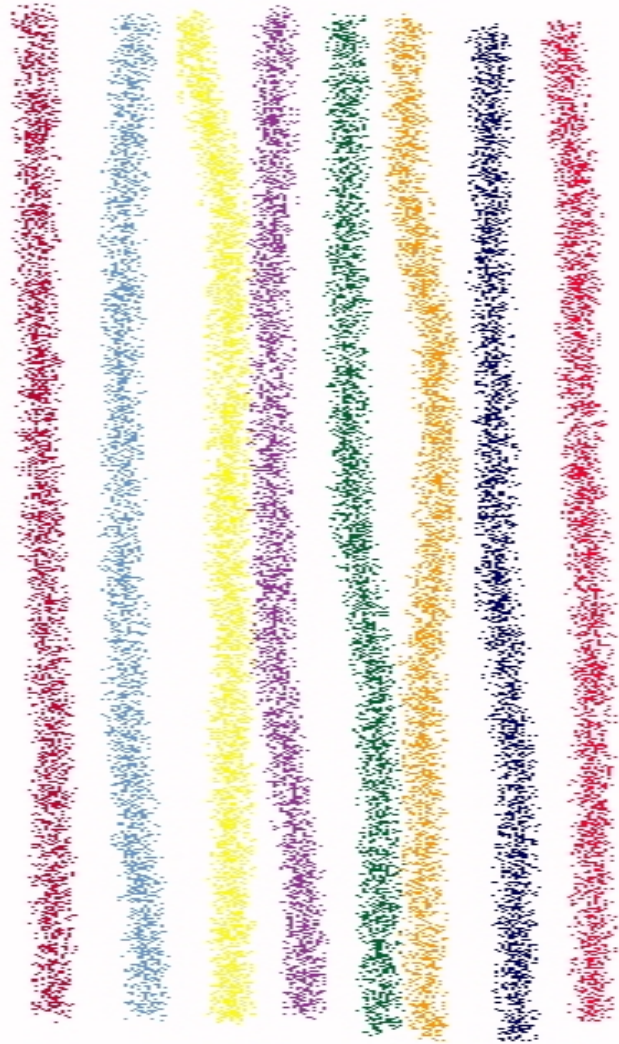


Intellectual Disability in Europe

Working papers



European Intellectual Disability Research Network

Aristotle University of Thessaloniki, Greece

Rijksuniversiteit Groningen, Netherlands

Universidad de Cádiz, Spain

Universität Siegen, Germany

Universiteit Gent, Belgium

University of Kent at Canterbury, Great Britain

Uppsala Universitet, Sweden

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Preface

This report is the first output of the European Intellectual Disability Research Network (IDRESNET), a group of academics working together with support from the European Union Fifth Framework for Research and Development.

IDRESNET includes colleagues from seven Universities: *Universidad de Cádiz*: J. García-Ibañez, T. Magallanes, Ramon Novell, Miriam Poole, Prof Luis Salvador-Carulla, *Universiteit Gent*: Catherine Molleman, Prof Dr Geert Van Hove, *Rijksuniversiteit Groningen*: Prof Dr Carla Vlaskamp, *Universität Siegen*: Laurenz Aselmeier, Dr Johannes Schädler, Prof Dr Norbert Schwarte, Timo Wissel, *University of Kent at Canterbury*: Prof Jim Mansell, Dr Julie Beadle-Brown, Paul Cambridge, Dr Rachel Forrester-Jones, *Aristotle University of Thessaloniki*: Dr Susana Padeliadu, *Uppsala Universitet*: Dr Kent Ericsson. The network is coordinated by Prof Jim Mansell of the Tizard Centre at the University of Kent at Canterbury.

The network held its first meeting at the Universität-Gesamthochschule Siegen in January 2001. Two further meetings have been held with support from the European Union, in Barcelona in April 2002 and in Ghent in October 2002. These meetings focused on a comparison of services for people with intellectual disabilities in the countries represented. This report is the first output from these meetings. It presents descriptions of services for people with intellectual disabilities in each country, together with an overview. It is intended primarily as a resource – a starting point – for those interested in developing a comparative perspective. Service structures, funding arrangements and policy guidance are all different in the countries involved in IDRESNET and descriptions of the situation in each country immediately raise interesting questions. Partly these concern terminology (and so this report includes a glossary of service types) but they also concern the assumptions underlying decisions about how services should be organised and how they should work.

As a working document, the report does not include comprehensive coverage of every issue. It focuses mainly on services for adults with intellectual disabilities and on residential care and day-time activity.

The countries taking part in the network include a wide range of the different types of service structure and provision found in Europe. However, there are also important regional variations in many countries and descriptions presented here need to be developed and extended to take account of these.

A second report is planned for the Summer of 2003. This will present an analysis of policy and services for people with intellectual disabilities in the IDRESNET countries, in which the underlying assumptions, structures and processes are explored from a comparative perspective.

Acknowledgements

We would like to thank the University of Siegen for funding the initial meeting of IDRESNET, the Government of Catalonia for hosting and supporting the seminar in Barcelona and the European Union for funding the seminars in Barcelona and Ghent from the Framework 5 programme of research and development.

We would also like to thank the representatives of service providing organisations, non-governmental organisations and user organisations for their participation in the project. Thanks are also due to people with intellectual disabilities and the staff supporting them in services in Nordrhein-Westphalen, Hessen, Catalonia and Flanders visited by members of the network during the seminars.

Editorial assistance in the production of this report was provided by Hanna Peters of the University of Siegen and Carey Sellwood of the University of Kent at Canterbury.

Intellectual Disability in Europe: Overview

Julie Beadle-Brown, Jim Mansell¹ and members of the European Intellectual Disability Research Network²

Introduction

People with intellectual disabilities represent one of the most disadvantaged social groups in European countries. The pervasive nature of intellectual disabilities creates very high levels of need for assistance often throughout every aspect of the individual's existence and over the whole of the person's life. Traditional patterns of care have been heavily based on institutions, which tend to segregate and isolate people from the main stream of society. Some countries are now beginning to replace these with more individualised, more integrated services which aim to support inclusion of people with intellectual disabilities in society (Mansell & Ericsson, 1996).

In the European context, comparison between countries is useful in this enterprise, for three main reasons:

Comparison may lead to actual harmonisation of practice and thereby to improvement in the quality of life of people with intellectual disabilities and to greater social cohesion in the European Union

Improvement in services may result from comparison, as a broader range of possibilities are considered by Member States due to the dissemination of good practice. Comparative studies increase the range of possible innovations in service organisation, design and delivery.

Greater understanding of the process of service development may result from comparison, due to the identification of contextual factors which may be implicit in the national account but are necessary conditions for implementation elsewhere (Jones, 1985, p4).

Comparison requires, first of all, description of the situation in the different countries involved. This report presents descriptions of each participating country, prepared to a common template. It is intended as a starting point for comparative analysis.

This chapter provides an overview of the material presented, briefly highlighting arrangements in different countries and recording questions and issues identified for further study. The first part of the chapter concerns the nature of intellectual disability: the way in which it is defined in different countries, the implications of intellectual disability for the individual's legal status and the implications of definition and status for eligibility for services. This is followed by a section on the policy framework in each country, addressing specific policies relating to

¹ University of Kent at Canterbury

² Other members of the network participating in this project were: *Universidad de Cádiz*: J. García-Ibañez, T. Magallanes, Ramon Novell, Miriam Poole, Prof Luis Salvador-Carulla, *Universiteit Gent*: Catherine Molleman, Prof Dr Geert Van Hove, *Rijksuniversiteit Groningen*: Prof Dr Carla Vlaskamp, *Universität Siegen*: Laurenz Aselmeier, Dr Johannes Schädler, Prof Dr Norbert Schwarte, Timo Wissel, *University of Kent at Canterbury*: Paul Cambridge, Dr Rachel Forrester-Jones, *Aristotle University of Thessaloniki*: Dr Susana Padeliadu, *Uppsala Universitet*: Dr Kent Ericsson

people with intellectual disabilities produced by central, regional or local governments (for example, specifications of the kinds of intellectual disability services that should be provided), but also extending to general policies produced for other reasons which nevertheless have an impact on services for people with intellectual disabilities (for example, specifications of which public authorities are responsible for social welfare services) and the policies and guidance produced by other organisations (for example, professional organisations) which, though not carrying the authority of government policy, are still influential in services for people with intellectual disabilities.

The third section concerns the way in which services for people with intellectual disabilities are funded, including the balance between individual contributions, discretionary funds and entitlements and between central and local government. This section also addresses the balance between public and private provision and whether this is changing in the face of demographic and fiscal pressures. This is followed by a section which focuses on services for people with intellectual disabilities. Part of this examines the main types of service structure emerging as services develop beyond the institutional era (for example, splitting the purchasing and providing of services between different agencies to operate a quasi-market); part examines what kinds of service models are favoured as services develop (eg supported living over group homes); and part concerns the number of places provided and the shortfall in provision.

Finally this chapter explores the impact of services on the people who use them – people with intellectual disabilities themselves and their families.

In each section, there is a short overview of the main issues and then a presentation of the major issues which emerged from discussion in the two seminars.

Definition, legal status and eligibility

Overview

There are a number of different terms used within the seven states in the network, the most common being mental or intellectual handicap, mental retardation, learning disabilities and intellectual disabilities. In all countries more than one term is in current usage in different systems or by different groups. For the most part, the more derogatory terms such as “idiot”, “mentally subnormal” or “incurable” are not used in official documentation, although they may still be used in practice. The exception to this is the term “mental defective” which is still used in the British legal system.

In terms of definition, the influential definition is that of the American Association on Mental Retardation (1992), which defines mental retardation as involving significant impairment in intellectual functioning with significant impairment of at least two areas of adaptive functioning and age of onset before 18 years. However, although this is the definition most often used or adapted for use in each country, there is wide variation in how definitions are used to determine eligibility for services.

In all states people with intellectual disabilities are deemed to have the same civil rights as any other citizen. In most they have a legal right to an education and in some they have a legal right to services. In some countries discrimination against people with intellectual disabilities is unlawful. However, in most countries there is scope for having people with intellectual disabilities declared legally incompetent and therefore either removing any decision-making authority from them or providing third-party supervision or substitutes for decision-making. Even for those who are deemed competent, other barriers may stop them actually exercising the rights afforded to them by law.

Part of having civil rights is being able to participate in the life of the home and community, access the same activities, facilities and services as other people. However, in all countries people with severe and profound intellectual disabilities are unable to exercise these rights to

the full extent possible because services fail to provide enough skilled support in the community or are based on congregate care in large and for the most parts isolated institutionalised services.

In most countries people have to meet a certain set of criteria to obtain the service required or desired. If judged ineligible the ability to appeal varies across states. However, what seems to be common is that the fighting capacity of parents is important, in any state, to actually get the services required, even in states where people have a right to services. In general, people are now afforded rights rather than offered charity but this tends to be different from actually getting those rights and accessing the services – intentions are good but practice is different from what is available on paper in many states.

Although in most countries people with an intellectual disability have a right to services, this does not always mean that they obtain the services they really need or want. Scarcity is what necessitates the use of eligibility criteria – in most countries there is a shortage of services and as such there has to be some way of making services available to those who most need them.

In most countries three approaches to determining eligibility are used: one based on functional limitations (such as need for income or housing or work), another on the nature of the person's disability (such as whether the person is determined to have intellectual disability) and the third on the individual's social insurance status. Many different criteria are used at different levels and, often, criteria are used to select people who will suit the facility or service available – that is, criteria are determined by the service to screen out people the service considers should be ineligible, rather than determined by status or need or preference. There is little standardisation from one facility or service to another, let alone across countries. Given the connection between eligibility criteria and funding which exists in some systems, there is evidence of discrimination against people with more complex needs where funding is not adjusted to reflect this.

Prevalence figures in all the countries studied were less than 1% of the general population (although figures for the Netherlands were relatively higher than in other countries). However, methodological difficulties make it very difficult to make accurate comparisons across countries. Even in countries for which there are government statistics or epidemiological research, there are inherent methodological problems that reduce accuracy and reliability. In some states, such as Germany and the United Kingdom, official prevalence figures refer to all those using services for people with intellectual disabilities, irrespective of whether they have a diagnosis or assessment of intellectual disabilities. In epidemiological research, those studies which screened whole populations, report generally higher prevalence than those which looked at only those people accessing services. Epidemiological studies suggest that the overall prevalence of severe intellectual disabilities (approximating to IQ<50) is between 3 and 4 people of all ages per 1000 total population, implying that in the 15 countries of the European Union (total population 380 million) between 1.1 and 1.5 million people have severe intellectual disabilities. The equivalent figure for mild intellectual disabilities (approximating to IQ 50-70) is 2.3 to 2.7 million people, but many of these individuals will not need special help in adult life.

Issues raised in discussion

What use is the label “person with intellectual disability”? The term is an administrative rather than a biomedical category that encompasses an extraordinarily wide range of people with very different problems. For this reason, ‘intellectual disability’ is not included in the World Health Organisation and World Bank database for evidence-based planning - it is perceived that there is no clear consensus on the concept and no clear data on which planning could be based. In addition, defining an individual as having an intellectual disability raises the possibility that they will experience less good treatment because of the label and the stigma attached to it. A label of intellectual disability is sometimes a passport to poorer living conditions.

On the other hand, a policy which does not differentiate people with intellectual disabilities from other groups of people receiving public services also runs some risks. It may mean that the special needs of individuals with intellectual disabilities are overlooked – the differentiation of intellectual disability from other problems was in many countries a precursor to improving services. It may also mean that it is more difficult to target resources to the most disabled people – that the most resources will go to people who are more vocal lobbyists and who can re-enter the labour market more easily.

This is not a completely resolvable dilemma. So long as people are in competition for scarce resources, there are likely to be advantages in differentiating groups of people with particular needs where advocates for the interests of these groups perceive a competitive advantage in doing so.

Part of a response to this issue lies in applying the principles of 'universal design' and a 'society for all' – making products and environments usable by everyone, to the greatest extent possible, without the need for adaptation, special design or help. In so far as this is possible – for example, through reducing the cognitive burden of using equipment and environments – people with intellectual disabilities can participate in mainstream activities and situations. Examples of this approach relevant to people with intellectual disabilities include use of iconic instead of word signs, simpler language and fail-safe or error-preventing equipment.

However, many people with intellectual disabilities have such severe problems that this is not likely to be sufficient. Where extra help is required, it may be appropriate to reduce reliance on diagnostic or quasi-diagnostic labels in favour of increased use of functional assessment. Instead of allocating services on the basis of 'intellectual disability', services would be allocated on the basis of 'housing need' or 'assistance needs' or 'financial needs' and these services would be the same whatever the presumed cause of the need. Functional assessment might help prevent worse treatment than for other members of the population.

For people with severe and profound intellectual disabilities, especially for those with multiple disabilities or other complex needs such as challenging behaviour, any assessment is heavily dependent on assumptions about 'the present boundaries of the possible'. Judgments about what kinds of services would be best for an individual depend on a knowledge of what can be achieved – both in terms of an awareness of the range of options ideally available in the community and what it would take to help individuals live this type of life if they wanted to do so – what is needed is not so much a clinical assessment but rather an ecological assessment. The latest revision of the American Association on Mental Retardation definition of mental retardation (Luckasson et al., 2002) and the new International Classification of Functioning (World Health Organization, 2001) both strengthen the extent to which assessment includes the kind of supports and assistance an individual requires to function in the way they wish.

Finally, consideration of entitlement to and eligibility for services has a geographical dimension which is seen most clearly in countries with market-based approaches to service organisation. Where those with intellectual disabilities are the children or siblings of local people, acceptance into the community may be easier to justify and to achieve. However, where people have been displaced from their local community, treated as a commodity and traded across community boundaries, the basis on which someone can be introduced into a community as part of that community has disappeared. The disruption of family and community ties was an important disadvantage of the institutional era of services but it lives on in some market-based systems.

Policy Framework

Overview

Each country produces policy guidance from government that relates specifically to people with intellectual disabilities as well as policies which are intended for more general purposes but which have an important impact in intellectual disability. The balance between generic and special policy varies, with some countries in the group (Greece and Spain) not yet producing extensive special policy on intellectual disability. The consistency of different parts of the policy framework also varies widely, from Sweden, with a coherent, integrated framework developed over many years and enshrined in law to the UK, with multiple and inconsistent policy initiatives. Where policy is produced by different parts of central government (eg by education and health and welfare ministries) or by different levels (eg local and central government) there is the potential for conflict. For example, in Belgium and in the UK there is some evidence of policy support for segregation at school but integration in adult services, and in Germany and the UK there is evidence of tension between central and local government policy in adult services. Partly as a consequence of this, policy is developing unevenly in different territories within the same country – whether as a result of national (UK) or regional (Spain, Germany) government structures or as a result of more local variation in implementation.

The extent to which policy is made in partnership with people with intellectual disabilities and their families also varies. In some countries (eg Sweden, Belgium) there are relatively well-organised mechanisms supporting this involvement. Where government direction is relatively undeveloped, parent and volunteer organisations play a much larger role in setting out the policy agenda.

