then had fallen under a few broad categories (i.e. idiocy, deafness, dumbness, blindness and incurable conditions). Descriptive data began to reveal differences between these categories (Manion and Bersani 1987: 233). Cretinism was described in Switzerland, an account seen by many as the first scientific account of mental retardation (van Gennep 1980). Little however was said about possible treatment of people thus afflicted.

During the second half of the 18th century the American and French Revolutions introduced new social attitudes and the idea that all persons are fundamentally equal with the right to a humane existence, while the Renaissance and the Enlightenment had brought a renewed interest in education and humanitarianism. Ideas on and theories of education or re-education of disabled people started to develop during this period (van Gennep 1980; Ingstad 1995: 210). Different ideas on the role of society and education in the development of the human person led to the nature/nurture debate through Locke and Rousseau, a debate that continues into modern times. Locke believed that idiocy was related to the efficiency with which individuals sorted 'ideas': "it is from the incapacity for abstract thinking that the modern idiot classification flows" (Goodey 1995: 244-245). These theories would eventually lead to beliefs that intellectual disabilities or 'idiocy' may be treated, or at least its effects minimised.

The nineteenth century

Itard's ideas on and treatment of Victor, the "wild boy of Aveyron", reflected the growing optimism and belief in the treatment of 'idiots'. Itard devised an education and socialisation programme for the boy, who could not speak. It showed that even low functioning children can be encouraged and stimulated in their personal development (Jak1988; van Gennep 1980). The teacher Sequine, a follower of Itard, wrote the first special pedagogy for the mentally retarded: "Traitment moral, hygiene et education des Idiots et des autres enfants arrieres". He pleaded for the moral education of these individuals as opposed to pure physical and medical care (Jak 1988; Miller 1995; van Gennep 1980).

The first institutions for 'idiots' appeared during the period between 1800 and 1850. Initiated and headed by doctors, educationalists and clergy they were based on a variety of optimistic, theoretical considerations in relation to the nature and possible treatment of mental retardation (Jak 1988; van Gennep 1980). Mental retardation in the nineteenth century was also a social problem. Developing capitalism, the Industrial Revolution and a great move towards the cities meant a decline of the old work and family structures. This may well have influenced the position of the non-productive members of society and played a role in their increasing institutionalisation (Digby 1996; Manion and Bersani 1987; Oliver 1990; Thom 1995). "Although early Victorian asylum superintendents had discharged the weak-minded without apparently seeing them as a threat to society, from the late 1860's by contrast there were demands for the certification and institutional isolation of the mentally retarded" (Digby 1996: 6). Many institutions of that time were run by the church and other charities (Digby 1996). They reflected the view of the person with learning disabilities as an object of pity and charity.

In the United States similar developments took place. Institutions for people with intellectual disabilities emerged based on humanitarian principles, and on an educational philosophy that stressed the importance of the environment in human interaction (Manion and Bersani 1987: 234). At the end of the 19th century the need to identify, control and educate the 'mentally handicapped' became a matter of increasing urgency, both in Europe and in the U.S.A (Thom 1995: 251).

The intelligence test, eugenics and a medical classification

In 1906, in Paris, Simon and Binet published the first true intelligence scale (Ingalls 1978, van Gennep 1980). Binet, a psychologist, had been commissioned by the Minister of Public Education in Paris to develop a test that would detect children in need of special education. The intelligence test was to serve the needs of the child with learning disabilities as well as the schools. Binet's thinking was in line with the prevailing medical view which locates learning disabilities within the individual. He also believed that something could be done to improve or even cure the child.

> Binet argued that mental handicap could be measured, but he also argued that it could be cured, in that such children could be helped. In this respect he differed from those of his contemporaries and successors who took the concept of measurable intelligence and allied it with theories of degeneration and the assumption that this measurable quality was a permanent thing, innate in the individual (Thom 1995: 253).

With the help of further improved intelligence tests, great numbers of children in Europe and the U.S. were classified as retarded, rejected from mainstream schools and sent to attend segregated, special education (Scheerenberger 1987; Thom 1995). An influence from sociology may also have contributed to the increased and widespread use of intelligence tests. In 1914 the American sociologist Goddard published his study of the family tree and lines of heritage of the Kallilak family (Liebert, Poulos and Marmor 1977: 79). Influenced by the works of Darwin and Galton he attempted to prove that intellectual disabilities are hereditary, related to poverty, and the cause of social deviance and criminality. While the classification of children and adults with learning disabilities may, in many cases, have improved their situation through special education and programmes the notion of genetic determination and possible related social degeneration was to have far reaching consequences of a very different nature.

Eugenic sterilisation and extermination as a way to produce a superior race inspired Hitler and his Nazi regime (van Gennep 1980). The 1933 National Socialist policy of sterilisation in Germany, however, was by no means unique. In the United States, 27 states had already passed a law encouraging the sterilization of so-called mentally defective persons and by 1928 some 15,000 men and 8,000 women had been sterilised. In Britain such policies were discussed but discounted although some operations were carried out on an individual basis. In Denmark, abortion and sterilisation of people with learning disabilities had been introduced but remained voluntary, with little uptake (Thom 1995: 255). Back in Hitler's Germany, between December 1939 and August 1941 more than 100.000 people were murdered, 80.000 of whom were psychiatric patients and people with intellectual disabilities (van Gennep 1980: 44-45). At present, while no such extremes are found, ante-natal scans to detect disability and the abortion of babies with, for example, Down's syndrome or spina bifida is accepted practice in many European countries.

Policies and laws of a different nature, the mental deficiency acts in the U.K. and the United States, instigated the growth of special services and the appearance of new medical and psychological professionals with an interest in mental handicap (Thom 1995: 253). These legislative acts reflected the increasing responsibility governments had assumed for the care and treatment of people with learning disabilities and supported the notion of segregation. Large numbers of people were locked up together, with minimal care, poor accommodation and little respect for human dignity (Jak 1988; Ryan and Thomas 1980; van Gennep 1980). The dominant theoretical view continued to be a medical model or 'defect theory' (Oliver 1990, van Gennep

1980). This locates the cause of learning disabilities within the individual, who needs to be diagnosed or categorised and receive special care and treatment.

Normalisation and social role valorisation

After the Second World War special provisions for children and adults with learning disabilities in Britain and the United States continued to grow. Politically, the policies of the so called welfare state were aimed at meeting peoples' basic needs in social security, social and health services, education and housing through public measures (Blomberg 2003). They reflected the notion that the weak need to be cared for as a responsibility of the state (Oliver 1990; Oliver and Barnes 2002). Compulsory medical inspection on school entry led to separate care and education for those defined as handicapped (Thom 1995: 256-257). Many people with learning disabilities, both in Western Europe and in the United States, were cared for in large institutions or hospitals. The conditions within these institutions were often far from humane which led to criticism from practical, theoretical and political origin (Atherton 2003; Malin, Manthorpe, Race and Wilmot 2000; Scheerenberger 1987). In June 1959 the Danish government passed an act, which proposes to 'normalise' the lives of those who were mentally retarded (Emerson 2001; Scheerenberger 1987: 116). Nikkelsen and Nirje proposed a lifestyle for people with learning disabilities, which was very different from prevailing institutional practices. Early Scandinavian approaches to normalisation focussed on the rights of people with learning disabilities as well as on the nature of services that should be provided for them. Their philosophy was that "patterns of ordinary living should as much as possible be made available to people with intellectual disabilities" (van Gennep 1980: 89; Hattersley 1991: 1) and "they advocate that services should seek to maximise the quality of life of service users by reproducing the lifestyle experienced by non-disabled citizens" (Emerson 2001: 2). In the United States the ideas of normalisation were further developed by psychologist Wolf Wolfensberger, who himself had worked in various institutional settings (Scheerenberger 1987). In his influential book *The Principle of Normalization in Human Services* (1972) Wolfensberger argued that existing state facilities had merely drawn attention to the negative or devalued qualities of mentally retarded individuals. A new initiative was needed to provide an appropriate framework for human dignity (Digby 1996: 15). The normalisation principles advocated by Wolfensberger expanded on the ideas of Nirje (Emerson 2001; Hattersley 1991; Scheerenberger 1987; van Gennep 1980).

The original focus of 'normalisation' had been the improvement of the quality of life for people with intellectual disabilities as well as the physical environment of the institutions in which they were living (Emerson 2001; Hattersley 1991; Scheerenberger 1987). For Wolfensberger, however, reforming institutional life was not enough: re-integration within society was an important condition within his version of normalisation. De-institutionalisation was advocated by Wolfensberger as a way of socially integrating people with learning disabilities who would thus acquire freedom, independence, individuality, mobility, personalised life experiences and a high degree of interaction in a free society (Scheerenberger 1987: 241).

In addition to de-institutionalisation, Wolfensberger drew attention to the behaviour of mentally retarded persons. In his view normalisation should include the aim "to normalise to the greatest extent possible the conduct of socially perceived deviant mentally retarded people" (Scheerenberger 1987: 119). In 1983, Wolfensberger tried to redefine and clarify the concept of normalisation. His attempt to re-name it as social role valorisation reflects the perception of 'learning disabilities' as a devalued social role (Race 1999; Scheerenberger 1987). Wolfensberger drew heavily upon contemporary developments in sociological thinking. Historically, sociology had largely endorsed the medical model of deviance, which explains deviant behaviour as the result of innate characteristics of deviant individuals (Alaszewski and Ong 1991: 13). In the late 1950s and 1960s sociologists began to challenge this view. Their focus was the social processes and interactions that lead to the category of disability and the resulting social roles of deviant, in this case disabled, persons (Alaszewski and Ong 1991; Goffman 1990; Oliver 1990; van Gennep 1980; Scheerenberger 1987). "The fact that being cast into a specific social role inexorably results in the individual fulfilling the expectations associated with that role, is a dominant theme within normalisation and social role valorisation" (Emerson 2001: 6).

An important concept in this context is stigma; a label or attribute that is deeply discrediting and affects the social perception and treatment of the stigmatized person to such an extent that even his or her full humanity may be contested (Goffman 1990: 13-15). "By definition, of course, we believe the person with a stigma is not quite human . . . and on this assumption we exercise varieties of discrimination . . ." (Goffman 1990:15). Social role valorisation theory is based on the principles discussed above. It describes the devalued roles forced upon people with learning disabilities. It looks at characteristics related to these roles and thus ascribed to these persons. Furthermore, it suggests that people with learning disabilities experience certain 'wounds' as a result of the devaluation process. Finally, it attempts to identify and analyse factors affecting the degree of devaluation (Race 1999: 37). Social role valorisation theory has been claimed as a means of further understanding the processes of devaluation, as well as a tool to combat devaluation through enhancement of the social roles of people with learning disabilities (Race 1999).

De-institutionalisation and community care

From the 1970's onwards, normalisation theory greatly influenced the care and treatment of people with learning disabilities, firstly in the United States and later in Britain and other western European countries. Criticism of inhumane practices in large institutions, pressures from growing parent movements, increasing difficulties for the welfare state to provide all it had planned or promised to provide and a growing civil rights movement formed the political and social context in which normalisation and de-institutionalisation took hold (Atherton 2003; Malin, Manthorpe, Race and Wilmot 2000; Tyne 2001; Whitehead 2001). In the United States, professionals, parents and politicians sought complete closure of large institutions. In legal terms, it became increasingly difficult for people with learning disabilities to be placed under court order. It was stipulated that admission to residential facilities would be discouraged unless all other community resources had been exhausted (Scheerenberger 1987: 243). In reality, however, it proved easier to close large institutions than to provide appropriate resources and programmes within the community. The policy of de-institutionalisation of mentally retarded persons in the United States was a mixture of failure and success. Yet, gains in alternative living situations were made and some historical attitudes were altered, in particular in relation to mentally retarded children (Scheerenberger 1987: 250). "For many – especially the more mildly affected, deinstitutionalisation, while rarely perfect in all aspects, did offer a new sense of freedom, self-worth and happiness" (Scheerenberger 1987: 254).

In the U.K., official and unofficial reports revealed to the public for the first time the sordid results of public neglect and under financing in many long stay hospitals (Atherton 2003; Malin, Manthorpe, Race and Wilmot 2000). British studies also supported anti-institutional criticism of hospital patterns of care in general, which Goffman (1991) had described as being characterised by rigidity, block treatment, depersonalisation and social distance between staff and patients and by a loss of social roles for the inmates of these institutions (Goffman 1991; Malin, Manthorpe, Race and Wilmot 2000). Criticism from both theory and practice, as well as pressure from parent organisations led to a government policy of de-institutionalisation and community care or “care outside large institutions” (Atherton 2003; Malin, Manthorpe, Race and Wilmot 2000: 3). This concept became well known in the field of learning disabilities. In practice, the numbers of residential homes and daycentres for people with learning disabilities has increased and most of the long stay hospitals have now been closed. The Department of Health’s White Paper, *Valuing People* (2001), advocated a reduction of 50% in hospital places in the U.K. by 1991 and an increase in the provision of local authority based residential and day care (Atherton 2003: 53-56). The NHS and Community Care Act of 1990 was aimed at providing the support necessary to enable people to remain in their own homes where possible, thereby reducing the demand for long term residential care (Atherton 2003: 55). Since then, government policies and legislation have been aimed at further improving the position of and services for people with learning disabilities.

The generally promoted idea is to enable and encourage people with learning disabilities to lead ‘as normal a life as possible. Community based services, special education and related resources for mainstream education, social and leisure clubs for people with learning disabilities, special benefits and allowances, community hostels and group homes have been set up on the premise that they facilitate and support normalisation and integration into the community (Atherton 2003: 56; Ingstad 1995; Jenkins 1998; Whyte 1995).

Yet, as in the United States, the above does not automatically mean that the majority of people with learning disabilities are now fully (re)-integrated within the rest of society. "The extent to which the individual needs of people with learning disabilities are being met in a climate of true acceptance and inclusion is debatable."(Gates 2003:56) Notes of caution have been made by various authors and it has been suggested that two kinds of integration exist. Physical or functional integration assumes a physical presence in the local community and the use of ordinary housing and other community facilities. Social integration or real inclusion means involvement in local community networks, making friends and maintaining relationships and the ability to make choices (Oliver 1990; Race 1999). Physical presence does not automatically imply inclusion. Inclusion also implies rights and recognises that systems and structures within society may need to be changed in order to accommodate people with learning disabilities (Jenkins, Mansell and Northway 2003: 363).

Social Theory

Sociologists studying disability in general, have increasingly questioned the true influence of the principles of normalisation on services for and treatment of (learning) disabled people (Davis 2002; Fulchner 1996:167; McDonald 1991; Oliver 1990, 1996). Two major areas of criticism are the already mentioned lack of true integration or inclusion for people with (learning) disabilities and the control of services. This control is still exercised by non-disabled people; professionals and politicians who decide how much money will be spent, what kind of services are provided and who will be employed within these services (McDonald 1991, Oliver 1990). The source of this criticism lies in the ideological base of the normalisation debate which implies that people with (learning) disabilities should be encouraged to assume the life styles and cultural values of the majority whose roles and status are most valued (Barnes 1996:58). Normalisation does not challenge those lifestyles, nor the social structures and values that accompany them (Barnes 1996; Bayley 1991; Hattersley 1991; Oliver 1990). It is argued that the trend towards 'care in the community' and 'normalisation' is still conditional and that the person with the learning disabilities has to adapt to and play by rules he has not invented (Jenkins 1998) (see also Part B of this chapter).

The alleged failure of the principles of normalisation and social role valorisation theory to challenge the fundamental ideological base of the care and treatment of people with learning disabilities has also been criticised on a theoretical level (Hattersley 1991). Advocates of a social theory of disability argue that Wolfensberger's theory considers deviance and labelling as constructed in interpersonal interactions and as an inevitable consequence of the evolution of society. The underlying structural reasons for this labelling remain unquestioned (Barnes 1996:43). A growing number of British sociologists advocate an alternative theory of disability. Social theory re-conceptualizes (learning) disability as structurally created through ideology and social relations within a context of disabling environments and attitudes, in particular those of a capitalist society (Barnes 1996; Davis 2002; Oliver 1990, 1996) This locates the problem of disability within society rather than within individuals who happen to have impairments. It also has consequences for the treatment of (learning) disability. "Thus, the way to reduce disability is to adjust the social and physical environment to ensure that the needs and rights of people with impairments are met, rather than attempting to change disabled people to fit the existing environment." (French 2002(a): 15). Social theorists, many of them disabled themselves, view social theory as a way towards inclusion and true integration within a society that accepts and respects difference (Barnes 1996; French 2002 (a) and (c); Oliver 1990, 1996).

Sociological interest in disability is now well established. Focussing on the social causes of disability, it has contributed to a shift in attention from the impaired individual to disabling environments and corresponding ideological influences. In practice, a growing disability movement, an increase in the number of organisations run by as opposed to for people with disabilities as well as a greater visibility in public life have impacted on the experience of disabilities. They are also likely to contribute to slowly changing attitudes and services.

Within the field of learning disabilities two initiatives to organise the practice of inclusion for people with learning disabilities are worth mentioning. 'New Dennendal' in Holland (Meyering 1974) and the 'L'Arche' communities which originated in France (Clarke 1980) are both based on the principles that all humans are equal and that people with learning disabilities have the right to live a life according to their individual characteristics, abilities, interests and personalities. Their methods advocate communal living of people with and without disabilities (see also Part B: Culture).

The personal experience of impairment

Not all problems experienced by people with impairments may be solved through a change in social structures and ideology. Failure to include individual experiences of impairment may lead to alienation, or even collude in the oppression, of disabled people by minimising, ignoring or even denying their personal experiences (French 2002(a); Morris 2002(a)). Recently, some sociologists have argued that personal experience of impairment should also be the subject of sociological research and theory. They advocate a social model of disability that includes the personal experience of impairment (Barnes 1996; French 2002(a); Morris 2002(a)). A similar call for a focus on personal experiences and for the participation of disabled people themselves in research has come from the field of learning disabilities. Methods are being developed which address the specific difficulties involved in this participation as active rather than passive subjects. Various studies and collections of papers now include experiences and/or life stories of people with learning disabilities themselves (Atkinson and Williams 1990; Davies 1998; Davies and Jenkins 1993). This contributes to a fuller picture of (the experience of) learning disabilities as well as to more positive personal images than that of the traditional victims of unfortunate circumstances.

Civil Rights Movement

In 1971 the United Nations General Assembly adopted a Declaration on General and Special Rights of the Mentally Retarded, based on the Universal Declaration of Human Rights. Rights however only exist to the degree that they can be exercised. Schemes such as citizen advocacy and self-advocacy groups were developed within the United States to assist people with learning disabilities in speaking up for themselves and to defend their rights. In addition, People First International was established in the state of Oregon in 1974. Its primary membership consists of mentally retarded people who identified themselves as consumers and demanded an input into decisions affecting their lives (Gates 2003; Scheerenberger 1987). The phenomenon of self-advocacy groups, as well as the People First movement spread to many countries including Britain. Within the context of a growing awareness of the rights of people with learning disabilities many day services now operate self-advocacy groups and/or have a policy of consumer participation.

Recent discussions in Britain have focussed on the right to citizenship for people with learning disabilities. While traditional interpretations of citizenship may have created an unattainable status, recent developments in the field suggest that this is not an empty dream. People with learning disabilities who are taught the relevant skills, are able to participate in a meaningful way in decisions about their own lives. They can and do act as active citizens (Walmsley 2002: 259). They often contribute to their community through work in various day placements and through reciprocal caring relationships. They are entitled to political, civil and social rights along with other members of their society (Walmsley 2002). Yet, while in theory people with learning disabilities have been granted human and citizenship rights, many still lead lives that are not comparable to those of other members of their society. People with (learning) disabilities still come at the bottom of the scale in relation to housing, transport, leisure, finances and this is closely related to their dependence on social benefits (Bush 2003; Hirst and Baldwin 1994). The disability movement and advocates of a social theory of disability aim to address these particular issues and highlight that people with disabilities are still discriminated against (Oliver 1990, 1996).

Definition, classification and prevalence

From the historical overview it is clear that the definition and classification of people with learning disabilities in the western world has changed over time. Even today no consensus exists about appropriate terminology; for example 'learning difficulties' means something quite different in the United States than it does in the United Kingdom (Jenkins 1998:8). Labelling terms in the United Kingdom have changed from 'idiocy' to 'feeble-mindedness', to 'mental sub-normality' to 'mental handicap' to 'learning difficulties', and finally, by the Department of Health to 'learning disabilities'. In the United States people with intellectual disabilities have been called 'defectives', 'imbeciles', 'morons', 'mentally retarded persons' and 'persons with a developmental disability' (Jenkins 1998; Miller 1995). One of the reasons for recent changes in definition is the idea that differences in names of the condition influence the self-esteem of the people concerned. This is pursued by various campaigns in western societies such as the Campaign for Mental Handicap in the United Kingdom and self-advocacy movements in Europe and the United States. Categorical ambiguity of this kind may also indicate unease about the nature - the social and ontological status - of the people included (Jenkins 1998: 8).

One of the functions of a definition is the inclusion of some people in a specific category to the exclusion of others. Historically, people who currently may be described as having learning disabilities were grouped amongst other 'deviant' individuals. Psychiatric patients, criminals and homeless people were perceived as similar and in need of care, protection and isolation from the rest of society.

> Although the general tendency at the start of the 19th century was to distinguish between idiocy, on the one hand, and madness on the other, not all authorities were entirely clear about this. There were those who regarded idiocy very much as a variety of madness. This view was also buttressed by the fact that idiots were commonly admitted to asylums for the insane for much of the nineteenth century." (Miller 1995: 215)

This lack of distinction between people with learning disabilities and people with mental illness, or between learning disabilities and physical conditions such as epilepsy and cerebral palsy, continued until quite recently and is still reported from contemporary societies (Edgerton 1970; Jenkins 1998; De Vlieger 1998; Whyte 1995; Zevenbergen 1986).

In Western societies, medical and educational interest had brought about a general distinction between intellectual disabilities and other conditions such as mental illness and criminality. 'Idiocy' had the basic criterion of intellectual failure manifested early in life, to which in the nineteenth century another characteristic was added i.e. some physical characteristics and /or deformities (Jak 1988; Miller 1995). The emphasis was placed either on underlying physical factors or the perceived need for simplified or special education. Under the influence of the intelligence test, the definition of intellectual disability expanded and it became a statistical category linked to I.Q. scores. "Intelligence tests were used extensively during the 1960's and 1970's; however, recognition by psychologists and others of the many limitations of their use has made them less popular today. These limitations include cultural bias, poor predictive ability, and an incomprehensive relevance for the identification of learning disabilities" (Gates and Wilberforce 2003: 5).

Traditional attempts to define mental retardation have thus fallen into three categories: those based on general social incompetence, those based on a physical defect (medical classification) and those based on low I.Q. scores (statistical category) (Ingalls 1978). Definitions currently used in the western world include the following aspects:

1. Impaired intelligence (or ability to understand new or complex information)
2. Impaired social functioning (or ability to cope independently in the areas of communication, self care, social skills, home living, community use, health and safety, leisure and work)
3. Onset before adulthood with lasting effect on the development of the person (Gates and Wilberforce 2003: 7).

The social context of learning disabilities has increasingly been recognised and is reflected in the 'official' distinctions between impairment, handicap and disability.

> Impairment: any loss or abnormality of psychological, physiological or anatomic structure or function
> Disability: any restriction or lack (resulting from an impairment) of ability to perform an activity in the manner or within the range considered normal for a human being.
> Handicap: a disadvantage for a given individual, resulting from an impairment or disability, that limits or prevents the fulfilment of a role that is normal (depending on age, sex and social and cultural factors) for that individual. (WHO 1980 in Ingstad and Whyte 1995: 5)

Thus, impairment may not necessarily mean that the person in question is handicapped. According to the above definition social and cultural context as well as impairment influences the number and nature of persons included in the category of ‘people with learning disabilities’. This raises the question of whether a similar concept of intellectual or learning disabilities exists in other parts of the world (Jenkins 1998). As a consequence of changes in definition over time and place, it is possible that someone classified today as having learning disabilities and treated accordingly, could have been leading an ordinary life had he or she been born in a different time, or have lived in a different place. More recently, advocates of social theory have taken the social aspect of (learning) disabilities further in their suggestion that the category is actually produced by society’s failure to accommodate certain people within its ‘normal’ structures.

The prevalence of intellectual disability is influenced by definition as well as by classification processes (Ziggler and Hodapp 1986; Jenkins 1998). At different times and in different places more or fewer people have fallen under the gaze of the institutional and bureaucratic systems that have been developed to address the problem of intellectual disabilities. About 25% of the modern, Western population of people with intellectual disabilities suffers from a traceable organic dysfunction (Edgerton 1979:49, Ingalls 1978, Jenkins 1998). This generally includes the so called moderately and severely impaired individuals. It is unlikely that definition or processes of classification will make a significant difference in their prevalence. The other 75% may suffer from an as yet unknown organic cause for their disability. It is possible, however, that some of these people would not be visible as such in every cultural setting and their learning disabilities may be socio-culturally defined.

An important factor is the classifying agent. Mercer was one of the first to draw attention to mental retardation as a social status that may be held in one context but not in another, depending on how a person is regarded by others within that context (Scheerenberger 1987). A well known example are the 'six hour' retarded American children who were considered mentally retarded by their teachers and other school personnel, but not by family, friends and neighbours (Ingalls 1978: 77, Scheerenberger 1987). Socio-economic factors can directly influence the number of children classified as intellectually disabled (Jenkins 1998; Luckin 1986; Zevenbergen 1986). Lead poisoning, under nourishment, poor maternity and paediatric care are most prevalent in the poorer parts of the population, whether it is inner city communities in the West or developing countries in the Third World. Each of these factors can lead to physical damage resulting in intellectual disability. Poor parenting and lack of stimulation are also often associated with poverty and may result in developmental delay, which in turn can lead to the classification of having learning disabilities.

Variety within the category is formally recognised in relation to the level of disabilities. Initially, categories were created according to I.Q. level. In 1983 the World Health Organisation (WHO), in the 'Manual on Community Based Rehabilitation for Developing Countries', paid attention to both the disabilities and the abilities of a person:

> Mildly mentally disabled: development appears to be normal until school age, when it is noticed that the child learns with difficulty. A person is able to learn a lot of skills especially practical skills. Possibilities for a career exist and the disabled person is self-sufficient.
>
> Moderately mentally disabled: the child needs special attention during the first years of life, with regard to feeding, personal hygiene, movement and social skills. Sometimes the person is able to read and write. Usually, he/she can be trained for a certain job, especially those that are practical and routine directed. They are able to live independently with some help.
>
> Serious mentally disabled: systematic guidance, constant supervision and total nurturing are necessary. Mostly multiple handicaps occur. The main aim is to stimulate them in the development of activities to make them independent, for example to eat independently, to wash themselves, to go to the toilet by themselves and to dress themselves.
>
> (Coumans 1989 in de Jong 1998: 4)

Finally, definition influences permanency of classification. The more emphasis, for example, is placed on irreversible physical aspects, the more permanent a classification is likely to be. If, however, the emphasis is on social and adaptive skills, then the classification might fade over time. This has been demonstrated by Edgerton (1966), in his study of a group of people with a history of institutionalisation in an American hospital for the mentally retarded. Interestingly, the people studied by Edgerton reported that coping with stigma, not impairment was their biggest problem following release from hospital. This gradually changed as they managed to build up their own lives, giving them meaning through friends, leisure and work. Distinctions between them and other members of their society became blurred. In conclusion, while intellectual or mental impairment may be recognised in most societies, definition, context and agents of classification influence the nature and number of people included in the category, as well as the permanency of the categorisation.

Part B: Learning Disabilities in Socio-Cultural Context

Contemporary societies

This paragraph explores the contextual influences of the classification and treatment of people with learning disabilities further by looking at non-Western societies. Unfortunately, cross-cultural data on the treatment of people with learning disabilities is scarce. Information must be gathered from the few people who have, in the past, specifically studied learning disabilities, or mental handicap in cultural perspective (Dybwadd 1970; Edgerton 1970; Kidd 1970; Manion and Bersani 1987; Zevenbergen 1987). In addition two recent collections of papers, the first on disability and culture (Ingstad and Whyte 1995), the other on culture and the classification of learning disabilities (Jenkins 1998) may provide useful information.

Edgerton (1970) looked at possible links between economic structures and the treatment of people with learning disabilities in non-Western societies. He investigated the assumption that “complex, industrial societies demand greater competence than do small, technological societies” (Edgerton 1970: 524). Reviewing available ethnographic evidence relating to the treatment of people with ‘mental retardation’ he warned that “what we know is little and the little that exists is only the first halting step towards a natural historic description of some of the dimensions of the problems” (Edgerton 1970: 528). Edgerton described and researched the four, at that time, most common assumptions about this treatment in, presumed, ‘simple’ non-Western societies. Are people thus afflicted dispatched of as infants, do they live out their lives well treated, are they stigmatised and do they constitute a problem to their families or the wider community? He found that there were examples of all of these kinds of treatments in the societies he looked at. Firstly, infants described by ethnographers as 'idiots' may have been shot or strangled, buried alive or left at the mercy of the elements to die in South Africa and with native Indians in America (Edgerton 1970: 528). Secondly, there are reports from the early twentieth century that 'idiots' and other imbeciles were alive, cared for and/or allowed to roam freely, providing they did not constitute a danger to persons or properties, in India, Africa, Borneo and Australia (Edgerton 1970: 528-530). Thirdly, evaluation of people with learning disabilities happens in positive as well as negative ways, 'the retarded' may be treated as saints or other sacred creatures or they may be discriminated against; they may suffer the full spectrum of abuse from mild verbal abuse to quite physical and public abuse (Edgerton 1970: 532-534). Finally, in relation to the problem people with learning disabilities may pose for their community, Edgerton states that this varies from no problem at all to a problem for which communal solutions are found such as special, segregated care and occupation (Edgerton 1970: 537).

Edgerton was one of the first people who came to two important conclusions in the social-cultural description and understanding of learning disabilities. Firstly, there is no uniform way in which people described as 'idiots', 'imbeciles', or mentally retarded are treated in 'simple' non-Western cultures. Secondly, the explanation for the different kind of treatments cannot be found in just the physical environment or the economic structure but instead in what he calls an 'ecological model'. The ecological model recognises, and attends to, links between the treatment of 'mentally retarded persons', the physical environment or habitat, the social system and cultural factors of a particular society. According to Edgerton, the answers to the understanding of the treatment of mental retardation must be found "somewhere in the complex web that unites cultures and social organisations within their physical environment" (Edgerton 1970: 547)

Zevenbergen (1986) follows largely in Edgerton's footsteps, looking at links between attitudes towards, and treatment of, people with learning disabilities in Western and non-Western countries. Warning that evidence is scarce, she relies largely on literature reviews as well as on interviews with immigrant professionals in the Dutch health services who have worked in (their native) Third World countries. Zevenbergen, like Edgerton, describes a variety of ways in which the learning disabled are treated, from killing, abandoning, hiding or neglect; minimal care to the treatment of such people as, to a greater or lesser degree, full and respected members of the societies in which they live, either as equal to other people or as special, holy or sacred people. In respect to possible links between these findings and attitudes such as rejection and various degrees of acceptance, informed by culture, her conclusions suggested that these links are not direct (Zevenbergen 1986).

Miles (1992) carried out research into the concept of mental retardation in Pakistan. He describes how families in Pakistan treat children thus afflicted. Miles found that "in practice, Pakistani families display a wide range of behaviour towards their mentally retarded member, both in the encounter with professionals in counselling or therapeutic roles and in observed behaviour at homes" (Miles 1992: 246-247). However, he felt that generalisations that went beyond just a mentioning of extremes were inappropriate as "no representative sample has yet been studied" *(ibid)*.

Manion and Bersani (1987), again using ethnographic evidence of other authors, conclude that mental retardation is universally recognised but the understanding of the concept and the treatment of individuals viewed as 'mentally retarded' are culturally specific (Manion and Bersani 1987: 243). While this statement may seem quite general considering their limited evidence, it does again suggest that the treatment of people with learning disabilities varies widely and that so far no single, determining influence on that treatment has been identified.

In recent literature, more extensive descriptions of the cross cultural treatment of learning disabilities can be found (Ingstad and Whyte 1995, Jenkins 1998). In *Culture and Disability* (Ingstad and Whyte eds. 1995), different authors offer an insight in the treatment of people with learning disabilities in non-Western countries. In Bunyole County, Uganda, Ingstad found that people with learning disabilities, like those with other disabilities live with, and are looked after by relatives. Although some of them may not marry nor have children, they are all considered as persons in the sense of having social identities as kinsmen (Ingstad 1995: 155). Nicolaisen (1995) describes how with the Punan Bah in Borneo, mentally impaired children, again together with physically impaired children, are treated no differently than other children. As adults they take part in the day-to-day activities of the longhouse (physical structure for living and working); they stay in the family room and eat and sleep with their relatives, take part in leisure activities and in social events and rituals (Nicolaisen 1995: 47-48). Two points of interest may be noted in relation to her research. Firstly, she did not find any evidence of severely impaired individuals. This could be interpreted as support for the notion that not only do differences exist in the treatment of people with learning disabilities between and within societies, but also within the category itself. Second, as with many others, Punan Bah society is changing rapidly, and with it the care towards people with learning disabilities. I will return to both of these issues later.

A final description comes from Kenya. According to Talle (1995), the Masaai treat their mentally impaired children like any other; they are fed, taken care of and taken for vaccinations. Their impairment may be recognised and they may be called engugu (animal like creature) but this does not automatically imply mistreatment. In fact, it may be seen as openness and acceptance. Children with learning disabilities are also given the opportunity to marry and having children, although severely mentally impaired children may be disqualified in this respect (Talle 1995: 67-69).

There are several examples of differences in the treatment of people with learning disabilities within one society. Nuttall (1998) describes how in Greenland a child with learning disabilities was segregated, under Danish standards and values, within his school environment but integrated within his indigenous community. A village chief orders the killing of a child, which is subsequently taken to safety by the parents. One parent neglects a child and leaves it to die, while the other parent takes pity on it and feeds it in a society that is, in general, accepting towards children with impairment (Nicolaisen 1995). In Norway, a Turkish woman looked for traditional cures for her child while being urged, by the Norwegian doctors of the town in which she lived, to take the child to hospital (Sachs 1995). These examples are anecdotal and do not prove anything; their existence, however, does raise questions of culture, gender and class.

Classification and treatment of learning disabilities may be linked to individual level of impairment. The ethnographic record that Edgerton (1970) discussed mostly described more severely impaired individuals. He suggests that persons who are mildly impaired, or 'morons' may not be recognised as being "other than ordinary folk" (Edgerton 1970: 530). Nicolaisen (1995) on the other hand, in her description of the Punan Bah, found only individuals who could be described as having mild to moderate learning disabilities. These are important issues as they raise questions of the appropriateness of one category for all people with learning disabilities. This has already been discussed in the paragraph on classification and will be looked at again further in this thesis.

Thus, I conclude that reports from both Western and non-Western societies suggest that there are differences between as well as within societies in the treatment of children and adults with learning disabilities. Explanations may not be found in direct links, with cultural beliefs and attitudes, or with economic circumstances and social structures. Rather, it appears that, in order to come to a better understanding of these differences, we need to look at the ways in which cultural and socio-economic influences are connected, how they are interpreted in local situations and how they interact with the actual and/or perceived learning impairment of the individual person.

Social and economic structures

The social structure or the social organisation of a society may be understood as the sum total of all the institutionalised interactions within that society. Institutions are the building blocks of social structures. Such institutions may include the organisation of sexuality and human reproduction, the care and socialisation of new members, production and distribution of resources, methods of dealing with difference and deviance and the organisation of religious and cosmological beliefs. The family, school, the church and centres for people with learning disabilities are all part of social organisation as well as government and the medical sector. As suggested in parts A and B of this chapter, differences in social organisation between societies may, at least partly, account for differences in the classification and treatment of people with learning disabilities. In this paragraph I will look at these aspects in more detail.

In the cross cultural comparison of differences in the classification and treatment of people with learning disabilities we may examine links with general features of the social organisation of a particular society, and/or look at the implications of specific social characteristics of the societies in question (Ingstad and Whyte 1995). One dimension of social organisation is scale (Kloos 1981). Differences between small and large scale societies have been quoted and researched as bearing an influence on the treatment of people with (learning) disabilities (Edgerton 1970; Zevenbergen 1986). In small-scale societies people live and work together and there are no strict divisions between different areas of social life and no strict role divisions. People live in extended families and/or close communities which may offer strong mutual support for the care of weaker members including those with learning disabilities (Ingstad and Whyte 1995; Kloos 1981; Zevenbergen 1986). Several authors have sketched pictures of simple, small scale societies where people with (learning) disabilities are integrated as members of their (extended) families and communities (Edgerton 1970; Nicolaisen 1995; Talle 1995; Zevenbergen 1986). Small societies offer a structure that makes integration and mutual support possible, but not inevitable. Ethnographic evidence suggests the existence of contrasting attitudes towards and treatment of people with learning disabilities within and between small-scale societies (Dybwadd 1970; Miles 1987; Zevenbergen 1986).

In large-scale societies, social relations tend to be more impersonal and many functions traditionally fulfilled by the extended family are taken over by other institutions (Kloos 1981, Zevenbergen 1986). The division of social life such as work, leisure and education may affect the treatment of people with disabilities (Whyte

1995). With the earlier cited Punja Bah in Borneo the impaired person took part in all the activities (work, leisure and rituals) of the longhouse and was cared for by the other members (Nicolaisen 1995). Family relations changed however with the introduction of paid labour (ibid). Similar reports come from Third World countries where parents move to the towns and cities to work, leaving the grandparents to care for the children (Zevenbergen 1986). Large-scale societies, however, can also offer advantages. Easier access to information, education and institutionalised support for families caring for a learning disabled member may result in a more positive attitude and better treatment (Zevenbergen 1986).

The scale of a particular society appears to be at least of some influence in the classification and treatment of people with learning disabilities. However, when using it as an analytical tool for the description and explanation of differences, certain limitations need to be kept in mind. Not all relationships in large-scale societies are impersonal and task specific and vice versa and few societies today can truly be called small-scale and remain unaffected by national and global institutions and development (Ingstad and Whyte 1995: 12-14). People with learning disabilities may be part of and integrated within a (small) community but this does not necessarily mean that they are not perceived and/or treated as different. Specific roles may be ascribed to people with impairments such as begging (Ingstad and Whyte1995; Zevenbergen 1986), or the classic example of the village fool. Does this mean these people are treated like other adult members of that society? What happens if the village fool wants to marry? Are other adult roles and institutions in that society open to people with learning disabilities?

An important feature of social organisation in most societies is the concept of the family. Family life, as a sociological construct, may differ in a variety of ways.

Family size, the division of tasks and links with the wider community may all affect the ability of the family to care for weaker members. The concept of nuclear vs. extended family is a relevant theme in the comparison of social contexts of disability (Whyte 1995). Another relevant characteristic of a society in the classification and treatment of people with learning disabilities is the existence and role of special institutions for learning disabled people. Parent organisations, pressure and lobby groups influence the demand for and creation of special policies and services, which in turn may influence the construction of a social category of learning disabilities. The creation of these very groups may also be related to the changing form and perceived function of families (Angrosino, 1998; Devlieger 1998; Ingstad, 1995; Miles 1984).

Economic structures, including physical environment, the organisation of production, the nature of work and the distribution of resources have already been mentioned as possible influences on the classification and treatment of (learning) disabled people (Edgerton 1970; Oliver 1990; Zevenbergen 1986). Social theorists have made these links more explicitly. They argue that unemployable (or disabled) people are the consequence of the Industrial Revolution and modern industrialisation (Davis 2002; Oliver 1990). It may indeed be easier for a person with learning disabilities to participate in simple economic activities. Ethnographic records do report people with a variety of impairments, including learning disabilities, taking part in the care of animals and other aspects of farming, fishing and the home based production of goods (Nicolaisen 1995; Nuttall 1998; Talle 1995; Whyte 1995). Increasing complexity in a society and the specialisation of roles and work may make it difficult for people with learning disabilities to fit in with certain work structures.

The distribution of resources determines if people with learning disabilities have to support themselves financially, if they receive equally like other members of their community, if they are supported by charities or if they have a special income assigned to them. Certain systems of welfare may contribute to their dependency and they remaining on the poverty line (Davis 2002; Oliver 1990). On the other hand, however, having learning disabilities in the United States entitles a person to a certain minimum income and health benefits unavailable to many other people (Angrosino 1998; Devlieger 1998). A related issue is that of poverty. When the majority of the members of a society or a family are finding it difficult to fulfil their basic needs for food, shelter and human attention, weaker members may be neglected (Miles 1992: 131). Again, evidence is scant and reports on the treatment of people with learning disabilities from economically disadvantaged societies are mixed (Zevenbergen 1986; Ingstad and Whyte 1995; Jenkins 1998).

Culture

Talcott Parsons considered what would and should be included under the rubric of "culture": “Cultural objects are symbolic elements of the cultural tradition, ideas or beliefs, expressive symbols or value patterns.” (Kuper 1999: 53) Culture thus defined would include the aims and objectives of an institution for people with learning disabilities as well as the ideas at the root of the concept of normalisation. Culture may be seen as what Berger and Luckmann call the legitimisation system of institutions; the body of knowledge, beliefs and myths that explain and justify face to face interactions, particular institutions or social organisation (Berger and Luckmann 1967). It includes concepts of person- and adulthood, religious beliefs and knowledge.

Concepts of person-and adulthood

The 'concept of personhood' expresses views on what a person is and what a person should be; it is "a reference structure which provides guidelines for a person's own behaviour and for his/her judgement of others" (Kwant 1986: 10). The majority of people behave according to social rules and expectations that are often unspoken, but very well known, in the society in which they live. The relationship between these and a 'concept of personhood'- the idea of what a person is and should be is less well known. Before exploring the influences of concept of personhood on the classification and treatment of people with learning disabilities, it may be useful to distinguish between the (often used interchangeably) concepts of humanity, person- and adulthood. They differ from each other but simultaneously imply each other; adulthood implies personhood, which implies humanity. As with most social identities their real meaning is constructed in the boundaries, boundaries that are not firm and are constantly being constructed and reconstructed (Jenkins 1996).

The category of 'human' distinguishes human from animal life; it identifies a creature as a being of the human species. It may be looked at from a biological, psychological, sociological or anthropological perspective (Noordam 1978). Socio-anthropological views focus on the, partly biologically determined, aspects that make us dependent on social interaction to grow and become a full member of society. According to Jenkins (1996) humanity is the first, and a primarily social, identity that newborn babies acquire through the interaction between the infant and the people around him. Humanity however may be contested. In the ethnographic literature situations have been described where the newborn was not perceived as human but as non-human or as a sort of half human creature (Edgerton 1970; Jenkins 1998; Whyte 1995; Zevenbergen 1986). The humanity of severely disabled people may also be contested within Western societies. Abortion of the handicapped foetus, for example, has been quoted as a denial or questioning of the human-ness of people with learning disabilities (Jenkins 1998). The question of human-ness of the child with (severe) learning disabilities may also arise in relation to the reported "withholding of medical treatment" (Kurtz 1981:77). The fact that humanity may be contested supports the notion that it is an ascribed quality or indeed a social identity and as such influenced by culture.

The category of the person relates to human beings as social actors and as part of a society; it relates to our social being and identity. It describes and prescribes what is expected of a human being as part of a particular human society. The questions that arose around the earlier mentioned example of Victor, the 'wild boy of Aveyron', may be interpreted in relation to the notion of personhood. Was Victor a person and was he able to become fully part of French society? The ability for social learning and communication may be seen as necessary and conditional for inclusion in human social life (van Gennep 1980). Personhood as a social anthropological concept is ultimately expressed in inclusion in local social structures; to be human in a way that is valued and meaningful (Ingstad and Whyte 1995:10).

Adulthood refers to a special state of the person. It is influenced by the interaction between the biological (maturation) and culture (Riddell 1998). It colours the person's social relationships in a special way, characterised by rights and responsibilities, by certain social roles and life styles and by the accessibility of adult institutions such as the right to vote, marriage, parenthood and work (Griffiths 1994; Hirst and Baldwin 1994; Riddell 1998, Thomas and Ward 1994). It may be conferred formally by law, statutory or common, or more implicitly be constructed within the interaction process between the (new) adult, parents, professionals and other members of society. In small, simple societies adulthood is often achieved at the onset of puberty and through social rituals. Adulthood in Western, more complex societies may be harder to define and determine. In a complex society many different roles need to be performed and a wide variety of skills need to be acquired before someone is considered an adult (Griffiths 1994). In modern Western societies adulthood may be described as a progression through different stages in status. The adulthood of people with learning disabilities may be contested (Jenkins 1990; Davies and Jenkins 1993). Different social agents may not agree on the adulthood of a particular person or a group of persons. In addition, adulthood may be ascribed by access to certain (adult) institutions and actions such as the right to vote, but this may be in name only and/or not extended to other or all areas of social life.

Humanity, personhood and adulthood may all be seen as social identities and as such historically and culturally changing concepts (Jenkins 1996). In the ethnographic records various authors have discussed links between the different concepts of personhood and the view on and treatment of people with disabilities (Nicolaisen 1995; Talle 1995; Whyte 1998). With the Masaai in Kenya it is firmly laid down in the Masaai moral code that impaired children should be treated similarly to other children. A child is a child whatever it looks like. These rules apply to feeding and upbringing as well as to marriage and inheritance of life stock. All children, unless they are disqualified through grave misconduct or are severely mentally retarded, are given the opportunity of marrying and/or having children. This bares testament to the strong Masaai principle that each member of society should enjoy the most basic of all human rights, namely reproduction. With the Masaai, it is first and foremost through parenthood that an individual becomes a person (Talle 1995: 69).