The central axis of policy reported in these working papers is the extent to which policy supports the integration of people with intellectual disabilities in society rather than their segregation in specialised services, often institutional in character and away from their families and communities. Sweden has outlawed institutional provision altogether in favour of small-scale services in the community. England has substantially reduced the amount of institutional provision and announced the intention of completely phasing out long-stay hospitals, while leaving open the option of some larger congregate-care facilities. Belgium, Germany and the Netherlands all have strong traditions of institutional provision and these still dominate policy and provision. In each of these countries there are moves to shift the balance of services towards small-scale community-based alternatives, often restricted primarily to those people with mild or moderate intellectual disabilities.

Issues raised in discussion

The main task in developing a comparative understanding of policy in intellectual disability is to identify and weigh the different factors influencing policy, to try to explain differences between countries. These factors include:

the history and pattern of development of intellectual disability services

the state organisation, budget arrangements, and service structures

the care model being espoused as ideal but also care models actually in use

the ideology of decision-makers

History is not, in itself, an explanation. So the task in understanding the effect of the history of services on current policy is to identify the ways in which historical facts are expressed in the current framework of incentives and rules which shape policy now – and especially in the organisation of society and services. These might include direct effects, like the involvement of service providers working with people with intellectual disabilities in shaping policy, as a

result of a concordat made in the past (as for example in Germany). They might also include indirect effects, such as the difficulty British policy-makers experience in even discussing a mixed-economy of provision in health care because of the historical importance of the National Health Service. Here the effect of history is not just on the content of policy but on the questions that can be asked and the frames of reference that can be used.

Policy is clearly also influenced by the pattern of investment in existing services as well as by comparisons with alternative models. In some countries (eg Belgium and the Netherlands) the existence of waiting lists for the large institutions has helped legitimise this form of service. Governments face the dilemma of whether to invest in bringing institutions up to acceptable standards or to abandon them in favour of community services. This decision is made more complicated where the pattern of development is based on assumptions that only people with mild or moderate intellectual disabilities can live in community services.

There is quite marked difference in the role of evidence and empirical data in policy-making, with Sweden and the UK marking opposite ends of the continuum. Swedish policy appears to have been consistently dominated by ideological considerations about normalisation and the production of evidence about the effects of particular service models has been much less important. In the UK, in contrast, there has been increasing emphasis on evidence as a justification for policy decisions, with a large infrastructure of research and evaluation producing information about different services options on a whole range of criteria. This is not to say that the impact of evidence on policy is, in fact, any greater where it exists; new British policy, for example, makes almost no reference to the evidence base and rests primarily on ideological considerations.

Not all the effects of greater individualisation of services concern benefits to individual people with intellectual disabilities. From the policy-makers perspective, greater individualisation, with associated increases in the diversity and complexity of service organisation, may reduce the ease with which service equity and effectiveness can be monitored. Although this may cause problems of implementing policy it may also reduce the effectiveness of public scrutiny. An important part of the critique of community-based services is the extent to which it can mean greater privatisation with the burden of care (and costs) covertly shifted to individuals and their families.

Finally, consideration of policy in different countries raises a question about whether it exists in a developmental sequence. All the countries studied appear to be located at points on a journey from specialised, rather separate, services which group people with intellectual disabilities in institutional settings of inferior quality, towards more individualised, integrated services which aim to assist people with intellectual disabilities to live full lives in their own community. For countries which still have a large investment in institutional provision, is it necessary to follow the sequence apparent in others – to start by providing new services for the least disabled, gradually extending these to serve people with more and more complex needs? What conditions would be necessary for policymakers to move directly to individualised services?

Funding of services and role of public and private sectors

Overview

In order to make comparisons across the states, several key elements were identified:

The funding basis: Two models of funding existed in the countries being compared. In Germany, Netherlands and Sweden, where people have a right to services, funding is generally done on the basis of individual entitlement. In Spain, Belgium and Greece, discretionary funding is in place. In the UK there is mixture of the two – for the most part

discretionary funding is the basis but there is some individual entitlement through the benefits system.

Funding sources: In Netherlands and Greece, most funding comes from central government. In Spain and Belgium, funding comes from social administration on a regional level with some funding from charities, private sources and lottery sources. In Sweden funding is from social administration on the local level but funded through taxation on a local, regional and national level. In Germany, there is a more mixed picture, with residential services funded on regional level and newer forms of care such as supported living funded on from social administration on a local level and by care insurance or other social provisions. This inevitably means that there is conflict between the regional and local state level and historically residential provision has been favoured because it shifts the responsibility away from local authorities. The UK has a mixed system of funding. At a central (regional) level there is funding from the National Health Service for health related care and for those with more complex needs. Also at a central level, there is funding for individuals through social security such as mobility and disability allowances which are functionally defined benefits. At a local level, funding is provided through social services with some provision from housing services.

Degree: This was relatively high but in some countries (eg Spain) there were marked regional variations.

Public funding structure and person-centredness of funding: In the UK services appear to be moving from block-contract models in which people are offered services that have been funded on the basis of volume of need in the population and broad types of provision, to services planned and funded on an individual level (especially with options such as direct payments being available, even if not yet very accessible to people with intellectual disabilities). In Spain, Belgium and Greece, funding structures are mainly on the basis of politically decided subsidies meaning person-centredness is low. In the Netherlands, most funding is allocated to facilities and so is place-related refunding of costs (with users getting some "pocket money") and thus person-centredness is low. However, recent moves towards "personal budgets" for some individuals means that autonomy is high for these people. In Sweden, the structure is one of cost covering for various arrangements with personal assistance available but person-centredness is high in that there is good choice of individual arrangements. In Germany, the split between local and centrally supported services is again evident, with residential services funded by place-related refunding of costs but supported living funded on individual basis by hourly rates or staff ratio. For the most part, person-centredness is low although the first steps to personal budgets are starting to happen.

Agency Structure: In the UK, most services are provided by private and voluntary agencies. Some limited services (usually larger day services and residential homes) are provided by public services (local authorities) but in general local authorities purchase services from private and voluntary agencies. There are a small number of places for people with intellectual disabilities still in residential homes run by the National Health Service. In Greece, what services there are, are mostly public with some voluntary and private agencies that are publicly financed. In Sweden, services are mostly public but with some voluntary services. In Spain, Belgium, Netherlands and Germany services are mostly voluntary. These voluntary services are often church run (either Catholic or Protestant organisations) but are also run by non-religious welfare organisations or parents associations. In the latter three states, these agencies run the services through corporate arrangements with the state.

Autonomy of service providers: Is low in UK and Sweden but generally high in the other countries where majority of provision is by voluntary organisations. Linked to the autonomy of service providers, the potential for political influence is generally low in all countries but the UK and Sweden. However, in Belgium, Netherlands and Germany, there has been increasing attempts to break "corporate arrangements" by implementing instruments of "New Public Management".

Issues raised in discussion

Broadly speaking, points raised in discussion focused on three themes: the overall volume of funding of intellectual disability services, the incentives created by funding systems and the trend towards individualisation of funding arrangements.

It was noted that decisions about the volume of services, and especially about the amount of residential care, appeared to be principally determined by the previously existing volume. The increased demand for services in the future, which will be a consequence of better survival of disabled people, an ageing population of family carers and the pursuit of greater independence and equal rights by people with intellectual disabilities, will present a major challenge to Member States.

The importance of the family in society is central to questions of funding. In some countries, such as Spain and Greece, the family continues to be the main source of care, help and support for people with intellectual disabilities. In those countries where these responsibilities are shared with the community through the use of public services, an ageing family carer population was leading to increased demand for services. Similarly, changes in family expectations were important, with some evidence (eg Germany, UK) that families now had higher expectations of assistance so that they could maintain ordinary employment and family life while supporting a disabled relative at home; and also that they would increasingly expect disabled children to leave home at the same age as other children. It was recognised that at least in some countries (Netherlands, UK) there was evidence that families did not always get the support they really needed. So there are questions about what kinds of help, delivered in what ways, help families best, as well as questions about the amount of help.

In terms of funding, family care may be seen as the cheap option because many of the costs are borne by families and are hidden. It is therefore important, both as a matter of equity and of measuring efficiency and effectiveness in public services, to accurately estimate the costs of family care.

Funding systems create incentives, both deliberately and accidentally. Funding gives resources so that organisations can operate, maintaining their own systems and structures. However, it also structures the services available, in that in order to get funding, service organisations have to provide funding bodies with legitimisation – in other words, services must orient their performance to the expectations of funders. Funding connects an organisation with its environment, and influences services in their structure, culture and performance. In discussion, examples were given of how increasing the range of sources of funding for particular service organisations affected their autonomy. It was suggested that the more funding sources there are, the more expectations organisations have to take into consideration in the services they provide, but at the same time the more autonomy they have, in terms of no one funding body having too strong an influence. But in contrast to this it was suggested that in some cases greater variety of funding sources seems to allow funding agencies to disown responsibility for funding particular aspects of service, leaving the responsibility to secure funding for a particular need with the providers.

It was noted that funding arrangements can be used to create incentives to reshape services. For example, in the UK, 'dowry payments' followed a person who was moving out of an institution to the agency that provided community care as an incentive to promote deinstitutionalisation. This arrangement typically allowed individuals and their services to access extra funds in community services. It required to be managed (so that double-running costs of old and new systems could be met) and this was originally done by regional bodies. The introduction of quasi-market arrangements had tended to reduce this kind of deliberate, large-scale, long-term planned process.

The move in most countries towards greater individualisation of service organisation and greater control for service users was generally considered a very good outcome. Individualised, user-focused services were potentially more effective because they could better address individual needs and goals; they were potentially more efficient because they could provide a better 'fit' between level of provision and need, and because they could make

more use of individual sources of informal support from family and friends. However, individualised funding also raised a number of new potential problems. Individualised funding could make the needs of this client group less visible to political and public scrutiny, so that decisions about cost-reduction may be easier to implement and issues of equity harder to address.

Emerging service structures and models

Overview

The main focus of the group's work has been on services for adults, and particularly on the process of deinstitutionalisation. The state of community based service provision varies across all of the countries involved. It is probably most developed in Sweden, where institutional services are no longer permitted and all care is provided in small-scale community settings. It is least developed, both in theory and in practice, in Greece, where the majority of care is still provided in institutional settings or by family carers. The other countries have a mixture of levels of provision featuring varying degrees of deinstitutionalisation.

Within the UK, numbers in institutional care have been reduced dramatically over the past three decades and this has mainly been replaced by staffed housing (group homes). This is the predominant model of provision in England, although of course larger residential services still exist and, in contrast, recent developments towards supported living are increasing. In Germany, there is a drive for more community care in the form of group homes and supported living but this is mainly at a local level and the system of central funding for institutional care provides an incentive for this to be first resort for placing people with intellectual disabilities. In Belgium and the Netherlands, there remain large institutions and these are used especially for those with more severe levels of disability. There are moves towards more community-based services and in both countries people can have a form of personal budget that allows them to organise their own services. In Spain, three levels of care provision are distinguished – residential care, intermediate care and community care. Those with severe needs are provided for with specialised residential care managed by health services. Social services agencies provide care for those who have milder levels of disabilities where family care breaks down. The development of respite care and community care liaison units has just begun.

Issues raised in discussion

There are number of trends and issues that can be highlighted across the different Member States:

There is generally a lack of services for people with intellectual disabilities, especially in community based services. Access to services in many countries appears to be difficult, even when services are planned or available.

There is a common trend towards community living. There has been an ideological shift towards ideas of citizenship, personal control and equal access to the community. There has also been a trend to move away from the medical model. There is general criticism of institutions on the grounds of quality, exclusion and costs.

People with severe and profound intellectual disabilities generally have least access to new models of services, so that there is to some extent a two-tier system of services in which people with the greatest needs receive care in the poorest settings.

There is some variability in service models and structures, mostly due to the variability in social welfare structures and in the history and culture of each country. However, rather similar types of service seem to exist in each country, though this will bear further investigation. There is generally co-existence of old and new models.

Individualisation is of growing importance in services, with attempts to create arrangements for the planning, design and operation of services that are tailored to individual people with intellectual disabilities. Where developed, these appear to be important both as a means of providing better services to the individuals concerned and also as a means of restructuring monolithic service organisations based on past models.

Experience of people with intellectual disabilities and their families

Overview

In every country, there is some degree of collective involvement of families of people with intellectual disabilities in service provision. In some countries, such as Spain and Greece, this reflects the very limited amount and range of publicly-funded service provision, so that families organise self-help. In others (UK) involvement in service provision is encouraged by the use of quasi-markets in service provision and the poor range of options available. Whether or not families are involved in service provision, in every country they are involved to some extent in policy-making, as lobby organisations or as partners in more formal processes of consultation.

In recent years, and to varying degrees, people with intellectual disabilities themselves have gained a stronger voice in consultation and participation in service development. Greater individualisation of service delivery has been complemented by collective involvement of people using services.

Mapping and weighing the experience of people with intellectual disabilities and their families in the countries concerned is difficult, because information is not collected centrally or in readily accessible forms. One important source of information will be the reports of public bodies planning and commissioning services in so far as they reflect the involvement and view of service users and their families; and the reports of representative organisations and pressure-groups.

A second potential source of information comes from academic research and service evaluation. There is very wide variation in the extent to which this is carried out in the countries studied and no comparative material is available. In so far as it is benefits to people with intellectual disabilities and their families that are the primary justification and rationale for services to exist, evaluation of their effect is potentially important as a resource with which to choose between different courses of action.

Issues raised in discussion

The first issue raised in discussion was the extent and desirability of the involvement of people with intellectual disabilities and their families in controlling, directing and providing services. There is a strong presumption in favour of user control in some countries, where this is seen as an important way in which services can be made responsive to users' needs. However, it was pointed out that where user organisations provide services this is no guarantee that the services will avoid replicating the problems of institutional care. Involvement in policy-making and service development was important to ensure that the resources and ideas were available to inform and sustain good practice.

Related to this was the concern that an emphasis on user control could sometimes mean the disengagement of the state and the privatisation, to some extent, of the tasks of caring and supporting people with intellectual disabilities.

In all the discussion of involving people with intellectual disabilities in determining the pattern of service development and the way services are provided, a constant concern was the importance of adequately reflecting the interests of people with severe and profound

intellectual disabilities who were less able to participate in typical planning processes and meetings. Since the category 'intellectual disability' is a social construction, the population of people with intellectual disabilities includes people with quite different needs and wants. Severity of intellectual disability is one important dimension in this diversity, as is the presence of specific aetiologies (eg the needs of people with Lesch-Nyhan Syndrome or autism are likely to be different from those of other people with the same general level of intellectual disability) and additional problems (eg sensory or physical handicaps, mental health problems of challenging behaviour). Service systems have to be responsive to people's differences at the level of the individual, the clinical population, the social group and the wider community.

Finally, there was discussion of the potential usefulness of research and evaluation. Two points arose from this part of the discussion. First, there were wide variations between countries in the extent to which research and evaluation were seen as an important activity, implying that policymaking processes in different countries work to different criteria (or use different sources of legitimation). Second, even in countries where there is large-scale investment in research in intellectual disability services (eg UK) there is little evidence that the products of research and evaluation are actually used to determine policy.

A European agenda

It seems clear from this essentially preparatory work that there is much to be gained from a comparative analysis of service provision in different European countries. Although there are some similarities both in how services are organised and in the trajectory of service development, there are also differences. Analysis of how these arise and what is their effect, will illuminate the process of service development in all countries.

References

- Jones, C. (1985) Patterns of social policy: an introduction to comparative analysis. London: Tavistock.
- American Association on Mental Retardation. (1992). Mental retardation, definition, classification and systems of supports (9th ed.). Washington, DC: American Association on Mental Retardation
- Luckasson, R., Borthwick-Duffy, S., Buntinx, W. H. E., Coulter, D. L., Craig, E. M., Reeve, A., Schalock, R. L., Snell, M. E., Spitalnik, D. M., Spreat, S., & Tasse, M. J. (2002) Mental Retardation: Definition, Classification, and Systems of Supports (10th Edition). Washington, DC: American Association on Mental Retardation.
- Mansell, J., & Ericsson, K. (Eds.). (1996) Deinstitutionalization and Community Living: Intellectual Disability Services in Britain, Scandinavia and the USA. London: Chapman and Hall.
- World Health Organization. (2001) International classification of functioning, disability, and health: ICF. Geneva: World Health Organization.

Germany

**Johannes Schädler, Norbert Schwarte, Timo Wissel and
Laurenz Aselmeier**

Introduction

This paper is intended to convey an overview of the current situation of services provided for people with intellectual disabilities in Germany. On principle we presume that the field of services for intellectually disabled people in Germany, its problems, strengths and opportunities for development can only be understood if one is familiar with the historical development pathways that led to the current structures. Important developments in other countries of Central and Western Europe were the same or similar to those in Germany, especially in those countries that follow the same conservative type of 'welfare state regime' (Esping-Andersen 1990). Nonetheless, specific pathways have been taken in our country and specific historical experiences should be taken into consideration when making national comparisons.

Definitions, legal status and eligibility

For those persons described in the Anglo-Saxon languages as "intellectually disabled," "mentally retarded" or "mentally handicapped," the term "*geistige Behinderung*"¹ has asserted itself in the German language. The following statements on the definitions of intellectual disability leave aside the controversial discussion carried out until just a few years ago between psychiatrists and educators about the suitable understanding of this term². Instead they refer to the legal status of intellectually disabled people as well as to their eligibility for benefits.

Persons with intellectual disabilities as citizens

Formally, the term "intellectual disability" is of significance in Germany with regard to benefit law. Intellectual disability does not define a civil status.

In 1992 the Law of Guardianship that applied in Germany until then underwent major reforms. The old law flatly declared all persons in question incompetent in all relevant areas (choice of residence, assets and health). In contrast, the reform law (Caretaking Act; Betreuungsgesetz, BtG) attempts to combine the constitutional provisions "for the right to free personal development, also with regard to persons who are, in whole or in part, unable to take care of their affairs themselves, with the ideal of freedom of legal relations that distinguish civil law" (Lachwitz 1999: 69). The Caretaking Act puts a very flexible instrument in the hands of both the guardianship courts and the legally appointed caregivers to orient the required support to the abilities of the individual intellectually disabled person. It also sets down that the appointment of a 'caregiver' has no restrictive effects on legal competence. The consequences of the new caretaking law are

- that nearly all intellectually disabled persons can make use of their civil right to vote;

¹ Related to the British term "mentally handicapped"

² It was revealed that parts of the newer social psychiatry have extensively overcome its traditional oligophrenic ideal; in summary see Ziemer 2001).

- that they have the right to marry;
- that they receive 'employee-similar rights' (protection against dismissal, vacation provisions, etc.) when employed in a workshop for the disabled;
- that sterilization of intellectually disabled persons is prohibited.

A long battle by a broad alliance of organizations for the disabled to include a provision prohibiting discrimination against the disabled was successfully ended in 1994. The sentence "no one may be disadvantaged due to his or her disability" was adopted in Article 3 paragraph 3 of the constitution (Basic Law). Currently German lawgivers are working on a so-called "equality law," in order to make the significance of the new constitutional requirement more precise for practical legislation³.

In summary, we can establish that the development of the social status of intellectually disabled people in the past ten years has been positive. The developments with regard to eligibility for benefits are more contradictory.

Intellectually disabled people as persons eligible for benefits⁴

The most important services for intellectually disabled people are granted in Germany in accordance with the "Federal Social Assistance Act (Bundessozialhilfegesetz, BSHG)", which came into power in 1962. § 39, paragraph 1 of the BSHG is central for the services for the disabled, stating: "Persons who are not only temporarily severely physically, intellectually or psychically disabled shall be granted integration assistance." And § 39, paragraph 3 says: "The objective of integration assistance is to prevent an impending disability or to eliminate or alleviate an existing disability or the consequences of such and to integrate disabled persons into society..." § 2 of the implementation ordinance for the BSHG defines the "intellectually disabled" as persons who, as a result of a weakness of their intellectual capacities are not only temporarily (i.e. at least six months) severely impaired in their integration in society. Since 1962 "integration assistance" forms the central financing foundation for the facilities and services for assistance to the disabled in Germany. There are, however, other benefits that people are eligible for and these are outlined in the section on funding below. In addition to state benefits, people also may access private pensions that are held either in their own name or in the name of family members.

The prevalence of people with intellectual disabilities in Germany

The national data situation in Germany is imprecise. In their "Berlin Memorandum" the four large professional associations⁵ estimate that there are currently approx. 420,000

³ This happened in part due to two court rulings that were made public and considered social scandals. In one case a couple received claims for damages for impairments to their relaxation while on holiday, since the travel organizer had not informed them that a group of intellectually disabled people were vacationing in the neighboring apartment. In the other case in a dispute between neighbors the court ruled in favor of a couple that had turned to the court because of continued disturbance of the peace by a group of severely disabled people living next door (cf. Lachwitz 1999: 80).

⁴ See: Bundesvereinigung Lebenshilfe (2001): Finanzielle Hilfen für Menschen mit geistiger Behinderung, ihre Angehörigen und Betreuer/innen, Marburg, Lebenshilfe-Verlag

⁵ Berlin Memorandum of the contacting discussion associations dated 19.10.2001. These associations include the Verband für Anthroposophische Heilpädagogik, Sozialtherapie und Soziale Arbeit e.V., the Verband katholischer Einrichtungen und Dienste für lern- und geistig behinderte Menschen e.V., the Bundesverband Evangelische Behindertenhilfe e.V. and the Bundesvereinigung Lebenshilfe für Menschen mit geistiger Behinderung e.V.

intellectually disabled people in the Federal Republic of Germany, with roughly 185,000 juveniles and 235,000 adults.⁶ Approximately 85 percent of the intellectually disabled juveniles (approx. 160,000) live with their families and 15 percent in homes. An estimated 60 percent of the adult intellectually disabled also still live with their original families.

Policy frameworks and their developmental pathways

Organized services for people with intellectual disabilities in Germany look back at an over 150-year history. The origination of the 'system of imbecile institutions'⁷ in the first half of the 19th century must be seen in its close connections to the ways that the 'Social Question' was dealt with in those times. Rapid industrialization was accompanied by massive urban poverty. The question was how society should deal with people who could not care for themselves.

Church welfare, church power and voluntary welfare work

The first philanthropic or religiously motivated approaches were begun and further developed by the then materially, socially and politically weakened Christian churches. The church 'system of imbecile institutions' (Idiotenanstalten) of the 19th century was supported by monastic real estate and traditions marked, particularly in the Protestant area, by a pietistic attitude towards work education. The historic models for this form of care for the poor are the medieval lunatic asylum, prisons and church nursing homes. These culminated in an ideal leading to the concept of the large-scale asylum that was structurally segregated from the rest of society. The development of this concept among the churches was pillared – with the renaissance of monastic life – on the workforce of unmarried women and men who followed the tradition of medieval monasteries and convents.

The work of both Christian confessions in the 19th century formed the basis for the genesis of the 'Freie Wohlfahrtspflege' ('voluntary welfare work'), specific form of the third sector, which, after the collapse of the empire in 1918, also consisted of organizations from the labour movement (*Arbeiterwohlfahrt*, Workers' Welfare Association), the German Red Cross, the *Paritätische Wohlfahrtsverband* (Independent Voluntary Welfare Association or DPWV) and Jewish welfare organizations⁸. In the first half of the 20th century 'voluntary welfare work' was able to assert a government arrangement, which, in line with the principle of subsidiarity, obligates the state to leave the provision of social services to the voluntary welfare organizations while obligating the state to take up the relevant costs. On principle, this arrangement still applies. Hence in Germany now the situation is characterized by 'powerful' third sector organizations and a state that attempts to release itself from the role of mere funder through legal amendments, but without possessing the necessary professional skills and personnel resources.

Regulatory policy development

In Germany the "Soziale Frage" ('Social Question')⁹ gave rise to the division of state funding competencies into a local and a centralized level. In order to relieve the local structures,

⁶ The estimate is based primarily on the international prevalence assumption that 0.56 per thousand of the population can be categorized as intellectually disabled.

⁷ On the historic development of assistance for intellectually disabled people in Germany, cf. Bradl (1991)

⁸ On voluntary welfare work in Germany, cf.: Boeßenecker 1998

⁹ The 'soziale Frage' is a socio-political term, that comprehends the general question how the modern state should deal with society members that cannot sustain their lives by their own means, (cf. Dörner 2001)

intellectually disabled people were to be accommodated in large centralized and centrally-financed institutions. This created a mechanism, which, as a specifically German pathway, led to specific arrangements that one can say financially favour institutionalization from the perspective of the local authorities and impede the implementation of integrative approaches within the community. Types of services under the 'new paradigm' such as family support services and supported living for adults with intellectual disabilities lie in the local budgets, while residential services (community homes, institutions, etc.) are in the budgets of a central state authority (over regional public assistance authorities). This structural issue is being intensively debated currently in Germany.

Professional and association policy developments

The pedagogical approaches to special education that also arose in the 19th century and that early manifested an integrative orientation were unable to assert themselves against church or state concepts and powers and were increasingly disregarded. Instead, near the end of the 19th century the influence of psychiatry and its oligophrenic categorizations became more dominant. Psychiatry asserted its leadership in theory and in practice based on racist and hereditary theories and pseudo-scientific promises of cures. The religious pedagogical institutional ideals could not counter this.

This had fatal consequences for people with intellectual disabilities in Germany. The eugenic approach put forth primarily by psychiatrists in the early 1920s received ever-broader social assent. When they came to power the National Socialists were able to fall back on so-called 'hierarchies of social usefulness' (*Stufenleitern sozialer Brauchbarkeit*), and possessed legitimacy and instruments for mass sterilization and extermination programs¹⁰ between 1935 and 1945. Almost without interruption the influence of psychiatry dominated into the 1970s and, with its diagnosis and treatment models, offered the basis for legitimating the separation policies for intellectually disabled people to special facilities.

The family-oriented, community, partly-residential model of the parents' organization 'Lebenshilfe'

Since the 1960s the parents' association '*Lebenshilfe*' founded in 1958 pushed ahead an alternative to the models of the large church institutions. It holds that services for intellectually disabled people should be family-oriented until adulthood when they should take into account the separation of the living areas of home, work and recreation. With the reception of the Scandinavian ideal of normalisation, special kindergartens, special schools, community homes and workshops for the disabled were established. The legal right to early support, to a place in kindergartens, to a school education and to integration assistance for living and working for all intellectually disabled people was successfully anchored in law. By and by family-support services could be established on a broad basis.

The initial intense competition between the institutional model and the *Lebenshilfe* model was factually alleviated with time through an arrangement of 'border regulation'. This was a broadly accepted basic assumption that people with mild to medium disabilities should be cared for in community facilities and the more severely disabled in institutions. As early as the 1980s this led to a debate about the consequences of this implicit agreement for the institutions, which makes them "centres for the most severely disabled" (Gaedt 1992). The same debate is now taking place with regard to the interface between "homes" and "supported living."

¹⁰ On the euthanasia crimes in the Third Reich cf. Klee, E. (1984), on the role of psychiatry in the Third Reich, cf. the biography of the German psychiatrist Walter Villingner, commented by Schäfer, W. (1994)

We should note the significance that semi-residential facilities of the Lebenshilfe model are also centrally funded according to the above-mentioned financing mechanism and hence structurally fit into the traditional financing scheme.

Based on the concept of semi-residential facilities, since the early 1970s other voluntary welfare associations also began increasingly to get involved in the sector of services for intellectually disabled people. In particular in regions where they had political accesses on a local level the Arbeiterwohlfahrt, but also the German Red Cross established special kindergartens, homes and sheltered workshops for the disabled. Quantitatively speaking however they were unable to catch up with the church associations and the Lebenshilfe. The following two tables underscore this.

Table 1: Number of places in institutions / services for disabled persons in %¹¹

Arbeiter-wohl-fahrt	Caritas (Catholic Welfare Association)	Diakonie (Protes-tant Welfare Association)	German Red Cross	DPWV with Lebenshilfe and Anthro-posophists	Other
2.8	20.3	48.9	1.7	16.5	9.8

Table 2: Residential facilities according to voluntary association¹²

Association	%
Diakonie	33.7
DPWV, of which	37.3
Lebenshilfe	20.7
Anthroposophist	2.8
Other	13.8
Caritas	18.0
Arbeiterwohlfahrt	4.1
German Red Cross	1.9
Municipal/public	3.2
Private	2.8

¹¹ Data according to MUG2 (Moeglichkeiten und Grenzen selbstaendiger Lebensfuehrung)(BMG (Bundesministerium fuer Gesundheit) 1997: 46). This also includes facilities for all people with disabilities.

¹² Data according to MUG 2 (BMG 1997: 35). This also includes facilities for people with other disabilities.

The statistical data of the 4th Report on the Disabled of the Federal Government (Federal Ministry of Labor and Social Affairs, 1998) illustrate the actual relations between services inside and outside of residential and semi-residential facilities over time:

Table 3: Development of integration assistance ('Eingliederungshilfe') between 1980 and 1995 in Western Germany

Integration assistance	1980		1995	
	Persons	Payments in million DM	Persons	Payments in million DM
In residential facilities	142,500	2,540.3	250,700	10,690.9
Outside of facilities	52,500	126.1	85,100	553.9

Source: Federal Ministry of Labor and Social Affairs, 1998, p. 118

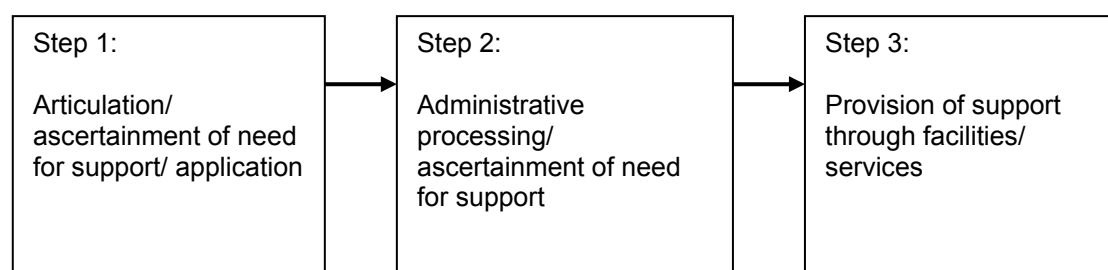
As in 1980, in 1995 the number of disabled persons in the 'old' federal Länder (former West Germany) who received integration assistance in residential facilities was roughly three times as high as the number of disabled persons who received integration assistance outside of facilities. And exactly as in 1980 the gross expenditure for integration assistance for disabled people in facilities in 1995 was also roughly 20 times as high as payments outside of facilities. On the whole we also see that within this time period, the number of persons in residential care grew more rapidly (factor: 1.754) than the number of persons who received assistance outside of facilities (factor: 1.620) (Federal Ministry of Labor and Social Affairs 1998: 118).

These statistics are accurate only to a limited extent for intellectually disabled people since, for example, payments for psychologically disabled, physically disabled and for persons receiving integration assistance for other reasons (§ 72, BSHG) are included in the calculations and more precise differentiation of larger expenditure blocks is lacking. Yet this data emphasises the fact that the assistance outside residential facilities has remained relatively unchanged in terms of its marginal importance in the disabled assistance system and that residential accommodation dominates throughout.

Planning after placement

In order to illustrate the current situation it is helpful to view the basic model for the granting of social assistance (Rohrmann et al 2001). It can be divided into three steps:

Illustration 1: Basic model for granting social assistance



Step 1: Articulating the need for assistance

The provision of assistance is based on a disabled person's need for assistance. This need for assistance is, however, not immediately recognisable and depends upon the individual situation of the person, on their subjective ideas as well as on social-ecological conditions of their environment. At the same time individual need for assistance is highly interpretable and hence dependent on the person who translates it through an application from its form in day-to-day life into the code of social law. For any provision of assistance requires that the need for assistance be formally articulated in an application. Both with regard to the later outward form of assistance provided and to the costs incurred, the contents of the application are of central importance, i.e. what type of assistance, the extent and the composition are pre-defined by the application.

Usually those parties offering assistance have power over the assessment of the need for assistance, since they either counsel the applicants or extensively prepare the actual application. Previously the assessment of need had only formal significance in making applications. Explanations of the need for assistance serve the providers in legitimating placement in an assistance facility, for example placement in a home. Actual assistance planning does not begin until placement is made.

Step 2: Ascertaining the need for assistance

Processing the application for social assistance – from assessing the right to assistance to officially ascertaining the relevant need for assistance under social law and drawing up an opposable decision – is the official task of administration. In most cases – e.g. with regard to living arrangements for intellectually disabled people – the application was/is prepared by the sponsor of the facility, signed by the applicant and submitted to the funding authority. The formal function of this procedure is to open the affected person access to a place in a home. After formal assessment (usually 'without viewing the person' i.e. according to documents) by the responsible clerk of the funding authority the application is then approved if the applicant possesses the individual right to assistance. With regard to the content of the aids applied for, the funding authority usually knows that the application was made under the professional guidance of a voluntary welfare organization and usually does not inquire further, since they respect their competence. The result of the administrative processing of the application is a so-called opposable decision, which, if positive, contains the funding of costs. Usually the social administration waives control options in individual cases.

Step 3: Provision of assistance

The decision of funding approval allows the applicant to be admitted to a residential facility of the voluntary welfare organization that monitored the application and the assistance applied for is provided there. After such successful placement, assistance planning takes place in the form of pedagogical planning within the facility, but no longer is linked to funding issues. Funding of the place is made regardless of the actual person who takes it. Often the objectives and contents of the assistance provision in facilities are derived from their own programs and common routines. In many cases assistance planning remains a subordinate task, since actual room for action is limited. In the end, even in sophisticated plans, activities are determined more by the institutional framework of the facility than the individual life ideals.

Lately, for motives of financial control, public assistance authorities attempt to have greater influence on the application process. The concepts for drawing up overall plans under § 46 of the BSHG, created for example by the Hamburg social authorities (Offermann 2000), should be seen as attempts to gain influence over applications in order to better control the content of the assistance as well as the choice of provider, also from a financial perspective.