Mauss (1938) recognised the historical and cultural dimension of the concept of personhood and stimulated much debate (Mauss (1938) in Carrithers 1985; Morris 1994). According to Mauss the socio-centric concept of personhood describes a person as in a particular relationship with other members of his usually primitive society. This concept developed and changed under the alleged influence of Christianity and the concept of citizenship; the egocentric person is an individual autonomous self with rights and responsibilities (Mauss 1938 in Carrithers 1985). The modern, Western concept of personhood is generally described as individual, autonomous and self sufficient, focussed on achievement and competition (Ingstad 1995; Murphy 1995; Morris 1994; Oliver 1990; Whyte 1995). Mauss's evolutionary vision has been criticised as somewhat simplistic and his dichotomy as too simple. Even in modern Western society a person is always embodied and embedded within social relations (Carrithers 1985; Ingstad and Whyte 1995; Morris 1994). A concept of personhood may have egocentric as well as socio-centric elements and it may be better to speak about gradations of individuality and sociality rather than a dichotomy (ibid). Both Morris (1994) and Ingstad and Whyte (1995) give examples of societies where the concept of personhood embraces both elements.

Different concepts of personhood may exist in a society, which harbours elements of two or more different cultures and social structures (Nuttall 1998; Sachs 1995). Conflicts between different concepts of person- and adulthood may be resolved in different ways. First, certain aspects of a concept of personhood may be challenged. For example, the experience of disability has led to the questioning of the element of independence in the Western concept of personhood (Corbett 1989; French 2002(c); Oliver 1993). Independence is often mentioned as one of the most important aspects of the modern concept of person- and adulthood and generally considered to be something disabled people desire above all else (French 2002 (c)). However, true independence may be a myth. In the modern world we can all be seen as more or less dependent on one another, living in a state of interdependency. This would mean that disabled people are not marked out as different in kind but different in degree (Kwant 1986; Oliver 1990).

The true value of certain forms of independence for people with disabilities has also been questioned (Corbett 1989: 46). The basics of self-help, for example, can be an intolerable chore rather than something to strive for, impeding the quality of life rather than enhancing it and inhibiting self-expression (Corbett 1989; French 2002 (c)).

> Real independence has nothing to do with cooking, cleaning and dressing oneself. If you ask me what is my experience of being independent I would not automatically think of self help skills but of being able to use my imagination to create fantasy, of enjoying music and drama, of relishing sensual pleasures and absorbing the natural life around me. (Corbett 1989: 46)

Devlieger notices how, in America, as the normative schedule of self reliance conflicts more and more with the experienced reality of non-disabled persons, this schedule is vigorously imposed on people with disabilities through the policy of normalisation. He has found that this can actually lead to a greater dependency for people with intellectual disabilities as they try to conform to this demand for independence (Davies 1998; Devlieger 1998). There exists a paradox in the modern, Western treatment of disability. The underlying ideal of equality and the right to participate equally, could in fact lead to intolerance of innate diversity, and an individualism that denies the social nature of persons (Striker 1982 in Whyte 1996: 8). This happens when people with learning disabilities are pressurised, through services and people representing these services, to behave in ways they would not have chosen for themselves but that are in line with what 'normal' people do. Parents too may be confused as to how to treat their son or daughter with learning disabilities; to what extent they should accept behaviour that is 'different'. In a study by Davies and Jenkins (1993) into the adulthood of 60 people with learning disabilities in Wales, several parents apologised for 'allowing' their son or daughter to engage in 'childish' activities such as playing with toy cars.

At the centre of the normalisation debate of course lays the question: What is normality? According to Drake, the concept of normality in no way describes a natural or pre-ordained state of affairs but instead represents an acknowledgement of the values that have come to dominate in a particular community at a particular time (Drake 1996:146). Secondly, one group may force upon others their own model of personhood (Kwant 1986). The following is an example of how one group, or one individual may feel forced to conform to the dominant model of personhood.

Mike Oliver (2002) in Britain criticises conductive education, an intensive, physical therapy used for children with cerebral palsy and related conditions that focuses on the acquisition of mobility skills. Oliver questions the perceived imperative for disabled people to put tremendous effort into the possible acquisition of certain skills, for example walking instead of using a wheelchair, as pressure to conform to a notion of personhood which emphasises normality. In the same volume a mother of a child with cerebral palsy replies to Oliver's point of view (Beardshaw 2002). She points out that the development of conductive education took place in Budapest, a town with a lot of hilly streets and steps. The use of a wheelchair there is not an easy option, due to a lack of resources as well as to the structures of the physical environment. In addition, Beardshaw feels that she cannot afford to wait for 'society' to change; her daughter will have to live in this world and it may benefit her more to try to adapt to society as it is now (ibid). This may be interpreted as the pursuit of achievement of the notion of personhood currently dominant within the society in which she and her daughter live.

Thirdly, a society can ignore the conflict between differences in concepts of personhood, or inconsistencies within the dominant concept. Through the creation of myths or idealising of reality consistency is pretended (Kwant 1986: 28). Taboos are used to ignore unsolvable conflicts, forbidding its members to carry out certain actions or to discuss a particular topic (Kloos 1986:107). Fennis describes how in the past, intellectual disability and in particular severe intellectual disability, was such a taboo that it was ignored and not spoken about (Fennis 1975). Even in modern society it may cause uneasiness for example between parents and their child with learning disabilities (Davies and Jenkins 1993). In other settings, people with learning disabilities may speak freely about their disabilities and their situation (Angrosino 1998; Devlieger 1998).

A final alternative is to focus on one or more different aspect(s) of the dominant concept of personhood. In the U.S.A., people with mental retardation developed a satisfying identity by focusing on the non-educational aspects of the American model of man, such as friendship and self-made personhood (Devlieger 1998). Devlieger agrees with Edgerton (1994) that ordinarily living in the United States does not necessarily require people to be able to read or be proficient in abstract thinking. In Western Europe, the afore mentioned 'L'Arche' communities and 'Nieuw Dennendal' in Holland both had as a founding philosophy the idea that our humanity lies in our need for each other (Meyering 1974; Clarke 1980). Parents and carers of people with intellectual disabilities in Wales constructed an alternative model of the self, based on social relations rather than on any concept of an internal, private self (Davies 1998).

This model has much in common with the socio-centric concept described by Mauss as well as with concepts of personhood reported from non-Western societies (*ibid*).

In Zimbabwe, rural adult competence relates to family and gender roles and the ability to communicate. Incompetent people are not drawn into the ethos of realisation of full potential, they are protected by their family and it is left up to the individual person to sort out his or her own capability (Devlieger 1998). In Eastern Uganda too, the local model of man is one of social relations rather than of individual achievement or potential. Social competence lies in the ability to extend and strengthen their families through social activities and relationships such as marriage (Ingstad and Whyte 1995). The difficulty for people with learning disabilities in shaping their own lives and influencing the way other people perceive them is an issue in this context. While the people discussed by Devlieger were able to shape their own life and identity, other people may not be in that position. This may be related to the level of their ability as well as to the social and economic circumstances in which they find themselves.

I conclude that ideas about what it means to be a full member of society are cultural in that they are adapted to and inform local situations and expectations, are woven into local economic and social circumstances as well as influenced by, and influencing knowledge, experience and religious beliefs. Differences between concepts of personhood may influence the classification and treatment of people with learning disabilities, sometimes directly, sometimes indirectly. Certain definitions of personhood may be more tolerant towards people with learning disabilities. A concept of personhood based on social relations rather than individual achievement may have more scope for the integration of people with learning disabilities than one based on individualism and independence. In this study I will examine the different ways in which learning disabilities may be in conflict with the local concept of personhood and how members within particular societies deal with this conflict.

Religion

Religious and other cosmological beliefs are related to concepts of personhood and may influence the classification and treatment of people with learning disabilities, either directly or through other cultural factors and social structures. Firstly, they may offer a view on cause and meaning of concepts such as poverty, sickness and suffering. In the five main religions we find the following explanations for intellectual disability: it is caused by God or Allah as a punishment, or as simply their will, it is Karma or the work of evil forces such as the devil (Zevenbergen 1986). The ethnographic literature yields varied descriptions of the cosmological explanations of sickness and suffering. However, only very few of them, in both the main world religions and in the cosmological explanations described in the ethnographic literature, relate specifically to people with learning disabilities. In relation to the treatment of people with learning disabilities, of the five main world religions, Islam, Hinduism, Buddhism, Judaism and Christianity, it is only Islam that makes a specific reference to this. Thus, religious influence, if present, limits itself to the deduction and interpretation of more general guidelines for behaviour.

Peace, love and charity are important concepts in all religions, just as kindness to your neighbour. Although it is debatable to what extent this is taken up by followers of these religions and who exactly is included in the concept of neighbour, these principles have motivated people of all religions to create homes and institutions for persons with learning disabilities in many places in the world. It is also possible that these principles influence people in their individual interactions with people with learning disabilities. In the eyes of the believer, religion may also bring solace or even a cure for intellectual disability (Zevenbergen 1986: 90).

Finally, religion or cosmological beliefs may say something about the place of intellectually disabled persons within society. In former paragraphs I have given examples of how they might be seen as sacred or living closer to God, or as possessed by evil forces. Religious and cosmological beliefs may influence the way people think about and act towards people with intellectual disabilities. Resulting attitudes include non-acceptance on the basis of the influence of evil forces, acceptance because it is the will of God or because these people are also God's creatures or lastly, the special and respectful treatment of the affected person who is seen as somehow sacred (Zevenbergen 1986).

Knowledge

Knowledge is another factor that influences the attitudes people have towards each other. Knowledge about intellectual disabilities will influence the way people think, feel about and act towards intellectually disabled persons. What parents know about the condition of their child and their future expectations influences their attitude, either in a positive or in a negative way (Fennis 1975; Jansen 1982; Zevenbergen 1986).

In the historical overview I described how different scientific theories and knowledge lead to different treatments of people with intellectual disabilities. According to Oliver social theory should work on three levels: grand theory or ideology, theory and methodology. These three levels are all related. The grand theory or ideology refers to the underlying basic assumption informing theory, methods and action. In social theory this is the idea that disability and devaluation of difference is socially created. Thus, it would not be enough to help people with (learning) disabilities to combat devaluation while leaving the basic reasons for and processes of devaluation intact. A social theory of disability implies challenging existing ideology with implications for theory, research, action and, ultimately, the definition of disability. Knowledge is acquired through information or socialisation (Berger and Luckman: 1967) but also through direct experience. Many families of people with intellectual disabilities have a great need for information. A common attitude with parents, especially in Third World countries, is the idea that an intellectually disabled child is not able to do anything. As a consequence the child may receive little or no stimulation, which may actually increase the extent of handicap (Rehabilitation International 1981, in Zevenbergen 1986).

It can be hard for parents to access information on intellectual disability. According to Berger and Luckman (1967) knowledge is socially distributed and one needs to know who possesses what information and how to acquire it. Talking about personal problems and going to professionals for help is a typically Western thing to do. In Third World countries professional help may be harder to access. Despite this, some parents go to great lengths and efforts to get professional advice. In Java, parents walked for days to get to a centre for mentally handicapped children (Zevenbergen 1986: 92). The growing number of parent organisations all over the world is another expression of the need parents have for information, recognition and mutual support.

Part C: Summary and Conclusions

In the above paragraphs I have discussed the classification and treatment of people with learning disabilities throughout history and across various societies. This account is far from complete. A comprehensive overview would require more space and is not relevant in the context of this thesis. Also, this historical overview predominantly looks at the industrialised countries of Western European and North America. Considering my own background and the availability of data it seemed appropriate to take the development of the western concept of learning disabilities as a starting point and as a tool to show the importance of historical context. (That this concept is not necessarily universal did become clear in the second part of this chapter.)

Various relevant points have emerged. Firstly, the classification and treatment of learning disabilities has varied over time. Secondly, the historical line in the care and treatment of people suffering from intellectual disability is not always straightforward. Various authors have seen an evolution in attitudes towards and in the treatment of people with (learning) disabilities, from rejection to objects of charity to full inclusion (Jak 1988). Ideas however may be abandoned and returned to at a later date. Thirdly, during one particular period in history and in one particular society more than one attitude towards intellectual disability may be found as residues of the past, the first seeds of a new era or simply conflicting ideas and practices existing simultaneously. Even in today's society many deviant people are not yet integrated in society and still function as a cause through which others can demonstrate their goodness (Jak 1988:140; Oliver 1990).

Three main models of theory on and treatment of people with learning disabilities may be identified. The medical model locates (learning) disabilities within the individual who needs to be treated or cared for. The social interactionist model (in particular, normalisation and social role valorisation theory) locates learning disabilities in the labelling process and social role expectations. Treatment of learning disabilities according to this model includes the combating of devaluation processes by addressing both the environment and the behaviour of the devalued person. Finally, the social theoretical approach locates (learning) disabilities in socio-economic structures and culture. It follows that to reduce (learning) disabilities social structures need to be challenged and changed. These views and practices do not develop and exist in isolation; they exist within a context of socio-economic structures and culture. Various authors (Edgerton 1970; Zevenbergen 1986; Jenkins 1998) have suggested that relationships exist between (elements of) economical, social and cultural factors and the classification and treatment of learning disabilities within a particular society. It has also become clear that these relationships are by no means straightforward and that many contradictions exist. Different explanations may account for this.

Firstly, contradictions may occur because of unclear definitions of the category of learning disabilities, and of individual variations within that category. Secondly, as pointed out in various places earlier, individuals within a society differ from each other in social, cultural and economic terms. In the 'rich' western world, there are still people who are homeless and/or living in poverty. In Third World countries some people live in cities, others in rural areas. Thirdly, while it is likely that the factors described above influence the classification and treatment of learning disabled people other, individual factors, including nature and level of impairment may also play a role. It appears that, in order to come to a better understanding of these differences, we need to look at the ways in which cultural and socio-economic influences are connected, interpreted in local situations and how they interact with the actual and/or perceived learning impairment of the individual person, as well as with possible other individual factors.

Berger and Luckman argue that society is part of a human world, made by men, inhabited by men, and in turn making men, in an ongoing historical process (Berger and Luckman 1967:211). Considering society in the sense of a social world creates room for variations within that society. All individuals ultimately live in their own social world. Some of the institutions are similar for the whole of society, some of them only for a small group or even just two individuals. The justification and explanation of these institutions may vary, between small or large groups within the particular society.

A day centre for people with learning disabilities for example, may be a place of learning and rehabilitation for some, for others it may be a place of temporary relief in the care of a severely disabled child. Ultimately, institutions become real in the interactions between individuals and in the meaning given to them by individuals. To understand what 'learning disabilities' means to people within their own social worlds we have to look at what actually constitutes that social world, or those social worlds, the institutionalised interactions as well as their justification or legitimization.

A description of factors or systems, influencing the actions of individuals is offered by Talcot Parsons (1951):

> "Talcot Parsons, in The Social System published in 1951 stated: "It is convenient in action terms to classify the object world as composed of the three classes of 'social', 'physical', and 'cultural' objects." Each class of "objects" forms a system: the social system, the individual-biological system, and the cultural system. These three systems interact to govern the choices every actor is called upon to make, but they cannot be reduced to each other." (Kuper 1999: 52)

Talcot Parsons division can be used to describe and explain face to face situations as well as what happens within a more abstract institution. His concept of culture may be compared to the system of legitimization of Berger and Luckmann(1967), including amongst others knowledge, beliefs and concepts of personhood. In addition, he ascribes a role in the process of social action for individual-biological factors.

Learning disabilities, impairment or socially created, individual-biological factors or social structures and culture? I will use the above discussed theory as a tool of analysis for my data, and attempt to describe and understand the classification and treatment of two specific samples of people with learning disabilities in the context of local socio-economic structures, culture and individual-biological factors. I will pay particular attention to the question of the what elements of socio-economic structure, culture and individual-biological factors facilitate, act as a barrier to the participation of people with learning disabilities as respected adults in the society in which they live.

CHAPTER TWO: RESEARCH QUESTIONS, METHODOLOGY AND SETTING

Research Questions

This study then is led by the following questions. Firstly, how do socio-economic structures and culture influence the classification and treatment of people with learning disabilities? Secondly, how do their lives compare to the lives of other adults of their society? Thirdly, what are the factors that contribute to the degree to which such individuals are included in their society? In order to shed some light on these issues I will look at the following:

1) How did local socio-economic structures and culture contribute to the classification of the people attending the centres in Aniksi and Ffynnon?
2) How do their lives compare to the lives of other adults in Aniksi and Ffynnon?
3) What particular elements of socio-economic structures and culture facilitate(d) their inclusion in local society?
4) What particular elements of socio-economic structures and culture act(ed) as barriers to this inclusion?

This thesis is not an attempt to produce general conclusions on the classification and treatment of all people with learning disabilities in Wales and Greece. It is primarily exploratory and led by the relevant general theory discussed in Chapter One. By focussing on a small group of people and looking at their lives and their stories I intend to identify clues to the explanation of the above issues. It is hoped that these findings will be relevant to future research on the topic.

The methods I have used reflect the purpose of the thesis as discussed above. Firstly, I wished to speak with the central people in this research, namely, people classified as having learning disabilities by their attendance at the centres. As the focus of this thesis is on the social aspects of this classification, I also thought it important to seek the views of the significant others in the lives of the people I researched. I choose parents and staff at the two centres. The reasons for these choices were two fold. One, because I assumed they would be and had been in close contact with the people concerned and would be likely to play an important role in the treatment of them as 'classified' or 'labelled' persons. The second reason was the nature of their relationships with people with learning disabilities. The roles of both parents and 'professionals' have been much discussed in relation to the category of learning disabilities (Davies 1998; Gates 2003; Jackaman 1991; Robinson 1991). In addition to talking with people, I wanted to observe for myself what happened in the centres on a day-to-day basis. What did the people attending them actually do, and what was the nature of their relationship with the 'non-disabled' people there? Finally, to add to the background information on the lives of individual people I wanted to look at relevant documentation available. My research was planned as follows:

1) *Participant observation* while taking part in the activities of both centres. In the period between September 1992 and June 1994 I spent a total of three months in each of the centres. The three months were consecutive in Ffynnon but in Aniksi the period was made up three separate periods of one month each.

2) *Interviews with workers in Aniksi and clients in Ffynnon.* I had initially decided to interview all (28) clients in Aniksi and a sample of a similar number in Ffynnon. This sample consisted of a selection of every third name of an alphabetical list of clients (total number of clients in Ffynnon: 100). This left me with a basic sample of 30 (as three people had left the centre). In the end however, I interviewed only those I was able to communicate with effectively. While I acknowledge the importance of a representative sample if possible, including those with whom I found it difficult to communicate, I lacked the time to form the necessary kind of relationships to allow me to do so. This left me with 12 interviews in Aniksi and 24 in Ffynnon. The discrepancy in sample size between the two places may be explained by two possible factors. Firstly, my own communication skills in Aniksi were more limited due to the language barrier. While I speak Greek on a conversational level, I found that in the communication with more severely disabled persons, language difficulties (from both sides!), both expressive and receptive, did play a role. Secondly, it appeared that in Aniksi the number of people with speech and language difficulties at the centre was greater than in Ffynnon.

3) *Interviews with parents.* In relation to the interviews with parents I contacted the parents of all the people I had interviewed and asked for their participation in the parent-interviews. In Ffynnon, two more people had left the centre when the time came for interviews with the parents. One parent was away at the time and three parents were not interested. One parent attended the centre herself and was not aware of her relationship with the person concerned. This left me with interviews with the parents of 17 people attending the centre in Ffynnon. In Aniksi the situation was different again. Of the 12 people I had interviewed two lived far away in isolated villages in the mountains. While I managed to visit the family of one, language

difficulties prevented me from including the data gathered from this interview. This left me with the parents of ten workers I had interviewed at the centre. In addition however, I had come to know some parents through the trip to the North of Greece to which I had kindly been invited. Five of them expressed great interest in being included in the interviews. As I did not want to refuse, I ended up interviewing 15 parents of in total 16 workers in Aniksi (one parent had two children at the centre, of whom I only interviewed one).

The aim of the interviews with the parents was to obtain information about their experiences of having a child with learning disabilities and about the factors influencing these experiences. Also I hoped to gain information about the reasons for and the manner of the classification of their child as having learning disabilities. Last but not least, I hoped that the accounts of their parents would contribute to a picture of the lives of individual people with learning disabilities. Therefore, I opted for an open kind of interview but with guidance of a list of pre-prepared subjects that I would like to cover. All interviews lasted between one and three hours, with an average interview time of around two hours. At the start of each interview I invited parents to talk about their experiences with their child with general questions in regard to the child's early years, time of official diagnosis and reasons or impetus for attending the centre. Most parents needed little encouragement to talk. In fact, regardless of my opening question or comment, the majority of parents were keen to tell me their story from the beginning. The fact that I was there, available, willing and interested in their stories was enough. This corresponds with my professional experiences of working with parents. There appears to exist not only willingness but perhaps also a need to share their often difficult but also joyful experiences. During the interviews I took notes for which I had sought permission from the parents beforehand. Immediately after each interview, an extensive report was drafted with the help of these notes.

In relation to all the interviews, including those with parents, staff and people attending the centres, I did consider recording them on tape. However, I decided against this. The amount of time needed to transcribe many hours of interviews would not have been in proportion with the purpose of the interviews in the light of the whole project. I feel the benefits of such a procedure would not have outweighed the costs and I do not feel the findings have been seriously compromised by a failure to do so. With just one exception, I only conducted one interview per day. This allowed me to focus completely on the experiences of one person or one family. Details, such as the chronology of events or method of diagnosis, were crosschecked between the interviews (with the parents and their children) and with the information given by the psychologist (Aniksi) or gleaned from the files (Ffynnon). In addition, I used my own observations. I would like to stress here that I felt this method was sufficient as I was mostly looking for significant life events and general feelings and experiences. For more in depth feelings and experiences recorded interviews would have been better; for example in recording the nuances in tone and manner of speech. I am aware that the interview method I used leaves room for a bias in the information selected based on my own pre-conceived ideas and attitudes. This however seems to be an inevitable factor in any ethnographic research and to be aware of this is perhaps one of the best ways of dealing with it. In addition, empathy is extremely important, the attempt to see the world through the eyes of the other person. This has always been an important part of my training and work and I feel this has been an advantage in this kind of research. In addition, having lived in both places and having spent a considerable amount of time there before the research was undertaken had already given me an experience and understanding of the local cultural context. As it is I feel confident that the conclusions I have come to in this thesis are well founded.

4) Interviews with members of staff. I had informal talks with staff in both places during my participation and also arranged more formal interviews with four (out of five) members of staff in Aniksi and five in Ffynnon.

5) *Analysis of clients' personal files in Ffynnon.* I was kindly granted permission to study the files of the thirty originally selected people in Ffynnon.

6) *Discussions with the psychologist and centre manager in Aniksi.* As no such documentation was available in Aniksi (I will come back to this in Chapter Three: Two Centres) the psychologist offered to brief me with any information he had on (the lives of) individual workers. In total, we arranged four meetings in which we discussed each worker at the centre. Subjects I focussed on, in both the file analysis in Ffynnon and the discussions in Aniksi were family background, current family situation and other significant influences on the life of the person concerned, official classification and time and nature of that classification, 'career' as a person with learning disabilities and significant events in that career in particular in relation to education and work, reasons for admission to the centre and long term plans (if in existence).

Limitations

In addition to the limitations of methods and number described above, there is the important issue of time. Society is not a static, inflexible reality. It is constantly constructed and reconstructed by ever changing people and their interactions, and under ever changing influences and circumstances. This is, perhaps, nowhere as clear as in the classification and treatment of certain minority groups within society, such as people with learning disabilities (see also Chapter One: Learning Disabilities in Socio-Cultural Context). In both Greece and Wales certain things changed during the period of research and continue to change. It would be incorrect to say 'this is how it is'. What I wish to explore, however, is not only how it is – how people with learning disabilities are classified and treated – but, and more importantly under what influences does it become 'like this'? What are the very factors that influence the *changing* social and cultural construction of learning disabilities?

Terminology

The following terms, associated with the lives of and theory on people with learning disabilities and frequently used in this thesis need further clarification. While different names and definitions for these concepts may be available and used by different authors (see also Chapter One: Learning Disabilities in Socio-Cultural Context) I chose the following:

- Intellectual Impairment: The loss or abnormality of intellectual functioning (W.H.O. 1980).
- Learning Disabilities: The social classification of "having intellectual difficulties in mastering knowledge and skills necessary to do the things most people in a particular cultural context are able to do" (Jenkins 1998: 9)
- Integration/Segregation: Refers to the presence in or removal from existing mainstream society.
- Inclusion/Exclusion: Inclusion and exclusion are relatively new concepts and while often referred to, or used as guiding principle for services and policies

(see Chapter One: Learning Disabilities Socio-Cultural Context) few authors provide a clear and explicit definition. The difference with the afore mentioned integration is that rather then mere presence, active participation in and contribution to society are important elements (Manthorpe 2003; Oliver 1996) as is the commitment to people with learning disabilities to actively enable them to participate and contribute by changing and adapting society if and where necessary (Blomberg 2003: 537). For the purpose of this thesis I will combine these elements and use the concept to describe the social position of the people I have researched in the sense of 'the possibility to participate in and contribute to activities and relationships common in local society'.

- (In)competence: (Not) having the skills and knowledge necessary to take part in and contribute to certain activities and relationships within a given social and cultural context.
- Workers: refers to the people attending the centre in Aniksi and is in line with local terminology.
- Clients: refers to the people attending the centre in Ffynnon and the word most used at the time to describe them.

Setting

Aniksi

Aniksi is an island off the coast of southwest Greece. A car ferry makes the journey to the mainland four times daily. From the island's airport there are daily flights to Athens and, during the summer, to and from northern and western Europe. Of the 30,000 inhabitants, one third live in Aniksi town, the rest in small villages spread throughout the island. The Centre for Disabled People is just as you come into the town. Near the harbour and seafront with its many cafes and restaurants, it is situated beside a small river and surrounded by a wall. The grounds also contain an old people's home and an orphanage.

The standard of living, by European standards, is quite low. The main source of income is tourism and agriculture. Agriculture in Aniksi means small-scale farms with some vegetables, goats and the occasional cow. More substantial are the grape vineyards and the olive trees that cover large part of the island. The majority of families, including those I interviewed, own at least a few olive trees and have enough grapes to make their own wine. Life in Aniksi is strongly determined by the seasons. October is the time for the grapes and the roads are lined with tractors and trailers, heaped up with grapes on their way to the factory presses. November and December is the time to harvest the olives. This is hard physical work. Large plastic sheets are spread out under the trees and the men beat the branches with sticks to get the olives to fall down on to the sheets. Most of the olives are pressed for oil either for private use or for sale. January, February and March are months in which to relax, paint the houses and carry out necessary building work. At the end of April, the summer season starts and the first tourists of the year arrive.

Tourism has grown rapidly in the past 15-20 years. The airport opened in the early eighties and that made it easier to bring in tourists in an organised manner from Holland, UK, Ireland, and Austria in particular. Small coastal villages, where the only means of existence used to be small scale fishing, farming and the harvesting of olives and grapes have been transformed in to tourist resorts with apartments, hotels, restaurants and bars. Due to local structure and planning regulations, most accommodation is in small hotels, pensions and rooms that are built and owned by local families. For most families tourism provides an additional income rather than a replacement of earlier sources of income. Except for some employment in the state sector, such as banks, schools and transport, work in Aniksi is seasonal and small scale. Irregular hours and more than one occupation are the rule. Aniksians work to earn a living, those interested in a career will, more often than not have to leave for the mainland, usually for Athens or even abroad.

Changes in infrastructure, a sudden rise in income and exposure to luxury goods through tourism and foreign visitors, a large influx of people during the summer months pursuing typical holiday activities have instigated many changes in values and in the structures of Aniksian society. For example, it is only in the last two decades that the island has had a noticeable police presence. Despite these changes however, for many people, the old values and social structures have remained and tradition is still strong.

Marriage and family life are important in the social life of Aniksi. In Greece, marriage is still regarded as a pre-requisite for procreation and, therefore, of the continuation of life (Loizos and Papataxiarchis, 1990:6). The Greek marital relationship is strongly orientated towards their roles as parents rather than around their roles as spouses (Vermeulen 1985; Kourvetaris and Dobras 1984). In Aniksi the mother is strong inside the house and the father is the person of authority in external matters. "Gender attributes are linked to domestic kinship roles" (Loizos and Papataxiarchis (1991: 7-8). Womanhood in Aniksi means nurturing, cooking and cleaning, activities that reflect women's unique psychology and their ability to love as mothers. Manhood means providing for the household, representing or defending kinship loyalties in line with men's psychological capacity for rational calculation and overarching responsibility. A man's obligation to his family, defined as those who eat and live together and who are protected by the same icons, is absolute and categorical (Campbell 1983). Brothers in Aniksi share authority and responsibility for their sisters with their fathers and this responsibility usually lasts until the sister is married. If possible, father and/or brothers also contribute towards their sisters' new family through the full or part payment for a house for the new couple. Children have a responsibility of care towards their elderly parents. Many who have been away from the island to work or study return, or feel unable to leave because of this responsibility.

In Aniksi, few women who have their own family go out to work unless they are divorced and need to be the breadwinner. Many lead isolated lives with their main social contacts being their families. Transport can be a big issue: only one of the mothers I interviewed owned and drove her own motorbike. This meant she had a certain freedom that she used extensively for visiting her birth family that live in the next village. In Aniksi a lot of women after marriage move to the house and/or village of the husband. Interestingly, none of the mothers I interviewed reported great closeness to their in-laws. Maybe this closeness may be taken for granted and thus not mentioned or was affected by the birth of the child with learning disabilities (see Chapter Four: The Parents' Stories for further discussion of this issue). In relation to friends, women in Aniksi seem to have few friends and the same is true for the women I spoke with. This may be related to cultural influences; people in Aniksi do not share family problems easily with 'outsiders', out of shame, out of fear of 'talk' or on the principle that each one of us has to deal with his or her own struggles.

Their children's education is a great source of worry and pride for parents in Aniksi and a frequent topic of conversation as most Greek people have "a strong passion for education" (Kourveraris and Dobratz 1984:151). Education in Greece is controlled by the state. It is centralised, free and consists of a nursery, primary, secondary and third level. There is no university in Aniksi. In theory, all children have to go to school and the state does provide some special education. In Aniksi however, there are no special schools.

The majority of people in Aniksi are Greek Orthodox Christians and although many people only go to church occasionally, religion and religious traditions are still important. Most newborn babies are not given a name until they are baptized at the age of six months. The name day of the child, which is the day of the saint after whom the child is named, is at least as important as a birthday and celebrated accordingly. The feast day of the island's saint Dionyssos on the 25th of August is celebrated extensively. In day-to-day life women bless themselves passing a church, and houses often contain icons. Except for church services there is not much social life connected with the church and priests are not seen as people who offer support in times of difficulty.

Men and women do not spend a lot of time together. Men go out to work or to sit in the local *kafeneion* where they drink coffee or raki (Greek alcoholic drink), play backgammon, watch television or discuss the news. Women usually stay at home. Traditionally, young girls are not allowed out without the permission of their fathers or brothers and/or under escort. In many of the families I met these rules were still more or less adhered to. Times are changing though, and an increasing number of girls rebel against these old values. The more modern version of the *kafeneion* is the *kafeteria*, a place where young and old people of both sexes and indeed whole families may go for coffee or ice cream. A traditional place for families to congregate is the *taverna*. It is not uncommon, especially during the summer and on Sunday evenings, to see a *taverna* at 11 or 12 p.m. filled with large groups of families and/or friends, including young children.

Going for *volta* (a drive or a walk with a social aspect, always in company) is another well-established leisure activity outside the family home. Groups of boys drive around on their motorbikes or in cars. Women, young and old, in pairs or with the whole family go for walks around the village or the square in town. On Sunday nights in the summer the square is full of people, eating nuts or ice cream from the many stalls around the square. Recently, some (seasonal) institutional leisure facilities have come to Aniksi: an open-air theatre and cinema offer occasional shows during the summer.

Public health insurance is available to everyone in Greece, which in principle pays for all medical costs. The practice, however, is often very different with shortages of material and personnel. Very few doctors live in the villages. In Aniksi there is a hospital but few consultants. Many people travel to Athens for specialised medical treatment and pay for it themselves. Medication is expensive and the insurance only pays for 20 percent of the costs. In addition to poor organisation in the public health sector, many people feel that quality care is only available if it is paid for, a perception that many doctors use to their advantage. Illness is a major inconvenience and financially taxing. The people of Aniksi visit medical doctors frequently for all kinds of complaints and there is a big emphasis on the use of prescription drugs rather than preventative care.

The people that I interviewed in Aniksi appeared to have an ambivalent attitude towards the medical profession. On the one hand they expect medical answers and cures for many of their problems but, on the other hand, and in particular if these answers and cures are not given, you hear people say: "Most doctors are no good." If the doctor cannot fix their problems most people tend to accept physical and related problems as a touch of fate against which one is powerless. “Ti na kanoume” (what can we do) is a phrase often heard in Aniksi. While there may be cultural elements in the way people cope with problems, these may not be typically Greek in nature. Similar attitudes in non-Western countries towards learning disabilities in particular are described by Zevenbergen (1986) and Edgerton (1970) in Chapter One: Learning Disabilities in Socio-Cultural Context.

In particular relation to the families I visited: more than half of the parents I interviewed in Aniksi lived out of town, most of them in villages. These are usually quite spread out over the countryside and few of the families had neighbours close by. They all had the most beautiful gardens that supplied vegetables as well as a feast of flowers. Most families also had some chickens. The families that lived in town were living in town houses or apartments and didn’t usually have a garden. The men of the families in the country worked in a variety of jobs as described for the rest of Aniksi. Those who lived in town were mostly small business people.

Fynnon

The Borough of Ffynnon in South Wales – with a population of 75.000 – is very different to Aniksi. Ffynnon Town is the main industrial and commercial centre. The villages in the Borough have regular bus or train links with Ffynnon and with other towns and cities in the rest of Wales and England. The nearest city can be reached within half an hour by train or car. It has a University, department stores and other facilities and resources usually available in a city. There is also a well-equipped athletic stadium that is used by the centre as part of their sports and Special Olympics programme. Fynnon itself is well served with leisure and sports facilities. They include pubs, restaurants, cinema, bowling alley, leisure centre including swimming pool, and of course, rugby and football grounds. A nature park is close by, where people go for a drive, a walk or a day on the beach. There are many shops in the centre of the town and a busy market three times per week. On the edge of the town and best reached by car, there are a number of large supermarkets where the majority of people do their weekly shopping. The Social Activity Centre for people with learning difficulties is on the edge of town near the industrial estate.

Until recently the majority of the male population in Ffynnon was employed in tinplate mills, steelworks, foundries, and engineering works. The closure of many of these industries, particularly the mills and steelworks, created a serious unemployment situation from the late 1970's onwards. Agriculture in the Borough takes the forms of small family farms, which do not employ a large number of people. Besides industry and agriculture people work in commerce, service provision, education and health.

Most people in the area have just one source of income from their regular employment. The unemployed are dependent on state benefits for survival. Ffynnon, as part of Wales, has a welfare system that provides benefits and allowances for those without work or past working age. The state, through the local authority and together with other agencies is also trying to attract new industries into the area and efforts are being made also to develop tourism. Despite these efforts, unemployment remains high. The state run Job Centre provides advice and incentives for training, retraining and job seeking. People with learning difficulties are not part of these schemes. They receive disability allowance or attendance allowance, rather than unemployment benefits. This indicates that they are not seen as unemployed (i.e. as eligible for employment). The families I visited did not seem to have any pressing financial difficulties. The parents were near or past retiring age and would have had a pension from past employment or the state. Few mothers went out to work. I did not see much luxury, nor did I see poverty.

In the Ffynnon area, strong family ties exist. The families I interviewed were no exception to this rule and many live in close proximity to their extended families. Support from grandparents for young families is normal, especially in the area of childcare and in particular if the mother goes out to work. While quite a few of the mothers I interviewed had received support from their own mothers in the past, they were less able to do the same for their own children if they still had the person with learning disabilities living with them. In fact, one mother told me: "She (married daughter) looks after S. (daughter with learning disabilities) more often than I look after *her* children". In Chapter Four: The Parents' Stories I will discuss the support provided by extended families in more detail. Young people stay in the parental home until they marry, find employment elsewhere or choose to follow third level education in a different part of the country. Others leave as soon as they are able to support themselves and move into flats or share a house with friends. In Ffynnon, leaving home is seen as an important step towards adulthood, as are marriage and employment. Young people feel it important and necessary to distance themselves from direct parental authority. Living independently is desirable so as to enable a young person to live as they choose and 'proof' their departure from childhood. None of the families I interviewed had adult children still living at home and most of those that had left home were married with their own family. Young people with learning disabilities are also encouraged to leave home by the provision of independence training at the Social Activity Centre (see Chapter Three: Two Centres), by the provision of hostels and group homes and by the provision of adult carers or 'foster parents' by the Department of Social Services. Their purpose is twofold; to provide respite for parents or alternatives to parental care after the death of one or both parents, and to provide people with learning disabilities with the opportunity to move away from home in a similar fashion to other (young) adults in Ffynnon. Their existence may be seen as an expression of the idea that people with learning disabilities have a right to live as 'adults' and of the notion of collective (state) responsibility for the support of families with, and care of people with learning disabilities.

Social life and leisure is centred around the family and 'going out'. Young people go to the pub, to the disco, the cinema or just 'hang out' in town. The theatre or going out for a meal is an option for all ages. Sport is popular too; to play for a football or rugby team, visit the leisure centre or bowling alley. Bingo is a popular leisure activity that quite a few of the parents and people with learning disabilities took part in together. Many women, and people with learning disabilities that I met, like to go into town to shop, or just to look around and go for a coffee with friends. Leisure and social life are quite structured. Church or chapel plays an important role in Ffynnon. People belong to the Baptist or Wesleyan chapel, the Anglican Church of Wales or the Roman Catholic Church. Church services, choir practices or special social functions related to church are important ways in which time is spent and friends are met. In general, it seems that in Ffynnon, work and social life are highly organised (to the extent that there is even a befriending scheme for people with learning difficulties). Many of the above activities have rules and regulations attached to them and take place in designated places during designated time. They also invariably involve expense/money. Facilities and clubs especially for people with learning disabilities often have their own transport arranged and a bus will pick all the participants up and bring them home again.

Although the Borough outside Ffynnon is quite rural, few people live 'in the country'. The families that I met all live in the town or nearby villages, in terraced houses or small bungalows. Quite a few live in estates build by the Council where they rent a terraced house. These estates are lively places. Many people have lived there for many years and have friends and family within the estate. People call to each other's houses frequently, for a cup of tea and a chat. Children play (and quarrel) or get up to mischief together outside on the streets in the estate. Most houses have enclosed gardens where the younger children play. Despite the fact that most people do not own their houses outright – they are tied to mortgages or rent – the standard of living is reasonably high and no parent appeared to have any pressing financial difficulties.

People classified as having learning disabilities

The following tables show the number of people researched in both centres, the age distribution, gender and where and with whom they live.

Table 1: Age and gender distribution Aniksi

	16-20	**21 - 25**	**26 - 30**	**31 - 35**	**36 - 40**	**41 - 45**	**46 - 50**	**TOTAL**
Women	2	3		2			1	8
Men	4	7	3	2	2	2		20
TOTAL	6	10	3	4	2	2	1	28

Table 2: Living arrangements Aniksi

	Home	**Orphanage**	**Old People's Home**
Women	6	1	1
Men	16	2	2
TOTAL	22	3	3

Table 3: Age and gender distribution of original sample in Ffynnon

	21 - 25	26 - 30	31 - 15	36 - 40	41 - 45	46 - 50	51 - 55	TOTAL
Women	2	2	3	2	5		1	15
Men		4	4	2	5			15
TOTAL	2	6	7	4	10		1	30

Table 4: Living arrangements of original sample in Ffynnon

	Parent	Single Parent (Father)	Single Parent (Mother)	Sibling	Adult Carer	Hostel	Parent & Hostel
Women	4	5		3	2	1	1
Men	6	1	1		3	2	1
TOTAL	10	6	1	3	5	3	2

CHAPTER THREE: TWO CENTRES

Introduction

Aniksi and Ffynnon each have a day centre for people that have been classified as different from other adult members of their society. In Ffynnon these people are said to have 'learning difficulties' and on Aniksi they are referred to as 'disabled people'. I undertook my research within these two institutions. Institutions such as centres for people with (learning) disabilities are influenced by culture (including knowledge, policies, values and norms) as well as by the social and economic structures of a particular society. Global values and developments may also play a role, and in turn, these institutions may influence local or even global norms, values and structures as well as individual lives (Malin, Manthorpe, Race and Wilmot: 2000).

Institutions can take different shapes and forms. In this thesis I use the term 'institution' in the sense of a 'social establishment' i.e. "places such as rooms, suites of rooms, buildings or plants in which activity of a particular kind regularly goes on" (Goffman 1991: 15). Institutions of this kind may differ from each other in a number of ways:

- the kind of people who are using them and for what reasons;
- how much time those people spend there and
- the areas of an individual's life that are addressed by the activities taking place there.

Goffman (1991) describes how institutions vary from places where people come together in an informal way and on a voluntary basis to places where large numbers of people live together in a formal way and cut of from the rest of society. He called these total institutions. Characteristics of total institutions, often cited by critics of institutional care are:

- the social distance between staff and inmates;
- the mortification or loss of previous social roles for residents and
- the lack of barriers between different areas of life.

Criticism of institutional care for people with learning disabilities has come from practice (Gates 2003; Race 1999) and from theory (Malin, Manthorpe, Race and Wilmot 2000; Oliver 1990):

> One key characteristic of traditional institutions has been that they affect all aspects of people's life, restricting lifestyles, individuality and access to ordinary living. (Malin, Manthorpe, Race and Wilmott 2000: 18)

In addition to their restriction of life styles and inhibition of individual development, from a standpoint of normalisation, integration and inclusion, institutions may be criticised for facilitating segregation. According to Oliver, institutions successfully remove from society those unable, or unwilling, to conform to capitalist values (Oliver 1990: 32).

However, massive de-institutionalization during the second half of the twentieth century has not always brought the desired improvements for people with learning disabilities:

> Many of the assumptions about community integration contained within normalization may be potentially erroneous and damaging. Dispersal within the community does not guarantee that people learn to behave in a way that will overcome intolerance towards them. Instead, people may feel increasingly stigmatized and cut by social distance from non-disabled people while being physically separated from others who share their difficulties. (Szivos 1991: 125)

Negative aspects of de-institutionalisation in the United States have been the loss of long standing friendships and the lack of community based ‘integrated’ services to provide an alternative to the large ‘segregating’ institutions (Scheerenberger 1987).

The word ‘institution’ has many negative connotations (Szivos 1991). “They have come to stand for dehumanizing practices, segregation and the mortification of the personality, a far cry from the educative and humanitarian impulses which motivated Sequin and other reformers responsible for their inception" (Szivos 1991: 117). Institutions however, could also play a positive role in the pursuit of the very principles of normalisation, social role valorisation and inclusion for their clients. They may offer a programme targeting the personal development of clients and enhancing their quality of life, as well as attempt to change society.

In the U.K. the principles of normalisation have been incorporated into "service accomplishments" (O'Brien and Tyne, 1981) that provide "a framework on which to base the care for people with learning disabilities" and "developmental goals to which organisations then and now strive towards" (Atherton 2003:55). These five service accomplishments are:

- community presence in local community
- community participation through relationships with their families, neighbours and co-workers and where necessary increasing individual networks of personal relations
- competence; developing skills and attributes that are functional and meaningful in natural community environments and relationships
- choice; helping people to understand their situations and their options and to act in their own best interest
- respect; developing and maintaining a positive reputation for people with learning disabilities in ways that promote their perception as developing citizens

While these service accomplishments may provide us with some concrete standards to evaluate and measure 'normalisation' and at least some elements of 'inclusion' a further clarification of the meaning of the word community is necessary. As Szivos pointed out, the concept of 'community' has, and is used in, at least two meanings: community as a social-political-geographical area and as a network of friendship and support. This network may be located, but not necessarily, within the social-political-geographical area:

> In fact, with a few noteworthy exceptions, individuals in today's society tend not to draw upon their geographical community for social support (that is,

> friendships) but rather rely upon the sophisticated use of travel and communications technology to maintain extended friendship and kinship networks. (Szivos 1991: 117-118)

This chapter explores the influence of two institutions (daycentres) on the classification and treatment of people with learning disabilities, by asking the following questions:

1. How do local cultural values, social-economic structures and individual characteristics such as impairment determine what happens within and through the daycentres, and thus influence the experience and the definition of learning disabilities through the existence of the institution?
2. Do the lives of the people attending both centres compare to those of other adults in their society, using the principles of normalisation as a guideline for description and analysis, and taking into consideration the possible different meanings of community?
3. What elements of 1 facilitate, or act as a barrier to 2; what elements of culture, social-economic structures and individual characteristics and circumstances facilitate, or act as a barrier to the inclusion of people with learning disabilities within their local community?

In the rest of this chapter, I will first look at the establishment and objectives of both centres, the procedures and reasons for admission, the programmes, the staff and last but not least the profile of the people themselves. In comparing the two centres with each other, I will discuss differences and similarities in the above, in the light of local cultural values and socio-economic structures. Using the five service accomplishments, I will identify aspects of the two institutions, and of the societies they are part of, that facilitate the treatment of people with learning disabilities as respected and valued members of their society or indeed inclusion. I will also identify aspects that may act as barriers to that inclusion.

PART A: ANIKSI

Establishment and objectives

In Aniksi, the Centre for Disabled people opened in 1983. It was the first institution of its kind on the island. Up until then, children and adults with learning disabilities from Aniksi were found in large institutions or hospitals on the mainland, in regular schools on the island or at home. This resulted in the existence of a group of people with little or no education, unable to find a job and spending their days at home. Local government became aware of the existence of these people by examining the database of all people receiving disability allowance, and through representations made by local government councillors. Councillors are in close contact with the people of their village and aware of local and individual needs.

The establishment of the centre was part of an experiment that included five similar centres around Greece, a joint initiative by local governments, the Greek Department of Health and the European Union. It was made possible by two different factors. Firstly, the then pending admission of their country into the E.U. had made Greek people aware of standards of social care in other parts of Europe. Secondly, the E.U's Social Fund (see Chapter Two: Research Questions, Methodology and Setting) made it possible to attempt to live up to those standards. The Centre for Disabled

People is one such attempt, which also addressed a need that had slowly become recognised within the local community.

The centre on Aniksi was set up to cater for all disabled people. In reality however, the majority of clients have, what in the UK would be called learning disabilities or learning difficulties. (This is discussed further in the paragraph "People: Profiles" of this chapter)

The official aims of the centre and its programme are as follows:

a) To provide occupation for disabled people.

b) To teach disabled people the social and technical skills necessary to earn an income through work in their community.

c) To help disabled people find work in the local community and to create job opportunities within the centre.

Objectives (a) and (b) were the original ones and correspond to those of the other five Greek Centres set up during the same period. In the last couple of years, and in co-operation with the Horizon Programme (another E.U. Social Fund initiative - see also the paragraph: "Programmes" in this chapter), efforts have been made with regard to (c). Dimitris (manager and psychologist) explains:

> "First, when we started the centre, we had this idea. To occupy these disabled people. To socialise them. And to give parents a break. But then, for a long time, we stood still. We didn't go anywhere. Now we have new goals. To bring these people back into society."

In addition, according to its manager, the centre is used as a base from which to affect, and ultimately change, society:

> "We work a lot on attitudes towards people with disabilities. We use local radio, television, newspaper. We take the people around town. We tell about them and show what they can do. And it is picked up by other people. The architect, for example. He spoke about it on the radio when he spoke about town planning. But we want it further. We want proper jobs for our people.

> Permanent jobs."……"I see the process in three phases. One, we know about handicapped people and we say: 'We take care of you.' Two, we try to make you like us. You can be with us but you must do and be like us. Three, that is the revolutionary, the political stage. We must change society. To take people as they are." (He shows me some leaflets produced by the Horizon Project and the centre's own poster) "Look at these leaflets. They are in Greek, not English. It is not to make advertisement for our work to tourists. It is to inform the people, the Greek people, our people here and their parents. The poster says, 'A right to be different'. You must change society. A place for these people, for all. But you can be different. Black and white. Sexes. Ages. Handicaps". (Extract from an interview with centre manager and psychologist)

A variety of factors influenced the establishment, aims and objectives of the centre in Aniksi. It opened during a period of economic growth and optimism due to a rapidly developing tourism industry. The general feeling was that all could benefit including people with learning disabilities. Tourists were buying souvenirs, and simple craft products could be made by nearly everyone. In addition, the nature and structure of most of the work available in Aniksi is informal and easily accessible. Economic enterprise in all sectors consists mainly of small-scale family or one-person businesses. There is no need for intensive training, qualifications, interviews or employment procedures. The nature of the ultimate aim of the centre in Aniksi may also be seen as related to the local view on adulthood. In Aniksi, work and contribution to the family income are important aspects of being an adult. Independent living is not seen as important or worth striving for. Young people in Aniksi usually live with their parents until they marry or find work on the mainland. The men often return to the parental home with their wives. Finally, theoretical discourse, in particular the ideas of normalisation and inclusion influenced the set up, aims and objectives of the centre through international policies, programmes and funding; national and local government, and the international experiences of the manager.

The aims of the centre are intended for all its workers. It appears however that in reality, different aims are pursued for different individuals. In particular, a distinction is made between people with mild and those with more severe disabilities.

> Sylvia: "What about people like Maria and Marina?" (Two young women with moderate-severe learning disabilities)
> Dimitris: "Yes. It will not be for them (re-integration). They will stay in O.D.A.Z. for the rest of their lives. But to the others we have responsibilities. Of course we do not *have* to find them jobs but ... Really, we started, we did it wrong for this goal. Because we took everybody. Because our goal then was different. To take them out of the houses, to teach and socialise them. And to give parents a break. But now we want to bring them back into society, but not all are able for jobs." (Extract of an interview with Dimitris, psychologist and centre manager)

Work opportunities, within or outside the centre, are being pursued for some of the workers. For others, a supportive environment is offered for participation in the production of simple craft items. For a small number of people however, only objective a) is pursued: occupation and socialisation of the person with (learning) disabilities through activities within and outside the centre. The aims and objectives of the centre, the knowledge and motivations of individual staff members, and the impairment and level of abilities of workers themselves influence the particular aims pursued for each worker. (I will discuss this further in the paragraphs: "Staff" and "People: Profiles" further in this chapter)

Admission procedures

In Aniksi, parents are the only people who can refer their son or daughter to the centre. A variety of people however may be involved in the lead up to that referral. Families, friends, neighbours, (former) teachers of the child, or local village councillors may have heard about the centre, for example through the local media, and inform the parents. Teachers or village councillors may also approach the centre directly. Centre staff themselves may approach the family, following up on an informal referral. At the start of the project, possible candidates located through the Department of Health or village councils were contacted and visited by the centre manager and/or social worker.

The prospective worker plays a relatively passive role. On Aniksi, the responsibility for a person with disabilities lies primarily with the immediate family. This fits in with normal family values and traditions in Aniksi where members look after each other, live close together and parenting styles are, in general, authoritarian. Parents demand and command respect and take responsibility for their children very seriously, even into adulthood.

In Aniksi there is no official route of admission to the centre. It can be instigated by different people and appears to have little relationship to an official classification of the learning disabilities. Reasons for referral are difficulties in adjusting to secondary school or in finding and keeping work, in other words in adjusting to a life that is expected of an ordinary adolescent or adult in Aniksi. The causes of these difficulties may be of a psychiatric, physical or intellectual nature.

At the start of the project, the psychologist as well as the social worker visited most families of prospective workers. As the centre was the first of its kind on the island, staff felt that parents needed information, time and opportunity for discussion. Some needed a lot of reassurance and even counselling. Currently, home visits are limited to those situations where it is difficult for parents to come to the centre themselves, because of practical or psychological reasons. Following a meeting between psychologist, social worker and prospective worker, the psychologist carries out an assessment of the individual concerned. On his recommendation a place is offered. Officially a medical report is required, although in practice this rule is not always adhered to:

> A new worker suffered from epilepsy and was on medication without the staff of the centre knowing about it. After a few months, they became worried about the man's health and took him to the hospital. He turned out to be well known there. Apparently, the parents had not informed the centre because they were ashamed of their child having epilepsy. They were also afraid that he would not be accepted because of his condition. (From my field notes)

During weekly staff meetings the new worker is discussed and her progress reviewed. This review centres on the activities deemed most suitable for the individual concerned, as well as on how she is settling in socially. Due to limited numbers it is possible for staff to know, and be aware of the plans for each individual worker.

The referral of a person to the centre for people with disabilities is a classification in itself, in particular for those who have not previously been diagnosed in a formal way (see Chapter Five: Classification). It implies that a person is different and in need of a special service. This classification is not solely on the basis of impairment neither the direct cause of exclusion. The majority of the people attending the centre had already been excluded from the activities of other adults in their society i.e. education and/or work. They had been asked to leave school, left school because they were ignored, left because they were unable to attend, or they had been included in the system of education but could not find a place within local work structures. The official diagnosis of having learning disabilities made during the admission process is solely a tool for determining eligibility to the service.

Being (classified as) eligible or in need of a special service in Aniksi is flexible and may be influenced by circumstances, time or place. This flexibility in relation to place is illustrated by the following example:

> Antonio, a young man with Down's syndrome lives in a village about 10 miles out of the town where his mother owns some studios (tourist accommodation). In the summer Antonio stays at home, helping his mother at the studios,

> cleaning, and his uncle in the nearby taverna. Although, according to his mum, this helping is relative, it gives meaning to Antonio's days. Everyone in the village knows and talks to him; he is part of the social scene. In the winter mother and son live in town. It is then when Antonio comes to the centre and takes part in the activities there. (Extract from my field notes)

Antonio has Down's syndrome and this is recognised by the people around him. During the summer this does not prevent him from taking part in local daily life patterns in the small village resort. In the winter however, social and economic structures of the town such as density of population, traffic, a reversion to an indoors lifestyle and a greater level of formality in work structures are obstacles (barriers) for Antonio, preventing him from full social participation. In the town environment his disabilities increase and lead to him to being perceived and classified as in need of special care and attention. His exclusion, or indeed his disabilities, is related to his impairment (Down's syndrome with learning difficulties), scale and formality of local socio-economic structures, and the individual model of personhood in the town vs. the social model in the village.

The flexibility of classification is also illustrated by looking at examples of people who have attended the centre in the past and have now obtained work in the community. One of the women works in an art work-shop, a man has bought and manages a small newsagent (kiosk) with the help of his family, and a third person works for his uncle in a hotel. For these individuals, leaving the centre meant, in effect, moving out of the formal category of (learning) disabilities. I do not have any information, however, on the possible perception of these people as being (learning) disabled, by their families or by members of the local community. Therefore, I am unable to make any statements about their possible informal classification (see also Chapter Five: Classification).

Programme

In the Centre for Disabled people in Aniksi the following structured activities take place:

1. Work/Arts/Crafts

This includes: carpet weaving, the production of leather purses, diary covers and photo frames, paintings on metal and wood, embroidery and the painting of tablecloths, the manufacture of kolombi (bead strings that are characteristic of Greece and used by nearly every man sitting in a cafe) and plastic flowers.

2. Sports.

Twice weekly a local sports teacher visits the centre. He takes the workers to the local stadium for exercises and ball sports or plays volleyball with them in the centre grounds. This teacher has been doing this voluntarily for some years now. As well as being a source of fun and excitement it has greatly boosted people's confidence. Sport is important in Aniksian society with most young men playing football or basketball. It is difficult for the people of the centre to join local sports clubs because of the high standard of competition.

3. Reading and writing.

A primary school teacher takes small groups of 3-4 selected people on a weekly basis. For many workers, this is their first opportunity to learn to read and write at their own pace using individually tailored programmes.

4. Counselling.

Whether individually or in small groups, all workers have some time with the psychologist. This varies from regular, informal chats on 'how things are going' to specific therapy sessions. The discussion of individual programs is part of these sessions and part of the process to ensure that there is a suitable programme for each individual. Where possible, clients and psychologist set goals together as well as points to be worked on.

5. Videos

Twice weekly workers and staff watch a video together. Intended as a break from the daily routine it is seen as a treat by both workers and staff. The videos are mainly Greek dramas, comedy or sports programmes and are chosen by a member of staff. Occasionally the psychologist shows slides of his foreign visits, or of trips and outings undertaken by the workers themselves.

6. Parties, Outings and Holidays.

Parties are organised by staff, around holidays or at other special occasions. At these social events staff, workers and the children of the orphanage enjoy themselves together. The arrival of a group of 7 English intellectually disabled people and four members of staff was one such occasion. The children had picked flowers and one room in the orphanage was decorated. There was food and dancing. Every year two or three day trips are organised, the destination being decided upon by staff and workers together. These can take the form of a boat trip around the island with a tourist cruiser or a trip to Olympia on the mainland. These days too are days of celebration for every one; workers, staff, families and friends as well as the children of the orphanage. Most years, workers, staff and parents go on a holiday together. They travel for a week or so, to a different island or to a place on mainland Greece.

7. Morning break and lunch time.

The 10.30 morning break is for food as well as rest. In Aniksi, people do not usually eat breakfast but have something to eat at mid morning instead. Workers take turns in taking responsibility for collecting bread and cheese from the main kitchen and handing it out to their colleagues. This is a time for social interaction, sitting or walking together, chatting, playing a game of netball or teasing each other. Lunch is another social event with workers, staff and children all eating together. The cook hands out the (free) dinners and visitors are urged to join in. A distinction is made, however, between staff, visitors and children on the one hand and workers on the other hand. The disabled people get their food on metal trays, whereas the others get theirs on ordinary plates. The reasons for having dinner together are practical as well as social. Although the workers leave straight after lunch, many are not home until 2.30 p.m. as the bus calls to many villages over a wide geographical area. Dinner is also seen as part of the 'payment' for the workers.

8) The Horizon Programme

An initiative organised and funded through the Social Fund and open to all disabled people of the island, this meant that people with physical disabilities, who do not normally attend the centre, also took part. So far the programme has consisted of two parts. First, an educational programme was implemented for 10 workers from the centre and 5 from outside. It included computer skills, money handling, using the telephone, going out into the community and reading social signs. The second part addressed the accessibility of the community. With the help of the town architect ramps were constructed around town. (The fact that simply changing the physical environment to facilitate inclusion is not enough is poignantly demonstrated by what happened next. People parked their cars at the ramps and restaurants in true Greek style and even put tables and chairs in front of them!) The next phase of the Horizon Programme was to educate the public. Information leaflets on people with disabilities have been produced and are distributed over the island. Within the framework of the Horizon Programme, the manager and some of the staff have travelled to Belgium and Denmark to visit similar centres.

The nature of the activities carried out at the centre is in many ways comparable to those in the rest of society. I will elaborate more on this in Chapter Six: Work. They address the social and technical skills as well as the social needs of the workers. Initially, people are assigned to certain activities by the team. They are, however, encouraged to try out other, perhaps more difficult activities. It is not always the least able people that do the easiest things and vice versa. This is illustrated by the following description taken from my field notes:

> Theo is quite a capable young man. The first couple of times I met him he was working in the room where leather diaries, phonebooks and copper pictures were made. He was able to work more or less independently with just a little guidance from the member of staff. However, during my later visits Theo had moved to the room where the more moderately and severely disabled people carried out simple activities such as making plastic flowers. He had taken on the role of helper here, getting everything ready and helping out the other people. He had chosen this himself and in fact would still move between the two rooms if and when he felt like it.

Most activities however are geared towards ability, interest and gender. The girls and women at the centre work at traditionally female activities like embroidery, knitting and rug making. A few men are involved in these activities also, but no woman works with wood or leather. This reflects gender differences in the area of work outside the centre. Women usually work at home or in the garden. If they do work outside the home it is usually as cleaners, clerical assistants or teachers. Men may work in these areas also but they are the exception. Similarly, I have never seen a female bus driver or Greek waitress in Aniksi.

People: Profiles

Twenty-eight people attend the centre for disabled people in Aniksi (approximately 0.10 percent of the population) (see table 1 in Chapter Two: Research Questions, Methodology and Setting). On Aniksi, some people cannot attend due to the poor road infrastructure in the area and lack of transport. The centre has one bus. It takes approximately two hours every day to collect everyone and take them home again.

It has not always been easy to persuade parents to send their child to the centre. In the majority of cases their child would not have attended a special facility before.

Admission to the Centre for Disabled People is one of the first public statements that there is something ‘wrong’. There is still shame about such matters as the following extract from my field notes shows:

> Today I went into the bank to change some money and became involved in a conversation with the lady behind the counter. She asked me what I was doing on Aniksi. When I explained, she told me about a friend of hers, a lady doctor. This lady had a child who, according to the lady in the bank, was mentally handicapped. The child was five years old and sat at home in a chair all day. The doctor was too ashamed to admit this openly. She could not take the child anywhere for advice or assessment, or even out to school or play-school, because of this shame. According to her friend, the bank employee, this was made worse by the fact that she was a doctor herself. These things should not happen to her and being a professional person made it harder to ask for help.

Although the centre was intended for all disabled people, the majority of workers are what in the UK would be called ‘people with learning difficulties’ or indeed ‘learning disabilities’. Some people could be described as having dual disabilities such as learning difficulties and psychiatric problems, or learning difficulties and physical disabilities. There are no people with only physical disabilities in the centre in Aniksi. They appear to be perceived, by themselves at least, as a different group as the following example from my observations illustrates:

> Tassia is a young deaf woman, who does not normally attend the centre. However, when the Horizon Programme carried out at the centre offered an opportunity to learn computer skills, she did join in. A member of staff asked her if she would like to attend the centre on a daily basis. Tassia explained that the centre was not really the place for her; she was engaged to be married and would probably find a job soon.

In Aniksi, two things seem to separate ‘normal’ people from ‘people with learning disabilities’, the ability to find a job, and the opportunity to get married. This young deaf woman did not see herself as part of the group that attends the centre. I did however find some people with only psychiatric problems. It appears that learning disabilities and psychiatric problems are two categories perceived as being more closely related to each other than the categories of physical- and learning disabilities. The question of "hierarchy of handicap" has earlier been recognised by Dybwadd (1970) and was considered by Jenkins (1998) to be of importance for the development of a cross-cultural model of "incompetence".

There are only a small number of more severely disabled people in the centre on Aniksi, and no one with profound disabilities. Because of the previous absence of any services for disabled people on the island, many people have been sent to special schools and larger institutions on the mainland.

There is great variety in the level of abilities/disabilities amongst the people who do attend. I found people with severe problems, intellectually as well as in social adjustment, communication and self-help skills. Others are well able to communicate, look after their own basic needs, and carry out a variety of activities more or less independently. This point is illustrated by looking at some individual people:

> Nina is 28 years old. She has suffered from epilepsy since birth and her abilities are greatly affected. She has attended the centre on Aniksi since it opened. Nina is barely able to communicate, except for making some noises and taking your hand when she wants something. Her gait is unsteady and she likes to hold somebody's hand whenever she goes outside. She spends most of her time at the centre at a table packing and unpacking her bag. Sometimes she does some colouring in a book that she brings in this bag. The other people pour her lemonade at break time, or put a straw into her carton of juice. Nina lives in town with her parents and siblings in an upstairs apartment without access to a garden. This means that for her safety (traffic, walking away etc) she can only go outside under supervision. Her behaviour at home is like that of a toddler, constantly moving around and seeking attention. Her mother has to occupy and look after her continuously.
>
> Yannis is a young man in his twenties. He has been at the centre in Aniksi since leaving primary school. At primary school he found the schoolwork hard but was able to keep up with the class. During his teens he started to suffer from mental health problems and did not go to secondary school. He is quiet but friendly and, if you take the time to sit down with him, enjoys a chat. In the centre he had, with some help now and again from a member of staff, been making leather wallets and covers for address books. For two years now, he has been working in a kiosk in the grounds of the centre, where he sells ice cream, sweets, cigarettes and lemonade to people from and outside the centre. He works out the bills on a calculator and his family help him with stocktaking

> and ordering goods. Yannis also lives in town and his father works close by and is thus able to help out at the kiosk.

The official age limits for the centre are between 16-65. The ages of the people attending at present range from fifteen up to forty. This is quite a young group with two thirds being under 25. Two explanations may account for this. Firstly, the centre on Aniksi is relatively new. The majority of people started when they were between 16 and 18 and are now under 25. Secondly only, few people started at the centre in their late thirties of forties. It could be argued that the parents of younger people were more interested than the parents of the older people, who may have been at home for years. Change may have been difficult and shame more of an issue with older parents. In addition, when a son or daughter with learning disabilities comes into his or her thirties families have often learned to cope without support, people may have been integrated into the activities within and around their home or have been admitted to a residential facility outside the island.

A cultural aspect such as shame may itself be influenced by social structures such as service provision for people with (learning) disabilities. A lack of special services contributes to the relative ignorance around the concept of learning disabilities. For many people, including parents, this concept did not feature in their social world before the classification of their child. This may lead to a conflict situation for the parents, which does not favour acceptance of the child's condition. In Aniksian culture this may lead to shame and secrecy, which in itself is another obstacle to learning disabilities becoming part of a common social world.

Another aspect of the profile is gender. There are quite a few more men than women in the centre in Aniksi; twenty-two men as opposed to only six women. This reflects strong differentiation in gender roles in Aniksian society. The man is expected to go out to work, earn a living, deal with affairs outside the house and take full responsibility for his family. Being 'slow' or having in particular mild learning disabilities is more likely to be perceived as interfering with these expectations than with female role expectations of housework, marriage and childbearing. This is illustrated by the following example from my field notes:

> Maria is a fairly capable young woman in her early twenties. She lives in town with both her parents and siblings. She has attended primary school and has been at home for a few years. She now works at weaving carpets in the centre in Aniksi. Her mother was initially reluctant to let her go: "I did not want her to go at first. I did not want her to work. Now, I see she likes it. She has her friends there. I would like her to marry one day. A working boy. She is healthy and she could have children. She does not know her letters but she is very outgoing".

In addition, girls in Aniksi are protected and restricted in their movements by their fathers and brothers. The following situation illustrates this:

> The twins Athina and Socrates attend the centre in Aniksi. Athina is only mildly impaired and her mother hopes that one day she will marry. She attends the centre to look after her much more severely disabled brother. Her father is not happy about Atina's attendance and her mother says that soon she will keep her at home to prepare for her future marriage (but no marriage is planned at present).

Staff

Staff members in Aniksi have no previous experience or training in the area of learning disabilities, nor a specific desire to do this kind of job. The main reasons why they are at the centre are economic. The security of state employment, in an area where most work is seasonal, is very attractive. The teacher was already secure in state employment; she came from a national panel of teachers and had not specifically chosen to work in this centre. Due to the permanent nature of state employment there is a low staff turnover. Officially one has to apply in writing for a state job. In reality however, politically influential people make strong recommendations. It is a personal and informal matter, which often gives rise to dissatisfaction among people working within and outside of the centre.

Lack of a particular interest in, or relevant qualifications for their work, has consequences for the way staff in Aniksi relate to their work and the people attending the centre. They have each developed their own way of working with and relating to the workers and each other, through experience. This allowed a few staff members to build up a relationship with the workers without prejudice or pre-conceived ideas, but based instead on personal knowledge of and respect for each other. These members of staff have become increasingly motivated and happy in their work. This is especially true for those who were qualified in their own field before they came to the centre, for example, the primary school teacher, the sports teacher, the instructor in art and craft and the carpet weaver. Their focus is the skills they teach and in this they try to see past the person's disabilities:

> Frieda is in her 40's. She has worked for a Greek government organisation that sets up and runs workshops for women all over Greece where they learn to make rugs and carpets. She had worked in different part of Greece before she came to Aniksi where she also set up one of these workshops. This closed down a few years ago due to an increase in tourism, which brought different work for the women in hotels, pensions and restaurants. Frieda then came to work in the centre. She was employed specifically to make carpets with three people, two men and one woman. Another young woman has since joined the little group. Frieda says her work now is very different than before, but she really enjoys it. This shows, in that she is always cheerful, helpful and encouraging to the workers. In the room where they work there is a relaxed atmosphere with a lot of laughter and talking.

For others, however, the lack of previous experience and motivation had different results. These members of staff do not get very involved in direct interactions with the clients; their work is more caring or 'babysitting'. There are exceptions though. One lady used to do the ironing in an old peoples home. Now she enjoys and puts a lot of effort into her work with the clients at the centre:

> Maria works with clients who embroider tablecloths. Some of these clients work more or less independently. Others are assisted by Maria. A couple of girls seem unable to carry out any part of their work independently. Maria works very closely with them. She puts the needle in the material and one of the girls pulls the needle through. The two girls concerned can work for hours like this, together with their instructor, and the three of them seem to experience enjoyment and satisfaction in what they are doing.

Staff members in Aniksi know the individual workers quite well. This suggests that it is the size and structure of the centre, and the related degree of personal contact, that determines the knowledge about the client in day-to-day situations, rather than formal referral and assessment reports. Smaller scale units and the associated informality may also contribute to a familiar atmosphere and reciprocal interactions between staff and clients; a smaller social distance (Goffman 1991). The following extract illustrates the familiar atmosphere in the carpet weaving room, where three workers and their teacher weave carpets and rugs:

> (Thursday morning)
> Tassos and Maria are present, Frieda (instructor) enters. “Hello. Good morning” Frieda asks Maria to get some water in the bathroom to make coffee. There is a little hot plate in the room. Maria brings in the water, Frieda makes the coffee and puts it on to boil. When it has boiled she pours some out for Maria and herself. She asks Tassos does he want some but he declines. Yiorgos, a client usually in the other room, comes into the carpet room to join the others. Frieda laughs and asks: “Did you smell the coffee?” She pours him one too. Tassos tells Frieda that Toula, the other worker usually in the carpetroom is not coming today. “Why?” asks Frieda. “She is not here. She is in Patras (town on the mainland)”. When the coffee is finished Maria says: “Come one, time for work.” All start working and Yiorgos goes back to his usual work area, the leather crafts room.

The psychologist on Aniksi, as head of department, is office based. His work includes administration, family liaison, assessment and individual counselling, supervision of programme and workers and policy development. His professional background includes a French and Greek qualification in psychology. He continues to educate himself in the area of learning disabilities.

In Aniksi, the manager, similar to the other staff, knows the workers well and has an informal relationship with them. This may be related to the size and physical structure of the centre (his room is just off the main room), but also to the structure of the admission process (the manager being the key person), the informality of the atmosphere (time to joke and mess around with the clients) and individual personality. The following extract from my field notes is an example of affectionate exchanges between the manager and the workers

> (Thursday afternoon-Large Room)
> Dimitris (manager) comes into the room. Antonio (one of the younger clients) is wearing a cap today. He is sitting at the table making plastic flowers. Dimitris goes up to him and takes his hat, puts it on his own head. "Ask the others now do I look beautiful," he says. Everyone laughs, including Antonio. "Where is Maria (member of staff)?," he asks Antonio. "Has holidays" is the answer he gets. Dimitris pinches his cheek and rubs his hair affectionately. "He knows it all," he tells me.

It could be argued here that Antonio was treated in a child-like fashion and indeed; other examples of staff-client interaction support this notion. This is usually done in an affectionate way, an element which is very much part of 'normal' adult interaction in Aniksi. In some situations however, the 'child-like treatment' lacks warmth as well as respect:

> Tassos, one of the clients, has brought in his new radio. He is very happy with it and shows it off to everyone. It is sitting on the table beside him, turned off. Andrea, the social worker, enters the large room. Tassos shows her the radio. "Mine, mine," he says. Andrea takes the radio off him, looks at it and subsequently puts it on another table. Tassos says: "Mine. Mine." Andrea tells him (in a short tone): "Nothing on the table." Sakis, another client gets involved too. "Yours, yours." Andrea walks away. Tassos calms down and continues the colouring he was doing before she came in. During break time I see him walking around with his radio again.

In a similar fashion to other work situations in Aniksi, work and domestic life are not clearly divided. The psychologist spends much his official working time supervising the construction of his new house and another member of staff takes a nap during the day in the centre as he works at night in a restaurant. Other staff members make the occasional comment but on the whole this behaviour is tolerated. Staff and workers spend a lot of time together chatting about their private lives; looking at photographs; they bring in their new their babies, or they bring in cake as a treat on their husbands' birthday (common custom on Aniksi). These factors contribute to an informal and friendly atmosphere.

Part B: Ffynnon

Establishment and objectives

Ffynnon has a long history of services for people with special needs. In the past this was centred on large institutions and hospitals but more recently community care has become more important. The state has assumed increasing responsibility for the provision of education, training and day-care for those who do not take part in mainstream education and the labour market. Day centres for adults with learning disabilities, in this case the Social Activity Centre in Ffynnon, reflect that responsibility. It was set up and is managed by the County Council's Social Services department, and fulfils the requirement to provide day-care for adults with special needs. Part of the local structure since 1976, it provides a follow-up service for young people who have been in special education and an alternative for those who, because of their learning disabilities are not able to find or hold a place in the labour market.

The local planning group for services for people with learning difficulties includes representatives from social services, the health authority and voluntary bodies. Their report "Into the Nineties" describes the designated purpose of the Social Activity Centre in Ffynnon as follows:

(a) The needs of the individual, not their handicap, should be the prime criterion for attendance.

(b) The programme should cover all aspects of the individual's needs and not be concentrated on repetitive and mundane tasks that have no relevance to daily living or the encouragement of independence.

(c) Maximum use should be made of all the resources in the community.

(d) The service should develop the ability and confidence of a person in his/her daily life.

(e) The running of the centre will be achieved through regular meetings of the manager, staff, consumers and parents.

Originally set up as a sheltered workshop with a focus on work and employment the programme now aims at the overall development of the person: to teach and enable people to live a life that is as independent and as 'normal' as possible. Independence is understood as social independence, especially in the area of personal and home care. This shift in purpose was influenced by economic, theoretical and political developments.

The economical climate in the late seventies was not good. Unemployment had risen due to the closure of much of the industrial work places. Experience showed little success in the employment of people with special needs. As the centre manager put it: "If normal people cannot find a job, what chance do people with special needs have?" In addition, the work and employment structures in Ffynnon are formal; greater demand for formal qualifications, interviews and strict rules for starting up one's own business do not favour the employment of people with learning disabilities.

Theoretically, in the field of 'mental handicap' the idea of 'normalisation' had become widely accepted. Originally meant to promote the rights of people with learning difficulties to a life filled with the same kind of meanings as other members of society (Wolfensberger 1972), it came to be interpreted to mean that everyone should live as independently as possible and do the same things as "everyone else". The focus shifted from employment, work and occupation to individual needs, and personal, academic and social development.

The "All Wales Strategy", a government policy for the development of services for people with learning difficulties in Wales, drew upon the principles of normalisation. It advocated a system of community care (Blunden 1991). The principles set out in the policy were to apply to all people with learning difficulties:

- Mentally handicapped people should have a right to normal patterns of life within the community.
- Mentally handicapped people should have a right to be treated as individuals.
- Mentally handicapped people require additional help from the communities in which they live and from professional services if they are to develop to their maximum potential as individuals. (All Wales Strategy: 1983)

The aims and purpose of the centre reflect the important aspects of the local concept of adulthood. In Ffynnon, work and marriage are important but are not the only factors determining adulthood (Jenkins 1990). Other important aspects of adulthood in Ffynnon are individuality, choice and independence (Malin, Manthorpe, Race and Wilmot 2000).

Fynnon is similar to Aniksi, in that objectives are tailored to each individual. They are related to the individual abilities and disabilities of each client at the centre, and to differences in motivation and abilities of individual staff members. I will discuss these in more detail in the paragraphs "Staff" and "People: Profiles". Both factors are illustrated in the following extract from an interview with Judy, an art and drama teacher:

> "The policies were changing. Get them out into the community. I was given the ones that were left. I did not realise this at first. I was taken on to do drama with them. In the hall. Then I realised they weren't there because of any interest but because they had nothing else on. . . . Then I was asked to do art with some people. A fixed group now and again, and the 'odd' people that just come in, that don't want to go out or do not want to do their regular activity or have no group at all (*These people would usually be the people with the moderate-severe learning disabilities)*. Just to keep them occupied. Sometimes I feel it's a babysitter service, I just keep them occupied to prevent them from getting into mischief. Even Bernard (*Manager*) mentioned it once or so, that we are supposed to give respite. I realise there is that aspect to it but there must be something else too. It is not right. Look. Like Peter. He will keep on painting, producing these paintings all day, the same. I feel an hour or so is enough. Everyone should rotate. Now it is always the same people that go out (*into the community*). Like Mary. I never see her in. And maybe she would like to do an hour of painting. It is so frustrating, demoralising" (Judy, art and drama teacher at the centre in Ffynnon).

Staff members are enthusiastic and supportive of the aim to encourage the overall personal development of the client. However, working with large numbers and a variety of interests and abilities, they find it difficult to realise the aims and objectives of the centre for all clients equally.

Admission procedures

In Ffynnon, referrals to the Social Activity Centre in Ffynnon come from a specialist social worker based at the local Community Mental Handicap Team. The admission procedure is structured and similar for each prospective client. Following a home visit and completion of an assessment by the social worker the prospective client and his or her family/carers will attend a clinic with the Consultant Psychiatrist in Mental Handicap, based at a hospital in the neighbouring town. If it is deemed that admission to the centre is according to a person's needs and wishes, he will visit the centre together with his parents. A three-month probation period is usually recommended in order that both parties have the time to make observations and comments and decide if the centre is the right place for the individual concerned. However, this probation period and review is not always adhered too. Quite a few people are admitted to the centre because there is no suitable alternative available to them, not because it is believed that the S.A.C. can provide them with the service they need:

> "Basically, one has to accept any prospective user who wants to come - there is no alternative. Officially I cannot refuse anyone. However, I would remove someone from the centre if there were reasons, and have done so, for extreme behaviour. The fact that there is no alternative is bad for us in the way that we are not under competitive pressure, no matter how bad a service we provide, people will have to come to us." (Extract from interview with centre manager)

Centre management, staff and people with learning disabilities themselves have little input into the admission procedure. The social worker's report and subsequent review include discussion of needs and recommended programme. It also covers other aspects of the person's life such as accommodation, work prospects, family, leisure, friends and intimate relationships. Regular reviews are recommended but in reality do not happen very often. They include discussion of all areas of someone's life by a variety of people, from both inside and outside the centre. Bulky files, including history of, reports on and recommendations for most clients are available in the manager's office but seldom used by staff working with them on a day-to-day basis.

There are a variety of reasons why people attend the S.A.C., the most common ones being:

1) The development of independence skills.

2) The development of academic skills.

3) The development of social skills

4) The prospective client has no other appropriate place to go to.

5) Parents are in need of respite.

The first three are those most frequently given in official admission reports. They may not always correspond to views of staff, parents or clients themselves, or indeed with what happens at the centre. Recommendations are often outdated.

Admission to the centre for people with disabilities does not create or directly cause exclusion. Most people were already excluded and in special education or in a Junior Training Centre. Their exclusion is usually long term, following formal diagnosis (see Chapter Five: Classification). Statutory responsibility in Ffynnon spreads out over many areas of the person's life of which admission to the centre is just a part. The label 'learning disabilities' secures day services and social services support. This is something that the many other young unemployed school leavers do not have, namely a right to redistribution of resources and an excuse for not having to fulfil the demands of full-time employment. The price of this, however, is a low wage or allowance without little chance of economic improvement. In addition, people with learning disabilities have to accept long-term involvement with 'professionals' leaving little room for privacy and personal freedom, so highly valued in the rest of society. This may be illustrated by the following observations at the centre:

> (Nora, a member of staff, is cooking with a small group of clients. She is also talking to me about Diana, also present in the group. Diana is in her twenties.)
> Nora: "Diana is only awake when there is food."
> Diana: "Rang Emma, I shouted at her."
> Nora: "I rang Emma, her guardian (*foster parent*), last night to discuss why Diana is always asleep. Diana shouted at me for that."
> Diana: "No business. Rang Emma. All staff are asleep." (looks angry and raises her voice)

Nora, as a member of staff, found it completely acceptable to check and discuss with the foster-parents why a client is tired and sleepy during the day. While this may have happened out of interest and concern, it is questionable if the same would happen to other adults in Diana's society. Food is another issue of which professionals take control for the 'benefit' of the individual with learning disabilities as the following example shows:

> It is morning break in the flat. Staff and clients are having tea together. John (in his thirties), one of the clients, is about to put a third spoon of sugar in his tea.
> Fiona (staff) (with loud voice): "Noooooo..."
> John: "You are cross."
> Fiona: "If you had a third one I would be cross."

These examples raise the question of perceived adulthood for people with learning disabilities. Other adults in Ffynnon would perceive the above as unauthorised interference in areas considered to be a matter of privacy and individual choice. For people with learning disabilities, once in the system of special services, this 'interference' is part of their daily experience. That they are not always happy with this shows in Diana's anger when she found out that Nora had phoned her foster parents.

Programme

The activities offered at the Social Activity Centre are aimed at the development of the full potential of the client (See also paragraph: "Establishment and Objectives") and follow the recommendation of the admission report:

1) Arts and Crafts

These subjects include amongst others painting, pottery, woodwork and seasonal crafts (making Christmas presents). They take place either in the workshop or in the art room in the centre of the building.

2) Sports and Leisure

These activities are organised and carried out outside of the centre. Sports (athletics, within the framework of the Special Olympics) takes place in the local sports stadium, swimming in the leisure centre, bowling at the bowling alley and dance and drama with a member of the centre staff in the local community centre. Trips and holidays with centre staff for example to a nearby caravan park are popular with all. While these activities take place 'in the community' this sometimes means just using facilities with a group from the centre while no one else is using this facility. For example using a room in the community centre for dancing or yoga during an afternoon when no one else is around.

3) Independent Living Skills

Cookery instruction is carried out in the staff room. The flat is a separate, self-contained unit within the centre and clients spend half a day at a time there, cleaning, cooking and having lunch. Shopping is done during cookery class, in a local supermarket or as a trip to the town centres of nearby towns.

4) Self Care

It is mostly the women in the centre that attend these classes. They include hair care and make up.

5) Academic Skills

Literacy, numeracy and money handling are subjects taken by large numbers of clients.

6) Work experience and/or voluntary work

Only a few people take part in this. In theory it is used to find out what the clients are interested in and capable of, with a view to future work placements. In practice however, the view towards the future is not an issue. It does, however, give the clients concerned the feeling that they have a job to go to (see also Chapter Six: Work).

7) College

A few people attend adult literacy classes at the local college. The college is a general college for adult education, but the classes for people with learning disabilities are separate classes. People attending these classes mix with the other adults using the college during break times and/or in the canteen.

Individual programmes are supposed to be reviewed during regular case conferences. As discussed above however, these meetings are rare and the matching of people and activities are the result of the wishes of clients and staff. Once a client follows a particular programme there is not much room for flexibility or change; people are expected to keep to their timetable, which many carry around but few are able to read (see also Chapter Six: Work).

The Social Activity Centre in Ffynnon is especially for people with learning disabilities and the majority of client's fall within this category. There is a small minority of people with psychiatric problems and with dual disabilities but none with just physical disabilities. Here as in Aniksi, psychiatric problems and learning disabilities appear to be perceived as more closely related than the categories of learning disabilities and physical disabilities. In Ffynnon however, the separate nature and needs of this group has been official recognised as another communal responsibility and services do exist for people with physical disabilities.

The people attending the centre are divided into two groups. Twenty-five people, with severe and profound disabilities, attend the special care unit. One hundred people with mild and moderate disabilities attend the mainstream group. In this thesis I concentrated on the mainstream group, as they appeared to be most similar to the people attending the centre in Aniksi.

Within the mainstream group people vary greatly in their level of abilities and disabilities, interests and circumstances. This is illustrated by the following examples:

> Fiona is a woman in her forties. She started school at the age of four. A year later she suffered two brain haemorrhages and was left with severe learning disabilities. She left school and stayed at home, playing on the farm with the animals she loved and 'helping' her father. At the age of eight she went to the Junior Training Centre and from there on to the S.A.C. After her mother died she moved to a hostel during the week and goes home at weekends. Fiona has little speech and difficulties in communication. She finds it hard to concentrate on an activity for any length of time and can get quite frustrated and agitated. Sometimes she rips her clothes or hits herself. She spends a lot of time doing art with some of the other more severely disabled people. Occasionally she goes out with a group, usually shopping for food when she has a cookery class. During this class she will take part by stirring jelly or putting out plates. Changes in routine are difficult for her. She also finds it difficult to leave her dad after having spent a weekend with him. Discussions are going on between

> her social worker, her father and hostel staff about cutting down these visits. It is felt they may be too upsetting for her.
>
> Ann is in her thirties. She is from a council estate in Ffynnon, the only daughter from a large family who still lives with her parents. Her siblings have all left home. Two of them live close by, with their own families, and they visit each other and their parental home regularly. Ann has attended the centre in Ffynnon since leaving special secondary education. Ann likes to keep herself to herself, but will talk to you if you make the effort. She is able to look after her own personal needs and some simple cooking and housework. At the centre she is popular with her own group of friends. She is active and joins in with many activities. Her speciality is sport: she is a member of the Special Olympics team at the centre and spends a lot of time running. She is also good at, and enjoys, the more complicated craft -work. Once a week, Ann helps out at a local mother and toddler group organised by the Salvation Army, as part of a work experience scheme.

In relation to age (see table 3 in Chapter Two: Research Questions, Methodology and Setting), if we take the sample to be representative of all the clients attending the S.A.C., the majority of people in Ffynnon are between 31-45 years of age. The older age group (over forty-five) is in the minority. Young people are well represented but their number may be a smaller than expected. In Ffynnon the centre is a well-established part of community facilities and over the years has become an acceptable follow up to the secondary (special) school or, in the past, the Junior Training Centre. The majority of clients have been in the centre since they left one of these two establishments. This accounts for the fact that there are quite a few people in their thirties and forties but does not explain why the number of young people is relatively low. Special schools still exists, with a number of school leavers each year. The explanation for the drop in younger clients may be that at present alternatives to the daycentre are available to some people, and/or that the numbers in the special schools are dropping as a result of recent policies of inclusion in the area of education. The age limits in Ffynnon, 18-65, reflect the 'normal' time of leaving school and start of further education or work, to official retirement (see further in the chapter on work).

In Ffynnon more women than men attend the centre, something I do not have an explanation for but would be worth looking at in further research.

Staff

In Ffynnon the majority of staff has, in addition to a specific interest in working with people with learning disabilities, relevant training and experience. Their professional backgrounds include education, social work and nursing. Staff training is seen as valued; every year social services, together with the centre, sponsor two or three people to attend a special needs course. For the other staff, in-service training is organised.

Economic factors are, in the context of local society, relatively unattractive. A number of people do not have a permanent contract and it is commonplace for temporary staff members to be made redundant after an employment period of two years. Remuneration is relatively low with poor prospects of improvement and/or promotion. Although the state has taken on the responsibility of day care for people with special needs, the quality and stability of the care depends on political and economic factors. Constant changes in the budget for the centre lead to regular staff changes and /or shortages, causing disruption to the programme. The following incident is from my field notes:

> It is lunchtime and the instructors are sitting at a table together in the hall. Jason (one of the instructors) comes in with a note and some lists. The lists have the afternoon groups on them and the names of the clients normally attending each group. "Bernard (*the manager*) told me to divide these clients out between who is here." There is not enough staff present to run the usual groups because of illness and days off. The instructors who are present just laugh, it isn't the first time this happens. They divide the clients out between

> them. After lunch each instructor starts looking for and gathering the clients up for their new, temporary group.

Appointments for a post in the centre are made through an interview panel. This panel includes the centre manager, a parents' representative and a representative from the clients' committee. Interests, experience and qualifications of the candidate are matched with the job specification. There are also a number of young volunteers in the centre. Sometimes they stay beyond their allotted time and take up permanent positions as the following example illustrates:

> Sylvia: "How did you come to work here?"
> Orla: "I came through the Princes Trust *(a youth development organisation under the patronage of the Prince of Wales).* They organise different social work places. I enjoyed it. I was called in here for relief but I am here everyday."
> Sylvia: "Do you do any specific activities?"
> Orla: "I never know what, I know on the last minute what group I have. I usually bring my guitar."

Others have followed a social care course at a local college and come to the centre on a placement. The following is an extract from an interview with one of the younger members of staff:

> Sylvia: "How old are you?"
> Ann: "Twenty-one."
> Sylvia: "Do you have any qualifications for this work?"
> Ann: "After school I did this care course. We had different placements. I had a placement in a patch based pilot study, a modern way of day care but it wasn't permanent."
> Sylvia: "What sort of things do you do here?"
> Ann: "Basic skills in cooking, that can be carried on at home. I also do a life book. Many clients are my age and that is a good laugh sometimes. They want to know all about me too. I really enjoy it but it keeps me on my toes to do it as good as the week before. It is difficult though if the groups have mixed abilities."

The personal motivation of staff working with people with learning disabilities influences the kind of activities that clients engage in as well as client–staff relationships. These influences can be positive as well as negative. One afternoon, while I was speaking with some members of staff in the flat for independent living skills, the following discussion took place:

> Nora: "It makes me mad some people, you wonder are the clients for them or they for the clients. Some clients just do not want to be there (in the flat-Sylvia). Some of them, like Trudy, yes, she enjoys it. But Claire and Freddy, I have seen them. They do not want to do all that. Look at the clients' choice lists. Lots of people want to do it. But they only take the most able ones. It is easy, that is why. And the personal satisfaction (for staff). Why not take the less able ones."
> Ken: "It is like all this stuff on normalisation. Rubbish. All it can mean is respect for them as other people. You can not expect all the same things from everybody."
> Ann: " No. Like all this 'put them into the community'. It is for social workers. It makes them feel good. Like from here, two couples got married. But they were pushed. One couple should never have got married."
> Nora: "It can work. I know a couple in Cardiff. Cerebral Palsy. They are lovely together. A cat and a dog, all the works. But lovely together. But you have to look at the individual."

Staff members have different ideas on what the service should provide and may feel that their own subject is particularly important:

> Trudy (who teaches independent living skills): "The purpose of the centre is for the people. For example, people with low ability, they are actually able to do a lot more. Like Ellen, her mother spoils her. She does not have to do anything. But I think there is a lot more to Ellen."
> Sylvia : "And why cooking as opposed to other things?"
> Trudy: "For survival. Arts and sports, they have their place. But cooking is important for their survival."
> Sylvia: "But do they get a chance to practice?"
> Trudy: "No, even in the hostel, they have no coping skills and it is getting worse."
> Nick: "It is like your children. If you do not push them they regress to all sorts of behaviour. Look at Mike, he is getting out of hand."
> Trudy: "These skills are for basic survival. If they were ever thrown out into the community… You never know. With all these people coming out of hospital, just left by themselves. Say, God for bid. Eddy was left by himself, maybe he would remember some things."

Members of staff often have strong views on the perceived needs of the clients and how the services should address those needs. These views do not always match. Some put their emphasis on the self help skills, feeling that these people need teaching and encouragement to be as independent as possible. Others put their emphasis on personal interests and abilities such as sports and arts. Additionally, the service is expected to provide respite for parents.

Daily, informal discussions on work and clients between the staff members take place. There is a lot of personal involvement, which may raise the question that some staff members have already asked: "Is the staff for the clients or the clients for the staff?" For people who have chosen and trained for this work, and for whom it is such a personal matter, work is an important factor in the shaping of their own identity. This may lead to dissatisfaction and frustration because of conflicting views between staff, because of disagreement with the formal, objective aims, or because of difficulties experienced due to the variation in abilities on the part of the clients.

Surprisingly, considering this level of involvement, some staff in Ffynnon appear to have relatively little knowledge of the plans for individual clients, as the following observations illustrate:

> It is lunchtime and clients and staff are in the canteen, queuing up for their dinner. I am in the queue too. Freddy, one of the clients, in his thirties, asks me: "How long will I be here?" I don't know so I ask a member of staff. Harold (staff) to Freddy: "I don't know. You have to ask your social worker." A few days later Freddy comes up to me again. He asks me: "Did you see my social worker?"