The sponsors of voluntary welfare organizations meet these attempts with great mistrust and considerable resistance, since they consider it encroachment upon their previous autonomy. On the one hand the relevant resistance shows that these are attempts at breaking up relatively inflexible systems that are also often highly ideological. On the other hand the scepticism of the organizations, which see them as economising schemes, are not unjustified. Linked to this is the concern that the attained working standards could be broken down through greater administrative influence.

Economization

Since the early 1990s, the German administration as a whole, but specifically the social administration, is undergoing a process of modernisation. Internal restructuring and changes in the service financing schemes are intended to increase the efficiency of the authorities' activities. Therefore, like in other fields of Social Work, an increased effort was also made in the services for the disabled to introduce market mechanisms that are to be linked with 'output-oriented forms of control' (Schädler 2001). Following the approaches to a hospital financing reform, one of the aims was to substitute the conventional principle of "cost recovery", i.e. the retrospective compensation for all costs incurred e.g. in residential facilities, as this principle hardly provides an incentive for the funding authorities to work economically. Instead, the aim was to establish a financing scheme in the field of social services based on compensations for "prospectively" agreed services, i.e. agreed in advance and including the description, scope and quality of services. These compensation agreements then have the character of fixed "prices" for agreed services, the quality of which has to be ensured by the provider of these services. Consequently, a budget scope is given for the sponsors of social facilities within which they have to finance the provision of the agreed services.

Furthermore, it was the stated intention of the structural reforms to accomplish savings by creating an enhanced market and competitive situation by admitting new service providers. Therefore, as a concrete step, the attempt was made to attract an increasing number of private providers for contractual agreements with funding authorities in addition to the non-profit institutions by changing the corresponding laws. These were the objectives when the Federal Social Assistance Act (BSHG), especially § 93 of the BSHG, was amended in 1994, 1996 and 1999, thus creating the appropriate provisions for the services for the disabled.¹³

Rather than being merely a "funding authority", the social administration is therefore claiming the role of an active "social services funder", who by this definition specifically purchases high-quality services for the benefit of individual users, taking quality and cost aspects into account. It therefore assumes a new role in the planning and provision of services and attempts to go more and more on the offensive in making use of its legally granted control possibilities.

When studying the attempt that has been made for almost 10 years now – to attain a modernisation of the service system that will bring more quality of life and self-determination to intellectually disabled persons and increase the efficiency of the employed resources by creating market structures – the result is sobering. An incredible number of conferences and committee meetings have been Organized and an enormous amount of paper has been filled with closely spaced lines, and yet the system has turned out to be highly resistant to change.

¹³ Provisions going even further on the price structure and opening of the market are contained in the social Long-Term Care Insurance Act enforced in 1995 (SGB XI). The amendment of the Law for Children and Young People (KJHG) that involved the addition of analog paragraphs for the field of youth welfare (§§ 77, 78 KJHG) was passed in 1998. These legal changes help to support processes of economization in the social facilities and services that have an impact both on the internal and external processes and relationships (Heinze et al. 1997: 242 - 271).

The residential model is still predominant; in fact the social administration has issued a restriction for the facilities and services under which cost increases of only 2 percent maximum may be asserted per year since 1996.

Funding of Services and role of public and private sectors

Facilities and services

Facilities and services for intellectually disabled persons are funded in the scope of the so-called “triangular relationship” between users, funding authorities and assistance providers (Münder 1988). Thus an intellectually disabled person is legally entitled to receive social assistance from the social administration. The social administration, however, does not provide these services itself but usually commissions a voluntary welfare organization with which a service contract has been entered. This organization then provides the granted assistance service to the user concerned, while the cost is borne by the social administration.

Funding of residential and semi-residential facilities (institutions, community-integrated homes etc.) is comparatively easy at present. In this case the arising costs are not paid individually, this rather is a form of institutional funding. On the basis of a service contract, the social administration (i.e. the public assistance authority above the local level) will reimburse the agreed average costs for the places in the home to the sponsoring organization of the concerned home. These amounts differ slightly between the federal states and the sponsors, the concrete daily rate currently averages 70 Euros (new federal states) and 100 Euros (old federal states). In this calculation it is assumed that the users do not require care in the facility on five workdays between 8 a.m. and 3:30 p.m., when they are in workshops for the disabled.

In facilities accommodating an especially high number of severely disabled persons the daily rates can also be up to 150 Euros, in few cases even more. The sponsors can calculate with a 2 percent annual increase of this budget.

Subsidies for investment costs, e.g. for building or altering residential facilities are granted independently of this through other promotion programs of the federal states. To finance the cost of building homes, sponsors of voluntary welfare can resort to generous grants from the funds of a lottery foundation (“Aktion-Mensch”) that has been supporting services for the disabled in Germany since 1964. Part of the investment costs (10 – 20 percent) must be borne by the applicants themselves. It should be emphasised once more that the users of residential homes or their relatives are either completely exempt from any own contributions or – if they hold major assets – are required to pay a maximum of approx. 25 Euros per month.

A much more complicated procedure is the funding of assistance for independent living. Here the first step consists in examining the legal claims of the individual intellectually disabled persons vis-à-vis the various funding authorities. Then the corresponding applications have to be filed. For the services of Assisted Living the hourly rates currently granted by the funding authorities are approx. 40 Euros, in this regard there also are major differences across Germany. No government subsidies are granted for investment costs for non-residential services. However, there also is the possibility to resort to promotion programs of the “Aktion Mensch.” Until a basic security is introduced in 2003, users of services for Assisted Living can be requested to contribute to the costs of the service from a certain level of income and assets.

In some federal states, the number of hours of assistance that individual persons can receive is limited by government directives, which prescribe an average staff ratio of 1:6 or 1:12. This means that one worker has to care for either six or twelve clients. This is regarded as far too little, since, consequently, access to this type of assistance is only possible for persons with a low need for assistance. In the context of the new regulation of Individual Assistance Planning more flexible solutions are under discussion.

Individuals: - income and benefits

As outlined above, “integration assistance” forms the central financing foundation for the facilities and services for assistance to the disabled in Germany. In the year 2000 total expenditure on “integration assistances” was approx. 8 billion Euros (or DM 15.2 billion)¹⁴. There are, however, other benefits that people with intellectual disability can access in Germany.

Benefits for integration assistance for juveniles (e.g. for early support or for attending a special or integrative kindergarten) are granted in full. The same applies for the costs of attending school. For accommodation in a home or institution the families can choose between an income and asset audit or payment of a sum of approx. 25 Euros (DM 50).

When intellectually disabled people live in their own homes and have no or little income and assets of their own, they, like other citizens, are entitled to support under § 22 of the BSHG (approx. 280 Euros / month), to reimbursement of their rent costs as well as other one-time assistance payments.

Since 1995 intellectually disabled people can apply for assistance under the Long-Term Care Insurance Act (Pflegeversicherungsgesetz) (Social Code Book XI) if they are insured either through other family members or themselves. Particularly for intellectually disabled people who live with their families or independently, long-term care insurance offers a budget that can be received either in cash or in kind or as a combination of the two. On the basis of a social-medical report the degree of the need for care is determined according to three ‘steps of care needs’ (‘Pflegestufen’).¹⁵ In step 1 the cash payment is 205 Euros and payment in kind 384 Euros; in step 2 cash payment is 410 Euros and payment in kind 921 Euros, in step 3: 665 Euros and 1,432 Euros respectively. If it is received in kind, the amount of money available is in step: 1 850 Euros; in step 2: 1.000 Euros; and in step 3 1.500 Euros. Other individual payments, e.g. in case the caregiver is on holiday, up to 1,450 Euros per year.

If the individual lives in a home, long-term care insurance pays the funding authority of the home a flat sum of approx. 250 Euros.

Intellectually disabled children are co-insured under statutory health insurance (Social Code Book V) regardless of age if, due to their disability, they are unable to support themselves. Disabled people who are employed in recognised workshops for the disabled must insure themselves. Their contributions must be paid by the workshop.

The Act on the Severely Disabled (Schwerbehindertengesetz) offers persons who are recognised as ‘severely disabled’ under law government support for overcoming disadvantages caused by their disability. The term for this support is of programmatic meaning: ‘Nachteilsausgleich’ (‘disadvantage compensation’) Severe disability is ascertained upon application by so-called ‘pension offices’, which usually make their decision on the basis of submitted physicians’ reports. The pension offices are bound to a catalogue of characteristics, which categorises the ‘degree of disability’ according to the damage. The physicians of the pension offices are decisive for this procedure.

When the pension office approves an application, the person receives a ‘Severely Disabled ID card’, which entitles him or her or their families to tax reductions, to payment of child benefits

¹⁴ Federal Office for Statistics, Daten zur Entwicklung der Sozialhilfeausgaben, September 2001-2002.

¹⁵ Categories are physical care, eating, mobility, house-keeping. Step 1: persons with a minimum care needs of approx. one hour per day : step 2 : persons with an average care need of three hours per day; step 3: Persons with minimum care needs of five hours per day.

beyond the age of 28, to free use of local public transport, to special parking allowances, to residential and building assistance, etc.

Intellectually disabled people who work in workshops for the disabled (*Werkstätten für Behinderte* or WfB), are included in the statutory health insurance. The WfB or public assistance authorities pay a monthly pension contribution to the pension fund based on a fictitious income of approx. 1200 Euros (DM 2400). Qualification for a pension ensues at the age of 65 but after 29 years of contribution payments at the earliest.

The Rehabilitation Act (Rehabilitationsgesetz) (Social Code Book IX) which came into force in June 2001 provides new perspectives. For instance it obligates the public assistance administration to take up model experiments in order to gain experience with the use of 'personal budgets'. A number of such model experiments are presently in preparation. The law attempts to reduce fragmentation in the rehabilitation sector. One approach to this is seen in the creation of service offices for the disabled, which should make it easier for them to access needed services.

The improvement of specific discriminating provisions for additional payments of integration assistance was especially important for people with intellectual disabilities. There were no fundamental changes regarding the assertion of non-residential over residential services (Bendel / Rohrmann 2002).

Emerging service structures and models

Growing criticism of institutions gave rise to a significant internal modernisation of the large institutions in the 1980s and 1990s that can be seen for example in modern internal furnishings and group differentiation. On the other hand, there is a noticeable tendency of community-integrated homes to become similar to institutions (e.g. as regards size or number of places even in newer homes, see below). As the statistical data below will show, the institutional model still dominates the services for disabled adults in Germany as regards quantity, in fact, the predominant practice still is the workshop for the disabled combined with a community integrated home with 24 places.

The fundamental changes in the field of assistance for the intellectually disabled greatly evidenced since the late 1970s both in theory and practice result from the commitment of a "new" parent generation. These parents demand integrative education opportunities for their intellectually disabled children at kindergarten or school age¹⁶ as well as new forms of integrated residence and work opportunities (Rosenberger 1988). It has also been possible to develop new types of assistance in the field of family-support services and assisted living. In this respect it was helpful to be able to make use of a large number of low-cost workers carrying out community services as an alternative to military service. The fact that the demand for new types of assistance has already led to far-reaching changes in specific areas (especially kindergarten) made possible among others due to the fact that on the theoretical level approaches oriented towards social sciences were able to reduce the influence of psychiatry.

¹⁶ In 1998, the Federal Government estimated the percentage of intellectually disabled children attending integrative kindergartens across Germany at 40 percent. However, there are significant differences between the individual federal states (Federal Ministry of Labor 1998). The Federal Government estimates the number of intellectually disabled children receiving integrative schooling at 2 percent. In this field there also are strong differences between the federal states due to their independence in respect of cultural and educational matters.

The new paradigm of self-determination is firmly rooted in the professional debate and, as illustrated, this has also become evident in positive changes in the legal status of intellectually disabled persons. Its implementation in new forms of organised assistance, however, has so far been accomplished only to a very low degree. True, with the support of the social administration, all associations have for some time been working on expanding community integrated services ("Offene Hilfen"), however, so far these still only have a marginal significance. A deeply rooted persistence of old structures is evident. Obviously the dominant actors fear a loss of power, instability within organizations, high material and immaterial costs and conceptual uncertainties that are not easy to overcome.

The characteristic impact of the mentioned development paths on the assistance system can be seen not least from the fact that a little over 10 years after German reunification, almost identical constellations of actors and structures have been created in the federal states of the eastern part of Germany.

The figures across Germany on the types of assistance and/or residences provided to intellectually disabled persons are vague. According to the above-mentioned memorandum, approx. 120,000 persons with intellectual disabilities live in facilities. Approx. 16,000 intellectually disabled persons live in semi-residential community homes, approx. 60,000 live in institutions or other large institutions with educational orientation. A further estimated 20,000¹⁷ intellectually disabled persons are treated in psychiatric facilities or large institutions with a medical orientation.

Table 4: Intellectually disabled persons in Germany

Family	
Children and young people	approx. 160,000 persons
Adults	approx. 140,000 persons
Homes for children and young people	approx. 15,000 persons
Community-integrated homes	approx. 16,000 persons
Large facilities with educational orientation	approx. 58,000 persons
Psychiatric facilities with primarily medical orientation, nursing homes, etc.	approx. 20,000 persons

The percentage of intellectually disabled adults who live neither in their families of origin nor in facilities but live independently and use non-residential services has not been recorded in any federal statistics yet. The difference of approx. 10,000 persons that can be calculated from the above figures could provide a realistic indication.

To further explain the situation, statistical data from the federal states of North-Rhine Westphalia (population approx. 19 million) and Saxony (eastern Germany, pop. approx. 6 million) will be presented below, for which a reliable empirical basis is available.

¹⁷ The high figure especially reflects the situation in the new federal states where despite major efforts in the past 10 years there still is an obvious delay of action regarding dehospitalization.

In North-Rhine Westphalia, there are approx. 30,000 places in residential facilities as compared to 1,500 “places” in assisted living (“Betreutes Wohnen”) (LWL, LVR 2001¹⁸). According to the current data¹⁹ of the Landschaftsverbände (associations of counties and municipalities) of Rhineland and Westphalia-Lippe, the structure of the facilities in North-Rhine Westphalia is as follows:

Table 5: Structure of facilities in North-Rhine Westphalia

Number of places	Number of facilities
up to 9 places	96
10 to 49 places	680
50 to 99 places	99
100 to 499 places	46
over 500 places	5

The field of residential facilities is clearly dominated by large facilities and the assistance system for intellectually disabled persons is characterized by a high number of institutions.

The following current set of statistics from the Free State of Saxony is also revealing:

Table 6: Residential types of services for intellectually disabled persons in the Free State of Saxony (as of October 2001)²⁰

Type of facility	Number of places	Number of facilities	Average number of places in the facilities
Home for children	1,552	45	34
Home for adults	7,177	144	50
External residential groups	340	49	7
Assisted living	1189		
Total	10,528		

¹⁸ Data represented during the hearing at the Ministry of Social Affairs of the federal state of North-Rhine Westphalia on April 2, 2001

¹⁹ LVR / LWL (eds.) (2001): “Eingliederungshilfe heute. Entwicklung und Perspektive.” Information provided by the Landschaftsverbände of Rhineland and Westphalia-Lippe (LVR/LWL). Approx. 70% of the persons concerned are classified as persons with intellectual disabilities or severe multiple disabilities (ibid. S.16).

²⁰ Presented by the Saxon Ministry of Social Affairs during the “Assisted Living” meeting of the “Diakonische Bildungsakademie” in Moritzburg on October 25, 2001

Therefore, whereas in North-Rhine Westphalia the ratio of home residents vs. intellectually disabled persons living independently is approx. 20:1, at least in Saxony the ratio is 10:1. Home accommodation still is obviously predominant in these ratios.

However, this becomes relative when considering that Saxony has a strict staff allocation of 1:12 for assisted living. This means that only persons with very low needs for assistance can live independently. The average facility size of 50 places underlines the institutional orientation of the Saxon assistance system. In this context, it is also relevant that according to estimations of the Saxon Ministry of Social Affairs, approx. 2000 persons under 65 years of age live in nursing homes for senior residents, most of whom also have to be classified as persons with intellectual disabilities.

The Ministry does not have any information on the number of persons that are placed in psychiatric facilities for "alien" reasons. In social policy terms, it is a highly sensitive fact that still approximately two thirds (6,891) of the persons employed in workshops for the disabled still live in their families of origin, since a large part of this group of persons will soon also require professional assistance for living. This would mean an increase of the service capacities by approx. 80 percent compared to the current level.

The Saxon figures reveal a tendency that is evident across Germany that causes pressure to act both from a social policy and social planning perspective.

In the Federal Government's most recent Disability Report, the stated number of so-called "specialised integration services" (Integrationsfachdienste), that aim at assisting and accompanying disabled persons in finding employment on the general job market, is 140 services across Germany (Federal Ministry of Labor 1998: 155). Their level of development, however, varies strongly, and only a small part of them assists intellectually disabled persons (Doose 2000). On the other hand, there are 635 workshops for disabled persons (Werkstätten für Behinderte) where a total of approx. 170,000 persons are employed, approx. 150,000 of them intellectually disabled persons.