The information contained in clients' files (a lot of which is based on extensive assessment procedures) does not filter through to the people who actually work with the clients on a day-to-day basis. This may be related to the size and structure of the centre; one instructor may work with four or five different groups each day, each group consisting of up to eight clients.

The manager has a professional social work qualification. Both he and the deputy manager are office-based. Their responsibilities include administration and programme development, staff management, attendance at parent meetings and liaison with social workers. They meet with the clients at the time of admission and at occasional reviews. They also meet when there are specific issues around a particular client, for example, medication, transport arrangements or weekend respite, holidays etc. There is only occasional daily contact between manager and some of the clients (the ones that would walk into the office on their own initiative). He would not usually be aware of the day-to-day activities of the clients as the following situation illustrates:

> I am in the office with the manager. Deirdre, one of the service users comes in. She has some money in her hand. She shows the money to us and says: "Shopping, shopping." The manager says: "I don't know. That's not up to me. I don't know. Someone might have stopped you going. You'll have to wait and see." He then turns to me and explains: "If Deirdre misbehaves she is not allowed to go shopping."

This may be related to the workload, the number of clients in the centre, the structure of the programme and the physical structure of the building. It is not necessarily related to a lack of interest in individual clients; when the manager heard that one of the service users had been off because of illness, he instructed the deputy to phone the parents in order to check on the client's welfare.

Scale of the centre in size and number may affect relationships between staff members and clients; on an individual basis however there are many personal contacts and interactions:

> The instructors are drinking tea one morning before the groups start. Eddy (service user) comes in and starts singing Happy Birthday for Tilly. He gives her a kiss on her cheek a card and a box of chocolates. It is actually not her birthday today but tomorrow, a day Eddy does not normally attend the Centre. Tilly is visibly pleased with his efforts and both she and Eddy look very happy.

Some of the staff have developed there own activities in a smaller separate section of the centre, for example the workshop and the flat. I noticed that personal contact between clients and staff is greatest between people who spend a lot of time in these areas especially in the flat. These are homely and informal settings, the work is less structured as in some of the other groups and staff and clients appear to do more things 'together' and for a longer period of time. Clients would for example spend a whole morning or even day in the flat, cooking, cleaning and drinking tea with the staff together. This structure also facilitates a certain kind of private space for clients. Sometimes a client comes into the flat just to have a lie down. For other clients it is a place with a greater degree of privacy than the rest of the centre:

> Brenda undresses herself regularly. Tilly, who often works with her in the flat, has her own way of dealing with this. One morning we are in the flat and Brenda undresses herself again. Tilly says, "Don't take any notice; everyone has seen her by now. We found that if we leave her and don't pay any attention she usually gets dressed again by herself." When Brenda leaves the flat early according to the timetable and still without clothes, Tilly goes after her. They bump into the manager of the centre. Tilly is embarrassed and apologises, she tells Brenda to quickly get back into the flat.

In other situations, however, staff may have conflicting ideas on how to deal with rules. This may lead to clients getting confused and hurt:

> It is teatime. The tea trolley is out in the canteen and Maureen is supposed to hand out the tea to staff and clients. When she wants to start, Laura (instructor) tells her: "No. It is not half two yet (it is 14.25pm)." Kyna, another instructor comes in and takes her own tea. Maureen gets angry and she starts shouting. Nick (instructor) says: "Sssht, Maureen." She replies: "It is not half 2 yet." Nick: "The tea trolley should not have been brought out yet" (understands Maureen's confusion and anger). Maureen starts pouring the tea for the other staff but is still visibly angry and upset.

Many interactions between staff and service users show respect for the client as an individual. In others he or she is treated more like a child than as a respected adult. This is not only influenced by knowledge and motivation of both staff and clients but also by the scale, structure and rules of the centre. In addition the general ethos present in services for people with learning disabilities plays a role. This ethos implies that people with learning disabilities need special provisions and treatment/long term education, including guidance in and monitoring of many areas of a person's life.

Part C: Comparison and Discussion

Similarities and differences in context

In both Aniksi and Ffynnon a group of people have been identified who, for reasons of 'learning disabilities' or 'incompetence', do not take part in the normal, day to day, adult activities of other members of their society, in particular, work. In the context of principles of normalisation and a collective welfare system in Ffynnon, and similar influences in Aniksi through trans-national theories, support programmes and funding, the state in both communities has taken on responsibilities for the provision of services to these individuals. People with learning disabilities in Aniksi and Ffynnon are perceived as being in need of, and having the right to care, occupation and extra help in their development and socialisation within a special institution. This is reflected in the very existence of the centres, the reasons for admission and in their aims and objectives. These also reflect the notion that parents need and should receive support in the care for their adult child with learning disabilities albeit in special institutions. McDonald (1991) stated that the nature of services (including those for people with disabilities) is determined by professional or theoretical considerations, as well as by political factors i.e. how much public money will be directed to a particular area. I have found this to be true for both Aniksi and Ffynnon. This, however, is not the full story. There were other influences on the establishment, nature and objectives of these two services. They are illustrated by the differences between the two places I have researched.

On Aniksi, the ultimate aim of the programme is to occupy people and to enable them to secure work and make a living. In Ffynnon, the emphasis is on the overall development of the person: to teach and enable people to live a life that is as independent and as 'normal' as possible. 'Normalisation' is locally interpreted as economic independence in Aniksi and social independence in Ffynnon; with the emphasis on work as opposed to personal and home care. These differences are related to 1) differences in socio-economic factors including the pertaining economical climate and structure of work, 2) differences in cultural influences such as views on adulthood and general societal values and 3) professional knowledge and motivation of relevant persons.

In both Aniksi and Ffynnon people with learning disabilities themselves have relatively little input in the decision to attend the centre. While they are part of the discussion, parents and professionals through a process of assessment and recommendations make the ultimate decision. Influenced by local social structures, this process is small-scale, informal and parent-orientated in Aniksi and formal and based around a team of 'professionals' in Ffynnon. The fact that "people with a mental handicap often have no voice at all" (Robinson 1991: 80) appears to be at least partly true for both places. While efforts are made to let them take part in the discussion, their ability to exercise a choice is hindered by the nature of their impairment; "many people with mental handicap need both encouragement and help to enable them to exercise their rights and make more effective choices" (*ibid*). In addition, social barriers, including the power given to parents and professionals and a lack of alternatives, influence their lack of voice.

Admission to the centre did not create exclusion; in both places the majority of people admitted had already been excluded from locally 'normal' activities of work and education. It does however contribute to its continuation. In Aniksi this exclusion covers only a part of a person's life and is more likely to be flexible over time. In Ffynnon, exclusion is of a more formal and permanent nature and affects many areas of a person's life. In fact, the "provision of segregated services may infringe upon and even take away rights of citizenships.........and privacy has to be given up in assessment procedures" (Oliver 1996: 52). Statutory responsibility is reflected in extensive assessment, review and reporting procedures, and documentation. It is also used as justification for long-term professional involvement in and influence on the lives of the people attending the centre. The reasons for these differences between both places may be found in local and national policies, theoretical discourse, and in the general scale and formality of local social organisation. The fact that people attending the centre in Aniksi are less subject to this kind of long-term professional involvement and influence on their lives does not mean they are more able and free to make their own choices than their counterparts in Ffynnon. It simply means that possible influences on their lives are subtler and less formally organised (see also Chapter Four: Parents' Stories and Chapter Seven: Individual Lives).

In both centres, people take part in arts and crafts, sports and literacy skills. Differences are in the variety of activities on offer and the proportion of time devoted to each activity. In Aniksi the programme is work orientated with sports, literacy and social outings taking up only a relative small amount of time. The programme in Ffynnon offers a greater variety of activities and addresses many areas of a person's life and development including independence skills, personal care and numeracy. The nature and structure of these activities, including the one-hour timetables and staff-clients relationships make them similar to education. In Ffynnon "there is a danger of placing the person in a permanent 'trainee' or 'student' role, perhaps through lifelong attendance at an adult training centre" (Robinson 1991: 66) while they can not choose to stop 'being developed' at some point. There are links here, of course, with differences in the official aims and objectives of the two centres. They reflect local ideas of adulthood as well as theories and ideas on what should be organised by a service for people with learning disabilities. Activities at both centres and their links with the locally 'normal' activity of work will be discussed further in Chapter Six: Work. In both places leisure activities are used to promote inclusion. Holidays and trips away play an important part in the relationships between staff and workers/client, and provide a lot of fun and are an important part in peoples' social life in both places. This is quite similar to the social meaning of trips and holidays for other adults in their local society. Some aspects of leisure in Ffynnon however are more similar to physical presence in the community rather than inclusion when they happen in large groups and do not involve a lot of interaction with other members of local society.

The people attending each of the two centres are not a homogenous group. Their profiles vary so significantly *within* each group that I have to agree with Davies who questioned the cohesion of the category "learning disabilities" for exactly that reason (Davies 1998). In both places I found a considerable number of people with psychiatric problems. However, only in Aniksi I found people with only psychiatric problems and some that had cerebral palsy and learning disabilities. This may be related to social structures; special mental health services and services for people with physical disabilities are available in Ffynnon but not in Aniksi. Hierarchy of handicap plays a role too; I found no one with only physical disabilities in any of the centres. The categorization of people with learning disabilities, psychiatric problem and physical disabilities together has been reported in past and present (Edgerton 1970; Jak 1988; Whyte 1995). The residues of this appear to be strongest in Aniksi, related to the social structure of service provision and notion of 'hierarchy of handicap' (Dybwadd 1970). There are other differences between the two groups. Proportionally, about one and a half times as many people attend the centre in Ffynon than in Aniksi. Local geography, infrastructure, availability and structure of services and differences in cultural aspects may account for this, in particular the issues of shame and acceptance. Influencing factors are interlinked, for example, the cultural phenomenon of shame is influenced by the social structure of service provision. The attendance of a considerable smaller proportion of women in Aniksi is possibly related to existing local gender roles. These can make it easier for women who are 'slow' or 'can't read or write' to access locally normal adult roles. They can however also be a barrier to the attendance of women at the centre. Finally, differences in age distribution between the samples in Aniksi and Ffynnon are related to local social structures and culture; the length of time the service exists and general provision or lack of services for people with learning disabilities. The aspect of shame as discussed above, may be an issue with especially the older parents in Aniksi.

To what extent people with learning disabilities are treated as respected persons and adults will depend on the quality of the relationships professionals establish with them (Robinson, 1991: 67). In turn, relationships, as series of interactions, are influenced by theories, values and beliefs (McDonald 1991: 129). Staff in Ffynnon has higher levels of experience, qualification and motivation in the area of learning disabilities compared to those working in Aniksi. These differences are influenced by socio–economic structures, culture and politics. Differences in staff profiles however also exist within each of the centres. According to Robinson (1991) professional socialisation, in tandem with personal commitment may act as a social barrier between service users and professionals. In both Ffynnon and Aniksi 'professionalism' and personal commitment sometimes increase or create social distance between staff and clients. They may however also facilitate communication and the formation of personal and respectful relationships. Knowledge, skills and motivation have been particularly useful in establishing relationships between staff and people who have a higher level of impairment and disabilities in communication. On the other hand and in some situations, lack of knowledge contributed to relationships without prejudices or specific personal attitudes.

Relationships between the people attending both centres and those who work with them, is also influenced by formality of admission procedures and scale and physical structure of the centre. Informal and small-scale structures in Aniksi and in parts of the centre in Ffynnon facilitate familiarity and personal relationships between staff and clients. Formal and detailed policies, assessments, recommendations and reviews in Ffynnon did not necessarily influence or impinge on interactions between staff and clients. This raises the question of the purpose of formal bureaucratic structures.

Finally, personal characteristics influence client-staff interactions. In Aniksi, where size and programme structure favour individual staff-client relationships, these do not seem to extend beyond the centre walls as they sometimes do in Ffynnon. Human social behaviour is subject not only to culture but also to other pressure factors and frictions with, and between, other social systems within society (Kloos 1991). There are more similarities than differences between the two centres in individual interactions between staff and clients. In both places I have found interactions that speak of interest, warmth, respect and reciprocal relationships; in both places I have also found situations that raise questions about the treatment of people attending the centres as equal and respected adults. One element of that relationship: the use of power and control by staff over clients in areas that are locally considered private was most obvious in Ffynnon. The perception and treatment of people with (learning) disabilities as children has been mentioned by various authors (Jenkins 1998; Oliver 1990; Race 1999; Wolfensberger 1983) and confirmed by observations in both Aniksi and Ffynnon. This leads me to suggest that the adulthood of people with learning disabilities in both places is of an ambivalent nature.

Institutions and Inclusion

Economic optimism, small scale and informal work structures and a concept of personhood that requires an economic contribution rather than social independence appear to facilitate inclusion outside the centre in Aniksi. They also contribute to the centre playing a role in this inclusion. The fact that in Ffynnon, due to the prevailing economic climate and formal structures of work this inclusion is more problematic, supports and modifies the notion that in highly complex and industrialised societies certain individuals may be excluded from local work structures (Edgerton 1970; Finkelstein 2002(a); Oliver 1990, 1996; Zevenbergen 1986). This however, does not mean that in simpler societies there is no recognition of people with learning disabilities. An important distinction must be made between the perception of people with learning disabilities as 'different' and their exclusion. People attending the centre in Aniksi are seen as 'different' in a particular way and are, during at least one stage of their lives or for part of the day, excluded from locally normal patterns of life. In addition, for quite a considerable number of people in both places, albeit to a greater extent in Ffynnon, inclusion in the wider community will most probably never be realised and is not actively pursued. For these people the centres facilitate segregation from the rest of their society, in Aniksi and in Ffynnon.

If however we take inclusion to mean the participation of people with learning disabilities in activities and social interactions similar to those of other adults in their society, it may take place within as well as outside special services. In both Anikis and Ffynnon certain social relationships and activities within the centre contribute to inclusion for people with learning disabilities. By considering the two centres in context I have identified the following elements as facilitating inclusion:

- Small scale institutions or units within larger institutions
- Simplicity of programme structures that allow maximum control by clients/workers
- Nature and structure of activities similar to those of other adults in local society
- Economic optimism
- Concept of personhood that values economic contribution
- Pursuit of realistic aims for individual clients/workers
- The matching of activities with abilities and interests of individual clients/workers
- Support for the development of skills attainable for and desired by individual clients/workers
- Professionalism that enables communication with clients/workers in supportive but respectful relationships
- The monitoring of control in staff-clients/workers and other professional-client/worker relationships especially in areas normally considered as private
- Social and political principle that all persons in society have the same rights including a right to work

The following elements may act as barriers to inclusion:

- Large scale institutions
- Complex programme structures that limit control by client/workers
- Rhetoric use of aims for all clients/workers

- Concept of personhood that stresses social and economic independence
- Unnecessary control in staff-client/workers or other professional-client/worker relationships especially in areas normally considered as private

Local social and economic structures and culture influence the establishment, objectives and programmes of institutions for people with learning disabilities. They also influence the kind of people attending these services and their relationships with staff. I have identified elements of services that facilitate inclusion, as well as elements that act as social barriers. In Chapter Seven I will discuss the role institutions play in the lives of some of the people attending them; I will do this in the context of the above findings.

CHAPTER FOUR: THE PARENTS' STORIES

Introduction

To further our understanding of the classification and treatment of people with learning disabilities, it is important to consider their parents and siblings. There has indeed been "an increasing acknowledgement of the importance of parents both in bearing the bulk of the responsibility for care, and in influencing the way their children develop" (Robinson 1991: 63). The majority of people attending the day centres in Aniksi and Ffynnon live at home with their parents well beyond the age young people in both places normally live at home (see Chapter Two: tables 2 and 4, pg. 66, 67). They are also less likely to move out for the reasons that young people in Aniksi and Ffynnon usually leave home: work, marriage or the desire to live independently from their parents.

Parents are likely to play an important role in both the classification and treatment of people with learning disabilities for two reasons. Firstly, one of the criteria for the formal classification of 'learning disabilities' is that this classification takes place in early childhood (Gates 2003; Jenkins 1998) when most children are the full responsibility of their parent(s). Parents may contribute to or contest this classification (see also Chapter Five: Classification). Secondly, the category of 'learning disabilities' takes on social meaning only through the interactions between people thus labelled and other people within their society (Goffman 1990). If we want to examine the ways 'society' treats people with learning disabilities, it is important to look at their relationships with those members closest to them, and how the category of "learning disabilities" influences these relationships.

In the discussion of the parents' stories I will be led by the following questions. How, now and in the past, does the classification learning disabilities influence the relationships between the people attending the two centres and their parents and siblings? Are and were these relationships similar or different to "normal" local parent-child or sibling relationships (as described in Chapter Two: Two societies)? What did and does that mean for the people attending both centres and for their treatment as valued and respected members of their families? How did, and does learning disabilities affect relationships between the family and other members of their society? Was and is learning disability recognised in these families, is it a (social) problem for their members? If so, what socio-economic and cultural factors did and do contribute to it being experienced and formulated as a social problem?

Parts A and B of this chapter describe the main findings of the interviews with the parents in Aniksi and Ffynnon respectively. This is followed by a comparison and a discussion of these findings in the context of the above considerations. The purpose of this discussion is to further understanding of the roles of parents and siblings play in the classification and treatment of people with learning disabilities, and of the socio-economic and cultural factors influencing these roles.

Part A: Aniksi

The resources of the family

Physical care and attention

The majority of parents (mostly mothers) in Aniksi experienced practical difficulties in the care of their child with learning disabilities. These difficulties were mainly related to the high and prolonged dependency of the child in areas of personal care and mobility:

> "Until he was five he was like a doll in my arms' (Mother of a young man (21) with cerebral palsy and moderate learning disabilities)."

> "She went right back. I had to carry her like a baby." (Mother of a woman (35) who contracted meningitis as a child and was left diagnosed as having severe learning disabilities)

While some of these difficulties eased when the child got older and more independent, others arose. People with learning disabilities can be particularly vulnerable, which may become more obvious as they grow up. This raises the issue of personal safety and is illustrated by the following examples:

> Mrs. D and her family live in the main town. She has a son (19), Tassos with mild learning disabilities and psychiatric problems. Tassos has a history of being abused by men who buy him soft drinks in the cafes on the waterfront. His mother explains that she is worried when he goes out at night, but that she cannot stop him as he is tall and strong and very determined. She tells me: "When he was out all night, I worried. I stayed up and waited at the door. And now, I still worry. Where is he? What does he do? "

> Maria, a young woman (22) with mild learning disabilities also lives in town. Mrs. M. is desperate for her daughter to 'wake up'. She explains: "I want her to wake up. Inside I still worry. She is always close to me. I'm afraid. I did not work, I did not want to leave her. She does not know between good and bad. There is a man - in the house (in one of the other apartments). He is bad. He telephones her. I tell her. She is a good girl, but like a child. I want her to wake up. To learn to deal with money. One time, in the shop, they gave her the

> wrong money. Some people are bad. I taught her, and the teacher. She knows money now."

Letting go is another difficult and related issue. The father of Antonio (19), who has Downs Syndrome and mild learning disabilities, explains prior to Antonio's departure on his first holiday trip with clients and centre staff:

> " Tomorrow Antonio goes on the trip. The first time so far away from us. Why? Mother does not like it. But I say so. I say yes. What will happen if we die?" Both parents are worried about letting Antonio go on the week-long trip. Antonio's mother does not really want him to go. Father thinks of the future; he and his wife may not always be around to look after Antonio. He considers it important that his son learns to be away from his family and becomes more independent; he insists that he goes on the trip. In Aniksi, it is usually the man who makes the decisions regarding matters outside of the house and it is not surprising that Mr. E. has the last say."

Not all parents experienced the daily care for their child as problematic. Three parents did not mention the subject at all and three others specifically stressed that their children did not present any problems:

> The family of Dionyssos (32) live in the country, a few miles out of town. He is a quiet man who has moderate learning disabilities. His mother explains that Dionyssos has always been a quiet and placid person. 'He just kept himself to himself, stayed on his own and still does. He is no help, but no trouble either."

Finances

Six families in Aniksi explained how their child was an extra burden on the family budget, already tight because of high inflation rates and a local economy based on seasonal work. The fathers of these families work in the agricultural sector or at temporary labouring jobs earning just enough money to get by on a day-to-day basis.

Their financial burden is twofold. First, there are the expenses that relate directly to the condition of the child such as medical costs and the costs of travel required to obtain this medical help. While a free National Health Service does exist, it is generally perceived as being of a lesser standard than the private sector. In addition, access to and the scope of treatment is limited. Many consultants are only found in Athens and, in addition, medication may need to be paid for privately. Some parents go even further than Athens to receive the help they feel their child needs:

> Mrs. A. has a son Pavlos, who is 22. He has cerebral palsy and moderate learning disabilities. Every year she and Pavlos travel to Bulgaria, to receive specialist and private medical treatment for him. The medication her son is prescribed is available in Greece but also needs to be paid for privately. Their family budget is small; her husband has some olive trees and works occasionally as a labourer. Mrs. Y. explains: "I have no shoes. Everything in this house is for Pavlos."

Secondly, there are the indirect costs. In Aniksi, the majority of young people stay at home until they get married and those who work contribute to the family income. The majority of people at the centre also live at home, do not make a significant financial contribution to their families, and are likely to be dependent on their families in the long term. The following situation is not unusual:

> The family of Eftemia (24), who has Down's syndrome, moderate learning disabilities and a heart condition, live in a small village. Her parents are elderly; her two older brothers provide a large part of the family income. The oldest brother (27) took part in the interview with Eftemia's parents. He feels responsible for his sister but I also feel some resentment on his side, as he talks about his worries for the future, in particular in relation to the families' financial situation. He explains: "The money is a problem. We all work and pay. Eftemia does not work. The state pays very little."

These findings support the thesis that families in poor financial circumstances experience the (learning) disabilities of one of their members as an additional burden on their meagre resources (Edgerton 1970; Zevenbergen 1986). This economic burden is likely to contribute to a negative view of (people with) learning disabilities and is not conducive to their inclusion as valued and respected family members.

Worries about appropriate care and treatment

Nearly half of the parents in Aniksi (seven out of fifteen) expressed concerns about finding appropriate education for their child. All of these parents felt that their child, like other children, had a potential for learning. They also felt that to realise this potential, additional, they needed professional help. This was unavailable. They are frustrated and disappointed with the Greek system.

Two of these parents tried to teach their children at home:

> A widowed mother explains how her husband taught their son with Down's syndrome and mild learning disabilities at home. She now has to rely on the centre, but isn't very happy with either his progress, or with the programme. "He doesn't learn. These children need to learn. But who will teach them? Before, his father used to teach him. You see, to look after these children you must love them. And they (staff at the centre) don't love them. They sit around and smoke. The money is all that counts for them."
>
> Manos's mother wants him to learn to shop, clean and cook in case he needs to look after himself in later life. She makes a big effort to teach him at home and his daily programme at home includes washing, cleaning, shopping and cooking. She is very annoyed that these things are not taught at the centre. "The problem here is, there are no teachers. I have to teach him myself. He is learning slowly. He knows how to clean, to make the bed. All this I taught him. Mothers are the best teachers."

One other family bought private lessons for the daughter with mild learning disabilities and another father taught his son at home. The example of Manos is especially interesting in the light of local gender roles. Manos's mother actually expected more of her son than one would of other male children and adults in Aniksi. Mrs. Y. may feel that her son's learning disabilities will prevent him from getting married in which case he would have had a wife to do these things. Other parents employed private teachers (two), travelled to Bulgaria for help (one) or (temporarily) opted for residential education on the mainland (two). The latter brought its own problems; the child became homesick or the parents found it difficult to entrust their child to strangers.

Conflict may exist between the opinions of professionals and parents on the ability and potential of the child. While the above parents all wished for their children to receive further education, the psychologist told me that, in his opinion, many parents have unrealistic expectations for their children. This conflict may be related to a lack of formal support for parents and the poor availability of guidance and information. It may also be (partly) related to differing expectations of what the centre has to or should offer and what actually happens in reality. Some parents are looking for a formal education for their son or daughter or the teaching of self-help skills, rather than work orientated training.

Worries about the future

In Aniksi, where there are no (residential) services for people with learning disabilities, worries about the future are a huge emotional burden on the parents. More than half of the parents (eight out of fifteen) talked about the future as a "big worry". They feel that their children will never be able to look after themselves and that there is no help "out there":

> "There is no help out there. What about later, what will happen?"
>
> "What about later? It is o.k. now. But later, it is a big worry."
>
> "It is very difficult. A difficult life. I worry, what about later? Her father is 80. She has always been with me, with her mother. Always." (Mother of a woman (35) with severe learning disabilities and epilepsy)

> "I worry, I worry about later. But what can I do Sylvia?" (Mother of a man (28) with severe cerebral palsy and learning disabilities)

I asked the mother of a woman (24) with severe learning disabilities and dependent on her mother in all her care, about what usually happens in these situations. I was told: "I don't know. The family, or a hospital. A big worry." Two mothers have hopes for their daughters to marry as a way to secure their future:

> "Later, I don't know. I would like her to marry. A working boy. She can have children. The psychologist says: no problem. She is healthy. She does not know her letters but she is o.k. Very outgoing." (Mother of a girl (22) with mild learning disabilities)

Mrs. Y. who was teaching her son to be more independent (see above) had also taken other measures for the futures.

> "What will happen if I die? That is why I went to live in town. In our house at the beach it is great. A big house and in the summer parea (going out with friends). But in the winter we live here (town). Here we have people (family)." This widowed mother moves to town during the winter months to be near her extended family in the hope that if something happens to her, they will keep an eye on Manos.

Parents and siblings would like to see the development of (semi) residential services for their children with learning disabilities. They are frustrated because neither national nor local government, nor staff at the daycentre takes on this responsibility:

> "That is what I want. For them to cook together, to go out or watch television. All mothers say the same. That is what we want here. That is what we mothers want. But . . . (laughs). No. With whom?" (Mother of a son (36) with learning disabilities and psychiatric problems)
>
> The brother of one Dionyssos, a man with moderate learning disabilities asks me what is available in Wales. I tell him about hostels and group homes and he says: "That kind of thing, they would be ideal but it would never happen. People here wouldn't be bothered to do the work involved. Who would do it?" Them, the staff at the centre?" (Laughs) (Brother of a man (32) with moderate learning disabilities)

Marital relationship and gender roles

In Aniksi no parents mentioned marital difficulties resulting from having a child with learning disabilities in the family. One woman, however, did express how alone she felt in the care of her daughter (32) who suffers from severe learning disabilities and epilepsy:

> "She was like a doll until she was nine. She did nothing, just having fits all the time. There was no help, just me. My husband is a good man, but I do the work."

This example reflects gender roles on the island where the care for the house and the family members living there are the responsibility of the women while the men work, earn a living and maintain social contacts outside the family home. Childcare, is usually the responsibility of the mother. This tradition is also illustrated by the following situation:

> Spiros is a young man (17) with severe learning disabilities. He is the only child from his father's second marriage. After his mother died, he and his father moved into the nursing home. The elderly father was not able to take care of his learning disabled son on his own, nor did the community expect this of him.

Exceptions however do exist. In three of the families I interviewed, fathers made a point of taking part in the care of their sons with learning disabilities, especially as their children were getting older.

The father of Sakis (28), who suffers from cerebral palsy and learning disabilities, is unable to speak and confined to a wheelchair, takes his son swimming every afternoon during the summer. In order to do so he closes his hairdressing salon for a few hours. When Sakis went on the yearly summer trip with the day centre, both parents came along to look after him and to share the holiday. His father was the only father on the trip.

- The father of Antonio, a young man with Down's syndrome and learning disabilities, has been teaching his son at home from the moment he was born. He also walks him to the centre regularly and liaises with staff.
- Pavlos' father shaves his son every day.

The families of the examples above seem to be close with the husband involved in the care for the child, something quite unusual in Aniksi. It is possible that the care of a child with learning disabilities affects the gender roles in some of the families in Aniksi. It may also be the case that the fathers in these families were already more involved with their children than is the norm locally.

Siblings

In Aniksi there are reports of positive and negative aspects on siblings of having a sibling with learning disabilities. Five families expressed concerns about their other children in relation to their child with learning disability. They reported how the siblings did not get on with the child with the learning disability (two), how it was difficult for them to study because of the noise and distraction in the house (two), and one brother complained about the financial burden.

> "When they were small it was a big problem. They did not want to play with him. They were bigger." (Mother of man (21) with mild learning disabilities and psychiatric problems)
>
> "They are very good with Nadia, they love her. They take her out, volta (going for a drive or a walk- sylvia) But it is difficult when she is like this (restless and noisy, usually around the time of her period). The other children, like my girl now, she is upstairs. Trying to study. It is very difficult for them. How can they study?"(Mother of woman (24) with severe learning disabilities)

> "The house is very small. The other girls had to write, to study. Maria had to go to her teacher's house."(Mother of a woman (22) with mild learning disabilities)

Around half (eight) of the families I interviewed still had siblings of the person with learning disabilities living at home. Two of them spend time with their brothers, going 'volta' (or 'hanging out'); seeing friends, going for coffee. One sister is caring and protective; she brings her brother to the centre and discusses him with staff and myself. In two families siblings were not close (one) or fought a lot (one).

> "I have one other boy. He lives in Athens. But he and Tassos, no good. Big problem. He is 21, Yannis is 14. He is tired of him (his older learning disabled brother). One day he is like this, the other day like that. He is always asking questions. Why do you do this, why is the egg like that? Everyone gets tired of it."(Mother of young man (21) with learning disabilities and psychiatric problems)

Finally, a twin brother and sister attend the centre together. From what I have seen they are very close. Athina is allowed to attend the centre in order for her to look after her brother. Without this responsibility she would probably spend most of her time at home with her mother.

Eight people have people have siblings who have moved away from home. They are studying in Athens (one), working in Athens (one) or have married (six). As the children got older and siblings moved away from home, the relationships and practical difficulties that beset them seemed to lessen and relationships became more positive.

> "It is all Pavlos here. The children are mad with him. He is the youngest. When they telephone they don't ask how I am but how is Pavlos?" Mother shows me photographs of her children all together on holidays on the neighbouring island."In the holidays they come over and take him on holidays. They went to Krete, also with the girlfriend of his brother. I cry on the phone: my baby . . . and they laugh at me. And he loves them. Loves them. Especially my son who is in the army."(Mother of young man (21) with learning disabilities and mild cerebral palsy)

Four of the six people with married siblings are in close contact with them and fond of their nieces/nephews. Two of these people visit by themselves as they live close to one another. In both cases the babies in the respective houses are big attractions.

> "At home we love him very much. He is a good boy. And clever. In the afternoon in the summer we go swimming. We close the restaurant for a few hours and go swimming. Later we go volta (for a walk or drive around the town or village) with my mother walking with the baby, or with father in the car."
>
> <u>Sylvia</u>: "You have a baby?"
> <u>Sister</u>: "No. My younger sister. Pavlos loves the baby. He wants to hold him all the time. We all live in one house. My sister downstairs and we upstairs."(Sister of a young man (19) with Down's syndrome and mild learning disabilities)

> "I have a daughter. She is married and lives in town. She has a little boy of 2 ½. We are very close. She comes often and is mad with Nikos. In winter when we live in town he often visits her on his bike and she always gives him money."(Mother of young man (24) with Down's syndrome and mild-moderate learning disabilities)

Jealousy may become an issue, however, where nieces and nephews are seen as competition for attention.

> "I like it when my daughter visits from Athens. But it is difficult. Helena is always jealous of the grandchildren and then she is very difficult."(Mother of a woman (32) with severe learning disabilities)

In Aniksi I actually spoke to five siblings themselves. This was partly because they spoke English and parents saw them as better able to communicate with me. It also showed their involvement. In Greece, older siblings are seen as responsible for younger ones and older brothers are especially protective towards their unmarried sisters. People with learning disabilities without the prospect of marriage and/or independence may be considered as part of one of these groups and in need of that protection.

The majority of families report positive relationships between the persons with learning disabilities and their siblings. Most problems occurred when the children were young because of a lack of understanding on both sides or as a result of the impact the behaviour of their brother or sister had on their home study. Education is extremely important for Greek parents, both for their child with learning disabilities and for their siblings. As the person with learning disabilities and his/her siblings get older, relationships generally improve with siblings becoming an important part of the social life of the person with learning disabilities and a great source of support for their parents.

Relationship between parents and child with learning disabilities

The majority of people attending the centre live with their parents in common with other young people in Aniksi. For the majority of the people in this research, neither a job away from home, nor marriage is a likely event. As a result they will remain at home with their parents and will not make the normal transition to adulthood.

It is likely that this influences the relationship between parents and child. In Aniksi, people with learning disabilities have no alternative but to live with their parents, for whom they are often a source of emotional, practical and economical difficulties. However, there is another side to living with an adult child with learning disabilities. Two of the three widowed women talked about how they enjoy the companionship. They may share walks, social visits and household chores.

Impairment (in particular level of (prolonged) dependency and challenging behaviour) social situation and availability of alternative living arrangement influence the relationship between parents and their child. Lack of choice and worries about the future in particular are likely to pose a barrier for equal and respectful relations between parents and their child with learning disabilities, as well as for the achievement and recognition of their adulthood.

Relationships between the family and other members of society

Feelings of loneliness and isolation

How does having a child with learning disabilities in Aniksi affect relationships between the family and other members of their community? One third (five) of the mothers in Aniksi spoke of strong feelings of loneliness and isolation in the care of their child with learning disabilities:

> "It's very difficult. A difficult life. I don't go out for volta (walk), not in the village here. My family is in Athens. I have little contact. Very little contact. And few friends. People here stay to themselves. In the village people stay in and keep to themselves. What can I do? I'm all alone here. All alone with Helena." (Mother of a woman (32) with severe learning disabilities, living in a small village)

> "Here in Aniksi Sylvia, they don't want to know. Other children, other people, they don't want to know." (Mother of Tassos (21), young man with psychiatric problems who lives in town)

Feelings of loneliness and isolation in Aniksi may be related to the nature of local social relationships between women in general. In Aniksi people are very private by nature and close friendships within the local community are the exception rather than the rule. People are friendly in a superficial manner. The fact that many of the women I interviewed actually complained about this lack of friendship suggests, that having a child with learning disability may for some women increase or create a need for a kind of friendship and support which is not available in their local community.

Lack of familiarity with (people) with learning disabilities and related feelings of shame may also form barriers to the formation and maintenance of social relationships outside the family.

Relationships with extended family

Two thirds of the parents in Aniksi spoke of positive contact with their extended family, in particular with siblings, nieces and nephews. Families spend time together at weekends and during holidays. Their children with learning disability are reported to get on well with and to enjoy the company of their cousins:

> Sylvia: "Have you any other family?"
> Mother: "Yes. My father in law had epilepsy too. The family is very good, my husband's and my own family. We go visiting a lot. The nieces and nephews they all love Toula and they are very good to her." (Mother of daughter with severe learning disabilities (24) and epilepsy)
>
> Sylvia: "Do you have any other family?"
> Mother: "Yes. Very close. I am from B., my husband from S. (two villages close by). My brothers and mother live in B. I was there this morning, with the motorbike. I often go by bike.
> Sylvia: "How do you get on?"
> Mother: "Very good. One has three children, the other two. Together, we are with many. It is nice for the children.
> (Mother of twins (17) with learning disabilities, the brother severe and the sister mild)

One parent stressed it was her own family she got on with and not her in laws, whom she did not find supportive

> Mother: "I have a sister in Athens. We are very good friends, we talk about everything. They come to Aniksi; we go there. Together we go to the village, in the car. I have a sister here, but not so good contact."
> Sylvia: "What about your husband's family?"
> Mother: "They don't want to talk problems." (Mother of a young man (21) with mild learning disabilities and mental health problems)

Family is the main source of social contact in Greece (see Chapter Two) and it can be difficult for those women who are widowed, live alone or live at a distance from their birth place and family. One mother explained how lonely she felt as she was from the Peloponnesos (mainland) and had "no-one here". Another mother, who is from the island and rents rooms in a small seaside resort, feels alone since her husband and her brothers died:

> Sylvia: "Do you have any other family?"
> Mother: "Yes. But not nice. I had four brothers. Two were nice, very nice. They lived close by. They both died. I cried and cried. My husband. My brothers that I was very close with and helped me. All dead. I have no contact with the others. It is very difficult for me Sylvie. Very difficult. I am all alone. My husband's family doesn't speak to me. There were problems after my husband's death. They had a bus together. My brother in law kept it. Later there were problems. We don't speak. People here are not nice Sylvia. It is very small, people talk."(Mother (widow) of son (24) with Down's syndrome and mild learning disabilities)

The majority of the families I interviewed spend valued time together with their extended family, apparently unaffected by the learning disabilities of their child. Normally however, they are not considered a source of practical support.

> Mother: "Yes. I have family in the village. We visit together."
> Sylvia: "Did you have any help from your family when the children were small?"
> Mother: "No. They all had their own family. I had nobody. And when you have six, it is very tiring." (Mother of young woman (24) with Down's syndrome and severe heart problems as a child)

> "I have seven brothers and sisters. But nobody helped. They are living far away and they have their own lives."(Mother of a young man (28) with learning disabilities and mild cerebral palsy)

Only two parents felt really helped and supported by their extended family. The mother or Tassos, who has mental health problems and mild learning disabilities explains how her family helped her son to speak:

> Sylvia: "Have you any other family?"
> Mother: "I have six brothers and sisters. One lives in America, one in Athens. We go to Athens every year, Tassos (son) and I, for a month.
> Sylvia: "The others are still here?"
> Mother: "Yes. We see each other a lot. We are always together. Very nice. We love each other, we are very close. Now it is different, the old days were

> like that. Family and friends they all love each other and are together."...//.. "When he was smaller, he had the speech problems. And we all try to help. All the family together, we told him how to say things, letters for example. And that helped, he learned then."(Mother of man (22) with mild learning disabilities and mental health problems)

The other parent, the widowed mother of a man (34) with mental health problems and learning disabilities moves to the town in the winter to be near her family (see above). The following is from my notes:

> When I arrived at the house of Mrs. Y., I found her in the sitting room together with another woman. Mrs. Y. introduces her as "my best friend" who "knows all about me". It transpires that she is a cousin. She then explained why she lives in town. "In the winter we live here in town. Here we have 'our' people. My husband was from here. Family lives close by. They are friends. If something happens, they help."

Friends

Four women felt they had one or a few good friends:

> Mrs. K. lives with her husband and youngest son Pavlos (22), who has cerebral palsy and learning disabilities, in a small house in the country. When I call out to the house one morning, I find her in the kitchen doing the laundry with another lady. Mrs. K. introduces her as 'my friend'. When I ask her later about friends she explains: "Yes, I have one good friend. She is his godmother, she lives close."

Two mothers explained to me how in Aniksi good friends are rare.

> I have one very good friend here. But, and my friend here will tell you like I will, here in Aniksi most people are not friends. Parea (company)- yes. But not from the heart. Some, but not many. Only so far. Not with the heart. I lived in Thessaloniki. It was very different; people are warm, very good friends. One reason why I came back here was, I thought it is small here. There will be friends for him. But no, they do not want to know." (Mother of a man (36) with learning disabilities and mental health problems)

> My family is in M. (A village in the mountains). I have little contact, very little contact. And few friends. People here stay to themselves. In a village people stay inside and keep to themselves' (Mother of a woman (32) with severe learning disabilities, living in a small village in the hills)

The majority of people who did not feel they had any support from friends did not elaborate any further on this. In Aniksi having many close friends from whom you would receive practical and emotional support would not be a normal expectation. The two women who did complain about the lack of friendship had lived away from Aniksi and both had reported different experiences in other parts of Greece. These women had different ideas and expectations about friendship than the reality they found on Aniksi. Living in a village or a town may be a factor; the four women who do have a special friend all live in town.

I conclude that while the women in Aniksi who did have good friends found them a source of emotional and practical support but the majority did not find nor expect this support. They were, however, aware of the lack of it.

Neighbours

Two women in Aniksi reported positive relations with their neighbours. Family surrounded one of these women. Supportive relationships with neighbours who are not family are rare, which fits in with earlier reports about friends and feelings of isolation. In addition to the general nature of social relationships in Aniksi, learning disabilities also increase or create a social distance between people and their neighbours and communities.

Relationships with other parents of children with learning disabilities

The mothers of the people attending the centre have organised themselves in a parent group which is part of the National Organisation of Parents of Disabled People.

They meet once a month at the day centre. The day of the meeting they come in with their sons and daughters on the centre bus and go back home with them in the afternoon. The parents have elected a subcommittee of 5 mothers who meet with the staff of the centre and organise the annual trip away.

There are no fathers in the group or on the subcommittee; this is clearly considered the domain of the women. To speak publicly for and about their children and officially meet and liaise with people outside the house is, however, not the norm for women in Aniksi. "The supposition suggests itself that having a retarded child is an experience of such intensity and universal qualities that it can transcend the existing societal behaviour patterns."(Dybwad 1970:561) This is not always easy, as one mother explains:

> "I often speak up at the ODAZ and at the parent meetings, I have to for the 'pedia' (people attending the centre- translation: children or lads) although I am shy and ashamed" (Mother of man (36) with mild learning disabilities and mental health problems)."

For the majority of these mothers the parent meetings at the centre are their first forum of contact with peers. They do feel supported by this contact but as a group they feel quite powerless and would like more influence on what happens in the centre:

> "We have meetings with mothers, five mothers. Also with all the mothers together. But in ODAZ it is not a demokratia. We wanted a sewing machine, they (staff) said no. We want groups, and more teaching." (Mother of boy with Downs Syndrome (24) and moderate learning disabilities)

> "If we mothers say something, it might change for a little bit but soon it goes back to the old situation. I am head of the mothers group. Once a month all mothers come in on the ODAZ bus. We discuss and Dimitris (manager) joins us for some of the time."

The meetings may not always achieve as much as parents would like to achieve, but they do have some influence. This becomes clear in this comment from one of the parents on the recent trip of staff, clients and some parents. This mother was unhappy with the input of staff during this trip:

> "What did the teachers do, nothing. With the mothers and the pedia, yes, it was very nice and we enjoyed it. But what did they do? Nothing. Only Nora (one of the female staff) worked. The others had a free holiday. We paid for Tassia to laugh with the gym teacher. Only Maria, she washed and dressed the boys. Tell me, what did you see? . . .Well, I spoke to Dimitris (psychologist and centre manager) today and to the mothers yesterday. If it is like this next time, we will only take one or two teachers. Like we had before (on other trips)."

Trips away are organised by the parent committee and it is they who have the final say on who accompanies them. However, this same mother was pessimistic about the real change she feels parents are able to make.

Besides being a forum for contact, peer support and possible influence on services provided for their children, parent meetings also fulfil a social function. The yearly trip in particular can bring parents together, as this mother explains:

> I did not know the other mothers at the beginning, just some of them from face. Now, also after the trip I know them better." (Mother of young woman (22) with mild learning disabilities who has recently started at the centre)

Not all mothers however come to the meetings and/or on the trip. Some mothers say they live too far away to come in to the centre and have no transport:

> Sylvia: "Did you ever go to the centre?"
> Mother: "No, how?"
> (Mother of a man (28) with moderate learning disabilities, who lives in a village about 15 km from town).

This mother would, similar to the other mothers be able to come on the centre bus with her child in the morning. She feels however that it is too far away and too difficult. This woman lives in an isolated village in Aniksi that she rarely leaves. For her shame, uneasiness in a group of strangers or a disapproving husband may also play a role.

Relationship with professionals

Parents in Aniksi complain bitterly about the lack of professional support they have received over the years. They feel they did not receive any help from the medical professionals during the initial assessment of their child (see chapter on classification). At present, the lack of services available leads them to seek help from staff at the daycentre. However, they often find them passive and uninterested (see some of the examples above). These negative experiences seem to be influenced by two factors. Firstly, the social structure in Aniksi provides, apart from the newly established day centre, no system of support services for parents and their children with learning disabilities. The second factor relates to the importance of the medical view and profession in general and in the classification of learning disabilities in particular. This view suggests that there is 'something physically wrong with their child'. However, the medical profession has little to offer in terms of 'fixing the problem' or initiating a programme of education and training for the person with a learning disability. The relationship between parents and professionals in Aniksi is coloured by the unmet needs of the parents as well as the lack of emotional and practical support offered by the professionals with whom they have had contact.

Social life of the parents outside the home

> "I never was able to work outside the house. I was 18 when I had M. Now, what could I do now? I only have the mornings. (*In the afternoon N. is at home*). I never had any help. It was all me."(Mother of a woman (24) with severe learning disabilities)

Two mothers in Greece explained how the extra work involved in looking after their severely disabled child restricted their own lives. They would have liked to have worked outside the home but did not feel this was possible as "I have to be home when she gets home from the centre".

Apart from these two women no parents in Aniksi mentioned any impact on their social life. This is not because they were less housebound, nor had more help in comparison with the Welsh families. In fact the opposite is true. The difference in experience however is likely to be related to the nature and structure of social life in Aniksi, which for women is centred in and around the home. Most women only go out for the occasional visit to family or friends or weekly shopping, and the husbands sometimes do even this. They have the car and often go to the big supermarket. Going out at night for a meal or visiting family at weekends is usually with the whole family together. Not many women work outside the home (see Chapter Two: Research Questions, Methodology and Setting). Women, who are the main carers in Aniksi, do not expect to socialise much outside the house and having a child with learning disabilities does not change this.

Part B: Ffynnon

Resources of the family

Physical care and attention

In Ffynnon, the majority (twelve out of seventeen) of parents experienced the daily care for their children as problematic. Difficulties ranged from those caused by the nature of the dependency of the child (in areas such as toileting, feeding, mobility, safety awareness and personal hygiene) to specific behaviour problems such as hyperactivity, aggressive behaviour or a tendency to run away:

> He didn't walk until he was seven. We had to carry him. He couldn't suck. I was still feeding him when he was six. I put soup and everything in the bottle, he didn't have the sense to swallow. I used to sing to him feeding him, Lilly Marlene. Everyday. I still cry when I hear the song. He was in napkins until he was sixteem - and I had two babies beside him. We'd be up all night bathing him because he messed himself. But now there are diapers. I had to buy cotton sheets to cut napkins. I was boiling the babies nappies in the morning and J's in the afternoon."(Mother of a man (43) with cerebral palsy and moderate learning disabilities)

> "I remember him in the hospital. He was crying, they would not feed him with a spoon and he was hungry. I had to feed him with the spoon, his milk. He could not suck. He can't wash or dress himself; he needs attention in everything. But he has come on marvellous considering what I had to put up with for years. And with the toilet and all - he was in napkins until well...... I could not just put him to bed; he would wet the bed. Now he gets up" (Mother of a man with (33) cerebral palsy and learning disabilities).