Experience of people with intellectual disabilities and their families

Families

'Lebenshilfe für Menschen mit geistiger Behinderung' was founded as a parents' organization in 1958, and is now operating on a local, regional and national (and international) level. First in open opposition to the traditional religious 'institutions' the Lebenshilfe is now cooperating very closely with the protestant, catholic and anthroposophic associations. In the sixties and seventies of the last century it was the Lebenshilfe that pushed forward the rehabilitation model for educating and caring for 'the mentally handicapped'. Based on the philosophy of 'optimal stimulation in special facilities done by specially qualified specialists' a nation wide system of special kindergartens, special schools, community homes and sheltered workshops was established and legally ascertained.

Only by the end of the seventies the situation of parents and the situation of brothers and sisters started to become a topic that was taken more and more seriously and also as an area of research (Balzer / Rolli 1975). Corresponding with the 'expert model' the question was asked: "What are the problems of families with mentally handicapped children?" Research results on family situations showed a similar pattern: The families concerned have problems in the following areas:

- Emotional problems
- Financial problems

- Burn-out symptoms because of overburdening care, specially mothers as main carers
- Sibling problems
- Problems in partnership
- Health problems
- Problems with social isolation
- Problems with social discrimination
- Information deficits

Much professional attention was laid on the development of models to explain how parents cope with the emotional crisis that resulted from having a handicapped child. Especially the 'spiral model of acceptance' (Schuchard 1987) became very important for many professionals in Germany. It sees parents in an emotional development that passes from phases of rejection and denying to the final phase and state of acceptance and activity for the handicapped child. This model was more and more criticised by feminist professionals and by parents from the 'parents for integration'-movement, which increasingly influential in the eighties (Schumann 1997). Feminist professionals claimed e.g. that the 'acceptance model' implies a normative 'duty to love' the handicapped child without leaving room for negative feelings that are also a part of parents' situation (Jonas 1989). The 'integration parents' accused special education professionals to misuse the 'acceptance model' against parents that disagree with the special school system and want integrative education for their handicapped child (Körner 1987).

It took some time before research questions followed new ecological directions, eg. "How come that some parents with handicapped children cope very well with their situation? What are the environmental conditions for good quality of life for these families? Why do some families use counselling or respite care services and others don't?" (Thimm et. al. 1997, Engelbert 1999, McGovern et al. 1999) Interesting eg was the result that services perform mechanisms of selecting their clients by establishing 'barriers' of various kinds, and 'access competences' are needed on the users' side (e.g. communicative skills) that are more available to middle-class people.

Users of new types of services need to have certain abilities and skills for articulating their needs, what could explain socio-economic differences in user status of service clients. Especially the implementation of respite care services was backed very much by this new research approaches, and respite care nearly nationwide became a part of the local support system (Schädler 1990).

In preparation of the law on 'care assurance' (established in 1995) as a fifth column of the social assurance system in Germany, much and comprehensive research was done on the situation of carers (Schneekloth / Potthoff 1993). So in Germany generally there is a relatively precise database in that area. In the field of intellectual disability there are also results of quantitative research on the situation of caring family members available (McGovern et.al. 1998).

Persons with intellectual disability

Life courses of persons with intellectual disability in Germany are mostly structured by the 'chain of rehabilitation facilities'. Adults with disabilities either live with their families, in community homes or in big 'institutions' (either religious or anthroposophic providers). More than 90 % of them, also persons with very severe impairments work in rather modern 'workshops for handicapped persons'. These workshops provide very often real work opportunities and people have a status similar to other workers (social assurance, pension,

holidays etc.). Workshop employees have the right to form an employees committee that has participation rights and must be involved in management and organization related decision-processes.

Especially since the big Lebenshilfe conference on self-determination in Duisburg in 1995, 'self-advocacy-groups' or 'people first-groups' were founded in many places in Germany. Empowerment seminars for people with intellectual disability are continuously being held by many associations that deal eg with self-determined living, sexuality, self-defence, personal future planning etc. Training seminars for professionals or conferences often have programme parts with people with intellectual disability to realise direct user participation. Sometimes this happens with good results, sometimes it may be tokenistic. Developed from the concept of the 'trialogue', a setting where the person with intellectual disability is supported by a 'facilitator' in communication situations (Hähner et al. 1997). For some years, there have been serious attempts to strengthen the role of intellectually disabled people as citizens. eg. to prepare and inform people with intellectual disabilities as voters very well designed brochures were spread by the social administration.

Much effort in research was lately laid on the question how people with intellectual disability can be involved in quality management or quality development processes in services (Gromann 1999). Questionnaires and other methods were developed to get information on 'consumer satisfaction' or 'customer satisfaction'.

There is research on the situation of intellectual disabled parents (Pixa-Kettner 1996), the self-concept of persons with intellectual disabilities (Hoffmann 1998), empowerment effects of 'people-first-groups' (Engelmayer / Kniel 2000) and on assessment, individual service planning and 'personal budget' (Rohrmann 2001).

Conclusions

Under § 3a BSHG it has significantly been the legal mission of the social administration since as early as 1984 to give priority to the expansion of non-residential services. Since this has not succeeded so far, massive political control problems of the German service system are becoming evident. Various development paths have resulted in structural arrangements from which three key problem areas arise:

The assignment of responsibilities between local and regional or state authorities funding social assistance has given rise to a practice that does not rely on close-to-home support but is orientated towards supply structures stretching over wide areas. The continuation of centralized, residential service forms is favoured to such an extent that the development of community services is impeded. Criticism of the traditional structures is also growing in view of increasing cost pressures. This produces also pressure to develop new kind of funding models, that include models of 'personal budgets'.

In 1996 the legislator had restricted the priority of community integrated services ("Offene Hilfen"), if "suitable residential assistance is reasonable and a non-residential assistance causes disproportionate additional costs (§3a BSHG)." However, non-residential services and residential services are neither comparable neither in regard to costs nor in regard to accepted standards or effects on the quality of life. Therefore new approaches to Individual Assistance Planning are currently under discussion.

Altogether, one could suggest that the climate for reforms in the disability field in Germany is not too bad, even though stormy weather has to be expected.

References

Balzer, Brigitte / Rolli, Susanne (1975): Sozialtherapie mit Eltern Behinderter. Orientierungen für eine Konzeption eines psychohygienischen Gemeindeprogramm, Weinheim/Basel

- Boessenecker, Karl-Heinz (1998): Spitzenverbände der Freien Wohlfahrtspflege, 2nd edition, Münster
- Bradl, Christian (1991): Anfänge der Anstaltsfürsorge für Menschen mit geistiger Behinderung („Idiotenanstaltswesen“). Ein Beitrag zur Sozial- und Ideengeschichte des Behindertenbetreuungswesens am Beispiel des Rheinlands im 19. Jahrhundert., Frankfurt
- Bundesvereinigung Lebenshilfe (2001): Finanzielle Hilfen für Menschen mit geistiger Behinderung, ihre Angehörigen und Betreuer/innen, Marburg, Lebenshilfe-Verlag
- Dörner, Klaus (2001): Die institutionelle Umwandlung von Menschen in Sachen. Behinderte und Behinderung in der Moderne, in: Emmerich, Michael (Hg.): Im Zeitalter der Bio-Macht, 25 Jahre Gentechnik – eine kritische Bilanz, Frankfurt / M.
- Doose, Christoph (2000): Fachdienste zur beruflichen Eingliederung, Hamburg
- Engelbert, Angelika (1999): Familien im Hilfenetz. Bedingungen und Folgen der Nutzung von Hilfen für behinderte Kinder, Weinheim
- Engelmeyer, Elisabeth / Kniel Adrian (1999): Wir vertreten uns selbst, Kassel
- Esping-Andersen, Gouda (1990): The three worlds of capitalism, London 1990
- Federal Ministry for Labor and Social Affairs: Die Lage der Behinderten und die Entwicklung der Rehabilitation. Fourth Report of the Federal Government, Bonn 1998
- Federal Ministry of Health (ed.) (1998): Leben im Heim. Angebotsstrukturen und Chancen selbständiger Lebensführung in Wohneinrichtungen der Behindertenhilfe; Bericht zu einer bundesweiten Untersuchung im Forschungsprojekt „Möglichkeiten und Grenzen selbständiger Lebensführung in Einrichtungen“ (MUG), Baden-Baden
- Gaedt, Christian: (1992): Die vermeidbare Entwicklung von Schwerstbehindertenzentren. Ein Plädoyer für Großeinrichtungen im System der Wohnangebote für geistig Behinderte. In: Geistige Behinderung, 2/1992, pp. 94 – 106
- Gromann, Petra (1996): Nutzerkontrolle. Ein wichtiger Bestandteil von Qualitätssicherung,. In: Geistige Behinderung, S. 211 –222
- Hähner, Ulrich u.a. (1997): Vom Betreuer zum Begleiter. Eine Neuorientierung unter dem Paradigma der Selbstbestimmung, Marburg
- Heinze, Rolf G./Schmid, Josef / Strünck, Christoph (1997): Zur politischen Ökonomie der sozialen Dienstleistungsproduktion. Der Wandel der Wohlfahrtsverbände und die Konjunkturen der Theoriebildung. in: Kölner Zeitschrift für Soziologie (49) 242 – 271
- Jonas, Monika (1990): Trauer und Autonomie bei Müttern schwerstbehinderter Kinder. Ein feministischer Beitrag. Mainz Hofmann, Christine / Kunisch, Monika / Stadler, Bernadette: „ich spiel jetzt in Zukunft den Depp“. Geistige Behinderung und Selbstbild. in: Geistige Behinderung, 1 / 1996, S. 26 - 41)
- Klee, Ernst.: Euthanasie im NS-Staat. Die Vernichtung lebensunwerten Lebens, Frankfurt 1983
- Körner, Renate (1987): Integration und Menschenbild, in: Hinz, Andreas/ Wocken, Hans: Gemeinsam Leben- gemeinsam lernen beim Hamburger Integrationszirkus. Bericht vom 5. Bundeselterntreffen am 9. und 10. Mai 1987 in Hamburg, Hamburg
- Lachwitz, Klaus (1999): Der Mensch mit geistiger Behinderung – ein Bürger oder nur ein Leistungsempfänger, in: Geistige Behinderung, 1/1999, pp. 65 – 83
- McGovern, Karsten u.a. (1998): Familienunterstützende Dienste in Nordrhein-Westfalen, Siegen

- Pixa-Kettner, Beate et.al. (1996): Geistig behinderte Eltern, Marburg
- Rohrmann, Albrecht u.a. (2001): AQUA-NetOH- Arbeitshilfen zur Qualifizierung örtliche Netzwerke für Menschen mit Behinderungen, Siegen
- Rosenberger, Manfred (Hg.) (1988): Ratgeber gegen Aussonderung, Heidelberg
- Schädler, Johannes (1990): Zur Situation ambulanter familienentlastender Dienste in der Bundesrepublik Deutschland, in: Geistige Behinderung, 2/1990, pp.1 -13
- Schädler, Johannes (2001): Qualitätsentwicklung und Qualitätssicherung – Plädoyer für ein professionsnahes Konzept in der Sozialen Arbeit, in Schädler, Johannes / Schwarte, Norbert / Trube, Achim (eds.) (2001): Der Stand der Kunst. Qualitätsmanagement Sozialer Dienste, Münster, pp. 13 – 38
- Schäfer, Wolfram (1993): Bis endlich der langersehnte Umschwung kam – Zur Lebensgeschichte des Psychiaters Werner Villingner, in Fachschaftsrate Marburg (ed.) (1993)
- Schneekloth, Ulrich / Potthoff, Peter (1993): Hilfe- und Pflegebedürftige in privaten Haushalten, Bundesministerium für Familie und Senioren, Bd. 20.2, Stuttgart
- Schuchardt, Erika (1987): Biographische Erfahrung und wissenschaftliche Theorie. Soziale Integration Behinderter, Bad Heilbrunn
- Schumann, Monika (1996): Zur (Eltern-)bewegung gegen die Aussonderung von Kindern mit Behinderungen „Gemeinsam Leben - gemeinsam lernen“, in: Behindertenpädagogik, 1/1996, S. 37 – 55
- Thimm, Walter u.a. Quantitativer und qualitativer Ausbau ambulanter Familienentlastender Dienste (FED), Baden-Baden 1997
- Ziemer, Kerstin (2001): Geistige Behinderung – Reflexionen zu einem Begriff, in: Die neue Sonderschule, 2001/4, pp. 269 – 279.

Spain

L. Salvador-Carulla, M. Poole, T. Magallanes, R. Novell, J. García-Ibañez

Introduction

During the last 20 years, three parallel processes have taken place in Spain, which had a significant impact on care for Mental Retardation: a decentralisation process from national to regional agencies, a health reform and a mental health reform. The combination of these dynamic processes has produced an extremely complex situation, which makes the description of the current care organisation system a difficult task.

From an administrative point of view, Spain is divided in 17 autonomous regions called "Autonomous Communities" (AC). The ACs have their own government and administration, full autonomy in health and social services, and varying degrees of autonomy in other issues such as crime and justice or education. In practice, Spain's administration works as a federal state although the background is different. This decentralisation process followed a different pace in every AC depending on regional policy and the model of administration transfer from the central government. Two different AC transfer models were developed in the late 1970's: a "slow" transfer process and a "quick" one for the so-called Historical Autonomous Communities which included Andalusia, the Basque Country, Catalonia and Galicia. However, this process has not been accompanied with a parallel development of national agencies or efficient inter-autonomic co-ordination systems. Internationally, services and provisions are described at national, regional and local level. We use "regional" here as a descriptor for provision at the AC level.

Following the decentralisation process, from a common health organisation mainly based on social welfare, a whole array of different health and social care systems have emerged at different periods of time. For example, Catalonia got control over both the health and social services more than 20 years ago while Andalusia assumed the health services by the same time Catalonia did, but delayed the social services transfer until the 1990s. Other 10 AC, such as Cantabria or Balearic Islands, assumed the social services by 1997 and the health services in 2001.

Before the decentralisation process started, national social services were coordinated from an agency called IMSERSO (Instituto de Migraciones y Servicios Sociales) of the Ministry of Labour which also includes Social Affairs. Health services were coordinated by the INSALUD (Instituto Nacional de Salud), a national agency of the Ministry of Health. The social services transfer was completed by 1997, and the health service transfer was completed in 2001. IMSERSO and the Ministry of Health are in the process of redefining their respective roles. Although inter-territorial councils do exist, the decentralisation process was not accompanied by a clear definition of the co-ordination mechanisms among the different ACs, or between them and the central agencies. Currently there is no national information system on service provision either for social or health services.

In terms of law and policy, major differences have emerged among ACs as well.

From 1993 on, our group has published several reports on services for MR in Spain (Salvador-Carulla et al, 1993; Salvador-Carulla et al, 1999; Costello et al, 2000). The main aspects considered in these reviews were:

- Lack of interest by the health department on MR

- Lack of co-ordination among different agencies and administration (e.g. between social services versus health services; or between central agencies and Autonomous Communities)
- Lack of reliable estimates and databases both in epidemiology and service provision and utilisation.
- Problems in accessibility of people with MR to general and mental health services
- Lack of specific services for MR (e.g. MR-MH)
- Lack of training programs
- Need of national co-ordination agencies and plans

Definitions, Legal Status And Eligibility

Terminology and classification

Although there is no common definition of mental retardation (MR) (Retraso Mental) in Spain, this term is widely accepted and it is used by the IMSERSO, the Health Services and the national federation of NGOs in this area (FEAPS). The Spanish Association for the Scientific Study of Mental Retardation (AEERM) has also adopted this term. "Intellectual disability" is preferred by some experts and organisations, but it is not widely used. "Learning disability" refers to other group of child conditions and is not used as a synonym for MR. MR definitions differ slightly in the health, social services and legal sectors.

Health Sector

Health services use the ICD-10 classification. Ministry of Health database use an adaptation of ICD-9 (CIE in Spanish) (CIE9-MC).

Social Sector

The AAMR-1992 criteria were translated into Spanish and are widely known. These criteria were adopted by the FEAPS but neither this organization nor any Spanish administration, either at national or at regional level, has effectively put it into practice. A number of Spanish organisations contributed widely to the new International Classification of Functioning, Disability and Health (ICF, WHO, 2001) (CIF in Spanish). The IMSERSO (Spanish National Institute for Migration and Social Services which depends from the Ministry of Labour) has sponsored both the International studies and the Spanish version of ICF. It has been adopted as the basis for definition and classification of disabilities in Spain. According to that policy, we may deduce that the IMSERSO considers MR as a disability included at code b117 of ICF. The AAMR-2002 definition of mental retardation coincides with this approach. It states that MR is a disability and quotes the ICF as a main conceptual source for related issues such as activity and participation, or context of MR. AAMR also keeps this term in the new edition of its classification (AAMR, 2001).

Education

Aspects related to disabilities (including MR) have been included in the general law of education (LOGSE) which will be reviewed in 2002. The first draft of Law of Quality of the Education approved 10/5/02 by the Cabinet includes a series of dispositions relative to the schooling of the students with special educative necessities. The law dedicates four articles to students who require throughout special support during their school years due to "physical, psychic, sensorial disability or to serious upheavals of the personality or behaviour". Special education will be "based on the students' characteristics,

integrating them in ordinary groups, in special in ordinary centres or centres of special education, after a “psychopedagogic” evaluation to assess diagnosis and assessment of special education needs.

Law

A series of Spanish laws and their statutory developments (Royal Decrees – Decretos reales) refer to people with “handicaps”. This name, used in the former WHO classification ICDDH-1980, is utilised across the Spanish legislation. The Spanish law for the Social Integration for the Handicapped known by its acronym LISMI, provides a legal framework for the definition (Título II, Artículo 7): “A person will be considered as a handicapped when there exists a decrease in the physical, psychological or social abilities as a consequence of a deficit which may be permanent, and which may have or may have not a congenital basis”. A Royal Decree issued on 23 December 1999 (RD 1971/99) defined the procedure for legal recognition and grading of handicaps (procedimiento para el reconocimiento y calificación del grado de minusvalía). It states that: “the legal status of handicapped is provided by the official agencies which are accredited for such task”. The procedures followed by these agencies are described in the next section. MR is here defined as a general intellectual ability significantly lower than the mean, which is accompanied with limitations in the adaptive behaviour i.e. the person’s ability to cope with daily living activities, and adjusting to the personal autonomy norms which should be expected according to age group, socio-cultural background and community placement.

The Royal Decree enabled the development of a table list (baremo) for grading all handicaps according to the degree of handicap and a global percentage index of severity. In order to assign a percentage to a particular person, medical and social factors are considered. Its main source is the WHO 1980 classification of impairments, disabilities and handicaps (WHO ICDDH-1980) (In Spanish CDDM-1980). MR is assessed according to IQ level and several areas of functioning. IQ levels define four groups (Borderline functioning, IQ: 70-80/ Mild MR, IQ: 51-69/ Moderate MR, IQ: 35-50 / Severe-profound MR, IQ: less than 35). The areas of functioning assessed are: Language and psychomotor functioning, social and personal autonomy, educational record, occupational past history, and behaviour. The grade and a percentage index of handicap are decided by an official assessment team (Equipo de Valoración y Orientación- EVO, – Assessment and Orientation Teams). This coding is used for entitlement and legal issues. Thus, professional judgment is accepted by the legal system for qualification. The assessment can be reviewed every two years (or more frequently if professionals question it, though this is rare).

Individuals may actually escape from official qualification if they do not fill in the application to the EVO. A person may have a clinical record which includes ICD-10 diagnosis of MR and, at the same time, he or she may not have the official qualification and pension entitlement unless the request to the EVO is completed and the report released by this office.

In general, a common approach may be found to the diagnosis and classification of MR in Spain. The term “Mental retardation” is generally accepted, and it refers to a low intellectual functioning (measured by IQ) associated to impairment in functional abilities, which start before age 18. Definitions are mostly based upon international criteria. Some criticisms have recently been raised to this approach (i.e. AEECRM – Spanish Association for the Scientific Study of Mental Retardation).

Legal Status

International treaties and international official documents are widely regarded as sources of national laws and norms in Spain. Thus, LISMI was inspired by UNO documents on rights for the people with handicaps (20 December 1971; 9 December 1975). Article 13 of the Amsterdam Treaty is considered the main source for future legal developments regarding people with disabilities.

The Spanish Legislation is halfway between the general protection of individuals without discrimination and regardless of their special needs, and the development of specific laws and norms addressed to this group of people.

Article 139 of the Spanish Constitution states that any Spaniard has equal rights and duties in any part of the Spanish territory. Thus, a person with MR is afforded the same civil rights than any other Spanish citizen. Article 49 says that public administration will carry out a policy of prevention, treatment, rehabilitation and integration of people with physical, sensory and psychological handicap. The administration will provide special care as needed, and will promote special support in order to guarantee the rights these persons are entitled as Spanish citizens.

The Spanish Law for the Social Integration of the Handicapped (Ley de Integración Social de los Minusválidos – LISMI) (7 April 1982, 13/82) provides a national framework for the care of these people. A number of Autonomous Communities have issued special laws on this area (for example: Ley 1/1999, de Atención a las Personas con Discapacidad en Andalucía).

This law has been further developed by the Royal Decree 1997/99. As said, this Royal Decree provides a definition of MR and describes the procedure for entitling a person as “handicapped” by issuing a handicap certificate (Certificado de Minusvalía). This certificate is provided by official assessment agencies deployed in every AC of the Spanish territory. Every Autonomous Community in Spain should develop its own regular norms (reglamentación general) although the Royal Decree provides a series of unified criteria to be used all over Spain. The qualification of handicap depends on the report of local assessment teams (EVO) including, at least, one psychologist and one social worker. A national commission has been recently established in order to provide harmonization criteria for the assessment procedure. It is made up by representatives of every AC and from the Ministry of Labour (which includes Social Affairs).

Incapacity

People with MR are regarded as legally competent unless a judge determines his or her incapacity. This legal decision, is included in the Spanish Civil Code (Book 1, Title IX). It should be aimed at protecting the person’s rights and not other people’s interests or benefits based on the ability of self-drive (capacidad de la persona de gobernarse a si misma). Self-drive is defined as the person’s ability of handling and directing his or her own civil rights. Incapacity causes are described in the Article 200 of Law 13/1986, as those physical or psychological deficits or diseases, which prevent the ability of self-direction. The legal procedure is governed by Law 34/1984 (6 August 1984). The provision of incapacity can only be made by a judge following a procedure called “minor trial” (juicio de menor cuantía) and the provision must take into consideration an expert’s opinion . The legal provision (sentencia) determines the extent and the limits of incapacity in every individual case. Three different civil status relate to incapacity: prolonged parental tutorship (patria potestad prorrogada), full tutorship (tutela) when it is not assigned to the parents, and partial tutorship (curatela) when incapability restrains some civil acts and not others (i.e. marriage, heritage, etc). The type of incapacity should be decided by the judge taking into account the severity of intellectual handicap. Hospitalisation and residential care in special institutions is also decided by the judge. A disability general attorney (fiscal) exists in many legal districts in order to handle and monitor these cases.

The tutor can give consent on behalf of an adult with MR. He or she is also compelled by law to promote the abilities of the person, his or her recovery and the maximum level of insertion in society. Tutorship entities are being promoted at local level. NGO’s and local administrations (i.e. municipalities) can assume this role. Incapacity can be reversed through a review process when changes in health or personal status do appear. The legal qualification of handicap and the provision of incapacity are independent and are provided by two different administrations.

Criminal offence

The Spanish Penal Code declares non-responsible any person with cognitive impairment. MR cannot be condemned in a trial. Nevertheless a significant proportion of convicted inmates have borderline intellectual functioning or MR.

Eligibility for services

The qualification of handicap entitles the person a number of special civil rights in order to compensate the social disadvantages produced by the handicap. The most relevant are fiscal benefits and pensions. From a legal perspective, two different types of provisions and benefits exist in Spain: right-based provisions and discretionary provisions and benefits. Education, health and social security are right-based while social services are discretionary. Thus, the demand of social security pensions, subsidies and benefits, or special support services in education are guaranteed while other individual support and social aids such as social funds for ngos, are not mandatory.

Eligibility for pensions and other social benefits

The eligibility for social benefits depends on the percentage of handicap severity (maximum level of severity: 100%). These benefits have been specified by a national norm (disposición) (BOE 26 January 2000):

Mild handicap (0-32%): Mild handicaps do not qualify for official recognition as “handicapped” and thus for pensions or special social benefits.

Moderate handicap (33-64%): The official qualification of “handicapped” is given when the EVO assigns a severity level above 33%. A pension is provided and a series of social benefits are afforded in order to compensate restrictions in functioning.

Severe handicap (Above 65%): A severity level over 64% merits full compensatory pension, and full handicap benefits.

The pensions and fiscal benefits for the handicapped are defined in a series of laws on Social Security (Legislación sobre Invalidez de la Seguridad Social); Welfare pensions (Pensiones no contributivas), Support pensions (Pensiones asistenciales) and the LISMI.

Eligibility for health services

Health services are guaranteed through the General Law of Health (Ley General de Sanidad). MR, as Spanish citizens, are entitled access to free general medical care. This law also entitles access to rehabilitation care to any handicapped person. However, law enforcements and empowerments have not been sufficiently developed and care gaps do appear in mental health, early care and other relevant areas. The law does not include prevention of handicaps, a topic included in the Law for the Handicapped (LISMI). To make matters worse, many services for MR have been transferred from the health sector to the social sector. As said, health care is right-based while social care is discretionary. The extent to which health services provide care and allow access to those with MR differs in each AC. During the last 20 years major regional differences have risen and inequities certainly do exist.

Eligibility for social services

Apart from being discretionary and not right-based, social service provision is not guaranteed by a general law as health or education are. The autonomous communities have full responsibility on this area and have issued regional laws regulating social services. All of them mention the handicapped and describe discretionary rights to special social services by this population group. However, most acs have not put forward decrees and norms to provide empowerment and regulate these rights. Local administration also has responsibilities on this topic. Major regional differences do not attain eligibility but provision and access to services.

Eligibility for education services

As said, special support services for people with handicaps are right-based. Aspects related to disabilities (including MR) have been included in the general law of education (LOGSE), which will be reviewed in 2002. Special education and centres of special education are mentioned in the Royal Decree 696/95. Norms have been also developed in the ACs. However the degree of provision of staff and support services is far beyond the real need.

In order to become eligible for these programmes a report from the psychopedagogical assessment team is required.

Eligibility for vocational services

Employment has generated a significant amount of norms and laws in Spain. Some of them are specific for people with handicap (ie LISMI), while others are general laws or norms which include specific aspects related to the handicapped. They include social security invalidity legislation, support pensions law (pensiones asistenciales), law on pensions not related to paid work (pensiones no contributivas), as well as fiscal benefits related to disability.

Several employment rights are obtainable, such as discounts and social security bonuses when hiring persons with a handicap qualification. Others are possible but they are not put into practice for a variety of reasons (i.e. the legal requirement of hiring 2% of handicapped employees in companies with more than 50 workers). Other services are discretionary and depend upon budget availability. For example, funds for developing support employment.

As a matter of fact, most supported employment places in Spain are for people with MR (Informe sobre Empleo con Apoyo, IMSERSO, 1999a)

Prevalence of mental retardation

There are several official statistics and studies on the prevalence of mental retardation in Spain. However, these data are incomplete since available information does not include population-based epidemiological studies. The main sources of information are the National Survey on Disabilities, Deficits and Health States (Encuesta Nacional sobre Discapacidades, Déficits y Estados de Salud; INE e IMSERSO, 1999), the National Database on People with Disability, as well as other sources of information such as the FEAPS database or a series of local epidemiological studies.

National Survey on Disabilities, Deficits and Health States (Encuesta Nacional sobre Discapacidades, Déficits y Estados de Salud; INE e IMSERSO, 1999):

This sociological study based on home interviews at national level, explored the rate of disabilities grouped by age, condition and type of impaired function. Criteria were drawn from ICDDH-1980, and data can be compared with a previous survey made in 1986. The sampling procedure excluded people living in residencies, institutions or secluded settings such as prisons. People with mild mental retardation and borderline intellectual functioning were grouped in a common category in this surveillance seriously hampering its overall validity and its ability to draw useful information out from the aggregated data. According to the 1999 survey, 9% of the Spanish population had some sort of handicap in 1999. The main causes were birth related conditions, traffic accidents and chronic diseases. According to the Disability Survey, 134.468 persons had profound to mild mental retardation or borderline intellectual functioning in 1999. That estimate represents 0.33 % of the Spanish population (40 million inhabitants).

Profound and severe mental retardation	32.186	(1.05%)
Moderate mental retardation	61.494	(2.01%)
Mild / Borderline mental retardation	40.788	(1.33%)

This survey shows a higher proportion of moderate mental retardation than mild/borderline intellectual functioning, which is highly improbable. Furthermore, people with borderline intellectual functioning have been aggregated with mild mental retardation. Following a conservative approach, this fact would imply that 50% of these cases should not be classified as mental retardation and that the rate of mild mental retardation would be around 20.400 people, which again seems highly unreliable.

National Database on People with Disability (Base de datos Estatal de Personas con Discapacidad):

This is a general register of all people with a legal status of handicap in Spain (last update: June 1999). This register includes 144.331 cases with mental retardation (0.36% of the Spanish population). This rate stands for 11.5% of all handicap registers in Spain (14.1% mental retardation males; 9.2% mental retardation females). The age distribution is as follows:

0-14 yrs	44.8%
15-34 yrs	27.0%
35-64 yrs	5.7%
Over 64 yrs	0%

Mental retardation is the main cause of disability in children. 63% of mental retardation are of unknown origin while the cause is known in 37% of cases. Down Syndrome is the most frequent diagnosed cause (12% of cases, 54% male); followed by brain infectious diseases (ie meningitis and encephalitis) (10% of cases, 53% males). The National Database does not record cases with mild impairment (below 33% in the official classification table), or those who have not applied to legal handicap qualification. The lack of cases above 65 years of age reflects the problem of this data system. In spite of all, the national database provides a good estimate of the lower range of mental retardation in Spain.

Regional registers of people with disabilities:

The ACs keep their own records of people who have qualified for disabilities. For example, in Catalonia 13.8% of all registered disabilities have mental retardation (34.006 individuals with mental retardation) (IEC, 2002). The registered prevalence of mental retardation is 0.54% in Catalonia, well above national statistics.

Other databases

FEAPS, the National Federation of mental retardation associations keeps a database of associates to 686 NGOs related to mental retardation. It provides any type of care to 232.236 associates (0.58% of the general population). This estimate is above the rate provided by other sources and closer to rates published in international literature.

Epidemiological studies

La Safor County Study on MR (Comarca de La Safor, Comunidad Valenciana) (Tomás, 1991).

This study analysed the prevalence of mental retardation and borderline intellectual functioning in a health area of the Comunidad Autonoma Valenciana. The sample was representative of the school child and adolescent population (0-14 years) in this area. Rate of mental retardation was 13.97 per 1000 while borderline intellectual functioning was 14.10 per 1000. If we adopt a conservative approach and assume a constant prevalence rate of mental retardation for the population below 45 years old (0.14 per 1000), half of it for the population between 45-60 years old (0.7 per 1000), and 0.2 above 61; the rate of mental retardation would be around 0.55% (225.000 individuals, which is still below the rates published in international literature).

Studies in Mental Health centres

The Catalan Health service records all care contacts with the mental health system. In year 2000, 1726 people with mental retardation contacted the mental health system (1.3% of all care contacts). The rate was similar in children and adolescent care (368 out from 26777 cases, 1.4%) and adult care (1358 out from 108.240 cases, 1.3%) (Servei Català de la Salut, 2002)

Studies in occupational centres and institutions

A series of studies have analysed the prevalence and typology of psychiatric and behavioural disorders in occupational centres (Salvador-Carulla, 1996; Salvador-Carulla, 1998; García González-Gordon et al, 1996). Over 30% of people with mental retardation have a formal ICD-10 or DSM-IV psychiatric diagnosis. Over 10% of people placed in these centres have borderline intellectual functioning.

Studies in prisons

According to the available data (Llobet et al, 1995; IMSERSO/Real Patronato, 1999), approximately 0.5-1% of the prison inmates in Spain have a mental retardation or are borderline cases. As this rate is based on unstructured reports, it may underestimate the actual rate. In November 2001 there were 48,162 convicts in the Spanish prisons (INE, 2002). It can be estimated that over 500 may have mental retardation, although the actual rate may be at least twice that. Mostly are men, re-offenders, less than 10% have a co morbid psychiatric disorder other than drug addiction, and 14% show violent behaviour in jail. 70% were newly identified cases during the studies performed by the task-force. However, these data are highly biased since they are based on reports from the institutions. There is a lack of epidemiological studies using adequate screening and interview methods as well as standardised screening instruments for CI and psychiatric assessment.

Policy Framework

The general characteristics of the Spanish administration were described above (introduction). As said, international documents and declarations are regarded as framework statements in Spain (i.e. Rights for people with handicaps, UNO, 1971 and 1975; Article 13 Amsterdam Treaty). In this context, the Madrid Declaration 2002 is considered a key document for future development of policies in this area in Spain. Unfortunately, the Madrid declaration is mostly concerned with physical disabilities and not a single mention of the specific problems of people with mental retardation is made in this document.

In the Spanish administration, social services share the main responsibility for policies regarding people with handicaps at national, regional (AC) and local level. Among the specific social policies defined at national level, disability stands 3rd after policies for the retired and the unemployed. ACs can and do promote new provision of services and benefits for people

with disabilities. Another important characteristic of the Spanish system is the major role of NGOs in care and policy making and planning in this area.

Specific policies relating to people with disabilities produced by central, regional or local governments

We may differentiate three aspects: legal framework, plans and institutions related to disabilities.