> "There were a lot of problems. He was incontinent, he would not sleep on his own, wouldn't go in his cot. He would not go into the bath."(Mother of a man (28) with mild learning disabilities who contracted meningitis as a baby)

> "He was such a busy child. I thought he was just naughty. He was my first baby, well, I did not know. I had so much work with him. In the summer it was alright, I boarded up the garden and we would be out there at half 10. I could not go shopping with the baby in the pram and S. He would run away."(Mother of a man (32) with mild learning disabilities)

> "He was a busy child, running away. Before he went to school. The children used to take him to the field and before they looked he was gone. The neighbours went looking for him and found him in a van." (Mother of a man (42) with Down's syndrome)

> "He hits me so often. I've been blue all over."(Mother of man (38) with cerebral palsy and moderate learning disabilities)

> "If things don't go the way he wants he gets very upset. He starts tearing clothes. If you upset his routines. And it is always something he likes that he tears up. It is like he is destructive towards himself." (Parents of a man (32) with mild learning disabilities)

Some parents in Ffynnon explained how they devised their own practical solutions, which helped them to cope.

> "How he came to walk ....My father in law had a walking aid. Edward was always catching on to his trousers. My brother in law made a walking frame for him of strong steel."(Mother of a man (33) with cerebral palsy and learning disabilities.)
>
> "I used to have 3 play-pens. The last one I had specially made. It was 5 feet high. She was safe in there, you see. When she was bigger I had a bed with cot sides. And cotton re-strainers, I made them myself."
> (Mother of a woman with Down's syndrome and mild learning disabilities)
>
> "I had to buy cotton sheets to cut napkins (nappies)"
> (Mother of a man with cerebral palsy and learning disabilities who was incontinent until he was 15)

Some difficulties ease as the child gets older and learns to walk, feed himself and take care of his own basic needs. Others however increase or new problems may arise. The child gets bigger and stronger and thus harder to manage and/or the coping ability of parents decreases with age, as illustrated by the following examples:

> Leo lives with his parents in a small council house. He suffers from learning disabilities and severe cerebral palsy. Leo's parents used to carry him up and down the stairs but are not able for this now. They have had a stair lift as well as a hoist installed in the house in the house but this has not solved all their problems. "We used to go and visit our other children. The problem is that we have to carry him upstairs. Here (at home) we have the hoist."
>
> "When Kyle was 15 I was very bad. I had bad trouble, bleeding etc., the doctor said to my husband: "'You have to do something. It is Kyle or your wife.'" It was the hardest thing we had to do. He went to Ely Hospital"
> (Mother in of a man (43) with cerebral palsy and severe learning disabilities)

In Ffynnon children with learning disabilities place extra demands on the resources of their parents, in particular when they are young. When they get older practical difficulties ease providing there are no major behavioural problems or intensive care involved.

Finances

None of the parents in Ffynnon mentioned financial difficulties in relation to their child with learning disabilities. Medical services are widely and freely available and adults with learning disabilities receive a state disability allowance. In addition, families are often entitled to extra social welfare payments towards furnishings and clothes where extra wear and tear on these is associated with the learning disabilities of their child.

The family as unit of socialisation

Worries about Appropriate Care and Treatment

> The realisation and diagnosis of a child with learning disabilities is of enormous consequence for parents. They have to adapt their expectations of the child, lack knowledge about its condition and future development, have to deal with their child's particular difficulties, as well as with special services. (Hilton Davies 1993; Ingalls 1978; Janssen 1982)

In Ffynnon nearly half the parents (seven out of seventeen) reported difficulties around finding suitable education for their child. The majority of these parents reported delays in the process of exclusion from mainstream schools followed by formal diagnosis and referral to appropriate (alternative) services:

> "He went to the day centre at 12. Before that he was at home. The Spastic Society came here, from Cardiff. They would not accept him in Cardiff, his I.Q. wasn't good enough for him to go there. He could go under the Spastic Society in Cambridge. They were building a new school there. It was not even finished and the waiting list was 3 years. We didn't want him to go away."(Mother of a man with severe cerebral palsy (38) and learning disabilities)

> "Connor went to the local school but I had problems with the headmaster. He did not want him in the school. I had to fight to keep him in. He said C. was not capable of learning and arranged for us to see the clinical psychologist (from the

Department of Education). . . The clinical psychologist we went to see just washed his hands of him. He said he dealt more with behavioural problems. He did nothing, offered no suggestions. My local councillor helped me. She referred me to this doctor within the Health Board. It was a year, that is how long it took to get appointments. He suggested that Connor was a candidate for "The Primrose" (Special School) and got him in there."(Mother of man (32) with moderate learning disabilities)

"The local school would not take her. Then there was a change in headmaster and he took her when she was about 6 or 7."(Mother of a woman (33) with mild learning disabilities)

"He was at home until he was about 10, or 12. He wasn't doing anything, just sitting around. This woman, she was like a welfare officer, she was coming around. She didn't come often; she knew he was well cared for. She got him in the Centre. They picked him up, to give me a break."(Mother of man with cerebral palsy and moderate learning disabilities)

"You see, there was an elderly teacher. She was marvellous with him. When they changed the teacher, they stopped him going. I had to go over to see the headmaster. He said Theo was running away. He offered no alternative. He was at school for five or six months. Those years, from six to eight, were the worst. I could not get him into any school. And Social Services did not want to know. In the end, my mother went up there. It was either him or me, I would have been in Carmarthen, in St. Davids. (*Psychiatric Hospital*). I lost so much weight. Social Services sent him to "The Primrose" but in the end he went to New Court first. From then on, we haven't looked back. Mrs. Brown (principal of New Court School), she was marvellous."(Mother of a man (32) with mild learning disabilities)

"In the beginning we had a hell of a battle to get her into the centre. She was in school until her second bout at 5 ½. After that she never went back to school. She was at home for two years. We were battling to get her into the centre. The man from the Education Authority, he said that Mary could not be educated anywhere in the County. It was through a friend that she was taken into the Junior Training Centre."(Father of a woman who suffered two brain haemorrhages as a child)

"On his 6th birthday I had a letter from the Medical Officer. He wanted me to sent him to North-Wales a residential school. I was unwilling. I took the letter to my doctor and he wrote a letter back; this special school was starting in April, why could he not go there? He started there then, in January, with Mrs. Lewis. Otherwise he would have been up there (North Wales) I knew about the school and I told the doctor. Yes, it was funny, the Medical Officer did not seem to know about it. And it was run by the Health Authority!"(Mother of a man (42) with Down's syndrome)

Some parents spoke of the difficulty of accepting their child's admission to a special school or adult service.

> "I can still see her going in that car, it broke my heart."(Mother of a woman (33) with mild learning disabilities who left primary school to go to special residential school, at the age of 9).

> "I went in there one day. He was sitting there with all these Downs, they were putting paints in boxes and G. was counting them. I thought it was terrible."(Mother of son (33) with moderate learning disabilities as a result of meningitis)

Three parents felt that the day centre was not the appropriate place for their child but that no suitable alternative was available:

> "Eddy only goes to the centre once a week. He isn't quite satisfied with the centre...//...There was a name change, probably because of the costs. When he went first it was Adult Training Centre. He was making plenty. Woodwork, wooden benches. We bought one for the garden. Basket making. Now they are confined to 'social activities', Social Activity Centre. I see them around town. Eddy would do a good job, in a restaurant for example. He knows how to lay the table; he is quite capable of doing little jobs."(Father of a son (44) with Down's syndrome and moderate learning disabilities)

Worries about the future

Nine parents in Ffynnon (more than half) said they worried about the future. Only two parents however described a specific and pressing concern. One of these parents, a widowed mother of a woman with Down's syndrome and mild learning disabilities, had made previous arrangements for her daughter. Unfortunately and tragically, circumstances had changed:

> "I had a son. He committed suicide two years ago. That was a big blow. He had promised me he'd look after P., after. I want her to stay at home; she loves her home, her own bed. She has always lived here; she is always here. I hope my daughter in law will still come here. Where she is in her own house."(Mother of a woman (42) with Down's syndrome)

The other parent, who has a son with mental health problems and mild learning disabilities, wanted him to enter adulthood by moving out and becoming less dependent on his parents but no suitable accommodation was available in their area.

> "As you might have been told by other parents, our biggest worry is what is going to happen when we are not around. I have a son and a daughter in

> London. No one here. My mother is old, lives in a nursing home here. The hostel would probably be one hell of a shock for Bernard. It is not ideal for him. We would like a group home, preferably when we are still around to see him settled, but as you know group homes are few and far between. A lot of difficulties for the future. I was contemplating to see him settled before he was 30. Now I have acccepted, Bernard will be with me." (Mother of a son (28) with mild learning disabilities and psychiatric problems)

The parents that did not report any worries about the future had made arrangements, either through family or alternative accommodation or their child already lived away from home.

Most children in Ffynnon eventually leave home to work, study or start their own family; parents of people with learning disabilities however feel they have to make special future arrangements for their child. A social structure that provides alternative living arrangements through hostels and supported community homes can alleviate some of the worries but many parents continue to be concerned. They feel that their child will always be in need of special care and attention and find it hard to rely on strangers for this.

Relationships within the family

Marital relationship and gender roles

> The birth of a child may be stressful to the marital relationship, even leading to divorce (Hilton Davies1993; Ingalls 1978; Janssen and Janssen 1982; Verstegen 1978).

In Ffynnon three parents, all of who were mothers, mentioned the effect of a child with learning disabilities on the marital relationship. They explained how their husbands could not accept the disabilities of their children and one mother gave this as a reason for her subsequent divorce:

> "My husband, he was very ill with cancer. He wouldn't accept that there was anything wrong with Ian. He bought all this (toys and books) for him but he wasn't interested."(Mother in Ffynnon of young man with moderate learning disabilities as a result of having had meningitis at the age of 9 months)

> "He could not accept it. That she was not perfect. In the end he left. He lives in South Africa now."(Mother in Ffynnon of woman (33) with mild-moderate learning disabilities whose husband divorced her not long after the child was diagnosed)

Difficulties may be related to differences between both parents in the acceptance process, the stress of the practical burden, and/or disagreement around the best treatment for the child. The latter is illustrated by the following example:

> "When he had to leave primary school for secondary school they put him in a remedial class in St. Mary's. Then they suggested "The Primrose" (*special school*). Dad wasn't very keen but I said if it can do something for him, take the chance. It was not easy. I had to take him to the bus, dad wouldn't."(Mother of a man with mild learning disabilities and psychiatric problems)

The marital relationship can also be a source of support. A few mothers talked about the involvement of their husband in the care for their child; in four families this was illustrated by the husband's presence at and participation in the interview:

> "Because my husband and I, we spend hours on the bed, before she went to school. We were pumping the words into her, to get her to talk. Then my husband made her a cart, to push herself. When she walked we both cried. We thought she would never walk." (Mother of a woman (42) with Down's syndrome and moderate learning disabilities)

In one family the mother has had a stroke and the father looks after his wife and his daughter, who has learning disabilities and psychiatric problems. In another family the mother died. The paternal grandmother took over the care of the family for a while and when she got older the father took early retirement to look after his son with Down's syndrome. Others became quite involved with the parent organisation Mencap:

> "We used to go to Mencap meetings together. I was the first secretary, 25 years ago. Brian Riggs (founder of Mencap) came to Ffynnon. I went to the meeting in the Town Hall. It transpired from there that I became secretary. It was hard work, rounding parents up, but we got it going."(Father of a man (44) with Down's syndrome)

Siblings

Having a brother or sister with learning disabilities can be difficult at times, as two mothers describe.

> "The only thing I did see, the eldest two, they understood. But the youngest, there was always a little jealousy. He thought he was the baby after all, he could not understand."(Mother of woman (33) with learning disabilities)

> "That was a bad time, when we had to take all the children up to see Bernard every Saturday. We would not miss a day. And one girl was carsick.
> Sylvia: "Did the other children ever complain?"
> Mother: "No, never. They knew we had to go and see them."
> (Mother of a man (43) with cerebral palsy and severe learning disabilities. While Leo was a teenager he was in residential care, in a large institution two hours drive from home. Every Saturday his whole family would drive up to see him).

The majority (eleven) of parents described how well their children got on together when they were small, and how the siblings looked after the child with learning disabilities.

> "They got on very well. They played together and went to other people's houses. Let's see, when they were 9 and 7 they used to go to the youth club and take him."(Mother of a man (32) with moderate learning disabilities and some behaviour problems)

Positive reports relate especially to the time when the children got older and nieces and nephews came on the scene.

> Sylvia: "Do you have any brothers or sisters?"
> Laura: "John, Adam, Susan. John and Noreen are married. Live in a flat. Adam, he's gone away for a week. Kiss him. Love him. I do love him."
> Sylvia: "Who is Adam?"
> Laura: "Brother in law. Got four children and a little baby. One baby, three boys, four children." "In the kitchen, I help her. I do love her. She is good. Buy her flowers. Baby, she got a baby. I am gonna see her when she is born. Not yet. I hold her. (*Shows me how*) Oh, I love babies. Gonna kiss her. After Christmas. A girl called Lisa."
> Sylvia: "You love babies?"
> Laura: "Yes, I do." (Hugs me) (Extract of an interview with Laura (33), a woman with mild learning disabilities)

The majority of the people themselves spoke with affection about siblings and their children. It can, however, not be taken for granted that people with learning disabilities always are always happy to be involved with their nieces and nephews. The following is an extract of an interview with a woman (32) with mild learning disabilities. She lives with her mum and her older sister is married with children:

> Linda: "I was brought up in London. My sister is in London, she is married."
> Sylvia : "Does she have children?"
> Linda:" Yes. Some are tall, some are small."
> Sylvia: "When do you see them?"
> Linda: "When she comes down for holidays. I baby sit."
> Sylvia: "Do you like that?"
> Linda: "I have no choice. If they'd ask me, if I'd say no, I'd have a row. Once I did want to say no. It's o.k. I wouldn't mind having children but I don't think I could cope. My parents, I'd be killed." (Interview with Linda, a woman (32) with mild to moderate learning disabilities)

The above illustrates again how people with learning disabilities in Ffynnon have less choice than other adults. I will come back to this issue further in this thesis and in particular in the concluding chapter.

Currently, for the majority (twelve) of parents, siblings of the child with the learning disabilities are the most important source of support and an important part of the social life of their brother or sister:

> "My daughter fetches her every Sunday. She has her dinner and her tea there. She also takes her for a spin in the car. Mary is happy as long as the wheels are turning."(Father of a woman (42) with psychiatric problems and learning disabilities) In this family this share of care is especially appreciated. Mother has had a stroke and is only slowly recovering. The father is not in the best of health himself, looks after his wife and his daughter with learning disabilities whose behaviour can be extremely disruptive. She may get up at four and start hovering, or turning the taps on and off for hours at night. This is related to her psychiatric condition, she has regular periods during which she displays psychotic behaviour. The relationship with her sister offers Mary a stable and reliable relationship in which she is valued, her interests are acknowledged (food and spins in the car!), and in which she is recognised as a sister and an auntie for her sister's children. For her parents it offers respite and emotional support.

The people in my study spend a lot of time with their siblings. This usually involves day trips, visiting them at home, having meals together, being cared for when necessary caring for their nieces and nephews and occasionally receiving money from them. Six of the people with learning disabilities in Ffynnon spend regular holidays with one or more siblings:

> "The other girl is a nurse. He goes there for a week's holiday now and then. It gives us both a break. And he likes it up there. It is a nice community where she lives and he knows all the neighbours."(Widowed father of a man (44) with Down's syndrome and moderate learning disabilities). This sister lives on her own and particular likes her brothers company, involving him in her live and her neighbourhood.

The relationship between the person with learning disabilities and his or her siblings is often a reciprocal one. Help and support are provided to each other, as valued company or as help and support with siblings' own children. Many of the clients I spoke with told me with great enthusiasm how much they loved their nieces and nephews and how they helped looking after them and their parents' stories confirmed this.

Not all siblings though share the above sentiments; according to one set of parents their other two children did not have much time for their brother with learning disabilities.

> "They did not really have a lot of time for him. Maybe it was my fault, maybe everybody's. No one ever said he is handicapped so we never sat down with them and said this and this is the case. They always expected more of them."(Mother of a man with learning disabilities and psychiatric problems)

Jealousy on the part of the person with the learning disabilities towards their nieces and nephews was reported in a couple of cases as complicating contact with siblings.

Relationship between parents and their child with learning disabilities

Feelings in relation to their child's disability may influence the relationship between the parents and child. Besides worries about the future, which I discussed earlier, some parents (four) still grief about the disabilities and quality of life of their child.

> "Mrs. A. has a son with cerebral palsy and severe learning disabilities. He was born at home after a difficult birth. His mother feels she should have had a Caesarean section, and considers the traumatic birth as the cause of her son's disabilities. Mrs. A. has been in bad health for years and her son was institutionalised when he was in his teens. Currently he lives with a foster family. During the whole interview this mother clearly conveyed the love and grief for her son and her doubts about the purpose of his life. Grief about having to let him go into care; about him not being able to do the things she expects a son to be doing; and about his traumatic birth. 'I go down every week to see him; he is still my boy. What a quality of life he has got. He should be out, playing…//….I used to wonder, I like to go and see the rugby. I think what would Martin have been, a footballer or a rugby player."
>
> "Sometimes I feel resentment. That is human. And sometimes I feel grateful, when I see severely handicapped children."(Mother of a man (38) with mental health problems and learning disabilities)

Three mothers report difficulties in the communication with their child as particularly stressful. Their children have limited verbal communication skills and these make it difficult for their parents to understand them. That these difficulties could also have other serious consequences is illustrated by the following.

> "For many months Martin had been with a foster mother who drank heavily. She was lying on the couch drunk everyday, her foster son and her own children did not get anything to eat until the husband came home in the evening. The husband was afraid to say anything out of fear of loosing his own children. No one else knew and the foster child wasn't able to tell his natural mother. 'It is heartbreaking when you don't know they aren't happy. And he couldn't tell me when he was with her'." (Mother of a man with severe learning disabilities and cerebral palsy who has been living away from home for many years because of his mother's ill health)

Makaton is a sign language for people with learning disabilities. It can help in the communication between parents and their child.

> "He can't speak. We went to Makaton and I passed grade 6. That's the best thing that happened. Before that I could not understand him. My friend used to come with me, her son is John (*another client at the Centre*). The Makaton has been wonderful. He wants to phone now too, he signs that he wants to phone. I say: 'Who' and he says (*signs*) 'sister' in Makaton."(Widowed mother of a man (33) with severe learning disabilities who displays a lot of aggressive behaviour at home)

Some parents (four) and in particular those whose partner has deceased, explain how they enjoy living with their learning disabled child who fulfils the role of companion. These parents do many things together such as watching cricket, visiting friends, going to bingo or on holidays:

> When I visited Mr. D. and his son, who has Down's syndrome and moderate learning disabilities, they are watching cricket together. Mr. D. is a widower and happy with the company of his son. "He is very good. No trouble at all. He brings me a cup of tea in the mornings. We get on fine. Eddy was offered a place in a group home, four of them together. Mr. K. (former day centre manager), he advised me to send him. But why, when I can still look after him, why would I live on my own."

> Sylvia: "What do you do at night?"
> Yvette: "I go to the club with my mum (*to play bingo*) and I go to Gateway on Friday. My mum brings me in her car."
> (Woman with mild learning disabilities (28) who lives with her widowed mother).

> "She is my only companion now. My husband died 19 years ago. You know, the compensation is when she says I love you. And she says it everyday, mummy I love you. They are very affectionate. She is always ready to help, to put out the tray, lay the table. Mummy shall I do this, shall I do that. And when my sisters come now, always ready with a hug and a welcome. Unlike many other youngsters today…//… Yes I enjoy her company. Well, she goes out from half 8 until half 4. And then when she comes in, I look forward to that. And another thing, she is always concerned. Asking if you are well, caring, that is very nice…//.. "We used to go to P. together (caravan) but now I have angina. And it scares me, when it is wet, people all go home and we are on our own. And if something would happen…Mind you, she would probably cope, you never know. I had a bad attack of sciatica one morning and told her to fetch aunty M. who lived two doors away. But she wasn't in and Rona went to the other neighbour. She had the presence of mind to go and get help from

> someone else." (Widow with a daughter (42) with Down's syndrome and mild learning disabilities)
>
> While this mother clearly enjoys and values her daughter there is still an underlying notion that all is not quite well. The positive experiences she has as her daughter as a much loved and valued companion and source of support do not fundamentally affect her feelings that Rona is different than other people ("they" are very affectionate) and that having a child with learning disabilities, or in this case Down's syndrome is a cause for grief. A kind of grief that is expressed when she says "that is the compensation" when she describes her present life with her daughter. It was also expressed in her reaction to the official diagnosis of Rona child, "the only girl" in the family. "We were worried before and had asked the health visitor, but it was still a shock, because she was the only girl in the family."

The availability of alternative living and care arrangements for their child with learning disabilities may facilitate an equal relationship based on choice, love and respect. If, at a more mature age, the person with the learning disabilities still lives at home, this is often a matter of a choice, albeit mostly on the side of the parent(s) and not out of necessity. The level of ability and behaviour of the person with learning disabilities does play a role too; aggressive behaviour, for example, may complicate the relationship and lead parents to worry more.

Another element in the relationships between parents and the people of my study is power and control. An example of that control was discussed in the paragraph on siblings but there were many more throughout my research. Decisions with regard to marriage, having children, having a boyfriend, visiting friends, joining the church, going out to work but also day-to-day decisions such being allowed to cook or cross the road for example were to a large extent determined by their parents.

People with learning disabilities may not question this power but many are certainly aware of it. This is illustrated by evidence throughout this thesis. This may to a large extent be related to the fact that these people were all still living with their parents, at an age that most other adults in Ffynnon would have left to build up their ‘own’ lives. It may also be related to an ambiguity in the adulthood of people with learning disabilities, already identified in a slightly different context in Chapter Three. The issue of power and control will be further discussed in Chapters Seven and Eight.

Relationships between the family and other members of society

Feelings of loneliness and isolation

In Ffynnon only one mother felt isolated in caring for her son and worries about him, socially as an individual and as a member of a ‘forgotten’ group. She explained how she felt part of a group that was ignored by society, and that this ignorance was caused by the lack of political influence on the part of the person with learning disabilities:

> “We are being ignored. There is commitment to the elderly but not with the handicapped. It is not a statutory right, they do not have to provide. The handicapped are a left out species. ‘Care in the community’, the emphasis is on the elderly. Fair enough, they do have needs; they have a right to be cared for. But they have had their lives, whereas our sons and daughters never experienced that. It is all politics, votes. The elderly have votes. My son votes, he puts a cross. I believe in him exercising his democratic rights. But most of them can’t. This job is a life long commitment. We love our son very much. But a part of our lives will never be lived. I can’t remember going out. There is always one of us here. I remember when I had to go out to sit with someone at night (for work); it was such an excitement to go out at night.”(Mother of a man (32) with learning disabilities and psychiatric problems)

The parents had hoped that at this stage their child would have been settled in a group home. This had not happened yet due to a lack of places. This mother strongly felt she had been let down by the rest of society and left alone in the care of her son.

Extended Family

In Ffynnon the majority of parents felt that they received great support from either the maternal grandmothers (seven) or the paternal grandmother of the child (three) while their children were growing up.

> "My in-laws were very supportive, they looked after her a lot."(Mother of a woman (33) with mild-moderate learning disabilities, whose husband divorced her after the birth of their child)

> "Both my mother and mother in law were very helpful. He still goes up to my mother on Friday and stays the night, on Saturday he goes to his other granny and stays the night and back to my mother on Sunday."(Mother of a man (32) with moderate learning disabilities)

> "My mother, she was better than me. She went up to Social Services."(Mother of a man (32) with learning disabilities and behaviour difficulties as a child)

Two families had actually lived with one of the grandmothers.

> "When my mother lived with us I worked three nights a week. My mother was marvellous. She kept the place so clean, she did everything except hoovering."(Mother of a man (43) with cerebral palsy and moderate severe learning disabilities)

Five people (one third) were reported to be in close contact with their brothers and sisters. Two of these families had moved back to the mother's home. Over the years these families were in close contact with their extended families. While they did not receive much practical help from them, there was a lot of contact and their children played together and they felt emotionally supported.

> One father, whose daughter (38) was left severely learning disabled after two brain haemorrhages at the age of five and who lived in a small village surrounded by family put it like this: "We never received nor asked for any real help as everyone has to carry their own burden".

> Support can take different forms as the following illustrates: The aunt and uncle of a woman with Down's syndrome live in a nearby village. Both families were in regular contact over the years, and she and her husband got actively involved in Mencap (organisation for parents and friends of people with learning disabilities). Rebecca's mother explains: "My sister and brother-in-law go to the Mencap meetings. They have supported them for years. He has just finished being treasurer". Rona also goes to church every Sunday with another aunt who is eighty but still picks her up in her car.

Friends

In Ffynnon nine parents (more than half), had close friends. The friends of seven of these families offered real practical and/or emotional support. They helped with transport, invited the whole family to their guesthouse for a holiday, and were there if and when called upon and / or became involved with the person with learning disabilities in their own right.

> "I have been lucky. I always had friends and my mother-in-law. Any time I could call on them."(Mother of a woman (33) with mild-moderate learning disabilities)
>
> "I had a holiday for the first time this year. My friends paid a deposit. It was a lovely week and I really enjoyed myself. The three of us (*friends*) went."(Mother of a son (33) with moderate learning disabilities)
>
> "She loves John Travolta. A friend wrote away to the fan club and she had a signed photo back and a birthday card."(Mother of a woman (23) with Down's syndrome)

One parent couple I interviewed had met their friends through the parent (Mencap) meetings; they also had a child with learning disabilities. Many parents attend these meetings (see paragraph on parent organisations) but, surprisingly, no other parents mentioned them as a source of friendship. For some there is a difference between friends and "real needed support"; "We had friends yes, but no one to baby-sit."

Eight parents said they did not have any real friends. One of these eight had moved to a different area after his wife died and felt quite isolated. Another couple said they had no time for friends. One (English) mother made a distinction between "acquaintances" and friends:

> "One thing in village life, or in Wales, no matter how long you live here, you are always an outsider. We get on with people, we have friends but very close friends, no."(Mother of a man with learning disabilities (28) and mental health problems)

Neighbours

In Ffynnon seven people (nearly half) reported that they have (had) helpful neighbours. This help could vary from taking the child with learning disabilities to church, looking after the child from time to time, doing the shopping, or just being "good, very good" or "there when you needed them".

Other parents of children with learning disabilities

> Throughout the world, very considerable progress has been made during the last decade or two in the area of mental retardation and one of the main forces in this advance has been a most interesting social phenomenon, the organised effort of parents of the mentally retarded, efforts that now can well be described as a world wide movement."(Dybwadd 1970: 560). . . . "following World War 11, literally around the globe, in countries large and small, developed and developing, parents began to rise up demanding proper attention to their retarded children's problems. (Dybwadd 1963 in Dybwadd 1970: 561)
>
> With but few exceptions the efforts were indigenous to the various countries as far as the job of organising was concerned. Now there exists the International League of Societies for the Mentally Handicapped with parent-sponsored member societies in nearly 50 countries from Malaysia to Ecuador, from Yugoslavia to the Philippines. Documentary evidence from the various countries tends to demonstrate an astonishing similarity not only in the motivation of the founding members of these groups but also with regard to their goals and methods. While this matter certainly deserves to be studied in more detail, all indications point to certain basic factors common to the experience of having and caring for a retarded child, be it in Indonesia, the United States, Spain, or Poland, even though there are striking individual differences in the response of parents to this experience-from extreme grief and anxiety and feelings of worthlessness, leading either to rejection or overprotection of the child on the one hand, to a positive acceptance on the other hand, resulting in a resolve to help this

> child and others of similar handicap. Obviously, the manifestations of these varying parental reactions is influenced by prevailing cultural factors, but the early history of the parent movement in many countries clearly shows how the initiating and organising group proceeded in the face of overwhelming societal obstacles and taboos. (Dybwadd 1970:561)

Parent organisations in Ffynnon play an active role in the treatment of people with learning disabilities and are an important forum for their parents. This is illustrated by the following interview extracts:

> Sylvia: "Do you go to parent meetings?"
> Mother: "No, never. I used to go, but there are plenty of young ones now to take over"
> Sylvia: "How did they get involved?"
> Mother: "Through me"
> Sylvia: "Did you find the parent meetings supportive?"
> Mother: "Oh yes. You get to know other parents. They want to know things, and you can ask them. You get advice. You get to know people, conversations and you get the news. And going on trips. There is a trip coming up now, the annual trip to Cheltenham. The first or second Wednesday in August. It's for parents and children, the child and one adult are free. Me and my sister are going. We go for a meal in the hotel and we have tea. And you can take Rona out for a meal, no problem. She is very well mannered. When my husband was alive, he went. My husband was one of the founding members of Mencap Society in Ffynnon. I didn't used to go when he was going to the meetings, I stayed at home with Rona."
> (Mother of daughter (42) with Down's syndrome)

> Mother: "I used to go to the parent meetings when my husband was alive, every month to the Society, Mencap. I was in the committee. I haven't bothered since my husband died. He used to look after Edward when I went."
> Sylvia: "Do you go to the parent meetings at the centre?"
> Mother: "No. I can't make it up the hill. I went about 4 weeks ago, I had to stop 4 times."
> Sylvia: "Do you go on the Mencap trips?"
> Mother: "No, not the last couple of years. I used to go, oh yes, every year."
> (Mother of a man with Down's syndrome and severe learning disabilities)

> Mother: "I used to sell Christmas cards for Mencap, for 14 years. I am still known as Mrs. Christmas cards. They all know me and I know all the kids when I go to the centre."
> Sylvia: "Are you still involved with Mencap?"

> Mother: "No. Martin went away then. Mind you, I was still selling cards when he was away."...//..."It is amazing how many people have them (child with learning disability) Brian Riggs, Mrs. X. But it was difficult the way I had him. Because if I had had a Caesarean...."
> (Mother of man (43) with cerebral palsy and severe learning disabilities)
>
> Mother: "About the sports, I was housebound because my mother was ill. I did not go to meetings at the centre. They told me John couldn't do sports because I did not go to the meetings. Now, my mother died and I go to every meeting. They are embarrassed. That is the Special Olympics Committee; it has nothing to do with the centre, it just using the rooms there. I go to Mencap once a month and to the Faith and Light. With them we went to quite a lot of places. But I only got involved since he went to the centre." (Mother of a son (33) with moderate learning disabilities as a result of having had meningitis as a child)
>
> Father: "My wife used to go to the meetings and that, to the Christmas party and things like that."
> (Widowed father of daughter (38) with moderate learning disabilities)
>
> "I used to go together with my wife. I don't go there now. I was the first secretary 25 years ago. Brian Riggs came to Ffynnon- I went to the meeting in the Town Hall. It transpired from there that I became secretary. It was hard work rounding up parents. But we got it going. There are all new members now of course."
> (Father of man (44) with Down's syndrome)
>
> "My son passed his driving test at 17. He said, mother you must learn to drive. I passed the test the second time. That was the best thing that ever happened to me. I could take him and go to the mother groups. They started when he was in the Junior Part. I am still going there. Some mothers from the Junior Part are still there too. A couple died." (Mother of a man (33) with Down's syndrome)
>
> "I used to be in the mothers group. I enjoyed that, in the Junior (*Training Centre*). I was vice chairperson for a while and we got them their first own minibus. They had one from the Education Authority to pick children up in the morning. But now they had one of their own so they could go on trips. I was quite proud; we did fundraising, a big charity draw. We had a great group of mothers. We got on well and worked hard together, things aren't the same anymore." (Mother of a woman (33) with moderate learning disabilities)

Nine out of the seventeen parents (more than half) I interviewed in Ffynnon had been, or still are a member of a parent group. They went to Mencap, the Special Olympics Committee, Faith and Light or the parent meetings run by the centre. They found understanding, support and advice. They went to raise money for their own and each other's children and organise equipment, events and trips and to socialise with other parents in similar situations. Their meetings had a social function; they also provided advice, practical and emotional support, especially when the children were young.

The attendance of most parents at these meetings decreased as the years went on. They still go on the occasional outings, but are not actively involved anymore. Practical difficulties prevent some getting to the meetings but for others it is just a thing of the past.

Professionals

Some parents in Ffynnon complained that they never see anyone, or are not offered any help from professionals. When I asked them however if they want help and what form it should take, they answer that they are o.k. and do not need anyone. Some parents feel they are entitled to help and support but at the same time do not know what exactly they are looking for:

> Sylvia: "Did you have any support from Social Services?"
> Mother: "We never see a social worker here. They don't know if we are dead or alive. We went to my sons wedding in 1985. John came to part of it. After that he'd stay 1 night in the hostel. A social worker came then. And you know, from 1954-1983 and they had no records of him (*laughs*). Mrs. J called years ago. She must have taken the records with her. After she left until 1983 we haven't seen one.
> Sylvia: "Did you feel you needed someone?"
> Mother: "No, we did not want one. No we had no problems. A social worker called around when Leo was a child"
> (Mother of a man (38) with severe cerebral palsy and learning disabilities)

Ten parents in Ffynnon remembered receiving help from professionals, social workers, doctors or teachers while their child was growing up. Their experiences of this support varied. Help in the referral and placement of their child in an appropriate day or residential service, the provision of information and respite care were considered the most practical and useful forms of support:

> "The head mistress, she was great. She took Laura home with her when I was away in Spain and she said, you stay those few days longer"(Mother of a woman (33) with learning disabilities)

Some people had particularly negative experiences:

> "John he could never say what was wrong with him. There are two brothers in the surgery. One is really good with him. He came last year; John was not well. The thing with him is, he cannot say what hurts him, where the trouble is so the doctor has to examine him to find out. I think he was put out about this. When he left I heard him say something like: "I should have been a vet." That is the truth, in the corridor, I heard him say it. We have not gone since. I was upset about that."(Mother of man (38) with severe cerebral palsy and learning disabilities)

> "The C.M.H.T. (Community Mental Health Team), they have been very good. They have done things. Richard, the key worker always rings his people when he finds out something about benefits or so. He got me a form to get clothes every six months. How that came about, I was telling someone I was getting Bernard a bed and Richard came by and overheard. He thought I might get one from the D.H.S.S. He found out about the clothes and I got the bed. The problem is knowledge is not shared. Often what Richard hears is from other parents. They cannot volunteer information; you have to ask the right question. The way we were brought up, you did not ask for anything."(Mother of a man (28) with psychiatric problems and learning disabilities)

Various parents brought up two issues. The feeling that they had to cope themselves and should not ask for help (in particular some of the older parents) and the fact that services and support are available but information about it is hard to access. The majority of parents agreed that formal support has improved since their children were young. Eight tell me that they now have a social worker whom they see regularly and who helps them with practical things such as information about benefits, taking their son or daughter to various appointments, arranging family aids or home help. An additional two do not see a social worker but know how and when to contact one.

In Ffynnon a formal support system exist but it does not always reach parents effectively. In addition, the relationship between parents and professionals is influenced by the extent to which parents feel understood and listened to. A social worker that comes in and gives unsolicited advice about the treatment of their child is not often experienced as helpful:

> "This social worker came around. She wiped the floor with me. Told me I should let her play outside with the others. So I did and she fell and came home with a broken tooth. Another time my son came home and told me she had stripped in front of the other children. What could I do?"(Mother of a woman (33) with learning disabilities)

Social life of the parents outside the home

> "The only break I get now is when he is at the centre. But I am happy; I am used to it now. Maybe we could get help if we wanted but what you don't have you don't miss. We could never go out together."(Mother of man (38) with severe cerebral palsy and learning disability)

> Father: "Our social life finished 40 years ago."
> Mother: ""We had two years."
> Father: "And then the children. We had no help."
> (Parents of a woman (40) with learning disabilities and mental health problems)

> Father: "This job is a lifelong commitment. We love him very much"
> Mother: "A part of our lives will never be lived.
> (Parents of man (32) with learning disabilities and psychiatric problems)

Single parents in particular experienced this restriction on their social life as difficult. Respite care gives some relief. One mother explained how she was able to go on holiday once a year because of it but this respite has now been discontinued as a result of a lack of funding:

> "There is only one thing. There is only one emergency bed now (in the hostel) None for holidays. I loved a week holiday a year, just for a break. Every year I had one week. And Laura went to the hostel. It was no problem. You could even ring up a week before. Since April now this has stopped. That's the only thing. I was happy to leave her there."(Divorced mother of a woman (33) with learning disabilities)

Part C: Comparison and Discussion

Comparison

In both Aniksi and Ffynnon the majority of people attending the day centres were reported by their parents to have placed extra demands on the resources of their families while growing up. The majority of these children did not follow the 'normal' and expected patterns of developing independence in self care, mobility and socially appropriate behaviour. The parents experienced their children as prolonged dependent in relation to personal care, mobility and safety: both physically and socially. This suggests that in both Aniksi and Ffynnon parents have certain and similar expectations around a child and the families role and responsibility in relation to that child. The 'normal' functions the family fulfils in the care and socialisation of its children is not enough; child rearing becomes 'caring' in the sense of something beyond ordinary support in duration, intensity and prognosis (Parker 1981 in Malin, Manthorpe, Race and Wilmott, 2000: 129). 'Caring' in this sense can be demanding and stressful (Szivos 2001: 119). Learning disabilities, to the families in Aniksi and Ffynnon, is related to the impairment of the child as well as influenced by socio-economic circumstances.

Financial difficulties for example was only mentioned in Aniksi, where the standard of living is low, little financial help is available and all members of the household are expected to contribute to the family income. In both Aniksi and Ffynnon parents felt or were told that regular education is not sufficient for their child. Yet they viewed their child as able to and in need of education and they look to the state for help. In both Aniksi and Ffynnon parents worry about the future. The majority of parents in both places view their child as being in need of continuing care and supervision and unable to follow the "normal" and expected patterns of increasingly independent and adult lives. These anxieties are influenced by local social structures. In Aniksi concerns are well founded, as alternatives to parental care are not freely available. The fact that in Ffynnon, where alternatives are available, parents still worry about the future suggests that culture or "norms and values" also play a role. In both Aniksi and Ffynnon there are strong norms and values attached to the role of the nuclear family as the place, and the taker of responsibility for the care of its vulnerable members, in particular the children. It is extremely difficult for most parents to accept and trust that the 'care' and the responsibility for their child will be completely in the hands of strangers.

In both Aniksi and Ffynnon, the mother was the primary carer for the child with learning disabilities. This is in line with local gender roles. There are however, fathers in both places who take responsibility for a particular part of the care. This may still be in line with local gender roles in that fathers may take responsibility for a particular area of care of their child(ren) or it may be related to general changes in gender roles where fathers increasingly get involved with all their children. It may also be that the child with learning disabilities places demands on families that override local gender roles. Considering the strength of tradition and gender roles in Aniksi I suggest that the latter explanation does play a role. There are other ways in which learning disabilities affected gender roles in Aniksi. Where some fathers may have taken on a more female role in the care for the child, the mothers took part in activities traditionally reserved for men. Attending and speaking up at meetings is not something many women are used to, but do now on behalf of their children in the parent meetings.

In relation to people with learning disabilities and gender the following emerged in Aniksi. While in the eyes of some of the mothers, learning disabilities did not influence the traditional expectation of marriage for their daughters; none of the parents of the men mentioned the possibility of marriage. In fact, the mother of one of the men expected him to learn and take on housework responsibilities, which is definitely not in line with local gender role and implies that she did not expect him to marry (As a married man he would not be expected to do housework). In Ffynnon I did not find such obvious links between gender and learning disabilities, this does not mean that there are none.

Both in Aniksi and Ffynnon relationships between some of the children with learning disabilities and their siblings were negatively influenced by the impairment and possibly, the accompanying behaviours in addition to a lack of understanding and/or tolerance towards this challenging behaviour. In addition, parents in Aniksi worried about the effect on the ability of their other children to study at home. This is related to culture and socio-economic structures. Parents in Aniksi place great emphasis on educational achievement, which is seen as guaranteeing a secure future for the child and its parents (who may depend on the child in old age). In both Aniksi and Ffynnon relationships between a child with learning disabilities and their siblings change with their age. As adults, siblings are an important part of the social life of the people attending each of the centres and the relationships are in many cases, a mutual friendship. The centres differences are directly related to social structures and culture. In Aniksi where there is no support, apart from the day centre, for adults with (learning) disabilities, the future care and responsibility for them will lie with their siblings. Concerns and feelings of responsibility form a barrier to reciprocal sibling relationships based on equality and respect.

In both places, the extended family is extremely important in the social life of the families concerned. It usually provides company, general support and social contacts for children and parents. However, there are differences between Aniksi and Ffynnon in the perception of the extended family as a source of support in relation to the care of the disabled child. More parents in Ffynnon received practical support from their extended family and in particular from the grandmothers of the children and less parents complained about the lack of support they received in this way. From this I conclude that culturally in Aniksi extended family is important in the social life but not in actual practical support for its members. However, families in Aniksi do desire this practical support.

The same is true in relation to friends and neighbours. In Aniki reports of close friends and/or neighbours are rare, in keeping with a local culture of keeping yourself to yourself and problems within the (nuclear) family. At the same time, many families that have a child with learning disabilities are unhappy about the lack of 'real' friendships and practical support. This suggests that in Aniksi, having a child with learning disabilities changes expectations and concepts people have of family, friends and neighbours. In Ffynnon, friends and neighbours are already important concepts in the social fabric of the community and they often go that 'extra length' in providing much needed practical help and emotional support.

A final issue in relation to support is the place of residence: village vs. town. Differences in place of residence influences the experiences of learning disabilities for parents. Some parents, in both places found more support in town then in the country because they lived near friends and family and had helpful neighbours. Council estates in Ffynnon were particularly facilitative of community support, but in Aniksi too a couple of parents actually moved into the town to find the support of family and friends. For geographical reasons people living in the country can feel isolated as houses are far from each other and transport may be a problem. This was particularly so for the mothers in Aniksi. In addition, culture may be of influence, with people in the country more likely to keep to themselves. This was reported from Aniksi, but also from one mother in Ffynnon. There are also the consequences for the person with learning disabilities to be considered. No parents living in the country reported that their child with learning disabilities had played outside with other children; whereas at least some people growing up in a housing estate in Ffynnon or in town in Aniksi did have that opportunity.

The difficulties parents in Aniksi and Ffynnon experienced in meeting the extra demands these children placed on the resources of their families related to impairment and behaviour of the child, socio-economic structures and circumstances, and culture. Just as there were differences and similarities between the two societies I have also found differences between families within the same society. There are three possible explanations for this. Firstly, social and economic circumstances as well as norms and values varied between families within the same society. Secondly, differences were influenced by individual characteristics of the person with learning disabilities; supporting the idea that learning disability is not a homogenous category. Thirdly, individual families may each react according to their own interpretation of socio-economic circumstances, cultural norms and values and the demands of their child.

Discussion

Adaptation to and coping with the extra demands on the families is related to individual dynamics of child and other family members, policies and professional practices and is situated in a socio-economic context (Malin, Malthorpe, Race and Wilmot 2000).

Factors that act as facilitators to the inclusion of people with learning disabilities as valued and respected members of their families include:

- Social structures that provide informal support to families in their 'normal' functions through networks of extended families, neighbours and friends
- Social structures that provide formal support to families in their 'normal' functions through effective and sensitive services
- Freedom for the family from immediate financial worries and economic insecurity
- A model of personhood that stresses value of person through social relationships as well as appreciation and acceptance of individuality, diversity and shared humanity
- A view of children and adults with learning disabilities as gradually, not fundamentally different
- A recognition of this gradual difference in the availability of 'normal' institutions with special provisions, in particular in the areas of education, housing and work
- A culture of collective rather than individual care and responsibility where it is normal for family members to be cared for by other members of the community

- Opportunities for people with learning disabilities to develop their own social life and social relationships; to be known and valued as persons in their own right.

Factors that contribute to the experience of learning disabilities as a social problem by families include:

- An emphasises on the importance of nuclear families, expected to take responsibility for all the care and support individual members need
- A low standard of living and in particular economic insecurity
- A model of person- and adulthood that emphasises independence, achievement and economic contribution
- A notion that only families can and should provide long term care for 'weaker' members of society
- An ethos that problems should stay in and be solved by the nuclear family.

The various authors discussed in Chapter One have mentioned many of the above factors. A number of novel and interesting points have also emerged. One of the suggestions discussed in the paragraph on social structures was that small scale societies may provide more support to families and individual members than large scale societies (Edgerton 1970; Zevenbergen 1986). I have shown that this is not necessarily so. Cultural factors such as local norms and values also play a role. These can be so strong that we may find more support within a large-scale society. In addition geographical factors are important. This may be linked to Szivos's discussion on communities (Szivos 1991) (see Chapter Two: Two Centres). I found that in both Aniksi and Ffynnon the practical support came from people living in close proximity of each other. While far away family and friends provided emotional support, it is the helpful neighbour or the mother in law living in with the family who provided the most practical support. It appears then that community in the sense of neighbourhood is more useful to families of persons with learning disabilities than networks of friends and family living far away from each other. In the light of the above the difference between small-scale and large-scale may not be so absolute. Within a large-scale society it is quite possible to have a small-scale community. If we look at inclusion again and at the opportunity to take part in social relationships there appeared to be more scope in a communities or neighbourhoods where people live close together in supportive relationships and where the person with learning disabilities can be known.