Legal framework for specific policies

The LISMI provides the main policy framework for mental retardation in Spain. A new review of the 1982 law is currently under way which will be specially focused on anti-discrimination policies. The publication of the LISMI coincided with the review of the Spanish welfare state and the redefinition of general civil rights such as health (1986), education (1990), employment (1980), and social security (1990-1994). The degree LISMI has actually influenced this areas is uneven both at national and regional level. Disability rights and benefits have been regarded in legislation related to education, social security and social services. A partial influence can be traced in employment laws. On the other hand, little has been done in disability benefits in the health sector, particularly in the case of mental retardation. The main objectives of the LISMI were normalisation and community care:

To promote personal and functional autonomy in people with handicaps, and to improve development and training of people with handicaps

To promote changes in physical, social and occupational context in order to improve social participation and equal opportunities for people with handicaps

To promote support for improving quality of life and provision of basic needs of people with handicaps.

After 20 years, LISMI has shown a limited success with uneven results across different sectors and across different ACs.

Policy plans relating to people with disability

National plans

- a.1. Plan Nacional de Acción para Personas con Discapacidad 1997-2002 // Plan Nacional de Acción para la Inclusión Social del Reino de España (2001-2003).

The “National Action Plan for People with Disability 1997-2002” (PNPD) and the “National Action Plan for Social Inclusion 2001-2003” (PINS) are two key documents for developing policies on this topic in Spain.

The PNPD was developed to provide a common framework for policies developed in different ACs. It has been widely taken into account for regional plans in several ACs, such as Madrid (Plan de Discapacidad de la Comunidad de Madrid) or Castilla-León. In the recent years, inter-territorial equity and co-operation have become key objectives, due to the special characteristics of the Spanish system. This plan is based on 5 general principles:

Respect of rights and freedom of people with handicaps

Development of personal autonomy and social participation of people with handicaps

Emphasis in user's perspectives and satisfaction

Fight against discrimination

Normalisation policies

The 4 main objectives of the National Plan were:

Promote Non-governmental social initiatives with the aim of promoting social participation

Co-operation between administration and provision organisations

Equity in care and basic needs

Improvement of quality and efficacy of services

The LISMI and its related National Plan has promoted in 6 main areas (Planes Sectoriales), each one with specific objectives or programmes (23 Programmes):

Health: Health promotion and deficiency prevention

Health care and Comprehensive Rehabilitation

Education: Special education and school integration

Employment and social security

Community Integration and Social Services

Accessibility and technical aids.

The Action Plan has shown limit results in several areas and lack of concern in others such as, co-ordination and national databases, or health services for mental retardation.

The PINS is focused in areas such as benefits, rights, goods, services (housing, health, education and social services).

a.2. Plan Nacional de Acción para el Empleo del Reino de España 2001

The National Plan Employment policies for people with handicaps are more advanced than in other sectors, in spite of the fact that legal requirements of disability employment are not put into force in Spain, and that the active population with handicaps is comparatively low. A series of programmes are aimed at promoting disability employment in Spain.

a.3. Regional Plans

Regional plans for people with handicaps have been developed in many ACs (i.e. Castilla y Leon, Castilla y La Mancha, Galicia, Guipuzkoa, La Rioja, Madrid). However, these plans do not address the specific problems of people with mental retardation. Plans addressed to specific groups have been developed in some ACs (Child and adolescents in Catalonia).

Institutions relating to people with disabilities

The IMSERSO has played a leading role in policy and planning for disabilities in Spain. Since the transfer of social services to the ACs was completed in 2001, IMSERSO has redefined its objectives to the following aims:

Inter-territorial equity,

Inter-institutional co-ordination and supra-regional planning,

international and inter-regional co-operation, and

promotion of research.

It has pushed forward research initiatives related to quality assessment, information systems and standard methods for service mapping in Spain. It has also promoted a common research program with the Institute Carlos III and the Ministry of Health starting in 2002. The “Observatorio Nacional de la Discapacidad” (National Disability Observatory) and its satellite office “Servicio de Información sobre la Discapacidad” (SID: <http://sid.usal.es>), is a dissemination and information centre promoted by the IMSERSO and the University of Salamanca, which is playing an important role in the area.

The Ministry of Health does not have a defined policy on handicaps. Apart from the governmental institutions and the regional offices in every AC, a series of mixed national and regional institutions play an important role in policy making and planning for people with disabilities. NGOs, academics and other social sectors play an extensive role in these mixed institutions.

Among the national institutions, it is important to mention a counselling institution called “Real Patronato de la Discapacidad” (Royal Patronate for People with Disabilities); the “Consejo Estatal de Personas con Discapacidad” (National Council of People with Disabilities) and the Comité Español de Representantes de Minusválidos (CERMI) (Spanish Committee of Handicap representatives).

Regional institutions are growing rapidly. Information offices have been developed in several ACs (i.e. Castilla La Mancha, Barcelona, Valencia).

General policies produced for other reasons, which nevertheless have an impact on services for people with intellectual disabilities

As said, social services are the main source of policies concerning mental retardation. However, social services are discretionary and not right-based, and this governmental area does not have a legal coverage similar to education, health or social security. It is important to note that health services disregard mental retardation and do not include specific coverage in most ACs.

Policies and guidance produced by other organisations (for example, professional organisations) which, though not carrying the authority of government policy, are still influential in services for people with intellectual disabilities

ONCE (National Association of the Blind) is a widespread NGO with a significant economical and political power mainly due to the monopoly of a national lottery game. Although mainly devoted to the promotion of integration for the blind, it has a foundation that provides funding and provision of services for other handicaps including mental retardation (Fundacion ONCE). FUNDOSA GRUPO is a corporation of 112 firms originated in 1989 which have developed 147 job centres all over Spain and provides job for 8.000 people with disabilities. However, the control over the national lottery and its blind-related policies and lobbying creates inequities in funding for disabilities in Spain.

FEAPS is the National Federation of Associations of Mental Retardation. It has an important database on mental retardation, as well as rehabilitation, prison and family programmes. FEAPS incorporates 686 NGOs devoted to mental retardation, providing job for 33,267 individuals with mental retardation (and borderline intellectual functioning) and leisure activities for 232,236 associates (0.58% of the general population). The policy of FEAPS has been summarized in a document called “Pacto de Toledo (Toledo Pact)”. FEAPS defines five

main objectives: 1) Family life, 2) Education inclusion, 3) Work, 4) Individual management, 5) Service/programme accreditation and assessment.

Funding of Services and Role of Public and Private Sectors

Social services fund most of care and programme interventions provided for people with mental retardation in Spain from the 0.52% of work taxes which are devoted to social programmes in Spain. This is managed by the IMSERSO and the Social Services in the Spanish ACs. A call for proposals from NGOs is made on a yearly basis. Apart from funding NGO activity, social services fund and provide direct care and programmes, Research and Development (R&D), residential beds, home support, as well as direct funds for social programmes by Spanish non-governmental organisations.

In most ACs social services fund care, rehabilitation and integration programmes for mental retardation. Management is mainly performed by NGOs working under agreement with the social services. Many NGOs are family associations or catholic organisations such as “Orden de San Juan de Dios” or “Hermanas Hospitalarias del Sagrado Corazón”. These two related organisations provide a significant share of mental health care in Spain and work under agreement with the health services. They also have programmes funded by social services. Social firms and private foundations have a significant role in vocational and social programmes. A number of these organisations underwent a significant change during the early 90s and have become market competitive firms with R&D departments and important participation in national R&D and international programmes. However, market shifts, changing governmental and regional policies, and the absence of special promotion planning from the Industry department and other governmental agencies make these firms highly vulnerable on the long term. Several examples of this approach can be mentioned, such as PROMI Foundation in Andalucía, AMICA in Cantabria or INTRAS in Castilla-León. Cost-effectiveness studies that may estimate savings for health and social services derived from vocational integration may contribute in the future to estimate reasonable and steady governmental funding for these initiatives.

Private funding and management plays a minor role in Spain, except for Fundación ONCE/Fundosa Group. This organisation invests 3% of its gross benefit from the disability lottery (Cupón) (or 20% of net benefits) to the Fundación ONCE.

Emerging Service Structures And Models

Three types of care can be found: residential, intermediate and community care.

The Spanish psychiatric reform and its consequences for people with mental retardation

The Spanish deinstitutionalisation process and the psychiatric reform were started in 1985. By then, 30,084 people were institutionalised in psychiatric hospitals, of whom 26% had a diagnosis of mental retardation (Jorda et al, 1986). After 1985, a shift from institutional to community care was started both for psychiatric patients and for people with mental retardation. People with mental retardation were transferred to social service residencies in many ACs. Several ACs kept residential services within psychiatric hospitals, promoting slow deinstitutionalisation and remodelling services for mental retardation within institutions. The 1991 report on the psychiatric hospitals by the Spanish Ombudsman revealed that this population decreased to 23,282 in five years. Chronic patients occupied 11,535 beds and the overall proportion of mental retardation in those institutions was 24% (over 3000 people) (Defensor del Pueblo, 1991). Another 2000 people were placed in special care residencies for mental retardation (CAMP: Centros de Atención a Minusvalía Psíquica) depending from the national social service (IMSERSO).

By 1999, all health and social services were transferred to ACs. We have recently analysed the psychiatric reform process in Spain. We compared 1999 service availability in Spain and in Italy. We also compared care indicator rates to standards published in the literature (Salvador-Carulla et al, 2002). Results were discouraging as the provision of intermediate services and non-hospital residential care was very low in 1999, in comparison to neighbouring countries and to published standards. The situation was worst for people with mental retardation and psychiatric problems. As said, no national database is currently available.

Care system organisation

Several ACs such as Catalonia have put forward a quasi-market system, splitting the purchasing and providing of services between different agencies, while others (Andalucia, Madrid) keep a public integrated health system. However, the quasi-market competitive system is the envisaged model for most ACs. Community care purchasing and provision have been always divided in the social sector as it relies heavily on programmes and services provided by NGOs. However it does not operate as a quasi-market since it is mostly based on subventions without competition. Residential social care provision depends on social services in each AC (i.e. CAMP) and partly from NGOs.

Analytic accountability, use of Diagnostic Related Groups (DRGs) cost-unit calculation and cost-effectiveness procedures are nearly absent in the social sector, while health services have adopted these standards and are implementing them nationally.

Care provision by health and social services

We lack a comprehensive mapping of services for mental retardation in Spain, or reliable information on how many places are provided or how many people do they serve. Unfortunately, the transfer of health and social services has been accompanied by lower information availability at national level. This trend has been described in all previous papers (Salvador-Carulla & Martinez-Maroto, 1993; Salvador-Carulla et al, 1999; Holt et al, 2000).

Health services

The role of general health services, primary care and mental health care, on mental retardation is fairly limited and most responsibilities have been shifted to the social services. The low utilisation rate of mental health services in Catalonia (1.4% of all people using mental health services or 0.02% of the general population) (ICS, 2001) reflects a clear under utilisation of mental health care services by this population group. It should be noted that this trend is changing nationwide due to several reasons such as the appearance of new demands (care for the elderly, or care for borderline intellectual functioning), lobbying of family associations, difficulties on integrating people with mental retardation and psychiatric and/or behavioural problems in residential facilities and vocational programmes intended for non-psychiatric mental retardation.

In a previous review (Salvador-Carulla et al, 1999), we highlighted the need of a health and social co-ordinated system for residential and community care. Liaison services in the community and diagnostic and evaluation residential units play a key role in the care network. Residential care may provide 3-5 beds per 100,000 population. The care system should include diagnosis and evaluation units, acute & sub acute units, long-stay units, respite and sheltered homes. Special attention should be paid to the functions of the diagnosis and evaluation units, which may co-ordinate care plans, hospital admissions and follow-up. A case-management system should be implemented and these units should be linked to specialised liaison services working in the community with primary care and general psychiatric services.

Liaison mental health services for mental retardation have been actually developed in Catalonia (2 planned), Galicia (1) and Castilla-Leon (2 developed by INTRAS Foundation).

Specific hospitalisation units for mental retardation patients with psychiatric problems are being developed in several ACs such as Andalusia and Catalonia. Catalonia is the only AC which has developed a global care plan on Mental Health for people with mental retardation implicating both social and health services. This effort has been put forward during the last two years and it is too early to assess the results.

Social Services

The social services provide residential care for cases without severe needs in occupational centres and for high dependency cases through residential facilities called CAMP (Centros de Atención a Minusvalía Psíquica). CAMP provide comprehensive care for mental retardation 16 or older who may need it because of family, social or financial problems. They are not specifically designed to help patients with dual diagnosis. Currently, there are 74 CAMP facilities in Spain. The total number of beds and characteristics of the facilities and of the people being cared for are being assessed by our group since there is no national database gathering this information. The average number of beds was 50-60 in CAMP and 30-40 in occupational centres in 1993 (Salvador-Carulla & Martinez-Maroto, 1993).

During the last 5 years a number of residential centres for people with dual diagnosis have been set up in several ACs (Catalonia, Andalusia).

Intermediate care including work, leisure and social activities are more developed for mental retardation than for mental illnesses. However, intermediate services provided by the social system are rarely able to cope with the specific difficulties of people with mental retardation and psychiatric problems as it happens with residential services.

Vocational support facilities are classified in four groups:

Occupational centres: Provide occupational therapy, and social and individual adjustment. These services are aimed at people who are unable to work in competitive placements or in special vocational centres. People at occupational centres do not receive a normal salary. Occupational centres may provide residential care.

Special vocational centres (Centros Especiales de Empleo): These centres are aimed at providing competitive employment and at producing competitive goods. Normal salary and social security benefits are provided to employees who should be disabled.

Support employment. Workers receive individualised support both at training stage and after starting normal employment.

Ordinary employment. Workers receive a normal salary and work in ordinary firms.

FEAPS includes 686 NGOs related to mental retardation. These organisations comprise 493 Occupational centres, 243 special employment centres and 277 leisure clubs. As a whole, 33,267 people with mental retardation are in job placements (23,890 in occupational centres and 9,377 in special job centres). 232,236 people with mental retardation participate in social and leisure FEAPS programmes. The exact number of people in Day centres is not available, those services are given to persons who get support in the day-time, but stay with their family at the weekends and evenings and is situated in the domain of adapted activities for adults who cannot work on the regular labour market. Support programmes for families and home care are also available, family support services can give educational and psychological support to families and parents who take care for a family member with mental retardation .

NGOs have also played a significant role in developing sheltered homes (maximum 10-15 residents per home). Those group homes are situated in the community, close to a residential facility, persons with disabilities can also participate in daily activities (maximum 10-15 residents per home).

Child and adolescent education services

Special services for this population include:

Early care/stimulation programmes for children with mental retardation

Special education programmes:

Special Education Centres, special nursery and primary education are aimed at children who need special help, temporarily or permanently. This can be due to a physical or mental impairment, serious behavioural or emotional problems, or serious learning difficulties.

Integration classes, for special groups/classes in regular schools, this education makes children with impairments or having learning or educational difficulties attend lessons or activities in a school for mainstream education with assistance provided by special education.

This may be temporary or permanent and apply to some of the lessons or all of the lessons difficulties

- *Psychopedagogic teams*: Support from psychopedagogic teams in the school for children with low learning difficulties

Emerging service structures

The lack of adequate resources implies that many services structures regarded as “usual care” in other countries can be considered as emerging services in Spain. Emerging care demands which are being deployed in some local and regional areas include:

1-Child and adolescent care. It deserves special attention in the Basque and the Catalanian planning. Specific units have been developed in Guipuzkoa.

2-Geriatric care: The Guipuzkoa province (Basque Country) keeps 5% of all geriatric places for mental retardation. Specific units have been planned in Catalonia. NGOs such as PROMI have put forward geriatric units for people with mental retardation.

3-Dual diagnosis: Four hospital units for people with mental retardation and psychiatric problems have been developed in Catalonia. Two NGOs working under agreement with social services have developed non-hospital dual diagnosis residential units in Andalucia.

4-Respite units: NGOs are developing respite units in most ACs (i.e. AMICA in Cantabria, FADEM in Madrid, and several NGOs in Catalonia). These units are mainly addressed to people with mental retardation and psychiatric problems. The FEAPS respite family programme started in 1995 has 5 modalities: weekends, crisis mobile support services, emergency residential short-stay.

5-MH-mental retardation Liaison Community care units: Catalonia has recently deployed two community care liaison units on its territory. A liaison unit is currently functioning in Castilla Leon (INTRAS foundation) and Galicia.

6-Tutorship organisations (entidades tutelares): Developed by local administrations (municipalities), or NGOs; these organisations provide tutorship when parents die and there is no other alternative available.

7- Supported living are being developed at local level. Services of supported living give psycho-social support or assistance in activities of the daily life for people in their own homes.

8-Teleassistance: Support for people through on-line TV communications are being developed in several Acs.

A number of training programmes deserve special attention:

1-Special Training Programmes The AEECRM has developed a training package for assessment and diagnosis of psychiatric problems in mental retardation addressed to general psychiatrists in Spain. The FEAPS is working on a package for carers. Catalanian government has developed a similar programme in order to fit future demands in this area. Although no formal training is provided on mental retardation either in medicine or in psychology, the IMSERSO and other agencies have promoted postgraduate training in many Spanish universities. These programmes are filling a gap in the graduate education system in our Country.