That the social problem of learning disabilities for parents does change over time is shown in both places. This is influenced by the availability of and changes in support services and structures, family composition, characteristics and changing abilities of individual parents and the characteristics and abilities of the person with learning disabilities as a developing person. Finally it has been shown that for the majority of parents, 'learning disabilities' is difficult to come to terms with, even when social support is available and positive relationships have been developed.

Chapter Five: Classification

Introduction

In chapter three I have described two different institutions, the Social Activity Centre in Ffynnon and the Centre for Disabled People in Aniksi. In this chapter I will describe and analyse the process by which the people attending the two centres became 'clients', in particular the process of formal classification. I will look at why, when and how classification takes place, the key people involved and what are its short-term and long-term consequences. I will compare the processes of formal classification in both places and identify links with local social and economic structures, norms and values, and concepts of personhood. I will also discuss what role formal classification plays in the exclusion or inclusion of people with learning disabilities in Aniksi and Ffynnon.

Different sociological perspectives offer different explanations and definitions of deviance. These perspectives may be placed on a spectrum according to the assumed location of the cause of deviance. At one end of the spectrum, the medical model locates the cause of deviance within the individual. Deviance thus defined is an individual characteristic, impairment or 'disorder'. At the other end of the spectrum, deviance is explained as being directly related to and explained by the personal characteristics of the person, or society, that does the 'labelling'. Deviant behaviour according to the labelling theory is behaviour that is called (or 'labelled') deviant (Lafaille (1978: 64-65). The statistical model, somewhere in between, describes deviant behaviour as behaviour that deviates from the statistically 'normal' or most common found behaviour in a certain social situation or world (Lafaille 1978).

The vocabulary of deviance is the arsenal of labels available within a society or culture to label someone; this may include terms such as cripple, prostitute, criminal, alcoholic, patient, or indeed person with learning disabilities. Certain institutions and their representatives may have been given authority to investigate, according to certain procedures, if a certain label is appropriate for an individual person and thus provide the person formally with a classification (Lafaille 1978: 68). In the case of learning disabilities this is often called a diagnosis, representing the historical dominance of the medical profession in carrying out this investigative procedure.

There may be a difference between formal classification and the never formally stated notion that a particular person has learning disabilities. My awareness of that difference grew during the research. With the initial focus on the process of formal classification, or, in medical terms, diagnosis of a person as 'intellectually disabled', I interviewed parents looking for information about when and how this diagnosis took place. Formal diagnosis however only takes on real meaning in the social interactions between the classified person and his family, friends and other people within his or her social world. Formal classification can be quite meaningless if not recognised in any way by either the person himself, or by the people he interacts with on a daily basis. By the same token, someone may be seen and treated as a person with learning disabilities, before or even without ever having been formally classified.

Part A: Aniksi

Time and nature of formal classification

Table 5: Time and nature of formal classification - Aniksi

	BIRTH	0 - 1 YEARS	1 – 5 YEARS	PRIMARY SCHOOL	SECONDARY SCHOOL	CENTRE - ANIKSI	TOTAL
Downs Syndrome	2	1					3
Cerebral Palsy			1				1
Meningitis			2				2
Mental Handicap					1	3	4
Mental Handicap & & Epilepsy	1						1
Mental & Physical Handicap	1						1
Psychiatric Problems					3		3
Totals	4	1	3		4	3	15

On one man I had no information in relation to his classification. The interview with this parent was quite difficult and the psychologist did not know if the man had been formally classified before he came to the centre.

Four of the people attending the centre and whose parents I interviewed had been formally diagnosed at birth. This number includes the children with Down's syndrome and those suffering from severe learning- and physical disabilities.

> "We knew from the first day that she had epilepsy. We had to go to the neurologist who told us to come back every six months. We still do." (Mother of a woman (34) suffering from epilepsy and severe learning disabilities)

Not all children with Down's syndrome however, were formally diagnosed at birth. The mother of a young woman (20) with Down's syndrome explains that she did not know until her daughter was eight months old. The local doctor referred the child to a paediatrician who told the mother: "You know your child is mongoloid?" This mother says she had had no specific worries about her child before that time and had not initiated any process of classification.

Three children were diagnosed during early childhood (between the ages of 1 and 5). Two of them had contracted meningitis, which subsequently led to their disabilities. Their parents were told that the illness would probably affect the development of their child. This was confirmed during the period following the illness. One mother explains.

> "She got very ill. High temperatures. I took her to the hospital and she was there for 40 days. After this she was like a doll. She did not do anything. She went to a special school (in Patras/Athens) but didn't learn, nothing, but she slowly recovered." (Mother of woman (35) with mild to moderate learning disabilities)

The third child had suffered from cerebral palsy since birth. For years his mother consulted doctors within Greece before her son was diagnosed in Bulgaria at the age of 5. This is part of her story:

> "When Pavlos was born it was a long and difficult labour. I was in the hospital. He had a lack of oxygen and when he was born he was like a doll. The doctor slapped him but there was not much reaction. I knew something was wrong. He did not do anything until he was 5. The doctors did nothing. When he was 5 I took him to Bulgaria and the doctors helped. He got medication and therapy." (Mother of young man (23) with learning disabilities and cerebral palsy)

No children were formally diagnosed during the primary school years. It appears that on Aniksi a child is either (in)formally classified at an early age and is not sent to the local primary school or it goes to and through school with the other children of its community. This does not mean that these children were perceived as 'no different' than their peers. Both his mother and another parent of a child with learning disabilities perceived Socrates as different and in need of a special service. His mother explains:

> "They both (*her twin children*) went to primary school. But Socrates, he did not do anything. Then the father of Andreas, (one of the workers in the Day Centre for Disabled People) said: "Why do you not send him to the centre?"Socrates stayed at primary school until he was 14. He did not go to secondary school. His parents followed the advice of Andreas' father, and approached the centre where he has been attending since he was 16.

Four children were formally diagnosed after they had left primary school. Three of them have psychiatric problems, which did not fully manifest themselves until their teens.

> "When Aris was small he was always healthy. Never sick. Not even a cold. There was no medication in the house, ever. Only his speech was a problem. We took him to a psychologist in Athens, he said Aris was ok, only his speech. He went to primary school. One day he threw the books of the boy sitting beside him on the floor. Why? I tell you. Because he was better in class (*than Aris*). Many things happened after that. He had an accident with the motorbike. Between 17 and 18 he developed shock reactions. He was very bad then." (Mother of young man with psychiatric problems (22) and mild learning disabilities)

The parents of this boy too had an awareness of their son being 'different' ahead of the formal diagnosis. The mother of Tassos was the only parent who did not report any concern, or awareness of 'difference' about her son prior to this time. Tassos has psychiatric problems that did not manifest themselves until he was at secondary school.

> "There were no problems in primary school or at the start of secondary school. After his second year in secondary school the suddenly did not want to go anymore. Than, at 15, we had a big crisis. He was very, very strange. We went to Athens. And Patras. We went to psychiatric and medical institutions. After two years he was getting better. He could go to the special school in Patras, but he does not like it outside Aniksi." (Mother of man (36) with psychiatric problems and learning disabilities)

The fourth child diagnosed in her teens was severely handicapped and recognised as such by her parents from an early age. She did not go to school. Despite parents' efforts to find out what was wrong with their child, she was not formally diagnosed until the age of 16.

> "When she was one year old we knew there was something wrong. We were living here and took her to the doctor here. Also to Athens. All the time. Later, we moved to Athens. Again we saw many doctors, but nothing. They said that she would be fine later. When she was 16 they told me that she was mentally handicapped. At 16! That she was 4 years old mentally."(Mother of a severely disabled woman (35)

Finally, three people were never formally diagnosed until they applied for admission to the centre. This included the aforementioned Socrates and his sister Athina. While the parents had perceived Socrates as different, they did not view Athina as such. She only came to the centre to accompany her brother. The psychologist there however diagnosed her as having mild learning disabilities. Tassos (19) had not finished primary school and had been taken by his parents to Athens for help and treatment, without much success. After experiencing difficulties in his work and social environment he came to the centre where the psychologist diagnosed him as having moderate learning disabilities (see also Chapter Seven: Individuals Lives).

Agents of formal classification

Table 6: Agents of formal classification-Aniksi

Doctors/Consultants - Athens	**4**
Neurologists – Athens/Bulgaria	**4**
Psychiatrist - Athens	**2**
Local doctor	**2**
Psychologist – Day Centre	**3**
No information	**1**

In Aniksi it is mainly representatives from the medical profession that make the official diagnosis (twelve children). The medical model of classification locates the problem within the individual (van Gennep 1980, Ingstad and Whyte 1995, Jenkins 1998; Oliver 1990). The psychologist at the centre diagnosed the other three people; according to statistical criteria (Lafaille 1978). Although 13 families lived on the island at the time of diagnosis, doctors in Athens and even Bulgaria made the majority (10 out of 15) of diagnoses.

Immediate consequences of formal classification

Table 7: Consequences of formal classification- Aniksi

Treatment including medication (in Bulgaria)	1
Therapy (Athens)	3
Referral to psychiatric hospital (Athens) or psychologist (local)	1
Medication and regular check ups by neurologist	2
Nothing	8
No info	1
Total	16

Conflicts may arise before and around the time of formal classification. These were mostly related to discrepancies between parental expectations of the consequences of diagnosis and what happened (or did not happen) in reality. Parents expected advice and practical support; at the most their child was offered medication and/or regular medical check ups (see also Chapter Four: Parents' Stories and next paragraph: Parental reactions to formal classification) The only special service for people with learning disabilities on the island (the Centre for Disabled people) has only become available recently and has a minimum admission age of 16.

Parental reactions to formal classification

In Aniksi I found four different parental actions and reactions around the formal classification of their child.

First, parents may accept an un-sought diagnosis as a fact of life they have to come to terms with (six). This reaction was mostly found with the parents of the children diagnosed at birth or shortly after and with two parents who had already perceived their child as different but had not looked for a formal classification.

Second, parents may accept the diagnosis but not the predicted consequences (two):

> One father, and indeed the whole family, could not accept the predictions made when his son (19) was diagnosed with Down's syndrome. The sister of this boy explains: "At 40 days the doctor said that he would die. That he would not do anything. We took him home and my father did everything for him. We had one room in the house for Antonio Exercises. Swimming everyday. Playing. We taught him everything." When Antonio got older the whole family moved to Greece in the hope of finding a special school.
>
> Maria has mild learning disabilities after contracting meningitis during childhood. While her parents recognise her difficulties they do not feel that she needs the centre and they plan to take her out soon. Her mother hopes that one day she will marry and does not view her disabilities as an obstacle to that.

Third, parents may deny or disagree with the diagnosis (one):

> Athina was diagnosed as having mild learning disabilities when she started to attend the centre (with her twin brother). Her parents do not agree with her formal classification as having learning disabilities. They insist that she is there just to mind her brother and that soon she will marry. This has led to a conflict with the centre manager and psychologist who feels that Athina should stay at the centre where she has learned to weave carpets and thoroughly enjoys her work and the contact with the other people at the centre.

Finally, and this is the largest group, nine parents actively sought a diagnosis as: an explanation of the perceived delay in their child's development or of their different behaviour; a way to formal support, appropriate placement, treatment or even a cure. These parents accepted the confirmation of their suspicions but at least half of them felt frustrated with the length of time it took to get a diagnosis and with the lack of support afterwards.

> "After years of bringing her up and down to the medical centre the doctor told us they could not do anything for her, they said: we cannot do anything for her". (Mother of a woman (22) whose learning disabilities resulted from meningitis)

Grief is often mentioned in the literature (Janssen 1982; Verstegen 1978) as a common parental emotion to a child's classification as having learning disabilities. Only one of the mothers in Aniksi described how she grieved when she was told that her son had Down's syndrome.

> "He was born here in the hospital. I was scared of the doctors here. After three days he was all yellow. We went to Athens for 3 days. He was fine. Then, the blood was good. The blood did not need to be changed. But the doctor said: 'He is not right. He has Down's syndrome.' I cried and cried so much. And my husband, he cried." (Mother of young man (24) with Down's syndrome and learning disabilities)

This mother was originally from Athens. She described herself as being different from the other women in Aniksi in that she wanted to talk about her problems. This suggests that maybe other women did experience grief but were not comfortable with talking about such personal matters.

Part B: Ffynnon

Time and nature of formal classification

Table 8: Time and Nature of Formal Classification - Ffynnon

	Birth	0 – 1 YEARS	1 – 5 YEARS	PRIMARY SCHOOL	SECONDARY SCHOOL	TOTAL
Down's Syndrome	1	2	2			5
Learning Disabilities after Meningitis or Childhood Fever		1	1			2
Learning Disabilities Unknown Cause			1	2		3
Learning Disabilities due to Brain Haemorrhage			1			1
Combined Learning/Physical Disabilities	2	1				3
Learning Disabilities and Psych. problems					3	3
Total	3	4	5	2	3	17

Three of the people attending the centre in Ffynnon and whose parents I interviewed were formally classified at birth. The following two mothers each had their children in hospital. Within days they were told that their children had Down's syndrome and Cerebral Palsy respectively:

> "She had two cockle shells ears – I sensed straight away there was something wrong. The doctor wanted to see both of us together but because of the holiday time he got stuck in traffic and the doctor had to explain it to me on my own. She was three days old."
> (Mother of woman (42) with Downs's syndrome and learning disabilities)

> "When he was born he had 6 toes and 6 fingers. The doctor said he was part of a twin that is why he had 6 fingers and toes and an extra tongue."
> (Mother of a man (33) with Cerebral Palsy and severe learning disabilities)

Four parents were told long well after the birth but before the child's first birthday. Although these children were not formally classified at first, the parents of three of them did have a suspicion that 'something was not quite right'.

> "They did not tell me (at birth). When I went to the clinic later, then the doctor told me. He told me: "We usually give the mothers three months, to get over the confinement." I was upset of course. But I could see it before that. I used to ask the nurse was she blind. She would not follow things with her eyes. And she was a slow feeder. When I knew she was retarded they told me: "Oh, they don't have a large span of life. Maybe 24 or 26 years." And look at her now, she is 42." (Mother of woman with Down's syndrome and moderate learning disabilities)

> "I thought she was deaf. I kept going back to the clinic, something was wrong. When she was six months old someone *(a health visitor?)* came up here. She said, 'you know she is backward'. Just like that. I had never seen a Down's before. I had no experience, I was 20." (Mother of woman with Down's syndrome and mild learning disabilities)

> Mother: "I had toxaemia and high blood pressure. I was in the hospital and they brought the labour on 3 weeks early. He was 5lbs and put in special care. They wanted to christen him then. We knew there was something wrong. When we brought him home the sister said, if you see something wrong, bring him back. I was going to the clinic after. When he was 8 months he wasn't sitting up."
> Father: "Nobody said anything."
> Mother: "Except: 'bring him back if there is anything wrong.' We knew then. After 7 or 8 months we knew for definite. I would have liked to know what had gone wrong. Next time I see him I will ask doctor W. (*G.P*)
> Sylvia: "Did you ever ask someone?"
> Mother: "No." (Parents of a man (33) with severe cerebral palsy and moderate learning disabilities)

The fourth child only developed symptoms in the second half of her first year.

> "She was beautiful up to 6 months. Then she started vomiting. The doctor said some glands in her head hadn't started working. Well, they never did."
> (Mother of woman (33) with moderate learning disabilities)

Five children were diagnosed during early childhood, between 1 and 5 years of age.

> "I did not know until he was nearly 6. My mother took him to the surgery and the doctor told her he was three years behind; that he was mentally handicapped. I had so much work with him. In the summer it was ok. I used to board up the garden and he would be out with his toys. He kept running away. I couldn't take him for walks with his sister in the pram; he would run away. Also, he had terrible trouble with his chest, asthma, from when he was 2 ½. I didn't have any suspicion. He was a busy child; I thought he was just naughty. He was my first baby, well, I didn't know." "He had almond shape eyes, that is how you know apparently, that's what the doctor said later. I should have known. But I did not notice his almond shaped eyes."
> (Mother of a man (32) with moderate learning disabilities)

This mother had noticed that her child was very active and 'naughty' but had not made a connection with learning disabilities, or 'mental handicap' as it was called at that time. She did however feel that he was 'different'; she allowed her mother to take him to the doctor and did not dispute nor doubt the diagnosis once it was given. In fact, she has wondered since, should she have noticed it earlier? This mother accepted the authority of the medical doctor in the 'diagnosis' of learning disabilities; even if she had not interpreted her child's behaviour as such before.

Interestingly, two of the children diagnosed between the ages of 1 and 5 suffer from Down's syndrome. As this is a condition, which has fairly clear physical features, it would be easy to assume that the parents knew before the diagnosis. Some parents however chose, consciously or unconsciously, to ignore the indications. They did however feel that something was 'wrong'.

> "When he was 9 ½ months old, he had 40 fits in 10 days. The doctors said that if he had been normal we would have lost him. When he was 15 months old I saw the child specialist. That's when they told me he was a mongol. That's how they used to call them before you know. I did think there was something wrong, and I didn't. I did not know what it was. The doctor (G.P.) had said before that he was backwards. That he would never be in grammar school like his brothers and sisters." (Mother of man (42) with Down's syndrome and moderate learning disabilities)

> "We weren't told until about 3 years later. We thought something was wrong, but we were putting off the evil day, hoping against hope. At 3 we took him to the clinic. There they gave us the news." (Father of man (44) with Down's syndrome and mild-moderate learning disabilities)

Two of the children diagnosed between the ages of one and five were diagnosed on the basis of symptoms developed after a major illness, such as meningitis or a brain haemorrhage.

> "At 9 months he had meningitis. He was dying. He was ill for 2 months. The doctor said: 'leave him go. If he comes out of that there will be something wrong.' We had to get another pram. He could not do anything. My husband and I read a lot. At 3 ½ we took him to a psychologist. He said that he had a bit of brain damage, a scar he called it. The psychologist said he was going to be scarred. He did not have a lot of speech. They found out at school then that he was educational subnormal, but he could learn." (Mother of man with learning disabilities)

> "She had two brain haemorrhages. The second one at 5 ½. She never went back to school. The man from Education, he said she could not be educated anywhere in the country." (Father of a woman (38) who was left with moderate learning disabilities after 2 brain haemorrhages)

Two children were formally classified during the primary school years.

> "There were problems in school. The headmaster did not want to keep him in. He sent us to the clinical psychologist in the Education Board. He said he dealt more with behavioural problems. He did nothing. My local Councillor helped me. She referred me to this doctor within the Health Authority. He suggested David was a candidate for H. G. (Junior Trainings Centre). He was slow in talking, but the Health Visitor had suggested to let him go to school first." (Mother of man (32) with mild learning disabilities)

> "Before we realised was mentally retarded she was about ten. When she was born she did not cry for hours. She was slow in walking, nearly two, and slow to sit up. No talking. That's why she went to school early. In school

> they gave me a report with nothing on it. She didn't do anything. We took her for an I.Q. test; she was ten. It said we couldn't expect over a higher level than a 10-year-old. I went to the doctor to ask when she would catch up. They did a brain scan and everything." (Mother of woman (33) with mild learning disabilities)

The above children were perceived by their parents as being slow, but did not pose such a problem to parents that they looked for help and/or formal classification, until they went to school. Complaints from the headmaster about their son's behaviour difficulties, and an empty report card implying that their daughter was not learning anything in school led to these parents seeking formal classification.

Two people were diagnosed during their years at secondary school. Both of them had a psychiatric illness that manifested itself at the onset of adolescence. Ellen is one of these people:

> "We were on holidays when she got ill. Hallucinating. The psychiatrist came out. He felt she was too young to go into hospital; that it would pass. A year later he asked could he admit her to the hospital. She was diagnosed as schizophrenic."(Mother of woman (40) suffering from psychiatric illness and moderate learning disabilities)

Only one person went through secondary school without diagnosis:

> Bernard (28) has psychiatric problems as well as learning disabilities. His mother feels it is a disadvantage that her son was not formally diagnosed until his admission to the centre: "When he was in remedial class at secondary school they suggested The Primrose (special education school). We knew he was slow, but we did not really know that he was different until he was 16"."Dora and Connor (the other children) did not really have a lot of time for him. No one ever said that he was handicapped so we never sat down with the other children and said this and this is the case. They always expected more of him." (Mother of a man with mild learning disabilities and psychiatric problems)

Agents of formal classification

Table 9: Agents of Formal Classification-Ffynnon

Consultant / Paediatrician	5
Local G.P.	4
Psychiatrist	3
Health Visitor	1
Psychologist	4
Total	17

Representatives of the medical profession formally classified the majority of the people whose parents I interviewed in Ffynnon (thirteen out of seventeen). Psychologists applied statistical criteria for some (four) of those who had started school at the time of classification. Classification usually takes place at the local hospital or health centre. One family did travel to London but this was to get a second opinion (which turned out similar to the diagnosis made locally).

Immediate consequences of formal classification

For ten of the people in Ffynnon formal diagnosis did not have any direct consequences, except for the provision of physiotherapy for two children with cerebral palsy. In fact, one of the mothers was told by the diagnosing doctor, 'not to treat her any different than her other children'. Those diagnosed before their fifth birthday did however go to a special school once they reached school age. This was then followed by special services provided by the Department of Social Services.

For four children referral to a special school was the direct result of formal diagnosis. This was not always an easy and straightforward and process and, if it involved a residential special school, not always wished for by the parents, as the following example shows:

> "The Spastic Society came here from Cardiff. They would not accept him in Cardiff, his I.Q. was not good enough to go there. He could go under the Spastic Society in Cambridge. They were building a school there, it was not even finished and the waiting list was three years!! We did not want him to go away. So the doctor in Ffynnon said to take him to the Junior Training Centre for a three weeks trial. After that they had a big meeting and he has been there ever since."(Mother of a man (38) with cerebral palsy and learning disabilities)

Three people (all with psychiatric problems) received medication after diagnosis as well as a referral to the Social Activity Centre.

Thus, for the majority of the people whose parents I interviewed in Fynnon, formal classification meant special education, followed by a special adult service. This was, however, not an automatic result of the formal classification itself. Parents play an important role too. The majority wanted and actively sought classification and appropriate placement for their child in a special school/service (see also Chapter Four: Parents' Stories).

Parental reaction to formal classification

No parents I interviewed in Ffynnon had contested the formal classification of their child. In fact, apart from the parents of those children diagnosed at birth, only one set of parents in Ffynnon said they had no idea and were shocked to hear their child was mentally handicapped. These parents had realised and accepted that their child was 'slow' but to have this slowness put in the context of 'learning disabilities' or 'mental handicap' shocked them deeply. The other parents all had an awareness of their child being 'different'; they thought their child to be slow, deaf or learning disabled. However, formal diagnosis still evoked a feeling of shock. Seven parents actually used this word to describe their reaction to the news.

> "We had suspicions. Slow. His behaviour. But it was still a shock, how the doctor said it." (Mother of a man (44) with moderate learning disabilities)

> "We were worried before and had asked the health visitor, but it was still a shock, because she was the only girl in the family. Also the doctor said they did not have a long life span." (Mother of woman (42) with Down's syndrome)

These shock reactions imply that formal classification as having learning disabilities is perceived as more than just the fact of a child being 'slow'. They imply that 'learning disabilities' or 'Down's syndrome' are labels that have wider implications and negative connotations than the impairment itself, and that norms and values do play a role in many parents' reactions.

Part C: Comparison and Discussion

Classification and learning disabilities in context

The majority of the people attending the Centre for Disabled People in Aniksi and the Social Activity Centre in Ffynnon have been formally classified before their fifth birthday or before the child reaches school age. Representatives of the medical profession usually carry out this classification. This is not surprising considering the fact that most of these people have a physically identifiable syndrome such as Down's syndrome, cerebral palsy or have learning disabilities as a result of meningitis or childhood fever. This makes the majority of people at both centres consistent with the supposedly minority group of people whose learning disabilities are related to a visible syndrome or physical condition (Jenkins 1998; Ingalls 1978)

In both places I have found some people with psychiatric problems who were also diagnosed according to medical criteria. This happened during their teens, the time when their difficulties became most obvious and expressed themselves in significant behaviour changes. Interestingly, all but one of these people had already been perceived as 'different' or 'slow' by their parents prior to this time, suggesting that they did suffer from some degree of learning disabilities. This on its own however had not led parents or teachers to seek formal classification.

One of the differences between the two places is the treatment of a few people who appear to have learning disabilities that went un-noticed or un-reported until school age. In Aniksi these children attended school without being formally classified, or dropped out after primary school. Formal classification for them was part of the process of admission to the centre. In Ffynnon they were classified during their time at primary school. While it may be tempting to suggest that in Aniksi these children are included in regular education, not classified and not noticed in a more simple society while excluded in Ffynnon, this does not appear to be quite true. In Aniksi these children were perceived as different in school, and, similar to their counter parts in Ffynnon reported as 'not doing anything' or 'not learning anything'. In addition and with the exception of one girl in Aniksi, formal classification of these children at a later stage was not contested. The difference between the two places seems thus rather to be found in differences in particular elements of social structures and culture.

Firstly, the structure of the education structure in Aniksi at the time of research meant that no special education was available on the island. There is more incentive for teachers and parents to keep a child in regular school if no special education is available and less reason to seek formal classification at that stage. Secondly, and related to the above, it is not easy for parents in Aniksi to seek help in what they perceive as family matters. When a child is obviously impaired parents may accept and/or seek classification early in the hope to find a medical explanation, and help for their child's difficulties. When difficulties only show up during the school years, and no alternative is available, cultural barriers may outweigh incentives for seeking formal classification.

In addition to the above-described differences between the two places and the link with social structures and culture, there is an interesting similarity. In both Aniksi and Ffynnon there are children, formally classified as having learning disabilities, to which a place in the 'regular' education system is denied. That this is at least partly influenced by norms and values is shown by the fact that the majority of children diagnosed before the age of five *never* went to regular school. They were excluded from education by parents who decided not to send them, or by the school that did not accept them.

For both groups diagnosed before the age of five, there were no *immediate* consequences except for medical intervention in relation to a possible physical condition. A difference between Aniksi and Ffynnon is found in the long-term consequences of formal classification for these children. In Aniksi they never went to school. In Ffynnon they went to special schools (run by the Department of Education) or Junior Training Centre (under management of Social Services) for those that were deemed 'un-educable' (as reported in the files of the children concerned). (This Junior

Training Centre has since been discontinued; all children are now expected to follow 'education', either in regular or in special school.)

The classification of learning disabilities may evoke feelings of shock and grief for parents in both places. That they were expressed most openly and frequently in Ffynnon may be due to a difference in culture rather than a difference in parent's feelings.

Classification and inclusion

While this title may sound contradictory it brings me immediately to two important points arising from this chapter as well as from the chapter based on the parents' stories. An important function of formal classification in both Aniksi and Ffynnon was 1) to provide an explanation of the child's behaviour or difficulties 2) the access of special services. This is clear from the classification process in which parents play and active role, and shows how classification de facto could contribute to inclusion, providing it leads to the desired consequences of 'appropriate' special services (see also Chapter Four: Parents' Stories). The relationship between classification and access of services that would otherwise not have been available was also reported from the United States by Angrosino (1998).

The formal classification of the people attending the centres in Aniksi and Ffynnon as having learning disabilities was the product of an interaction process between child, parents and professionals. Parents contributed to the process of classification when they accepted a medical diagnosis without discussion and treated the child accordingly; or when they actively sought formal classification because they perceived their child as different (and thus have already made some kind of informal classification). Parents may seek formal classification as a way to explain certain aspects of their child's behaviour or development or as a way of seeking support. They are often frustrated in these expectations (see also Chapter Four: The Parents' Stories).

Formal and informal classification are related but not necessarily similar and may even be contradictive, when 'authorized' and 'lay' people have different views on the classification of a particular individual.

Classification in both places was of a medical or statistical nature. There are people in both places for whom classification appears to be largely related to their individual characteristics or impairment. However, social structures and cultural norms and values also influenced when and where classification took place; in particular the structure of the health service, the existence of special services and elements of shame and pride. The emotional response of parents to this classification, including grief, is at least partly informed by norms, values and expectations in relation to the birth of a child and what they expect their child is and will be. The existence of special services influences the long-term consequences of formal classification. Norms and values play a role too, in relation to the place of children with learning disabilities in the local education system. Special services for children and adults with learning disabilities contributed to the formal classification of learning disabilities but did not necessarily create the informal existence of the category. The latter is often already present in the perception of others, in particular parents and teachers.

CHAPTER SIX: A QUESTION OF WORK

Introduction and definitions: What is work?

Work is one of the main adult activities, of great value to the individual as well as to society as a whole. Work, in its widest sense, is a basic condition of the existence and continuation of human life, it is independent of any particular form of society (Parker 1983). The fact that work is important, indeed necessary (even if only to secure human survival and reproduction) does not mean that it takes the same form or has the same meaning in every society. 'Work' is not a straightforward category. What is understood by work and how it is valued is not self evident, but culturally and historically constructed. The value attached to work has not always and everywhere been positive. In Western societies people of high social status have often looked down upon work, in particular manual labour, as the lowest and least of human activities. The widespread influence of nation-building ideologies, with their emphases on the virtues of work, and the introduction of mechanised production that made new forms of social discipline necessary, resulted eventually in the belief that people actually need to work (Sayers 1980: 734). Socialism, as well as capitalism, is based on the importance to the human individual of productive labour. Organisational structures, definitions and the values attached to work are interrelated. The literature on work offers a number of different definitions of work. Most of these reflect different types of social organisation.

A distinction may be made between the basic activity of work, and work as occupation and employment. The Oxford English Dictionary defines work as an "activity involving mental or physical effort done in order to achieve something"

(2002:1647). In an economic sense, "work refers to activities orientated to producing goods and services for one's own use or for pay" (Borgatta and Borgatta 1992: 2253). An occupation is "an economic role, separated from household activity as a result of the growth of markets for labour" (Marshall, 1998: 457). Within an occupation work is socially structured, recognised and valued in particular ways. Employment, which implies an employer, employee, pay and specific conditions of work, is one's organisationally defined role within an economic system (Harding and Jenkins 1989). Employment is essentially a contractual relationship, not to be equated with the actual performance of work (Parker 1983: 32). Work in modern, western society however, is often equated with employment: not to be employed is taken as the same thing as not performing work. Employment is not only a narrow definition of work; it is also a relatively new one. It was only in the late eighteenth and nineteenth centuries that the modern western world saw the rise of the male breadwinner in employment, as opposed to the household production and economic strategies of pre-industrial times (Pahl 1988). This structure of work did not take over all the work within society, but the proportion of people still working in traditional structures such as farmers and fishermen have become fewer and fewer, and even these categories of fishing and agriculture did not stay unchanged. The narrower the definition of work, the more sensitive it will be to cultural and historical influences and the more activities fall outside the category. An example of this is housework. Once seen as important work, carried out by a complete household, it became an activity that was 'outside' the economy, and the people responsible for it became the 'non-working' housewives.

A common notion about people with learning disabilities is that they do not, and /or are unable to, work. It is not as simple as this. Whether people are able – 'competent' – to work depends as much on the social definition, form and structure of work as on the abilities of the individual. Thus we can imagine someone with mild learning disabilities working within a simple employment situation, or someone with a moderate learning disability helping his father on the farm.

In this chapter I look at two questions. First, do the people with learning disabilities who attend the Day Centres in Aniksi and Ffynnon work or not? Second, is there a relationship between the answer to that first question and local structures and values? These issues require a definition of work. The form and meaning of work varies between and within societies, suggesting that no universal definition of work is possible and that comparison is difficult. Wallman's framework (1989:20) offers a solution to this dilemma:

> Work is the production, management and conversion of the resources necessary to livelihood....These resources are identified as: land, labour and capital, time, information and identity. Each resource may be assessed in terms of its economic, social or personal value and that resource value is by no means a measure only of utility or material worth.

Work thus described is a process, with various aspects or dimensions. Cultural differences do not change these basic aspects, only the way they relate to each other. It is in the form and emphasis of the relationships between the aspects of work that local structures and values become more apparent. For example, Wallman (ibid:4) defines work as involving the application of human energy to things, within a structure of time and place. It is thus important to know not only what is done but where and when. For example, weeding the school garden at ten o'clock in a Wednesday morning will probably be more valued as work then picking flowers in one's own garden on a Sunday afternoon.

Work is not done for its own sake; there are economic, social and personal incentives (Wallman ibid: 4-6). The most obvious incentive for work is sustenance; humans need to work to keep themselves alive. For some authors this is what makes work 'a general category of economically orientated transformative activity' (Harding and Jenkins 1989: 12), done "to meet the real needs of the most basic kind" (Sayers 1988: 723). Within each society work is necessary to ensure the survival and reproduction of its members, whether directly – hunting, gathering, farming, caring etc. and/or indirectly by earning a wage. However, there is more to work than material reward. Work is also seen as 'man's "calling", his craft, his means of self expression' (Ronco and Peatty 1988: 716), the way to self development and fulfilment, necessary for self esteem, identity and a sense of order. These are the personal incentives. Closely related to the personal are the social incentives. Identity gives a sense of self, but always in relation to the other. The social incentives for work vary from interaction with fellow workers, to relations with society at large, to status and social identity (Sayers 1988).

The economic, personal and social incentives to work, and its nature and structure, are the dimensions along which I will compare the activities of the people with learning disabilities in the centres on Aniksi and in Ffynnon. Ultimately, the question is whether people with learning disabilities can be said to 'work' in the society in which they live.

Part A: Aniksi

Nature and structure of work

> "I work here. Making blankets I do. It is nice here. I work here" (woman (32) with severe learning disabilities, epilepsy and psychiatric problems who spends most of her time at the centre knitting)

> "I work. I work with Frieda, I make carpets." (Woman (35) with mild learning disabilities)

> "To work. I work and talk with Dimitris (psychologist). I make flowers and portfolios (purses). (Man (26) with mild learning disabilities and psychiatric problems)

When I asked the people attending the centre in Aniksi why they came, they nearly all said, "Work", "To go to work", "To do work". When asked, "What do you do here?", the answer again was, "Work".

> "I like it here. I write my name with the teacher. I listen to music. Also, I work. I make kolimbi (beadstrings). Also, I talk to Maria (teacher)." (Young man (19) with moderate learning disabilities)

I asked Tassos (24), who has mild learning disabilities and psychiatric problems, why he was at the centre. He answered: "Because I have no job." When asked what he did there he tells me: "I work with copper. I like it. I learned it from my teacher."

The official purpose of the centre in Aniksi is to teach clients a skill, to give them the prospect of earning a living on the island in work that is appropriate for the area. In Anikis this means the production of things that can be sold as craft objects or souvenirs, mainly to tourists. The centre's purpose – to teach skills that can be used to earn money – is reflected in the main activities such as: working with leather (making wallets, diaries, folders for letters etc.) needle work (cushion covers, tablecloths, scarves); decorating wooden and metal pictures, and rug and carpet weaving. Literacy, numeracy and sports depend on individual and voluntary initiatives and are not a part of the official programme. Social activities outside the centre are special outings, similar to a day out or a holiday as opposed to part of a special programme.

With regard to the structure of time, the day starts early; the bus that collects everyone leaves before 7.30 a.m. After lunch, the centre closes and the people go home to rest and spend time with their families. This corresponds with many a working day on Aniksi where, in the summer, the afternoons are too hot to work. During the day at the centre, the clients work at their own speed and are allowed to do just that. There is little interference by the teachers, and no instructions or encouragement to work harder. The exception to the latter is the instructor in the carpet-weaving workshop. She likes to remind people that they come to the centre to do something:

> "It is nine o'clock now. You are supposed to work by now. If you do only one row a day it will take you two years to make a carpet. If you do four or five rows, it might be finished in six months or so."

Structure also includes structure in space. Leisure activities organised by the staff take place outside of the centre, including sport and trips away. Sports take place outside, in the grounds or in the stadium. Outings are around or away from the island. Both are completely separate from work. This structuring of activity, in terms of place, is comparable to elsewhere in Aniksi. Work within the centre is carried out in three large rooms, each devoted to particular activities. Clients spend most of their day in 'their' room doing their own 'work'. However, people are allowed to wander about to a degree. Only in the carpet making room did I witness people being sent out, back to their own room. It is routine for people to move around and have a chat here and there. Sometimes they try a different activity, often helped by other clients as the following extract from my field notes illustrates:

> Antonio, normally based in the large room where he strings beads, walks into the middle room. Tassos is there, working with copper. Antonio watches him. Tassos, without saying anything, shows him how to do it. Antonio wants to try and Tassos holds his hand, guiding him. Finally Antonio, concentrating, does it on his own. Suddenly he gets up and leaves. Tassos calls after him, but Antonio does not come back.

Help is offered when asked for in the middle room and routinely at one table in the large room (needle work). Like her colleague Frieda in the carpet room, instructor Soula often works together with 'her' girls:

> Frieda is setting up a new carpet. She tells Manos to come over and to start working. After a few minutes, Frieda takes over from Manos again, to show him how to do the flower pattern: "Ella (here you are)." Mano gets on with it. Now and again Frieda takes over or works beside him.

Soula is helping Eftemia with a wool collage for the wall. Soula glues the background while Eftemia sticks on the wool.

At the other table in the large room, clients do very little; their ability to work, and their teacher's ability and motivation to stimulate them is limited.

> Helena (32), a woman with severe learning disabilities and psychiatric problems usually brings her knitting in a bag. Sometimes she does not take it out at all, only very occasionally someone (one of the 'teachers') encourages her to do so. When she knits she knits very tightly but she makes few mistakes. When her wool is finished and needs changing she asks me to do it or brings it home to her mother. I have not seen anyone at the centre helping her.

> Nadia, a young woman (24) with severe learning disabilities brings a bag with colouring books and some embroidery. She too is left completely to herself, she will sit at the table with the books in front of her (after taking them out of the bag herself) occasionally scribbling in them or doing a bit of embroidery which usually ends up in large knots.

> Tassos (19), Sakis (21), Theo (26) and Nikos (24) are making plastic flowers. They seem to know the procedure themselves. Theo usually takes out the materials. The others work when they feel like it. They often stop the walk around and talk or joke with the others, even go to the other rooms. No one interfere much with them, the 'teachers' sit at the head of the table, talking together or joking with the clients, occasionally telling them to 'get on with it'.

Although people are generally left to function at their own speed, and are often slow, there is a productive element in what they are doing. This is also the way they see it themselves. They show off their work if one shows interest; they seem to enjoy what they are doing, and are proud of the results. This is as true for the relatively able man who makes leather purses, more or less without help, as for the girl who scribbles away in her exercise book. There is room for freedom; for the individual client to switch activity now and again; to work at his or her own speed, when he or she wants; freedom for a walk and a chat. On the other hand, this means that there is little encouragement to do better; there is little expectation, or indeed 'teaching' on the part of the staff.

Economic aspects of work

Examining the links between work done at the centre and the rest of society on Aniksi, reveals some interesting points. For example, the products made in the centre and sold twice a year during an exhibition are bought by visitors, tourists and families of the clients. This, of course, is not strange on an island where the main source of income is tourism. The money this brings in goes back into the centre for outings, day trips and holidays.

People attending the centre receive regular 'pay' in addition to a small monthly welfare payment payable to all 'disabled' people. This 'pay' is not all paid by Greek society; a large part of it comes from E.C. funds. The amount is not enough to give people attending the centre economic independence, but at about 50 pounds a month it is more than pocket money, especially considering that they work part-time (only mornings) and receive free breakfast and dinner. For the purpose of comparison, a staff member at the centre earns about 200 pounds a month.

A number of people (five) also work outside the centre; they help their parents in the vegetable store or woodwork shop, or hold part-time jobs in hotels or restaurants. This is what three of them told me:

> Sakis: "In the afternoon.....I go to the shop. My father makes doors, windows and tables. I help him. In the afternoon and when he is busy
> Sylvia: Do you get paid?
> Sakis: "Every few days."
> Sylvia: "How much?"
> Sakis: "Different every day. I buy drinks and when I go out"
> (Young man (21) with mild learning disabilities and psychiatric problems)
>
> "I work in the hotel. My uncles hotel. Every afternoon. I make the beds. I earn 20.000 drs. and 15.000 drs. (per month) I put the money in a box under my bed, locked." (Man (26) with moderate learning disabilities)
>
> Vasilis: "I am a garcon (waiter) in my village. In my friend's taverna. Every night from 9-1pm."
> Sylvia: "Do you get any money for that?"
> Vasilis: "1000 drs. a night. I put the money I get in O.D.A.Z. in the post office."
> (A young man (19) with mild learning disabilities)

A few people (four) do not work outside the centre now but did so in the past. This is what two of them have to say:

> "I went to Athens (from Aniksi) to work in a shop. For my uncle. Tiropetes (cheese pies) etc. I liked it a lot, easy work, many people. The shop closed. I came back to Aniksi." (Man (21) with mild learning disabilities and psychiatric problems)
>
> Manos also lived in Athens. "In Athens, I worked in an office. I put stamps on envelopes. Here (in Aniksi) I work at home and in the garden. I love gardening but here in town we do not have one." (Man (36) with mild learning disabilities and psychiatric problems)

An economic link with the future exists in the aim of the centre: to teach working skills appropriate to the area with a view for people to move on and find work in the local community. Since the centre has been open, six people have moved on to work or employment outside the centre. Only two have found craft-related work; the others are providing services for tourists within hotels, tourist information, or working in a kiosk (a small shop selling newspapers, sweets, cigarettes etc., to be found on nearly every street corner in Aniksi).

> When I asked Vasilis, a young man (19) with mild learning disabilities what he liked best at the centre he answered: "my work, I like my work, making (plastic) flowers with Maria." He also has a job in a taverna outside the centre. Vasilis tells me he puts the money he earns for both these jobs in a post office account.

Vasilis considers both kinds of activities, at the centre as well as at the taverna as work. This illustrates that the activities carried out by the people attending the centre fit in well with the work carried out by other adults in Aniksi. On the island few people have only one well-defined job. The majority of jobs available need no qualifications, application or interview; they are often advertised by word of mouth; they may be created by other members of the family. The economic situation for people with learning disabilities is poor, even if they work in the centre and have a job on the side. But they are not the only ones in that situation. Full-time, regular paid jobs are scarce, many people are more or less unemployed, and there is no unemployment benefit. Money is a big worry for most people in Aniksi. Economic dependency on the family is high, for people with learning disabilities and for 'ordinary' people.

Social aspects of work

The social aspect of working in the centre in Aniksi is important; 'meeting' and 'making friends' were the other main reasons that clients gave for attending the centre. For many people this was the first place outside their homes that they had visited regularly. It is a place where they are accepted as they are, and where some attempt is made to meet their particular needs. Most had spent their days at home before coming to the centre, or attended ordinary schools without ever having been able to keep up with their peers. This is what three mothers told me:

> Sylvia: "Did Yannis to school?"
> Mother: "No. At one time we sent him to an institution in Patras. But he did not like it and we took him home." (Mother of a young (22) man with mild learning disabilities and psychiatric problems)
>
> Sylvia: "Did Andrea go to school?"
> Mother: "It was no good. She did not learn. The teacher, she had a private teacher."
> Sylvia: "At home?"
> Mother: "No. The other children wanted to write, to study. Andrea went to the teacher's house. The psychologist said she wouldn't learn very well." (Mother of a young woman (22) with mild learning disabilities as a result of having had meningitis as a child)
>
> Sylvia: "When Eftemia was small, did she play with other children?"
> Mother: "No. She did not understand. The others went to school. She was too weak because of her heart condition."
> Sylvia: "Did she play with other children at home?"
> Mother: "The others were out. Played outside. She was here, inside. She would get upset and tired."
> (Mother of a young woman (26) with Down's Syndrome, moderate learning disabilities and a heart condition)
>
> One woman told me herself, when I asked her had she ever been to school: "Never, pedaki mou. Nothing, no school, never pedaki mou" (Woman (38) with moderate learning disabilities)
>
> Sakis told me he did not like secondary school but he liked the O.D.A.Z. " I go every day. I like it there. In the evening I go parea (out with friends) with my friend Yannis (who is also at the centre-Sylvia)" (Young man (21) with mild learning disabilities and psychiatric problems)
>
> Lavros, a man (33) with psychiatric problems lives with his parents in an isolated village in the mountains. There are no young people there and going to the centre provides him with an opportunity to meet and be with other people.

It is a relatively small group who daily come together in the centre. They know each other well and usually seem to enjoy being together. A lot of laughing and joking goes on. They also help and teach each other. For example, when I interviewed Sakis, who is not able to speak very well, Markos interpreted for both of us. And when Helena has a dirty nose, Tassos runs after her with a tissue and helps to wipe her nose.

Another social aspect of work is the link with and within the larger community. A considerable effort is made by centre staff and in particular the manager, to encourage integration. People are encouraged to leave the centre when the opportunity for work outside arises, and clients are helped to find suitable employment. A recent project is the opening of a kiosk in the centre grounds, which is currently run by two people previously based at the centre. It is used by the service users, by the people from the nursing home and also by some people from outside the centre. The next project planned is the opening of a car wash, again in the centre's grounds, to be used by people from inside and outside the centre. The driving force behind these projects is the Horizon programme (see also Chapter Three: Two Centres). It is however a limited number of people that participate in these programmes. The more severely impaired people remain making things within the centre, with no plans or prospects to move outside.

Another social aspect is the perception of the centre by members of the local community. Although the clients see it as their place of work, most outsiders and even members of staff call it a school. Thus, working in the centre lacks the status of real work in the eyes of other islanders. But it does offer some opportunity for people with learning difficulties to enter 'normal' channels of work.

A working day?

Let us now look at the description of a typical day for one of the people attending the Centre for Disabled People in Aniksi.

Sakis is a young man (21) with mild learning disabilities and psychiatric problems. He lives with his parents and younger brother in a village just outside the town. He went to primary school where is main difficulty was a slowness in his speech development and 'difficult' behaviour. During the first couple of years in secondary school his difficulties increased dramatically and he was diagnosed with psychiatric illness. He left school and has been attending the centre since he was 16.

07.45 Sakis is picked up at home by the centre bus, arriving at the centre just before 8.30 am. He goes to the room where he works, stopping in the big room on the way to talk to his friend Yannis (they are very close and can usually be seen together). He then makes his way to the carpet weaving room and meets up with her three fellow workers and the 'teacher'. She is making coffee on a hot plate in the room. They drink the coffee together and chat about anything, from weekend outings to friends who are ill and did not turn up for work. Some days Sakis likes to chat, other days he is quiet. Today he is cheerful and talkative.

09.15 Time for work. The four people and the teacher take their places at the large wooden looms. The teacher moves around from one place to another, helping and showing the others what to do and making sure they follow the right colour patterns. Sakis stops occasionally to talk with Manos, another worker, or with someone entering the room. Progress is slow but the teacher usually does a few rows before the others come in, or while they are rolling the wool into balls. With her help a new rug is finished every couple of months.

10.30 Breakfast time. Manos and Sofia have collected the rolls, meat and cheese from the kitchen and put them on a table in the largest room. Everyone takes a roll with some meat and cheese. One of the teachers helps with the distribution of the rolls and hands out packets of fruit juice. Sakis takes his roll, cheese and juice and goes outside with the other service users. Most people just stand around chatting in the shade, or sit at the tables of the kiosk. The younger ones play ball. Sakis looks for his friend Yannis and together they join in the game of netball.

11.00 Back to work. One by one everyone goes back inside. Sakis continues his work on the rug. He is happy to show me how to do it, everyone smiles and praises me when I do my first row. Maria, the cleaner, comes in to sweep the floor and empty the bin. Ari, a young man who is usually in the large room and also likes to do little jobs around the place, follows her and carries the bins. He shows Tassos and Sofia the money he received for doing jobs in the kitchen. Frieda, the teacher, urges everyone to get back to work. She is setting out the colour scheme for Sakis and tells him to pay attention.

12.30 Dinner time. Clients, teachers, and children who live in the orphanage, all eat together in the big dining room. There are two large tables: one for the children, one for the people of the day centre. For them the food is already laid out on metal trays on the table by the kitchen staff. The children's food is put on plates in a press to keep it hot: they all come in at different times during the next hour. Sakis and Yannis sit together and eat quickly. They want to go outside.

13.00 The driver of the bus shouts that he is leaving. Sakis and Yannis are playing netball again but now they have to go; Sakis on the bus, Yannis is walking home today. The bus fills up slowly. Two girls of the orphanage come for the ride and one of the teachers sits in the front beside the driver. It is noisy and the radio plays loudly. When the bus leaves the driver puts on a familiar tape and everyone sings and claps with the music. Another day at the centre is over.

Part B: Ffynnon

Nature and structure of work

When I asked the people I interviewed in Ffynnon why they came to the centre, six answered that they came to work. Many others, in their daily conversations, called going to the centre: "Going to work."

This is despite the fact that the centre in recent years is moving towards providing educational and leisure activities, and away from the idea of providing training in basic skills in workshops while doing contract work. There are various reasons why its users may still see the centre as a place of work. Perhaps it is a remnant from the days of contract work, or an identification with other adults they know, who are going to work. The centre as a follow-up to, and something completely different from school could also mean for them the difference between childhood and adulthood, between education and work. Whatever the reasons, for many people I interviewed going to the centre meant going to work. Some clients however, also expressed awareness of a difference between their work and work carried out by people outside the centre, or work they may have been doing in the past.

> Yvette:"I worked in the hospital. I packed all the things for the trays. I
> enjoyed that.
> Mary(other woman at the centre) went as well. The two of us worked.
> There. We also did cooking."
> Sylvia: "Did you get paid?"

> Yvette: (laughs): "No."
> (Woman (40) with mild learning disabilities and psychiatric problems)
>
> "I have nowhere else to go. My mother took me up to the factory. Tops. Meat. Paste. The manager told her it wasn't responsible. It was dangerous. I would be washing dishing in café. I wasn't quick enough." (Woman (33) with mild-moderate learning disabilities)
>
> One man tells me about other people attending the centre who go to work experience.
> Sylvia: "Why do the others work?"
> Connor: "They finished coming here."
> Sylvia: "Did you have a job or job experience?"
> Connor: " I am going to. I have never done. I like to do it. They like me to work in
> Odeon. M.(staff) tells me they like me to work there. I like to work."
> Sylvia: "Why?"
> Connor: "Jobs. For money. Laura (instructor) says go to Woolworths (shop) to spend the money. Work as well."(Man with moderate learning disabilities)

A few people are on the voluntary work experience schemes (see also Chapter Three: Two Centres)

> One of these people is Peter, a man in his early twenties who has been at the centre since he left special education. His big interest is cars and buses, and he loves washing and looking after them. For a while he had been washing the centre's bus, and cars belonging to the staff. Recently his social worker has arranged a job for him one morning a week at the police station, washing police cars and doing odd jobs. At the time of the research this was due to be increased to two mornings. To Peter, his job of washing cars is important in terms of his self esteem and his place in society. He is however aware that there is no 'real' economic reward: "I come here to work. I wash the bus first thing in the morning. If I have nothing else to do I wash a few cars, and buses maybe. The bus is shining today. Social Services leave it all to me. I enjoy coming here. If people work they enjoy it. I wash all the cars. They should pay me but they don't. I like washing cars, I like to do them all. I work hard for it. I should get money. I wash the staff cars too. A lot."

The centre is not completely isolated from society; in the area of work there is some interaction with the 'outside world'. In addition to the voluntary schemes service users spend time in the workshop producing seasonal presents and decorations around Christmas time. These products – dried flower arrangements, bags of potpourri, decoupage pictures, Christmas decorations, cards etc. – are sold on the local market at a special stall. Service users enjoy this work and are proud of their products. The decoupage was a particularly successful project. One young woman, who has great skill and patience, continues to do this work.

Until a few years ago, Christmas was not the only time that products made at the centre were sold to the general public. There used to be a woodwork shop for the production of garden benches and stools; in another workshop service users made soft toys. Both were popular products with people outside the centre. Service users, staff and parents express regret about the discontinuation of these projects:

> "We used to do a lot here. Soft toys, bins, soft Christmas trees etc. Every six months we would have an exhibition and sale here. It stopped because of the Safety Act. We needed labels and we did not get them. Things changed. Safety regulations on toys were implemented. We were told not to bother any more. It is all education now. Don't get me wrong, I am well for it. But, they need this too. To do something and have something to show for it. We all need occupation, we all need to feel we have done something. To learn about money and transport is important, but this is too". (Instructor)

> "Eddy isn't quite satisfied with the centre. There was a change. Probably the costs. When he went to the centre first it was an Adult Training Centre. He was making plenty. Woodwork. Wooden benches. We bought one for the garden. Basket making. Now it is a Social Activity Centre and they are confined to social activities. I see them around town. Eddy would do a good job, in a restaurant for example. He knows how to lay the table and he is quite capable of doing little jobs." (Father of man (44) with Down's syndrome and moderate learning disabilities)

The production of soft toys was discontinued because of new safety regulations; woodwork dwindled and eventually disappeared with the leaving of the old manager. Currently a new instructor is trying to start it again. This illustrates the extent to which what happens in the centre depends on economic climate and production regulations, on interest and motivation of individual managers and instructors. With respect to changing values, years ago the centre undertook contract work of various kinds; subsequently this was seen as exploitative and discontinued.

Centre policies have adjusted themselves to this trend, as can be seen in the document Into the Nineties, referred to earlier:

> The emphasis from a work- orientated environment to a service which looked to develop the ability and confidence of a person in their everyday lives would be signalled in a positive way and Adult Training Centres would be known as Social Activity Centres ...The centre programme should be organised to cover all aspects of the individual's need and not to be concentrated on repetitive and mundane tasks which have no relevance to daily living and encouragement of independence.

Woodwork, activities carried out in the workshop, especially around Christmas time, housework, cooking and shopping all count as work. So do the voluntary schemes: some service users spend time outside the centre, helping in a mother and toddlers group, helping to supply lunches for the elderly, and, as we have seen, washing cars for the police. In all of these situations people 'labour' to achieve a 'product' that would be seen as 'useful' or 'valuable' by the majority of local people.

Some of sports and crafts (see for extensive list Chapter Three: Programme) are borderline areas. In the latter case, there is often an end product involved, important to the service users – who frequently showed it to me with obvious pride and satisfaction – and sometimes to the instructor (depending on its quality). The quality and usefulness of a product are important criteria in its appreciation by people other than clients themselves. Instructors would show me bags of potpourri, Christmas cards or decorations. However, no one but a service user would show me an indefinable painting.

So, part of what the service users do at the centre in Ffynnon is work: labour to produce an end result or product that is generally seen as useful. For work to be really seen as work it also has to have some kind of structure: time, place and discipline, comparable to other work carried out locally. These elements can to some degree be found in the daily activities in the centre. Some of these correspond with the structures organising work in the rest of society: the five-day work week, the spatial location of the centre within the town, the identifiable areas allocated to the various activities and the expectation that people stay within a certain area during the set period of that activity. These are all general features of work organisation.

There are also differences from the world of work. The time structure of the various activities during the day at the centre, especially since the 'one hour period' system started, means that clients do an activity for one hour and then move to a different area, a different instructor, and a different activity. This is more like school than like a work place. The instructors experience this system as positive; it forces them to structure time as productively as possible:

> You have to be more structured. You need to structure it more so that all get to do something. But sometimes one hour is not enough. We skip break then and have one and a half hour. (Instructor)

For the clients it seems – to an extent – to prevent distraction and boredom. It also increases their dependency on the staff, as few of them know their programme for the day. They have a written programme, but the majority is not able to read. Situations occur constantly, where, at the start of a period, service users are wandering around and instructors are looking for them. The problem appears to be finding a balance between the needs and rights to respect, and relative freedom of choice and independence of the service user, the 'given' factors such as the size of the centre and the number of clients, and the staff's need for structure.

Economic aspects of work

Closely connected with the notion of work is the money that people receive at the end of every week they attend the centre. Both staff and clients refer to this money as 'pay'. The amount is very small, miniscule in comparison to average wages; between 50 pence and 2.00 pounds weekly, depending on when the person first started attending the centre. But to most service users it represents real pay. It is money that enables their access to things like snacks from the shop at break time, during the week in town, or during their evening out at local clubs like the Gateway Club (which organises social evenings and events for people with learning disabilities and is attended by a majority of people attending the centre). Thus, although remuneration is very small, to the people in the centre there is an economic aspect to their activities. Not nearly enough to sustain themselves, it is still offers them some access to things such as snacks and leisure. Compared to what people earn who work outside the centre however it is very small. This suggests that whatever the people at the centre do is not considered by management as sufficiently valuable to demand 'proper' remuneration. And some service users themselves realise the difference between the money they receive at the centre and what they would get if they were able to find a 'real' job.

> Margaret: "You know what I want to do. Like staff. Putting them to bed. Looking after them. Take them out for walk."
> Sylvia: "In a hostel or a home?".
> Margaret: "Yes. Old and sick people. Sick people. Write that down."
> Sylvia: "You would like that."
> "Yes. And money. Here I only get 50p."
> (Young woman (19) with mild-moderate learning disabilities)

Social aspects of work

According to the people I interviewed, important reasons for attending the centre are: to be with other people; to make and be with friends.

> Emma is a sociable and talkative woman with moderate learning disabilities. She spends most of her breaks with a steady group of women, sitting at the

> same table, chatting and laughing. The women in this group have known each other since they were all at the same special, secondary school. I asked Emma what she liked about coming to the centre. She told me: "I have all my friends here. Theo, he is my boyfriend."

The largest part of their time spent outside the home is spent at the centre. This is the main place for service users to meet people other than their family. Many have known each other for years, even from school. They also meet at local, mainly special, clubs, during outings and holidays organised by the centre or Mencap, and at events organised by the centre, such as the annual Christmas party. In fact, the majority of service users have little contact with 'ordinary' people outside their families. The social incentive is part of 'going to work' at the centre. Even if friendliness with each other varies – sometimes on a daily basis – service users often refer to each other as 'friends'.

Meeting and being with other people is not the only social aspect of 'going to work' at the centre. There is also the place of people with learning disabilities within their local society to consider. Some activities in the centre can be called 'work', because of the meaning clients give to what they do, the pay at the end of the week, the sale of products at Christmas time, the contribution to society through voluntary schemes, and the social aspect of meeting people in a regular place at a regular time. Despite this and the fact that people with learning disabilities are often able to do particular jobs – from woodwork to contract work, helping in a play group to washing cars, gardening to toy-making – very few end up in 'ordinary' jobs. In documents on the purpose and policies of the centre, and in conversation with its manager, the difficulty in finding suitable work for people with learning disabilities, especially, but not only, in times of high unemployment, was emphasised. There appears to exist an underlying belief that when it is hard for an 'ordinary' person to find a job, people with learning disabilities should forget about it altogether. This is reflected in the centre's day-to-day programme. Little attempt is made to train people for, or to find them, work in the larger community.

A working day?

I will now describe a typical day for one of the service users at the Social Activity Centre in Ffynnon.

Suzy is in her late forties. She lives in a special hostel about two miles away from the centre. From the time she first went to school she found it hard to keep up with the other children. She was transferred to the Junior Training Centre, from where she continued on to the Adult Training Centre (later to become the Social Activity Centre).

08.30 A Council minibus picks Suzy up from the hostel. A few minutes later she arrives at the centre, where she meets up with Maggie. Suzy and Maggie have been at the centre for many years and get on very well together. Today their group meets in the Hall with their Key Worker, Damien. From 09.00 until 09.30 they chat about the news of the day and any other topic that comes up, personal or in relation to the centre.

09.30 Suzy has Education with Sam this morning. Suzy follows Sam, who has come to the Hall to 'round up' her group and bring them to a room off the Art Room. It is to be 'sums' today and each of the six people in the group receives a paper with simple sums on it. Sam explains the first two sums and then they must do the others by themselves. Two people finish after ten minutes or so. Sam helps two others, who manage with a bit of encouragement. Suzy finds it hard and Sam goes through each aspect of the sum with her, until she understands. I help Mary, who manages each sum with guidance. Sam, the instructor, tells me it is hard work: "You have to keep at them, and then if they do not do it for a few months it is all gone again. Not with all, there are the ones who are very good. But some of them."

10.30 Tea break in the Hall. Everyone gets their own cup of tea, made by the group who have 'tea duty' this week. Most days Suzy sits at the same table with the same people. They talk, laugh, or complain about each other. A young man at the next table is crying. Suzy goes over to him and puts her arm around him. When I ask what is the matter, she answers for him: "Oh he is alright, he often gets like this".

11.00 Home Craft this morning means cooking lunch. Suzy makes her way to the Staff Room where there is a cooker and a sink. Three people out of the group of eight have not turned up yet and Anette, the instructor, goes out into the hall looking for them. When all are present, it is decided what to cook for lunch. Some people make suggestions. Suzy favours chips, someone else fancies trifle. Anette says chips would be fine, and suggests tinned fruit and cream for afters. She goes to the kitchen to get the potatoes, she sends Suzy to the flat to ask for a tin of peaches and cream. The other members of the group wait around. When all the ingredients are there, the work is divided. Some people volunteer for tasks. Suzy offers to peel the potatoes, someone else wants to cut the chips. Others get jobs assigned to them, for example washing up or opening the tins. Anette cooks the chips and when it is ready they all eat their lunch together. After that they join the other clients who are having their lunch in the hall.

13.30 Suzy has craft in the art room. Fiona, the instructor, decides they will make designs today. There are nine people in the group. They make designs with a ruler and pencil on big sheets of white paper and colour them in. Suzy enjoys this, she makes a clear design and is very precise in her colouring. She shows me her work when it is finished. Fiona makes the design for the people who find it difficult; they just colour in.

14.30 Tea break again. More chatting around the table where Suzy sits.

15.00 Instructor Fiona rounds her people up for Self Help Skills. Suzy, Tracey, and Liz are washing each other's hair in the special washing area. After that Fiona dries their hair and puts make-up on every one who wants it. The others sit around; Mary is doing her nails and Ann is having a doze.

16.00 Everyone gets ready to go home. Suzy is looking for her coat. When she finds it she waits in the hall until the bus is ready to take her home. It has been a long day but she tells me that she likes coming and 'would not miss a day'.

Part C: Comparison and Discussion

Pahl (1980) and Ronco and Peatty (1988) consider actors perception of what they are doing one of the foremost criteria with which to distinguish work from non-work. The majority of the people interviewed, in both places, consider what they do at the centres as work. The justification for this notion of work for them is in the nature of the activities, and in the economic, personal and social incentives attached to them. In relation to the nature of the activities, in the programmes of both centres I have identified activities which can reasonably be called work. The emphasis of these activities is on their product. On Aniksi these activities take up most of the day, as opposed to only a small part of the day in Ffynnon. Work used to be a more important part of the activities within the centre there, but a combination of factors changed this: the interests of the individual managers and instructors, and the notion that work, especially contract work, judged to be boring and monotonous and done for less pay than 'normal' workers, is exploitative. This illustrates the influence of local values – values that do no seem to consider the views of the people themselves – on the activities of 'incompetent' people. Some, for example, told me that they missed the work they were doing before, especially woodwork and toy making. It also illustrates the dangers of political correctness; it sometimes backfires, leaving people worse off than before.

In both centres there is some financial reward for working. Some of the products made at both centres are sold into the community, at local markets or exhibitions. The proceeds of these sales go back to the centres and thus, indirectly, to the producers. However, the money received as 'pay' is, in both places, unrelated to productivity; it also differs greatly between the two centres. In Aniksi it is a much more 'realistic' sum than in Ffynnon. True, it is not sufficient to sustain one self but this is true for many people in Aniksi.

It is clear that both groups of people enjoy productive activities, find pride and satisfaction in them, and are often quite skilful. The less able people might not produce things that the majority of people would rate high in quality and usefulness, but this fact does not seem to affect the positive experience of the workers themselves. The social incentives for the people attending both centres are to be found in the opportunity to socialise with people outside their own families and to make friends. Spending the day doing something similar to what 'competent' people do, makes it easier for both groups to identify with other adult members of their society.

The main differences between the two centres are in their links to the local community outside the centre. On Aniksi it seems to be easier for people to move on to work outside the centre, and active efforts are made by the manager to achieve this. Some people attend the centre in the morning, while working somewhere else in the afternoon. There is also the semi-independent work carried out within the centre's grounds, i.e. the kiosk and, soon, the car wash. In Ffynnon people engage in so-called 'work experience', but the boundaries between this and the labour market are much more fixed. Work experience takes place in the community, but it is voluntary and unpaid, and no-one moves on from it. In reality, it is more like an extra sphere of work between the centre and employment.

This difference between the two places seems to be strongly influenced by the structure and definition of work within both societies. The majority of jobs on Aniksi do not require formal qualifications; they are often self – initiated or obtained through family contacts; it is routine to hold several jobs at the same time, and everyone struggles to make a living. There is no such thing as unemployment benefit. The structure and organisation of work on Aniksi is fairly informal. In contrast, in Ffynnon it is much harder to get a job; qualifications and a formal interview and selection process are usual. The boundaries between working and not working seem less flexible.

This contrast, between formality and informality in structure, is the second major difference between the centres, particularly in the structure of time and place and, to some extent, the roles of staff. On Aniksi service users work more or less at their own speed and when they want to. They can walk around and have a chat with other service users in the same or another work room. They appear to be happy, relaxed and quite independent within the framework of the centre. In Ffynnon, where the centre is much larger, and thus harder to come to terms with, the structure of time is stricter and difficult for the service users to grasp. This makes them much more dependent on instructors. While time is more structured in Ffynnon, activities move around more, adding to the clients' confusion.

So, although on Aniksi things appear to be less organised, this seems to suit the service users better and offers them greater independence. It also means they are on a more equal footing with the staff members. Staff members on Aniksi do no interfere much with what the service users do and spend a large part of the day just sitting around and chatting together. In Ffynnon, however, instructors spend a lot of time telling service users what to do and when. This 'created' dependency in Ffynnon raises questions about the centre's aim to offer service users a variety of experience and opportunities in order to develop a broader range of skills. This results in a 'student-teacher' relationship, without much room for individual spur of the moment input. In a more one-sided approach, where people do one or two things more intensively, and are comfortable with it, they might not reach their full potential in *various* skills but they may experience more independence. Davies (1998) sees this loss of autonomy as the price to be paid for the creation of an adult image for people with learning difficulties. It is a price which may limit the meaning of such an image. Again, we see here the influence of policies – ultimately reflecting local norms and values – on the daily lives of people with learning disabilities and on the degree to which they are treated as adult members of their society. People classified as having a learning disabilities in Aniksi and Ffynnon are able to work and do work. That the emphasis on the various dimensions of work varies, between ‘incompetent’ and ‘competent’ people, and between societies and cultures, should not obscure this. Some dimensions of work are more problematic for ‘incompetent’ people than others, in particular the economic incentives and the structuring of time and place. And local values and structures matter. Contrasts between formality and informality, and between large-scale and small-scale, make access to the local structure of work easier in Aniksi than in Ffynnon.

CHAPTER SEVEN: INDIVIDUAL LIVES

Introduction

The category learning disabilities and its links with impairment, local social and economic structures and culture only take on real meaning through the lives of individual people. Ultimately, to come to a fuller understanding of local meanings of learning disabilities and their social embeddedness it is necessary to look at the lives of the people thus classified. In this chapter I will discuss the lives of 10 people, locally classified as having learning disabilities; five in Aniksi and five in Ffynnon. The material for this chapter comes from interviews with the people attending the centres in Aniksi and Ffynnon and their parents, personal files in Ffynnon and discussions with the manager and psychologist on individual service users in Aniksi.

Aniksi

Tassos

Tassos was 19 years old at the time of research. Tassos is from a poor family (even by Greek standards). He is tall and healthy looking and there appears to be no visible explanation of his learning disabilities. Tassos is a bit nervous but also sociable, friendly and chatty. A lot of what he says is repetition or may be difficult to understand but it is clear that he means well and is interested in other people. At the centre he is kind and helpful, especially to the people who have more difficulties than himself. He would often help Maria with opening her drink or wiping her nose. He rides Sakis in and out of the garden during break time. He always makes sure he greets and talks to me including when I meet him in the street one day.

Unfortunately I do not have much information on the initial classification of Tassos as having learning disabilities or on how his parents perceived him as a child. It is known that he went to primary school but left after a few years. According to the psychologist he is ‘severely retarded’ and it is quite likely that the school system and Tassos’s needs and abilities did not ‘match’ because of his intellectual impairment. It is also possible that in a family environment of poverty and illiteracy formal education was not perceived as valuable to the same extent as in other Aniksian families. Whatever the grounds, Tassos was excluded from mainstream education. Instead, he was introduced to the world of work.

His father works for a transport company and Tassos has been accompanying him to work since he was a small boy. When he got older he was allowed to ‘work’ as well, cleaning the cars and trucks, fetching things etc. Tassos enjoyed this but had difficulties in conforming to work structures. He kept wondering off, spending hours just walking around the town. Other members of his society perceive Tassos as unusually vulnerable, leading some people to ridicule or abuse him. The psychologist tells me that the men sitting in the cafes often asked Tassos to join them and bought him soft drinks. They laughed at him and there may have been a history of (homo) sexual abuse. Others wanted to protect him. Concerned local people approached centre management who in turn contacted the family. After some discussion between all concerned Tassos was admitted to the centre and has been attending for two years now.

He is popular with staff and other service users, not in the least because of his pleasant, sociable and outgoing nature. According to the psychologist he needs a sheltered environment and this is what he gets at the centre. He has his freedom to walk around; he frequently wanders from room to room talking to service users and staff. He works in the large room, making plastic flowers or bead chains, writing numbers and letters in his exercise book with Maria (one of the teachers) or helping the other service users. He tells me he likes it at the centre and that he writes his name and works making chains. The psychologist says: “For the first time Tassos is in a place where he feels truly accepted, where no one laughs at him and where he can feel good about himself." When Tassos started to attend he often looked scruffy and dirty. Now, at the last outing with the centre he appeared all clean and dressed up and very pleased with himself. Tassos seems to feel at home and happy at the centre. This shows in his mood and temperament, his increased confidence and pride in himself (dressing up) and his more settled behaviour at home.

Having left a mainstream work environment, Tassos is now subject to the authority of the centre staff and is at times treated similar to a child (see also discussion on relationships between staff and clients in Chapter Three, in particular the incident with the radio). However, the centre has also facilitated the development of various valued social roles for Tassos. He is now a capable worker who is able to function with a certain amount of freedom and choice but within a certain structure and while taking appropriate responsibility. He is a colleague and friend who gives and receives respect, affection and support. The centre also provides a setting in which he can express himself as an affectionate brother and proud uncle. Tassos is very fond of his sister. She lives next door to her family and has a new baby. He never stops talking about the baby and shows her photographs to staff and service users at the centre. Tassos is not able to function as a protective brother as is expected in Aniksian society but his family knows and accepts this and values the relationship he does have with her and her children.

Attending the centre did not alter all aspects of Tassos's life. At home (when he has the patience to stay at home) he still likes to listen to music. He has his own tape recorder and listens to "foreign" (English) tapes. He also likes swimming at the beach near his house, but not now (October) as it is too cold. On Sundays he goes to church. He lives just a few streets away from the church and says he likes to go alone. On Saturdays he goes around on the truck with his father, selling vegetables in the villages. He tells me he earns his own drachmas (Greek currency) with that and he gives this money to his mother "to buy food". He also gives her the money he 'earns' at the centre. In this, Tassos considers himself as conforming to the role of an adult son in an Aniksian family i.e. one who goes out to work and contributes to the family's income and livelihood.

Tassos' mother continues to worry about him. He still wants to go out and wander around even at night. She will always perceive him as 'different': vulnerable and thus in danger of ridicule or exploitation. "But", she says, "what can I do, I can't stop him from going out".

Tassos' formal classification took place as part of the process of admission to the centre. Long before that however, he was perceived and informally classified as 'different' even 'handicapped'; at school, by his parents and by the people he met in the streets. It was not this informal or indeed his formal classification as having learning disabilities that led to Tassos' partial exclusion from the 'normal' childhood and adult activities of his society (school and work). Unfortunately, I do not have any information on how and why he left school. I do know that in the context of Tassos' family early school leaving is not considered a huge problem. It just means an earlier introduction into the adult world of work and contribution to the family income. Work however, was problematic for Tassos. This was not because of his (informal) classification as he was accepted, given responsibilities and being paid at his workplace. Rather, it was a combination of various factors including his intellectual impairment, personal characteristics, social structures and cultural values that eventually led to Tassos being excluded from his work place. His personal characteristics i.e. the tendency to wander around, his friendliness and a possible homosexual orientation led him to meet many men in the streets. His intellectual impairment prevented him from obtaining a certain level of awareness of social rules and dangers. Informal work structures provided him with the opportunity to arrive at and leave work unnoticed. The presence of a male/macho culture in Aniksi, expressed in the numerous 'men only' cafes on the harbour front and an element of homosexual abuse that is allowed to flourish within this setting all contributed to the difficulties

Tassos experienced in the adult world of work. That these difficulties were socially problematic in local society is evident in his mother's concerns, his extreme nervousness and neglect of himself when he first came to the centre, the concerns of local people (who contacted the centre about him) and ultimately in his admission to the centre.

Tassos' attendance at the centre has helped him to develop some new work skills but above all has allowed him to express his very social nature, and to become a valued and popular friend and colleague within a safe environment. This is also experienced as such by Tassos himself. His nervousness has decreased and his confidence and pride in himself has grown. His participation in social relationships and in the adult activities of work and leisure are partly segregated from the rest of his society. It is also less problematic for society, his family and for Tassos himself. It could be argued that Tassos was excluded and segregated to enable society to get rid of a 'social problem'. However, he now participates in activities and relationships that ultimately led to an increase in his sense of (social) well being, valuation by others and related self valuation.

Tassos' relationship with his family has only partially been affected by his intellectual impairment. He still contributes to the family income and is a proud and affectionate brother. His vulnerability, which results from a combination of his impairment, his personal characteristics and local social structures, remains a powerful factor in this relationship. His mother will always worry about him, more so than other mothers of adult children in Aniksi. It does not however, stop her from treating him as an adult. For example, she does not stop him from going out nor does she see this as an option. Her son is big and strong and 'goes his own way' whether to the beach, for a walk or to church, similar to other young men in Aniksi. Having an intellectual impairment does not change this for Tassos and his mother.

Toula

Toula is a woman in her middle thirties who lives with her widowed mother in a small village, six miles outside the town. As a child Toula contracted meningitis. Very ill for six weeks, she made a slow recovery but was left with considerable learning disabilities. Toula went back to primary school for two years but, according to her mother, didn't learn anything. She then stayed at home with her mother for several years, until the centre opened.

At home Toula helped, and continues to help, her mother in the house and garden. Her mother explains that Toula can do all the housework except cooking. She does not seem to like cooking and Toula confirms this when I interview her, "I don't like cooking. It's dangerous". They also did and continue to do a lot of needlework together. They led and still lead a quiet but isolated life.

At the centre Toula has learned to weave carpets. She is good at it and enjoys it. She is able to work more or less independently once the carpet has been set up. She also enjoys the company of the other three clients who work with her in the same room and are of similar ability to her. She is well able to communicate but has a bit of a tendency to repeat what she has already said, something that all around her seem to accept as just being Toula.

The aim of the centre in Aniksi is to provide clients with a working skill. This has worked well for Toula. As well as the nature of her activities, the room in which Toula works is similar in structure to a normal work situation. Clients and teacher work together, making rugs and carpets that are sold during local exhibitions. Toula is extremely proud of her work. In addition to her finding 'work' Toula has increased her social contacts. Even with the 'teacher' the relationship is fairly equal and they share a lot of gossip, making it again, similar to a normal work situation.

There is one interesting point to be made here. While one of the centre's aims is to teach and encourage people to find work outside the centre, this does not appear to be pursued for the women. Toula is quite a capable woman but no plans have been made to find or create work for her outside the centre. I strongly suspect that gender plays a role here. Amongst all the women who attend or have attended the centre in the past, only one went on to a job. In Aniksi, few women work outside the home. Toula and her mum appear to be managing well with the income available to them. Her mother sees Toula's attendance at the centre primarily as a social outlet. Both women join outings and trips organised through the centre and thoroughly enjoy these. At home Toula continues to help her mother in the house and garden. In fact, the day I arrive at their house for the interview, Toula and her mother are hanging out the washing together. The only thing that distinguishes her from other women on the island is that she never married and has no children.

At home, the only regular social contacts for Toula and her mother are Toula's brothers and sister. One brother is married and lives nearby. Toula's mother looks after her grandchildren as her daughter-in-law works outside the home. Toula's sister lives in Athens, as does her maternal aunt and they visit them occasionally. However, these visits are rare as Toula's mother explains that Toula prefers to stay at home. On Sundays both women attend church together.

Toula's intellectual impairment and classification has been a barrier to her education within the existing system. The difficulties the existing system had in accommodating and teaching Toula and the lack of alternatives have contributed to her leading an isolated life with few social contacts. Her impairment may also have been a barrier for the local adult institutions of marriage and motherhood (which appears never to have been considered for her). Her formal classification and thus eligibility for the centre when it was established has however given her access to an income and participation in work and leisure activities she did not have before. Indeed they may never have been available to her if she were an unmarried woman of her age and background. Her background of an isolated country family and the (social) dependence of her widowed mother would most probably have prevented Toula from pursuing a career and severely restricted her social life. Formal classification and thus eligibility for admission to the centre has expanded her social roles to include colleague, worker, and friend. It has also expanded the social life of her mother and contributed to their family income.

Learning disabilities and attendance at the centre has not altered Toula's life outside centre hours. This is still fairly similar to the lives of other unmarried/widowed women in Aniksi. Toula's life with her widowed mother is also an example of an increasingly recognised social role of people with learning disabilities in western cultures; that of friend, companion and even carer of the elderly and in particular widowed or divorced parents.

Sakis

Sakis, 25 at the time of research, has cerebral palsy, is wheelchair-bound and has virtually no speech. He is completely dependent in his self-care. He lives with his parents in an upstairs apartment in town. It is small and there is no room for his wheelchair. He walks around the apartment, holding on to the furniture and sits in an office chair on small wheels. As a child, Sakis had a bike and played outside with other children. As time went on they went their own way and Sakis was left spending his days looking at magazines and the television. In the summer he goes swimming at the beach with his father.

Sakis' sister Frieda is seven years his junior and studies at the University in Thessaloniki. Brother and sister appear to be close. While away with the centre on a trip in the north of Greece, Frieda joined the company (including her brother and both her parents) for a few days. She spent a lot of time with her brother, pushing him around and sitting together away from the others. Despite Sakis' difficulties in communication, he and his sister seem to have a good understanding. When home in Aniksi, Frieda regularly takes her brother out for walks. Apart from this contact with his sister and his parents, Sakis has led an isolated life.

Sakis' mother explains that there was no school for him in Aniksi. She must have felt that he would not be able, allowed to attend or benefit from 'normal' school and sent him to a special institution in Athens. Sakis was homesick and refused to eat. The doctor of the institution wrote to the parents and they took him back home. He never went to school again. Thus he never again had the opportunity of a formal education.

Sakis started attending the centre from the day it opened. He has a friendly, outgoing personality and soon became a popular with many friends. During break times there is never a lack of people to wheel him outside, or to give him his bread. He laughs and jokes with everyone. His close friends are well able to communicate with him and volunteered to 'translate' for me during our interview.

Attending the centre fulfilled Sakis' social needs, helped him to develop his social and communication skills and enabled him to make the friends he didn't have since he was a child. In addition, the trips and outings with the centre are a great source of enjoyment and excitement for him and his parents. They never miss one. In relation to the development of 'work skills', he initially learned to make plastic flowers. This was a long and tedious procedure for him, which nevertheless gave him some work satisfaction and he was always keen to show off his work. Recently the centre has opened a craft shop in the town centre. Sakis has now left to work in this shop, together another worker and the art and craft teacher. His job is to price the goods and, while he prefers to just sit around, laughing and joking with customers, he knows he has to 'work' to be allowed to remain in the shop.

At home Sakis is still the same and doesn't do a lot apart from his magazines. His relationship with his parents too remains fairly similar to what it was before. They are his main social contact outside the centre and in his relationship with them he is very much 'the child' or the 'sick person' in need of help. His parents do everything for him, also things he may well be able to do for himself. His mother tells me he learned to make coffee at the centre. He will not however make coffee at home as "he is lazy" and "doesn't do anything for himself". It is a much-discussed issue between Sakis's sister and his mother. Frieda thinks he should do more for himself. "Look at him", she says to me. "He is 28 years old and my mother does everything for him. She feeds and baths him, shaves him." Frieda thinks he could do a lot himself, "he can use his hands more; he is able to push his wheel chair with his hands." Frieda has also discussed the future with her mother, and told her that she will not be able to do everything for Sakis forever. Apart from the issue of adulthood, social independence and the contentious issue of the desirability of the pursuit of independence in self-care skills for people with severe physical disabilities there is another matter to consider. In Aniksi, there are no special facilities for people with physical disabilities. Unable to care for himself, as Sakis is, he will end up in a large institution away from his island, unless his sister looks after him. This dilemma of was also recognised by Beardshaw (2002) in her discussion with Oliver (2002). His mother expressed her concern about this to me. Mother and daughter both agree, however, that it is difficult to change the habits of a lifetime and that it is too late now.

It is not only in the house that Sakis is under high levels of care and protection. Both his parents come with him on all the trips and on a day to day basis it is his father who takes him to the centre, he doesn't come on the bus. His dependence and his parents' protectiveness limit Sakis' ability to build his own social life.

Sakis' exclusion from the world of school happened because of his impairment, his parents' norms and values, his attachment to his parents and the lack of local special education. His subsequent exclusion from the world of his peers in the neighbourhood appears to be more influenced by the exclusion from a communal world of school and education than by his impairment.

Admission to the centre for people with disabilities branded him as somewhat more 'handicapped' (in an informal and formal manner) than someone who, for example, is deaf or blind. The psychologist's report stated that Sakis appeared intellectually impaired, most likely as a result of a lack of intellectual stimulation. His sister confirmed Sakis' status as 'more than just physically disabled'. While in themselves deafness, blindness or lameness do not appear to be a barrier to marriage in Aniksi, his sister laughed when I asked her about this issue in relation to her brother. She told me she had never heard of "people like him" getting married. Social structures and local culture contributed to the continuation of the barrier of Sakis' communications difficulties. While his impairment causes him difficulties, it is widely known in the UK and many other countries that alternative and/or augmentative methods of communication are possible and available. That this is not tried for Sakis in determined by the purpose of the centre, social structures that do not include the availability of speech therapy on the island and the lack of knowledge, interest and motivation in the case of centre staff.

From leading a relatively isolated life at home, Sakis has come a long way towards being a known, accepted and respected member of the society he lives in. Attending the centre has increased his social roles to include friend, colleague and shop assistant. It has taught him work skills and helped him to find work in the larger community albeit in a semi-sheltered setting. He is definitely one of the centre's 'success stories' in relation to their main objective, which is remarkable considering his severe impairment. This very clearly shows that the in/exclusion of people with (learning) disabilities does not need to be directly related to impairment. Physical impairment is a barrier to his social independence but there are additional influences, namely his personal characteristics ('lazy') and his mother's attitude towards his personal care.

Helena

Helena is thirty-seven years old. She lives with her parents in a small village. She has moderate learning disabilities, no speech and difficulties in communicating. According to the psychologist she also suffers from childhood psychosis. It is not easy to make contact with Helena as she usually keeps her eyes and her head down. I have never seen her smile. From when she was a small child her parents felt that there was something wrong with Helena and they took her to many different doctors. When she was 16 one doctor told the parents that she was severely mentally handicapped. Helena went to the local primary school for a year. Her aunt, who was teaching in the same school, told her mother that school was too tiring for Helena and that she was not learning anything. She was then taken out of school and stayed at home.

Helena has been attending the centre from the day it opened. The psychologist tells me that at first she was "very bad" and was scared and screamed a lot. He thinks her mother may have hit her at times. Things have since improved for Helena, and she now seems more settled. She is quiet but I have never seen her upset or scared. She attends the centre every day and usually sits at the same place at the same table doing her knitting that she brings from home in a bag. She knits long pieces of material that never seem to get finished. No one pays much attention, neither the other clients nor the staff. In fact, when the wool is finished she sometimes waits for hours doing nothing, until I help her or until her mother at home starts a new piece for her.

The two main reasons for her attendance at the centre are firstly, a place for her to go and secondly, to give her mother a break. Having spent her life at home, it is the first time she is doing something away from her home and her mother. She now has a different place to go and new people to meet; for the first time she has 'peers'. Although she does not take part in the activities in the centre and work outside the centre has never been considered for Helena, she does do 'something' of which she is aware and proud. She always shows off her knitting to me or to anyone who is interested. She has a routine to her days and people around her. She may not seem to communicate much with them but she is certainly aware of them and considers herself part of the group. During tea and lunch breaks she follows the others outside where she stands or sits beside the other workers in the garden. No explicit effort is made to develop Helena's work skills. However, she has made some progress in regard to her awareness and confidence by attending the centre and by taking part in their trips and outings. She now walks alone (before someone would have had to hold her hand) and is more relaxed. Her screaming bouts have stopped. At home she remains isolated. There are no siblings at home, her father does not get involved with her and her mother is mainly involved in 'minding' her. She does not go anywhere except for the centre and on trips organised by and for the centre.

For Helena's mother the centre provides a much needed break. At home Helena requires constant attention and supervision. They have both benefited socially and take part in outings and holidays together. Her mother also feels that she has benefited socially from Helena's attendance at the centre. As she feels quite isolated within her own village she is happy with her contacts with other parents at the centre. She gets on well with them and feels they have something in common.

Helena had been excluded from primary school due to her impairments and because of her family's perception that she would be unable to cope with regular school. Her severe impairment and the lack of practical and emotional support available to the family, as well as gender roles within the family which left Helena's mother solely responsible for her care cannot but have affected the relationship between mother and daughter. The daily care and supervision of Helena put great demands on her mother, who felt alone and isolated and found it hard to cope. Helena, affected by her intellectual impairment, epilepsy and psychiatric difficulties also had to deal with the feelings of frustration and loneliness of her mother and possibly suffered physical abuse.

Attending the centre has widened Helena's social world and experiences and has also decreased the social isolation of her mother. Helena's experience of and level of participation in the centre is determined by the qualifications and motivation of the staff (who do not interact much with Helena), her difficulties in communication with the other workers (and vice versa) and the centre programme (which is work orientated and into which her knitting somehow fits). Thus, while her participation in social interactions within the centre remains minimal she does to a certain extent 'work'. She feels she is doing something comparable with work and always shows other service users and me what she has made. Although her knitting never seems to get used for anything she herself perceives what she does as 'work' for which she receives payment. Helena also appears to feel part of the group of workers and takes part in and enjoys the outings with them. She is free during her time at the centre to make her own choices about where to go and what to do. However, she is limited by her (dis) abilities and by the fact that no one attempts to communicate with her and find out what her wishes are.

Nora

Nora was 20 when I started my research in Aniksi. She has Down's syndrome, moderate learning disabilities, and mental health problems. Nora's story is unusual. After her birth in Athens her mother left the home, taking Nora's older brother with her. Her father could not take care of her on his own and put her in an institution. Later he remarried a woman from Aniksi and they brought Nora to the orphanage there. After going back to Athens with his new wife he hardly ever returned to Aniksi; he visited Nora twice in eight years. Last year her father died and 11 months later Nora's mother came to look for her. She told the orphanage management that her ex-husband had told her that Nora was dead and that was why she never had come to visit her. When he died it emerged that Nora was still alive. After meeting Nora, her mother promised she would come back and take Nora to Athens to live with her and her son.

When I returned to the centre six months later, Nora had left and is now living with the family she never knew she had.

When Nora came to live at the orphanage she was many years older than the other children. The staff however made no differences between her and the other children and they were friendly towards her. They helped, protected and made special allowances for her because of her disabilities. I distinctly remember one particular incident where Nora (who is overweight) was pouring lots of olive oil over her salad. I wondered aloud if that was a good idea and one of the children said to me: "Just leave her, she has nothing else."

During the day Nora attended the centre for disabled people, which is adjacent to the orphanage. She came every day by herself, through the door connecting the two places, knowing her routine. She would go to the large room where she would sit at the table with Eleni (teacher) and the women with lower abilities. Her main activity was needlework; in particular the embroidery of tablecloths. She would often get it into knots and ask for assistance from the staff or one of the other workers. She seemed to enjoy her work and was proud of it, showing it off to me regularly. During lunch Nora would become one of the children at the orphanage again and she always had her lunch at their table. They talked to her and treated her affectionately. At the time when I started my research the children in the orphanage slept in three rooms; one for the boys, one for the girls and two older sisters shared a three-bedded room with Nora. She was part of the 'teenagers' even if her abilities and behaviour were not always that of a teenager.

Nora's social world consisted of the children at the orphanage and the people at the centre. She was a friendly and cheerful girl who often laughed and both staff and other service users were fond of her. They would joke with her, pat and touch her affectionately and help her if and when she needed or asked for help. Nora enjoyed her 'work'; joking and having fun with the other children, staff and people at the centre; dancing at parties organised jointly by the orphanage and centre; going on outings etc. When Nora left everyone missed her but the children were also happy for her and eager to relate the story to me. The children saw Nora as a person in her own right. While they were aware of her being different, they also recognised her need to belong and to enjoy a similar life to theirs.

It is unknown if it was the fact that Nora had Down's syndrome, a possible element of shame, her behaviour or caring needs that caused her mother to leave and her father to abandon her. It may have been a combination of these and/or other factors. While there were other children at the orphanage who had been left there by their parent(s), they still had regular contact with their family. While living at the orphanage and attending the centre the importance of her Down's syndrome diminished. While it inhibited her abilities, for example to communicate by speech, it did not stand in the way of affectionate and respectful relationships between her and the people close to her. She was seldom told what to do and her daily environment was such that she was well able to cope with it in a relatively independent way. The small scale of the centre and the routine associated with it suited her.

When the shop opened within the centre grounds she was also able to go to the shop. In the winter she did not leave the centre grounds much and in this way she differed from the other children who all went to school. However, when two girls at the orphanage got older and left school, they too stayed around the larger institution; one found work in the nursing home and the other at the centre for disabled people, again diminishing the differences between their lives and Nora's. In fact, the girl that came to work in the centre and was now one of the staff treated Nora mostly in a friendly and equal manner, joking with and helping her in a sisterly way. In the summer Nora usually went swimming every afternoon, along with the children of the orphanage, service users and staff of the centre. She also went on trips with them, around and outside the island. She had her work, like other adults in Aniksi. She did not have to go far for this but neither do many other people in Aniksi, who work on their own farm or look after tourists who rent rooms in their houses, or women who stay at home to look after their children. In fact, Nora probably had more social relationships than many other adults in Aniksi. There is very little turnover of staff in the orphanage. The children in the orphanage also do not leave once they are 18. They stay until they get a job too far away to travel back and forth on a daily basis or until they get married. The ones that have left stay in touch and know of each other's whereabouts. In this way it is like a family of which Nora is very much a part.

Nora's story shows how people with learning disabilities may be more vulnerable in Aniksi or Greece (Nora did not come from Aniksi), and may be subject to abandonment (there are other examples of this). It also shows how in a simple, small scale, loosely structured and steady environment, with no strong boundaries of structure and location between work and private life, people with learning disabilities may lead a full life. They can be relatively independent, active, loved and respected in their own right and not very different from other adults and children.

Margo

At the time of the research Margo was 32 years old. She had been attending special education since she was 13 and the Social Activity Centre since her 16th birthday. Margo lives with her parents, she has one sister who has moved away and has her own family. Margo regularly goes to stay with her sister to help out with her small children. Her mother explains: "She went up for three or four weeks when the twins were born. She changed nappies and everything. She is marvellous with kids." Margo is one of the few people who have a friend at home whom she knows from school and who does not attend the centre. She visits this girl regularly and vice versa and goes on outings with her and her family. Margo also goes to chapel with her friend on the bus. According to her mother Margo also goes to the shops on her own.

There was no admission report in her file. A report in a case review four years later concluded: "Margo will be unlikely to reach employment ability or independent living" and "will always be in need of care and support". It was recommended that she should continue to attend the Adult Training Centre (as the S.A.C. was called then). Further reports are scarce and state: "Margo appears very happy at the A.T.C. and Gateway club (*social club for people with learning disabilities*). She has only occasional verbally aggressive outbursts". According to her mother, Margo is happy at the S.A.C., "she won't stay in even when she is bad (*sick*)".

At the centre Margo is one of the most able people. She takes part in self-help and self-care skills instruction, numeracy and literacy classes and activities in the community such as shopping and bowling. Margo is outgoing and talkative and comes across as happy and settled within the centre with her own group of friends. They sit chatting together during breaks and together take part in their favourite activities i.e. shopping and bowling. For Margo, attendance at the centre is above all a social occasion where she meets friends, enjoys activities goes on trips. It also gives structure and routine to her days. The aim and objectives of the centre, to address individual needs and encourage independence, only partly work for Margo. Some of her social needs such as meaningful activities, friendships, daily routines, use of public facilities, are being fulfilled. She has also learned a lot in the area of social and independence skills and has grown into a relatively independent and confident person who can communicate and form and maintain friendships.

At present however the centre does not offer Margo any additional educational opportunities or facilitate growth towards adulthood and independence. Certain aspects of her attendance at the centre stop her from living and being treated as an adult. Firstly, there is the issue of parental influence and responsibilities. Parental permission is asked for when clients wish to take part in new activities or activities outside of the centre. When the doctor visited to carry out a medical examination, Margo's parents were informed and offered the opportunity to be present during the examination. Margo also required permission when one day she had arranged with her friend to be picked up from the centre. While these measures may be justified as being in the best interest of the client, other adults in Fynnon would not require them. They are also unrelated to ability/impairment; being similar for all clients attending the centre with no consideration being given to clients' individual abilities to make these decisions themselves.

Secondly, the nature of the activities Margo takes part in are mostly of a leisurely nature. Even in the (academic) literacy and numeracy classes she does not learn many new things. Margo enjoys what she does, and what she does is at least in some aspects comparable to what other adults in Ffynnon do. For those adults however, leisure is only part of their day while Margo spends most of her day 'at leisure'. She is not challenged (the true aim of education) and neither is she working like other adults of her age (see also Chapter Six). Even the leisure activities outside the centre may be described as a 'physical presence' in the community rather than inclusion. When public facilities such as a bowling alley, swimming pool or restaurants are used, Margo always does this as part of a group of people with learning disabilities and with a member of staff present. Apart from spending time with her friend from school, she does not really mix with adults from the larger community. Again, it is not only her (level of) impairment that stops her from using these facilities on her own, or with friends from within or outside the centre. Centre regulations do not allow for clients to go out and do things on their own during the hours they are in attendance. A befriender, an adult who volunteers to befriend and socialise with an adult with learning disabilities, helps Margo to achieve inclusion outside centre hours; during an evening or on a Saturday. They go to the shops together, for a coffee or to the cinema. Margo thoroughly enjoys this and always refers to this person as her "friend". This is not happening during the day when she is at the centre; staffing levels make it impossible to take just one client out into the community.

The question may be asked if the very existence of the S.A.C. with its safe and protective environment stops Margo from leading a life more similar to that of other adults within her society? With the availability of the centre there is no great need to look for alternatives, especially as Margo appears happy and displays little 'difficult' behaviour. In addition and related to this issue are the barriers society has created. Yes, it may be difficult for Margo to take the bus and use the local swimming pool or bowling alley completely by herself. It is also difficult for Margo to obtain and hold down a job without support (see also Chapter Six: A Question of Work). A sheltered or supported employment situation would be a logical next step for Margo but is unavailable.

The aim of the S.A.C. is to help people to reach their full potential, and as much independence as possible. For Margo, barriers to inclusion lie in her own impairment which makes it difficult for her to reach the level of independence needed to access the 'normal' area of leisure and work in her society. However, as shown above this is not the full story. Constraints within the institution such as rules and regulations, number of clients and staffing levels, parental responsibilities and involvement, the nature of activities on offer as well as local social- economic structures (see also Chapter Six: A Question of Work) act as social barriers to her full participation as a respected adult. This is particularly evident in the case of a more able person such as Margo. Attending the centre did not take away her social roles (in fact, it added to the ones she had) but full inclusion was not achieved either.

Ruth

Ruth is twenty-two years old. She had been attending the centre for two years. Ruth had been to a special school and after leaving there at the age of 18, spent some time doing menial work in a factory setting. While being able for the work itself, she was unable to cope in the work situation. At the time of referral she was described as insecure, lacking in confidence, in need of constant re-assurance and individual attention and suffering from bouts of anxiety. She had difficulties relating to her peers, was extremely nervous, made up stories and was left isolated and vulnerable to teasing.

Ruth's greatest difficulties are in the area of social relations. Although she has been formally diagnosed with moderate learning disabilities she is independent in her personal care, but needs help with cleaning, cooking, shopping and public transport. The purpose of Ruth's referral to the S.A.C. was to improve her social, communication, and independence skills. In addition, it was to provide her with an outside interest, meaningful activities through arts and craft and, through the above, an increased quality of life. For Ruth, attending the centre seems to have achieved this. She has been able to form relationships, firstly with members of staff and later with some of the clients. According to staff reports and her last case review, Ruth is now a lot calmer and less anxious. She still gets quite nervous, especially when talking with someone she doesn't know that well. While she was keen to be "interviewed", she soon became distracted and nervous and kept asking; "Is that enough now?" She tells me she enjoys taking part in art and cooking. I have also observed her taking part in and enjoying self-care. Attending the centre has helped her improve her skills and in general improved her quality of life. She was able to form new relationships in a safe and sheltered environment and this has helped her to blossom into a young woman. She still needs a lot of attention and re-assurance and continues to learn and grow, to develop her confidence and to expand her social roles.

For Ruth, taking part in a 'normal' work situation was problematic because of the lack of understanding, support and attention (social barriers) and because of her own anxieties and difficulties (impairment). Trained members of staff at the centre however were able to win her trust and form relationships with her, which in turn has increased her confidence. At present she feels happier in a safe, secure and predictable environment. The programme suits her needs and helps her to grow and develop. It is hard to predict what Ruth will need and wish for in the future. She may grow further towards and wish for a greater integration within her local community. Admission to the centre could, for Ruth, be interpreted as exclusion from her place of work and a kind of social death, the end of her roles as a worker and colleague. On the other hand, it has increased her ability and opportunities to participate in human relationships. Inclusion for Ruth outside the centre is difficult because of her own specific difficulties and the resulting need for an emotionally safe and secure environment. Within the centre she is accepted and respected as a person in her own right. Giving Ruth the special environment she needs can, for her, be seen as respect for her difference.

Donald

Donald, 42, has Down's syndrome, a visual impairment and a weight problem (obesity). He is from a large family and the only one left living at home with his elderly mother in a council estate. He has never been to school. When he was eight he started attending the Junior Training Centre and moved up from there to the Adult Training Centre (as the S.A.C. was called then).

When Donald started at the centre he was reported to have difficulties in communication (with limited speech), to be very resistant to change and a slow learner. It was hard to assess his abilities because of the way he 'stuck' to activities. His medical reports stated that he had no aggressive tendencies, obeyed simple commands, could feed himself with a spoon and was making slow progress. Donald's first review at the centre took place when he was 32. He was progressing well in work and social education and took part in a physical exercise programme. The focus of the review recommendations was the development of Donald's self-expression and communication skills. His mother too was worried about his difficulties in this area and eager to help and get help for him. He was also to continue in his present programme, which included self-help, social and work skills. A next report, at 37, states that Donald is a hard worker and very happy at the centre. His eyes continued to trouble him. Frequent eye infections caused him to loose his sight in one eye and he was not allowed in the workshop any more. The risk of infections due to woodwork and related machinery was deemed to be too great.

At present Donald spends most of his day in the art room by himself, separate from the other clients, doing the same activity many days in a row. For several weeks before Christmas he made Christmas decorations. After some discussion with the staff a new activity, weaving, was organised for Donald. It was a member of staff in the art room who organised this as no one in the centre appeared to take specific responsibility for Donald. He does not seem to participate in any other activities but I do not know if this was his own choice. I never saw anyone looking for him to join a group. He was left to his own devices, which did give him the freedom to do what he enjoyed doing. He was certainly aware and proud of his work and glad to show it to me or anyone else who showed an interest. On the other hand, considering his speech and communication difficulties and his habit of 'sticking to an activity' it may be that with a bit of help he could have enjoyed more of a variety of activities and the opportunity to interact with other clients. As it is, Donald is a loner, at the centre and at home. At home he spends his evenings 'writing' in books, on his own in his room, and he goes to bed early (around 7.00pm). Despite his tendency to be alone, he is very much part of his extended family as I observed when I visited him at home. It is always busy in his house as his brothers and sisters, nieces and nephews all live close by. They call in daily and seem to be fond of Donald.

As a respite facility for his now widowed mother, the centre has played an increasing role. Donald is dependent in most of his daily needs and requirements and the centre takes on part of that responsibility, providing care for a large part of the day, five days a week. Medical reviews and dental care are also organised through the centre. The social worker of the Community Mental Handicap Team has been in touch with the (extended) family to discuss Donald's care for when his mother gets older.

Donald takes part in work at the centre in that he produces something, an activity that he enjoys and appears satisfied with and proud of. Going to the centre also provides him with a routine to his days; the alternative for him would be to stay at home with his parents, which is not the norm for males of his age in Ffynnon. Attending the centre gives him some independence and a social life away from his mother. It offers the opportunity to be in a different place and to interact with different people. That his interaction is limited is related to a number of factors. Donald's own personal characteristics and impairment, the lack of a programme for Donald and the lack of interest and motivation on the part of the staff (due to centre structure and size) may all be barriers to a greater participation by Donald in a greater number of adult activities and social interactions. It also allows him the freedom to choose a place in the centre where he appears to be happy, doing activities that he enjoys. Donald may have continued to develop his work skills and his participation in work if it weren't for his visual impairment and the change in focus of the centre activities (under the influence of changing values and economical climate) from work to social activities (in which Donald does not really take part).

The centre was not a tool of exclusion for Donald. He had already been excluded from education and would now spend his days at home if the centre was not there. It did not change his participation in family life. In fact, it would be questionable if he would still be at home had the centre not been available to support firstly, Donald's parents and later his mum in the care for him. He would, most probably be in full residential care by now. There could be a greater degree of inclusion for him within the centre but on the other hand, Donald may be happy the way things are. This raises the issue about choice and inclusion in wider society, and the centre as a vehicle for that inclusion. Perhaps for some individuals, inclusion within a special service for people with learning disabilities, which in itself is part of the local community, is as much as they are able for or wish for. On the other hand, and with sufficient support, it may be possible to 'include' them more, again within and outside the centre in relevant 'adult' activities and in interactions with other adults. As long as the opportunity is not there it is difficult to say if ultimately it is impairment, social barriers or individual choices that prevent further inclusion.

Ian

Ian is 33 years old. A quiet but friendly man, he is well able to communicate and hold a conversation. He looks after his own personal needs and hygiene and carries out simple tasks around the house. He lives with his mother and stepfather in a small bungalow not far from the Social Activity centre in Ffynnon where he attends on a daily basis.

Ian was born as the second of two children. According to his mother he was the perfect baby, contented, sleeping all-night and developing apparently normally. He was speaking his first words and walking in the baby walker when he was nine months old. He then contracted meningitis and became critically ill. His mother says he cried day and night and the doctor told her: "Let him go, if he comes out of this there will be something wrong." Ian survived and had indeed changed. He was irritable, wouldn't sleep on his own, hated his baths and only slowly recovered the skills he had mastered before his illness. When he was three and a half he was referred to a psychologist who told his mother that Ian's brain was scarred and damaged as a result of the meningitis. Thus, Ian, at the start of his young life had to contend with a physical impairment that would influence his abilities, his personality and his life for many years to come. At the age of four he went to nursery, followed by primary school. While at primary school he was found to be 'educationally subnormal' (there is no information on who provided this diagnosis) and the headmaster told his mother that he would be better off in a special school. Ian went to a residential special school and came back home at weekends. Ian tells me that he was in a "special school" but when I asked him why it was special he answers that he doesn't know. While at school, at the age of 12, he was diagnosed with epilepsy.

In Ian's school leaving report the headmaster wrote that he was "incapable of employment", "lacked the motivation to see through even the basic chores" and would need a "sheltered work setting". Ian however, wished to work in a supermarket. His mother tells me that they went looking for a job together but were unsuccessful. It was a time of economic difficulties with the main industries in Ffynnon closing down and large scale unemployment. The welfare state would provide Ian with a disability allowance if he were not working. His mother explains: "When I heard about the allowance I said no to the (idea of a) job." Ian stayed at home where he was "helping my mummy". When Ian was 17 he received a letter (from social services?) about the then called Adult Training Centre. His mother got in touch with a social worker who sent in an application form for Ian. It stated that both his mother and Ian were in full agreement with this referral. His mother worked as a nurse in the local hospital and was happy to have Ian supervised during the day. Ian already knew one of the clients from his school years and was keen to 'start work'. Shortly after this Ian started at the centre. Ian himself, in his interview tells me that the social worker told him about the centre and that he did not like it at first.

When Ian was 18 he started to have violent, seemingly unprovoked and unpremeditated outbursts during which he attacked other clients and broke a window. This behaviour deteriorated to almost daily physical and/or verbal aggression. He was taken to the consultant from the Community Mental Handicap Team who could do nothing except to say he was "at a loss" and advised centre management to keep a record of exactly what goes on before and during these outbursts. When the social worker contacted the school Ian had attended previously it was confirmed that he had had aggressive tendencies, in particular during the time before the onset of a petit mal seizure. From the records it appears that these difficulties lasted for 3-4 years. After that social work reports state that Ian didn't show any more aggression and that, when he has a problem with another client he now seeks advice from a member of staff.

Apart from his violent outbursts, which may well have been related to his epilepsy and/or reported family problems at home during this time, Ian has always been described as having a pleasant disposition. The lack of motivation he showed in secondary school changed to an eagerness to attend and work at the centre. During that time the centre carried out contract work and it was Ian's job to prepare pieces of wood for jigsaws and furniture. He was described as a good worker and a "good candidate for a further extensive work programme".

At 31, Ian was assessed by Pathway; an agency with the task to find employment for disabled people. He was described as "a motivated worker, well liked by staff and other trainees, with an excellent attendance record and extremely kind to and patient with those with a lower ability then himself." He will try any task without complaints but if he runs into difficulties he always seeks help rather than trying to find a solution himself. A place at a community employment scheme for unemployed people was found for Ian and for a year he worked, three days a week, in a nearby park. Under supervision one of his tasks was the upkeep of a council shed. He enjoyed his work and tells me proudly that he "used to work", "as a gardener for the council" and "made the tea". He doesn't work now and is anxious not to discuss this. When I asked him would he be willing to be interviewed he got agitated and said: "It is not about work?" He tells me he is staying at the centre now. Ian's favourite activities at the centre are woodwork, painting and cooking. He is a bit worried about the new programme. This worry is related to his relationship with his favourite member of staff. All members of staff will be designated as key workers with responsibility for small groups of people. Ian is worried: "Steven will have his own group". Ian wants to be in this group but has not expressed this wish to any member of staff.

For a while Ian attended the local polytechnic college two days a week. He followed the "Life Skills Programme", a class for people with learning disabilities, and received an excellent report. It is interesting to compare part of this report with his school report. At school a "passive and withdrawn boy" who does "not join in with the other children during sports and games". At college, at the age of 31 and taking part in a special adapted programme, Ian is "a conscientious student with an active sense of humour who contributes greatly to discussions and activities". This confirms the notion of people, with or without learning disabilities, as developing and learning throughout their lives. According to Ian "they stopped me going to the tech" but "it was fair, I could read and write". He would have liked to stay, to learn "money" and "the clock". "I wanted to go but Bernard (manager) said no. He did tell his favourite member of staff, Steven, who questioned why he was prevented from going. He also told his mother who discussed it with the manager. The centre manager explained to Ian that the purpose of college was to learn to read and to write, skills that Ian had mastered by then. When his mother and Ian asked could he now go to learn "money" and "the time" they were told that he could do this at the centre. Ian says: "I want to go to college, not do it here. But I can't go anymore now." While I am not sure if this is the full story it is how Ian perceives it. In his view, other adults and in particular centre management have the power and the right to decide if he goes to college or not.

Sport, something he did not like in school, is important in his life now. He tells me he does no work in the centre because of sport. Not keen on it at first he now loves it and has earned "a lot of medals" at the long jump, 200 meter running and swimming. He is in the local Special Olympics team with whom he travelled to Spain to compete. On returning home he received a Civic Award. He also took part in the Duke of Edinburgh award scheme (a scheme whereby young people develop a new skill and take part in an outdoor activity). He and another client and a member of staff walked to a nearby nature park where they camped. "Just to see what you can do for yourself."

At home he keeps his own room tidy and helps his mother in the kitchen. On Sundays he makes the gravy for the lunch; "Mum starts it and I do the gravy". In his free time he makes puzzles and looks at magazines. He also has his music and a video recorder at home. There are also certain television programmes that he watches weekly. He tells me he doesn't go out at night but "I stay with my mummy". He refers to his social worker as "my friend" who visits, has tea with him and tells jokes.

Ian attends the local Faith and Light group. Initially he went with his mother and some other people of the centre. It was a social as much as a religious gathering and they go on days out together. During one of these trips Ian wondered why he couldn't receive Communion. His mother explained that you had to be a Catholic. Ian then expressed a desire to become a Catholic and a priest came to his house to instruct and convert him. He also goes to Gateway on Friday nights (a club for people with learning disabilities), where he meets his friends from the centre. A bus is organised to pick everyone up and take them home again. Apart from the above, organised clubs, socialising with friends outside the centre is difficult for Ian. No one lives near by, he does not use public transport and his mother does not like him crossing the road on his own in case he gets an epileptic fit (which only happens occasionally). Ian tells me: "I can't go out on my own. I am good on the road but in case I have a fit". There is a certain risk in what Ian undertakes because of his epilepsy. It is his mother who decides what risks Ian will take or not and Ian appears to agree with this. His sister is important to him. She lives in Australia and he is in touch with her by phone and by letter. She has three children herself and Ian tells me she sends him photographs of the children as well as gifts. She has also taken him away on holidays with her and her husband.

Relations between Ian, his mother and the centre have always been fraught with tension, in particular around issues of protection and level of independence for Ian. Notes between his mother and the centre discuss the supervision in the care of his clothes, personal hygiene, dressing and pocket money during a trip away with a few of the other service users and staff. During the interview his mother also complained that once after a holiday with the centre Ian had come home with a beard. Parental involvement in the centre is actively encouraged. There are parent representatives on the management committee and their involvement is also encouraged in sports and social events organised by or through the centre. When Ian first joined the Special Olympics Club he was not allowed to compete as his mother was not involved and helping out. She is now on the committee and attends regular meetings. While someone needs to take responsibility for organising these events, this is also a way in which parental involvement in the lives of people with learning disabilities is maintained. His mother's authority is also acknowledged in other procedures in the centre. When Ian was to join a Physical Education Programme his mother's permission is sought and when Ian started work on an employment scheme the centre manager undertook to monitor his work and keep her informed.

At home Ian's mother tries to protect him from meeting too many people. She describes Ian as being easily upset by changes in his routine and by strangers. Initially, she wasn't happy about me interviewing Ian at the centre and even phoned the manager to discuss this. She relented later and allowed me to also interview her at home. In a parents self-assessment form his mother states that she does not (wish to) encourage the use of public transport for Ian but likes him to develop a hobby at home as he has no friends living nearby.

During his life Ian has been included in, and excluded from the areas of education and work under the influence of his impairment. Again, this is only part of the story. Social structures, the exclusion from regular education and unavailability of special education locally, the prevailing economic climate and the existence of the welfare state that made a job less attainable and un-employment more attractive, the existence of special services for people with learning disabilities, the change of focus of this service and the economic and cultural foundations for this change, the control over Ian's life and choices exercised by his parents and the centre all played a significant role in shaping his life and making it different from that of other children and adults in his society. Ian is now in his thirties. According to his age he would be considered an adult in Ffynnon. While he takes part in activities, social interactions and special clubs, he is excluded from two main adult activities in his society i.e. work and adult education. Living at home, having learning disabilities and an emotional disposition that is perceived as vulnerable by significant others in his life also mean that his level of independence and his social life is highly influenced by and under the control of both his mother and the centre he attends. This is exclusion, or at least a limitation of another area of adulthood, namely independence from parental control and freedom of choice.

Lia

Lia is a woman of 33 who has Down's syndrome. She was born the second of two girls and lives with her mother in a terraced house in a village near Ffynnon. Her sister, who has four children of her own also lives in Ffynnon. When Lia was six months old her mother was told by the health visitor "you know she is backward". Her mother says she hadn't known before that moment; she was young, inexperienced and had never seen a "Downs" before. Lia's father, according to her mother, could not cope with imperfection. He divorced his wife when Lia was small and moved to South Africa where he remarried. Lia has no contact with him. Her parental grandparents however stayed in close contact with Lia, her sister and her mother and were very supportive throughout the years. They often looked after Lia and she in turn was close to them. Her mother also had a few good friends who visited often and sometimes looked after Lia. For years Lia also had a steady, paid babysitter.

When Lia came to school going age her mother wanted to send her to a special school but was told there was a long waiting list. As a result Lia was sent to 'normal' school first. Her mother subsequently phoned the principal of the special school and arranged Lia's placement directly through her. Lia stayed in special education until she was 16 years old. At school Lia was described as a clean girl who took care of her own personal hygiene. She liked to play alone or with smaller children, was easy and outgoing but liked to get her own way and was easily upset. Lia was also a neat worker whose concentration improved during her years at school but she never really mastered reading and writing, handling money or telling the time. Her speech, while initially problematic improved in expression and comprehension.

At 16 Lia started attending the Adult Training Centre. The referral report describes Lia as functioning at quite a low level and as someone who would probably not reap much benefit from an educational programme. Instead it was deemed that "instruction in simple craft would be of benefit" as well as road safety, personal hygiene, coin recognition and social sight recognition. When I ask Lia what she does at the centre she tells me: "Oh, I don't know. Cooking. Martin's room (*an instructor*). Pie and chips. Baked beans. I love beans. Pie and chips, pasty, sausage rolls". She also tells me about shopping trips to the town and market where she bought Christmas presents for her sister's children. Lia also loves singing and the time before Christmas was a happy time for her, singing Christmas carols at the centre and with the Salvation Army. When I ask her does she cook at home too she answers: "Yes. Not a lot".

While in her twenties Lia went through a bad spell. The consultant psychiatrist diagnosed her as having depression and prescribed sleeping tablets. Her mother did not agree with this diagnosis. "The doctor said she was depressed because her grandmother had died. Rubbish. These children, they are very cheerful, they don't get depressed for no reason. She loved her grandmother. But after a few days, that was it. They forget and get on with their own lives. If I dropped dead in the morning it would be the same." Lia however was quite ill and her mother suspected there was something else wrong. In the end she had a blood test and it was found that she had a thyroid dysfunction (quite common in people with Down's syndrome). She was put on tablets immediately and is fine now.

Lia likes to go to church but has not received any of the sacraments. Her mother feels that it is enough for "us" to cope with "promises and confession and sin and all that" and that "it is not fair to put that on them *("them" being people with learning disabilities)*." She knows a lot of people but has no special friends to socialise with outside the centre. Her mother explains: "The thing is, she can't go on the road, she can't go out to visit anyone. She has no close friends, it's a pity." Lia and her mother rarely go out together, her mother describes herself as "a home bird". Lia does feel she has special friends at the centre and calls out their names. She also loves to go to Gateway, the club for people with learning disabilities, where she meets up with most of these friends. She goes on regular trips with the centre and has many stories about being away with the staff and other clients.

At home Lia keeps her own room tidy and clean. Her mother explains that she never differentiated in this between her two daughters. She expected the same from Lia as from her older sister, "even if I had to go over it again myself". She does not however see the need for Lia to learn to cook, for "boiling kettles and hot stoves" One day Lia had come home with her thumbs all in plaster; she had cut herself trying to open a tin of corned beef. Her mother was quite "put out". "Why" she asks, "these openers they are lethal. She can buy corned beef sliced if she wants it". Lia however likes to cook and to make her own breakfast. She tells me she cooks at home but "not a lot" and also cleans and polishes with her mother.

Her hobbies at home are listening to music, especially Abba, Jason Donovan and reading books. She does this "in the parlour" and not in her own room. She also likes her bath, to be "nice and clean". Her mother helps her with washing her hair. Lia often visits her sister and regularly stays with her. During our interview she chats away about her sister, brother in law and their four children, three boys and a baby girl, and about how much she loves them. She still remembers the wedding day, the dresses, the church and the party. She tell me that when she goes to stay with her sister she helps her in the kitchen and also loves to hold and kiss her little niece and nephews. She shows me how she holds the baby and tells me "Oh, I love baby. Gonna kiss her".

Lia's future is uncertain. Her mother does not want her in a group home as "she has no real road sense or understanding of money". She has been to the hostel for one or two weeks every year to give her mother a break, but the future has never been openly discussed.

Although Lia was diagnosed with Down's syndrome, she was not 'different' in her mother's eyes until the minute the Health Visitior told her: "You know she is backward?" Lia having Down's syndrome caused her father to leave and cease all contact. It also contributed to her mother's ambivalent attitude towards her. While she insisted on expecting the same of Lia as of her other daughter (for example in regard to the tidying of her room), she continues to express her perception of Lia as 'different' in words: "*they* don't have the same feelings", "*these children* don't get depressed", "*they* should not have these responsibilities (of the Catholic sacraments) put upon them" and in actions: preventing her from cooking at home, going out on her own and from receiving the sacraments and partaking fully in her church.

Lia is of an age that she would normally be considered an adult in Ffynnon. A combination of factors however, has kept her away from many adult experiences. While Lia does participates in a social life with family and special clubs and with friends among staff and clients at the centre; takes part in trips to the bowling alley, the shops and the market in town and has short holidays, she has limited access to other adult experiences. Working, visiting friends by herself, doing her own cooking, being a full member of the church, living and building up a social life away from her mother are some of the things that Lia may aspire to but are unattainable for her. Her classification as Down's syndrome, her personal vulnerabilities and difficulties, her mother's ideas about "Downs" or "people with learning disabilities" affect her freedom of choice and the extent to which she can exercise her social independence. Social structures that provide special education and adult services for people with learning disabilities, while providing her with a 'training' presumably suited to her abilities, and with a social world consisting of peers and staff also facilitated and endorsed her segregation from regular education and work. The cultural values and the economic climate that have changed the centre from a place of work to a place for personal development stopped her from taking part in the adult activity of work; while her mothers attitude and influence appears to question the meaning of her independence training. Lia suffers from an identifiable physical syndrome and resulting intellectual impairment. As such her learning disabilities are at least partly caused by her personal characteristics, but this again is not the full story. The extent to which her impairment influences her life is also determined by cultural values and norms, by social structures and economical climate and by the personal characteristics of significant people around her (her sister does let her cook!).

CHAPTER EIGHT: SUMMARY AND DISCUSSION

Summary and conclusions

In this thesis I have examined the classification and treatment of two small groups of people with learning disabilities: one on the Greek island of Aniksi, the other in the small Welsh town of Ffynnon. By looking at this classification and treatment in their socio-economic and cultural contexts and comparing them to each other, I have identified elements of social context that act as facilitators of or social barriers to inclusion.

The establishment of the two state day services to people excluded from the local adult activity of work because of learning disabilities were influenced by local social structures, the economic climate, politics, and trans-national theories. The service in Aniksi is unique for the island and established within a political context of European support. It is aimed at the training for and encouragement of economic independence that is possible in a climate of economic optimism and where informal structures of work prevail. The day centre in Ffynnon is part of the statutory, lifelong and bureaucratic services for people with learning disabilities, within the framework of a welfare state. Its focus on social activities and independence is influenced by theoretical developments and the local inaccessibility of work for people with learning disabilities. The emphasis and structure of activities in Aniksi and Ffynnon reflect these differences, making them similar to work and education respectively. Relationships between people attending the centres and staff are influenced by personal characteristics and professionalism, as well as by the size and structure of the service. Individual differences within each group attending the centres led to the pursuit of different aims for different individuals. Cultural elements of shame and gender roles result in a smaller total number and a larger proportion of men in the centre in Aniksi.

Certain elements of socio-economic structures and culture facilitate the local inclusion of the people with learning disabilities within and by means of the two centres. Small-scale institutions or small units within a larger institution and simple programme structures facilitated maximum control by and thus participation of the person with learning disabilities in both places. The nature, structure and division of activities similar to those of other adults in local society, informal structures of work, and the notion that all people, including those with learning disabilities, have a right to work contribute to a higher level of inclusion in Aniksi. So does a concept of personhood that requires economic contribution rather than social independence. The recognition and valuation of individual characteristics and social relationships within and outside the centres acknowledges the personhood of people with learning disabilities in both places. Professionalism in the sense of knowledge, skills, empathy and objectivity improved understanding and communication between able and disabled people and facilitated the acknowledgement and experience of personhood through reciprocal relationships. Large-scale services, complex programme structures, invasion of privacy and unnecessary control in relationships between staff and service users acted as barriers to inclusion, particularly in Ffynnon.

People with learning disabilities make high demands on their families in both places and continue to worry parents far into adulthood. To what extent this is experienced as a social problem by parents is influenced by the characteristics and level of disabilities of the child, socio-economic structures, economic climate and culture. An ethos of collective responsibility, formal support services and supportive social networks of extended family, friends and neighbours made life easier in Ffynnon. The small-scale society of Aniksi does not provide much of this kind of support. It is still required however by parents who feel isolated in the care for their learning disabled children. Parent associations in both places provide peer support and a forum for the demand of services. Cultural valuation of the nuclear family as fully responsible, and the main provider of care, for weaker members of society contributes to the social problem of learning disabilities and thus acts as a barrier to inclusion. The expectation that children grow up to become independent of their parents may prevent the inclusion of the person with learning disabilities as a valued family member and add to parents' grief in both places, but more so in Aniksi where no alternative care is available. On the other hand, a model of personhood that stresses the importance of relationships facilitates inclusion in both places especially in single parent families. The fact that parents in both places experience grief and shock in relation to the classification of their child as having learning disabilities, even if support is available, suggests that there are intrinsic negative values attached to the category.

The majority of people attending both centres were formally classified as having learning disabilities. The local presence of classifying agents and specialised services influenced only the timing of this classification. Cultural influences on the timing included parental attitudes towards seeking help in family matters. While for many individuals attending both centres classification was medical and linked to an identifiable and organic cause, this was not their common characteristic. It was their "long term intellectual difficulties to master the knowledge and skills necessary to participate in activities and relationships common to their society" (Jenkins 1998) that led to the notion that the child or person was 'different' or 'slow' and had 'special needs'. This informal classification was made regardless of the time of formal classification for all but one of the individuals I researched. It is linked primarily to personal characteristics or impairment and can be sufficiently powerful as to result in exclusion. It also plays an important part in the process of formal classification between the characteristics of the child, authorized agent and parents who accept or actively seek it. Long-term consequences of the classification of a person as having learning disabilities vary between Aniksi and Ffynnon. Special and segregated services facilitate (continuous) exclusion but are not the sole cause of it; even when no such services are available, people in both Aniksi and Ffynnon have been excluded. They do however cause this exclusion to be more long term, widespread and inflexible in Ffynnon, as do formal social and economic structures. The wide definition, varied nature and informal structures of work for example facilitated a higher degree of inclusion in Aniksi.

Discussion

The following themes re-occurred across the different chapters and influence the social experience of learning disabilities in both places. They warrant further discussion and perhaps further research in a variety of socio-cultural settings.

Vulnerability, protection and control

One characteristic of people with learning disabilities frequently described in the literature and by the parents and professionals working with the people I have researched is their vulnerability (Alaszewski and Alaszewski 2002, Jackaman 1991, Long and Holmes 2001). The answer to this assumed or perceived vulnerability is protection, an element very much part of the relationships between people with learning disabilities, their parents and professionals that work with them. In fact, there appears to exist a notion that "society has a complex responsibility to someone who is both an adult and who is also substantially more vulnerable than other people" (Robinson 1991:82). In Aniksi, this notion may perhaps not be widespread and formalised in official policies. It was however reflected in the action of a concerned citizen, who phoned the centre for disabled people when she suspected the abuse of a young man with learning disabilities. In Ffynnon, this responsibility is reflected in statutory responsibilities towards people with learning disabilities and in protective policies minimising risk within services (Alaszewski and Alaszewski 2002: 56). These policies meant that Margo had to have a note from her parents to say that she was allowed to go shopping with a friend after she left the centre, and that people need parental permission to take part in certain centre activities. On a more personal level, in direct relationships between clients and staff or clients and their parents, there are many examples throughout this thesis illustrating the power and control that may be used towards people with learning disabilities, which is justified as a protective influence. Ian's mother does not allow him to cross the road in case he has an epileptic fit. Ruth is not allowed to cook at home in case she burns or cuts herself. David is forbidden by a member of staff to take three spoons of sugar in his tea in case he puts on to much weight and puts his health into danger. Emma's mother does not allow her to visit friends by herself. These concerns may be realistic, each to a more or lesser degree. Various authors have shown that people with learning disabilities are at an increased risk of criminal exploitation and abuse (Long and

Holmes, 2001: 139). Protectiveness and the related power and control in the relationships between people with learning disabilities, their parents and professionals may, however, also act as barriers to inclusion. A significant element is that it is usually not the person with learning disabilities themselves who weighs up these risks against the desired activities and makes choices and decisions accordingly. The authority of parent, service staff, professionals and policy makers in all of the above cases was accepted by most of the persons with learning disabilities in this research, who "often seemed willing to accept that others made judgements and decisions on their behalf" (but not always, as I have also shown in a number of examples). Dealing with risk is influenced not only by the vulnerability of the persons concerned, but also by social structures and culture. In Ffynnon, limited relevant work was carried out to empower service users to recognise and deal with risks. One of the programmes on offer was road safety. Interestingly, the mother who did not allow her son to cross the road did not allow him to take part in this programme. Few of the people I met at the centre were able or allowed to use public transport on their own. Programmes covering all aspects of safety are widely available for children in order to teach them the necessary understanding and skills to deal with dangerous situations but the equivalent does not appear to be available for people with learning disabilities (Long and Holmes 2001: 40).

Culture is important too. While social context contains increased risks for people with learning disabilities but provides less preparation and education in relation to these risks, culture in Ffynnon encourages risk taking as part of personal development (Alaszewski and Alaszewski, 2002). In Aniksi the people I researched were also perceived as more vulnerable than their peers. The manner in which parents and staff dealt with these risks however was different than in Ffynnon. One particular cultural factor, that of gender roles, appears to be of significant influence. The protection of the girls and women in the centre is not fundamentally different from the traditional protection of most girls on the island. In fact, gender roles may influence or even override the consequences of learning disabilities and associated vulnerability. This is illustrated by the story of Maria, a girl whose mother was particular worried. She frequently discussed her daughter's vulnerability to financial or sexual abuse with me. She explained this as a consequence of her daughter's difficulties in understanding certain social rules. Maria was not allowed out on her own, only reluctantly let go to the centre and not allowed on the trips. These protective measures were not unique however and many girls on the island are treated and protected in similar fashion. This mother did not see the vulnerability or indeed the learning disabilities of her daughter as a barrier to inclusion and marriage. She was hoping for her daughter to marry a "good, working boy" and have children. It is likely that as a woman, she would then be under the 'normal' protection of her husband.

For the men too vulnerability associated with learning disabilities was certainly recognised. It was expressed in parental worries for the future and in the concern for the young man who may have been sexually abused. Gender roles however appear to limit the influence of this vulnerability on the relationships between the young men at the centre, their parents and staff. Most of them had the freedom to walk around the town or village as they wished, to go to the beach or for a ride on a motor bike with a brother or friend, to cycle to the centre or to go to town at night. Their mothers, their main carers but *women*, did not stop them.

Protective powers and control may facilitate inclusion as happened in the already discussed situation of Tassos. His social situation considerably improved after the intervention by a fellow citizen in Aniksi, as did the life of Ruth in Ffynnon who was admitted to the centre after unhappy experiences in her work situation (see Chapter Seven: Individual lives). Both were better able to participate in a variety of satisfactory social relationships in their new, more sheltered situations. Also, the control and power exercised by others over people with learning disabilities as a result of their vulnerability is different perhaps only in degree, and not in nature from the control all people within a given society are subject to in the name of our 'protection'. We are all confronted with rules and limitations of choice we may not have chosen ourselves. People with learning disabilities however, already more vulnerable, are at a higher risk of abuse in this area (Alaszewski and Alaszewski 2002: 57, Jackaman, 1991: 48) It is when power and control in the relationships between people with learning disabilities are not commensurate with the possible risks they are exposed to that they become barriers to, instead of facilitators of, inclusion. After all, "The rights of people with learning disabilities to lead ordinary lives include the right and the opportunity to take associated risks" (Alaszewski and Alaszewski, 2002: 57). Closely related to the above is the extent to which people with learning disabilities themselves may exert control over their own lives and what elements of their social situation facilitate this control, which brings me to the next theme of this discussion.

Concept of personhood

While power and control in social relationships between people with learning disabilities and those close to them may threaten certain aspects of their adulthood, the issue of personhood is a more fundamental one. It has been suggested that a model of personhood encompasses various dimensions: material, social, psychological and spiritual (Morris 1994). It is possible to examine the influence of each of these dimensions on the experience of learning disabilities.

People with learning disabilities in both places do not conform to the local norms of 'being of healthy body and mind'. There is great concern in both places that children and adults not fitting in with this ideal should be identified and this identification is a predominantly a medical matter. This notion was not contested by any of the parents. What is contested is the relative importance of the material dimension in the perception or evaluation of someone as a person. One father in Aniksi actively disagreed with the doctor when he described the future for the boy as influenced primarily by his physical condition of having Down's syndrome. This father set out to prove that his son may be different in a material sense, but psychologically and socially fundamentally equal to any other child. As a son and a brother he was worthy of and given his family's love, care and attention. As a person capable of learning and development he had a right to and was given education. The concept of the person as learning and developing human being was important to this father, a teacher. In his eyes, the learning disabilities of his son made him only gradually, not fundamentally different from other children. Antonio was perceived and treated by his family as a person on the basis of his potential for learning and his social embeddedness. This was revealed in the father decision to leave his job so he could teach his son at home, and in the family's move from Albania to Greece to find a special school or training centre.

The emphasis on various dimensions of personhood may change over time. For the mother of Bernard the material dimension of personhood was initially very important. She had wondered why the doctors saved her son who has cerebral palsy and moderate learning disabilities, "if he wasn't going to be any good". Later however, Bernard was very much recognised as a person. He was "a lovely boy", a son and brother who was worth the effort of weekly visits by his whole family, including his carsick sister, when he lived in a hospital two hours away from home. His parents worked hard to establish accommodation for him nearer to home. At present he visits his family regularly and is much valued and loved by his siblings and widowed mother.

A concept of personhood, which stresses social embeddedness and the importance of reciprocal relationships, is inclusive of individuals with learning disabilities. Many of the people I interviewed in Aniksi and Ffynnon perceived themselves, and were perceived by others as valued participants and contributors to various social relationships. Being recognised and recognising oneself as a beloved son, a helpful daughter, a spoiled sister, a favourite brother, a proud uncle, a good friend, a respected colleague, a doting auntie confirmed their personhood. This supports evidence from Wales where "some young people with learning difficulties and their parents promoted their personhood based upon their roles within a social network" (Davies 1998: 121). The capacity of all persons for learning and development is another inclusive element of personhood, one that is endorsed by Antonio's father but also by many other parents in both places, when they pursue suitable education or hire a private teacher for their child with learning disabilities. Learning and development are closely related to achievement and independence, often quoted as being characteristic of the Western concept of personhood and as *exclusive* towards people with learning disabilities (Davies 1998; Ingstad and Whyte 1995; Malin, Manthorpe, Race and Wilmot: 2000). Interestingly, the majority of parents in both places expressed strong views of their child as capable of learning. In Ffynnon parents pointed out their children's achievements over the years and the progress they made. In Aniksi, parents believed that their child was capable of learning and felt frustrated because their sons and daughters were excluded from education. In both places people with learning disabilities themselves showed their ongoing capacity for learning, growth and increasing independence. A concept of personhood that includes learning and personal development, achievement and independence may be seen in gradations (Oliver 1990, 1996). A concept of personhood that encompasses these elements does not need to exclude people with learning disabilities. Funnily enough, this brings us right back to Itard, who believed people with learning disabilities were human because of their capacity for socialisation, if the right system of teaching was used (van Gennep, 1980). An early social model of learning disabilities? The fourth, spiritual dimension of personhood was inclusive for most of the people in my study. In both Aniksi and Ffynnon people with learning disabilities attended, were accepted and confirmed their personhood as members of one of the Christian churches, as brothers and sisters in Christ. This was perhaps more obvious in Ffynnon because of the social life attached to the church, which included people with learning disabilities, for example, in the church choir. One mother however questioned the appropriateness for her daughter of full participation in the sacraments of the church. She felt it would put to much pressure on "these children".

The model of personhood itself is influenced by socio-economic factors. Single parents in Ffynnon for example appeared to perceive their child with learning disabilities as a valued partner in reciprocal relationships within and outside the home. One aspect of these relationships is the support or 'care' given by the person with learning disabilities, especially if 'care' is used in the sense of emotional and practical support (Williams and Robinson, 2001). Various single parents in Ffynnon spoke of their son or daughter as supportive, helpful, or a valuable companion. Parents in similar circumstances with perhaps more able sons and daughters in Aniksi did not perceive them as 'helpful'. One particularly able man was taught, and now shared all the housework with his mother. His mother however still described this as a stressful situation where she was "teaching" her son "as no one else will do it". This mother's worries about the future in a social context where no sheltered accommodation is available for people with learning disabilities influenced her perception of him as a 'burden' rather than a 'support'. In Ffynnon, the one mother who was very worried about the lack of alternative accommodation for her son described a similar experience. In the eyes of these women, social independence was a more important element of personhood than reciprocal relationships. It appears that if support services are such that practical problems for parents lessen, with time the emphasis can shift from the material to the social dimension of personhood. This was confirmed by the experiences of parents and siblings in Ffynnon where many parents, similar to those in Davies's study (Davies 1998), spoke of the special social qualities of their children. Eddy's mother is delighted when her son who has severe communication difficulties answers the phone, 'talks' on the phone and subsequently signs to her that his sister is on the phone. Kim's mother says she is "great with her nieces and nephews". Emma's mother tells me how her daughter is loved and spoiled by family and friends who "give her everything". Other variables may also be of influence here: links with the personal characteristics of parents and child for example or other cultural elements. Further investigation is needed.

Boundaries to inclusion

"Personhood is based in cultural assumptions and confirmed through social relationships" (Davies 1998: 116). It follows that the perception of an individual as a person is socially influenced by the availability of opportunities to participate in and contribute to social relationships. This may be linked with the original Scandinavian idea of normalisation that focussed on the rights of people with learning disabilities to participate in 'normal' patterns of ordinary living (van Gennep 1980; Hattersley 1991). Wolfensberger's (1972) added condition of integration however may not always be helpful for people with learning disabilities. Inclusion for the people in this study is a gradual process that takes place within as well as outside the special 'segregated' centres through the participation in and contribution to social relationships with peers, staff and other professionals, friends, families, customers and many others. Inclusion is also achieved by participation in activities within and outside the centres such as education, work and leisure. Barriers to that inclusion were identified in individual characteristics and abilities and in the nature and structure of these relationships and activities rather than in the walls around a special institution. In fact, some factors that facilitated inclusion may be satisfactorily provided by a special institution. This was shown in the centre in Aniksi and in the flat in Ffynnon where smallness in scale and number, simplicity of structure and familiarity with staff facilitated high levels of personal control, freedom of choice and the participation in reciprocal social relationships for people with learning disabilities.

The psychological need for an environment that is secure because it is predictable and controllable is a well known socio-psychological need and a condition for a successful exploration of and participation in an expanding social world (Maslow in Tunali, Belgin and Power 1993). This is true for all human beings and learning disabilities do not influence this in any fundamental way. Learning disabilities as a characteristic of a person may however influence the level required. This was clearly shown by the examples of Ruth in Fynnon and Tassos in Aniksi who were excluded from an 'integrated' work setting. The small-scale setting and close personal relationships at the centres provided the level of safety and predictability of environment that allowed them maximum control and opportunities to expand their inclusion to a widening circle of activities and social relationships. Their experiences also draw attention to the very important concept of quality of relationships. This is an ambiguous concept and further exploration of its use for the evaluation of inclusion is outside the scope of this study but may be a subject for further research. Others too have found inclusion within the centres. Some of the more severely disabled people in particular found and took up the challenges of new activities and relationships within the boundaries of the institution. Helena for example, who had never ventured much outside the parental home and would not walk unless her mother held her hand, learned to walk independently and has come to view herself as part of a group that she joins in the garden at lunch time.

Boundaries to inclusion are thus found in the individual characteristics, abilities and choices of the individual but are also related to social context. Social context may limit opportunities available, including that of choice. Choice can be particularly problematic for people with learning disabilities. This is partly related to their impairment, but also to socio-cultural context that influences the experience of and opportunity for choice (Bayleys 1991) and in which power and control by others also play a role. Choice can be facilitated in different ways. When Freddy in Ffynnon cast his vote during a large client meeting, he felt proud and important to be included in this way. His influence on the ultimate decision that was taken by vote however was nil, as he put up his hand each time an option was put forward for a vote. It may have achieved a greater degree of inclusion for Freddy if he had been enabled to make his choice known through a more simple and controllable way.

In this study I have found boundaries to inclusion in individual characteristics and in social context, but not in the walls of institutions. I suggest then that inclusion is only truly inclusive of people with learning disabilities when it is viewed as a process of potentially increasing participation and contribution, with a focus on the identification of facilitators of, and social barriers to those opportunities including that of realistic choice.

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