2-Family Support programmes: FEAPS is promoting family support programmes across Spain.

3-Prison Programmes: FEAPS, Royal Patronate and several governmental institutions are promoting care programmes for people with mental retardation in prisons.

Experience Of People With Intellectual Disability And Their Families

General aspects: Experiences and Investigations on this Topic

The Experience of People with Intellectual Disability:

- Social exclusion is a consequence of a complex set of factors including care needs in daily life, crisis intervention, demand of psycho-social support, the economic needs that derive from the assistance and care, the housing assistance, the architectural barriers and, finally, their complicated insertion into the labour market.

- The absence of a link with the labour market, affects in great measure People with intellectual disabilities since they represent a small proportion of the active population, especially in the case of women. Something that is reinforced, generally, for their low educational and training levels. Furthermore, when People with intellectual disabilities get an employment, it is precarious, low qualified and low paid.
- Social stigma adds to this group of factors: the talk of their deficiencies, of their continuous medical needs, or the social rejection (due to ignorance) that brings forth the mental illnesses in the society in general and in the employers in particular. The sum of their complex labour insertion, of the physical barriers of the environment and of the stereotypes that the society assigns to them results in social exclusion.

- Another of the experiences lived by the People with intellectual disabilities is that the irruption of the new information and communication technologies generates new inequalities for them, and this adds to the exclusion from the labour market.

The key elements in order to fit the needs and demands of People with intellectual disabilities are: equal opportunities, client-centered planning, use of the necessary supports, normalisation and inclusion as references for social and health policies. Persons with ID should be included in the leading role of People with intellectual disabilities in decision-making processes. The goal is not independence, but interdependence AND needs fulfilment. In most situations, what is needed is not a special residential place, but a more intensive support in the community.

The Experiences of the families of people with intellectual disabilities

In Spain the great majority of people with intellectual disabilities live with their families and only around 1% lives in residential centres. The ID affects the family life significantly and more than half of the families live this situation as an obstacle for the development of a normal family life. Through the times this means an heavy economic, physical and psychological burden, and frequently, social isolation. This extra effort is undertaken basically by women

(83.8%), most of them over 45 years old. NGOs and the Government agencies have set up a number of different support programs for families (ODC 1999).

From this standpoint, there are four innovative experiences, all of them on support to the family, from different perspectives.

- **Network assistance of adults with disabilities in Cantabria:** program that gives general integral assistance to People with intellectual disabilities, giving assistance through networks in a co-ordinated manner without forgetting the family as a basic element (AMICA, Cantabria).

- **Temporary service of reception centre in families for mentally disabled people.** Pioneer service in Catalonia and in Spain, consisting in providing the reception of mentally disabled people, that live with their family at other people's homes in their social environment. This pretends to improve the quality of life of the families with a member with disability and on the other hand make the social integration of the People with intellectual disabilities easier (Area of Social Services of the Barcelona County).

- **Parent to parent program,** that has as its objective to inform and support parents of new-borns with the Down syndrome, and the innovation consists in that such supports are given through "experienced parents", that have already had the experience of having a child with the Down syndrome (Down Syndrome Foundation in Madrid).

- **Family break service,** whose objective consists in making bearable the overload that these families with children with ID carry (FEAPS).

The study carried out by the EDIS, Sociologic Investigation Equipment (ODC 2000), should be highlighted in this section, from where we point out the following conclusions:

- The level of assimilation and acceptance of the fact that the arrival home of a ID child is, mostly (80% of the cases), normal or satisfactory.
- The most frequent complaints of the parents of children with ID are related with the treatment given to them in the Primary care centres (information on preventive measures, referrals, and long waiting lists, and the disparity in many diagnostics).
- The demand a greater professional specialisation from the educators and more participation from the parents in the educational process.

Specific problems experienced by the individuals according to their different characteristics (for example type of disability, ethnic differences, gender, age).

The differences among people with ID are enormous and in Spain according to the following factors:

- The prevalence of assisted ID is higher in males at all levels of ability, with a ratio of 1.7 men for each affected woman.
- By age groups, the diagnosis of ID is less frequent during the early life years - before age 5, even though it is increasing during the school years, while a bigger intellectual outcome is demanded, until reaching its maximum between ages 14 and 15. In adulthood, it decreases around 1%.
- The levels of severe and profound mental retardation are distributed evenly throughout all the social scales, but the mild mental retardation, influenced by environmental factors as malnutrition (that affects the cerebral development) and the affective or cultural deprivation (that affects the intellectual and emotional development), is more frequent in the lower social classes.
- As for the data on the percentage of mental dysfunction in people with mental retardation are extremely varied and disparate, oscillating from 10 to 50% of the cases. The studies

published in our Country in occupational centres point out a rate between 20 and 35% (Salvador-Carulla et al, 1998).

The specific problems experienced by the individuals according to their characteristics are:

Ethnic differences: There is a lack of data regarding people with intellectual disabilities from ethnic minorities living in Spain, but the increase of immigration in our country has been so spectacular in the last two years that there is no doubt that this will be a key problem in the future.

Type of ID: Social disadvantages prevent, or at best limit, the performance of survival roles, mainly work. Even though work is the most visible element that is affected by the type of ID, other aspects like social integration, daily habits, projects for an autonomous life and, and definitely, future expectations are also conditioned.

Social classes

The little knowledge of the existence of support resources for ID by the low social class families. This ignorance that translates into an effective estrangement that leads to concentrate their diffusion on the networks of traditional users, projecting a charity image and creating a distrust toward the institutions that is manifested especially in some profiles of severe poverty.

Gender:

80% of women with disability are unemployed and 29% are illiterate. Discrimination of women in relation to men is added to a lack of education and training , and prevents full integration and adequate access to employment. While the right to maternity and contraception are fully recognised, ID women are subject to mandatory gynaecological controls to control their maternity. Inequality topics like race or social class contribute to increase the discrimination.

Age:

Persons with ID are living longer and as a result the number of aged ID is increasing with additional burden on informal carers which does not always translate into an appropriate assistance. In spite of this the informal family networks still play an important role and compensate the inadequacies of the formal networks. On the other hand this represents a major challenge for the future as such care pattern will probably vanish in a generation.

Mental retardation and Mental Health:

Major differences exist in the different ACs in Spain. In some of them (i.e. Andzalucia) , health policy planners consider that persons with ID should use the general psychiatric services and that special services should be restricted as much as possible. Other ACs (ie catalonia) have recently developed and implemented additional services for ID both at residential and community level.

In any case, care provision is far below the standards in other EU countries. It must be highlighted that 75% of the people with dual diagnosis are never identified, and people with ID receive less assistance in MH services, because these services do not have the adequate preparation nor the necessary sensitisation. 8-10% of the People with intellectual disabilities that live in institutions (residences for ID) present severe mental disorders that require treatment.

Models and Patterns Service Use Regarding these Characteristics

- Difficulties in the access of the patients with mental retardation to the general psychiatric services: Lack of specific psychiatric services for mental retardation.

Interest on Special Topics

Traditionally the person with intellectual disability has been regarded as a sexless person. All the concern was focused in preventing "immoral actions as well as in avoiding reproduction.

Since 1990 on, the perspective on the sexuality of people with ID has radically changed. Sexual education and prevention have become normal topics in ID planning and policy. However the impact of these policies in specific centres has been uneven and largely depend on the initiatives of local family organisations and care institutions.

The topic of sexual abuse and violence in women with ID is a key one. Recent governmental data point out that abuse may be five times larger in women with ID than in women from the general population

References

- American Association on Mental Retardation (AAMR). Ad hoc Committee on Terminology and Classification. AAMR News & Notes, 14 (5): 10-13, 2001.
- Defensor del Pueblo. La situación jurídica del enfermo mental en España. Oficina del Defensor del Pueblo, Report, Madrid, 1991.
- Holt G, Costello H, Bouras N, Diareme S, Hillery J, Moss S, Rodríguez Blázquez C, Salvador-Carulla L, Tsiantis J, Weber G, Dimitrakaki C: "BIOMED-MEROPE project: service provision for adults with intellectual disability: a European comparison". *Journal of Intellectual Disability Research*, 44 (part. 6), pp.685-696, 2000.
- Jorda E, Espinosa J, Gomez-Beneyto M. Estudio de los pacientes de larga estancia internados en ocho hospitales psiquiátricos españoles. En: *Cronicidad en Psiquiatría* (Ed. J. Espinosa). Asociación Española de Psiquiatría, Madrid, 1986.
- Llobet M. Estudio sociológico. La prevalencia del retraso mental en el medio penitenciario. Institut de Reinserció Social (IRES). Mimeo, Barcelona, 1995
- IMSERSO. Informe sobre Empleo con Apoyo, IMSERSO, 1999^a
- IMSERSO. Base de datos estatal de personas con discapacidad. Col. Documentos. IMSERSO, Observatorio de la Discapacidad, Madrid, 2000.
- Institut d'Estadística de Catalunya (IEC). Persones reconegudes legalment com a disminuïdes segons tipus de disminució. Catalunya, 2000. IEC, Marzo, 2002.
- Instituto Nacional de Estadística e IMSERSO: Encuesta Nacional sobre Discapacidades, Déficits y Estados de Salud; INE e IMSERSO, 1999.
- Instituto Nacional de Estadística. Población reclusa. Boletín Mensual de estadística, nº 122, febrero de 2002.
- Madrid Declaration: Congreso europeo sobre las personas con discapacidad. Madrid, Marzo, 2002.
- Memorandum acumulativo del Grupo de Trabajo de Apoyo a la Rehabilitación de Personas con Deficiencias Afectas por el Regimen Penal-Penitenciario. Madrid, 1999.
- Salvador-Carulla L, Martínez-Maroto A: "Description of General Services for People with Mental Handicap in Spain". *Journal of Intellectual Disabilities Research*, 37 Suppl 1: 34-37, 1993.
- Salvador-Carulla L, García-Mellado MJ, Romero C, Montero S: Evaluación Psicosocial del Retraso Mental. Conceptos, Metodología e Instrumentos. Madrid: Ministerio de Asuntos Sociales, Servicio de Publicaciones IMSERSO.1996.

- Salvador-Carulla L, Rodríguez-Blázquez C, Velázquez R: "Comparing Services for Learning Disability and Mental Health in Spain". Tizard Learning Disability Review, European Issue: 26-33, 1999.
- Salvador-Carulla L, Rodríguez-Blázquez C, Rodríguez de Molina M, Pérez-Marín J, Velázquez R: "Hidden psychiatric morbidity in a vocational programme for people with intellectual disability". Journal of Intellectual Disability Research, 44 (2): 147-154, 2000.
- Salvador-Carulla L & Novell R. Guía práctica de la evaluación psiquiátrica del Retraso Mental. Aula Médica, Barcelona, 2002.
- Salvador-Carulla L, Bulbena A, Vazquez-Barquero JL, Muñoz PE, Gómez-Beneyto M, Torres F. La salud mental en España: ¿cenicienta en el País de las Maravillas?. Informe SESPAS 2002, SESPAS, 2002. www.sespas.aragob.es/informe.html
- Servei Català de la Salut. Retard Mental: Casos tractats any 2000 en la xarxa CSM i CSMIJ. CatSalut, 2002.
- Tomás J. Estudio del Retraso mental en la Comarca de La Safor. Generalitat Valenciana, Valencia, 1991
- World Health Organisation. International Classification of Functioning, Disability and Health. WHO, Geneve, 2001 (Spanish version: CIF, OMS-IMSERSO, 2001).
- World Health Organisation. International Classification of Diseases, 10th Edition. WHO, Geneve, 1999.

Abbreviations used

- AAMR: American Association on Mental Retardation
- AC: Autonomous Communities (Comunidades Autonomas)
- AEECRM – Spanish Association for the Scientific Study of Mental Retardation.
- AID Software Package: Aplicacion Informatica para Centros de Discapacitados.
- BOE: Boletín Oficial del Estado
- CAMP: Centros de Atención a Minusvalía Psíquica
- CERMI Comité Español de representantes de Minusválidos
- EAPS: Equipos de Asesoramiento Psicopedagógico
- EVO: Equipo de Valoración y Orientación-
- FEAPS Confederacion española de organizaciones en favor de las personas con Retraso Mental
- ICDDH-1980: International Classification of Deficits, Disabilities and Handicaps 1980 (In Spanish CIDDH)
- ICF-2001: International Classification of Functioning, Disability and Health. (In Spanish CIF-2001)
- IEC: Institut d' Estadística de Catalunya

IMERSO: Instituto Nacional de Migraciones y Servicios Sociales (Spanish National Institute for Migration and Social Services which depend from the Ministry of Labour)

INE: Instituto Nacional de Estadística

INSALUD (Instituto Nacional de Salud)

LISMI: Ley de Integración Social de los Minusválidos

PINS: Plan Nacional de Acción para la Inclusión Social del Reino de España (2001-2003)

PNPD: Plan Nacional de Acción para las Personas con Discapacidad 1997-2002-

ONCE: Organización Nacional de Ciegos

R+D: Research & Development

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Sweden

Kent Ericsson

Introduction

Intellectual disability is an issue of great global concern. The major part of this group does not have the possibility of leading the life of others in the societies to which they belong. There is also a group among these, we do not know its size but it is considerable, who live under unacceptable conditions of life. When the possibility arises to make transnational comparisons of forms of support and the lives they offer, steps are taken to increase knowledge concerning the possibilities for a better life for this group. IDRESNET, the European Intellectual Disability Research Network, is such an occasion, which should be greeted with satisfaction.

This presentation of life of persons with an intellectual disability and their support in Sweden is written with the aim of contributing to a transnational exchange between seven European countries. Naturally it is necessary that a presentation is focussing a limited number of issues. Those which have been chosen are a) the policy framework for support, b) emerging service structures and models, c) funding of services and the role of public and private sectors, d) definitions, legal status and eligibility and e) relevant methodological issues. This presentation gives the experiences from working with persons with intellectual disability and their support from a Swedish perspective at the same time as these five issues are covered.

The last three decades in Sweden have been a period during which residential institutions have been dissolved and community based services have been developed. Lives of persons have changed dramatically. This has also been the period during which I have carried out my research projects. Naturally these have covered the issues which have been seen as relevant. This work has of course been carried out within the Swedish context, and the work has been published in the Swedish language. Some material has also been presented in English, the major one being "From institutional life to community participation" (Ericsson 2002). Here references will only be given to publications in English, not to the Swedish publications, which have been their source (Ericsson, K., 1985a; 1985b; 1992a; 1992b; 1995; 1999; 2000; Mansell, J. and Ericsson, K., 1996)

Legal status, definition and eligibility

Legal status

The shift between two traditions of support which was given as a frame of reference for the organization of support, was realised through four Acts of Parliament. While the Acts of 1954 and 1967 represent the institutional tradition, the Acts of 1985 and 1993 are formed so as to realise the community tradition. The latter are therefore based on the idea that persons with intellectual disability are citizens, with a right to participation in community life, like others.

This citizen perspective has some specific consequences. These, like other citizens, have the full right to avail of the welfare services offered to the general public. This means that the special services for persons with an intellectual disability become supplementary. If general services are not available, special services could be applied for. The need for these special services are therefore related to the degree of availability of general services to persons with a disability.

A citizen perspective is also the basis for the right to participation in community life for all persons with intellectual disability, even those with extensive needs for support. In order to

realise this community based services need to be developed so as to give all the support needed outside residential institutions. Which service the person is going to avail of, becomes the result of a process in which the organization offering support is one part, while the person with disability, together with his representative, is the other part. If agreement cannot be found, both parties have the right to go to an administrative court to contest the decision arrived upon. The recognition of the person as a citizen is the reason for closing residential institutions and not permitting them to remain as a public service.

The consequence of this perspective on the legal status of persons with intellectual disability is that the disability in no way restricts the person. He has the right like everyone else, to participate in society and to use its resources. There are however situations when any person, because of illness, psychiatric problems, disability or some other condition is unable to take care of himself. A formal representative can then be appointed by court to represent him. There are two forms of representatives. One of them, in Swedish called "a good man", has the task of assisting the person, without infringing his rights, in his contacts with formal bodies of society, for example to see that he gets a life of welfare. The other type of representative takes over responsibility, for example regarding economical matters, which are totally administered by him. In this situation the person's possibility to make formal decisions is withheld.

Definition and eligibility

Hand in hand with the shift between the two traditions of support handicap is seen as a relative concept in Sweden. This occurs if the person has difficulties in dealing with the activities of his everyday life because of a disability. Two criteria therefore need to be fulfilled, one regarding the disability of the person, the other covering his ability to manage his everyday life. These double criteria open up two avenues for work. One is of course the task aimed at limiting the disability of the person, for example by activities, which increase his abilities. The other is to adjust the environments in which everyday life takes place, to such an extent that demands confronting the person are reduced, thereby making it easier for the person to manage his daily life. The disability movement is a proponent of this relative view of handicap and this has led to strong demands for the adjustment of community so as to make it available to larger degree for persons with a disability

The Act of 1993 is applicable to three groups of persons with a disability. This is expressed in the first paragraph:

This Act contains provisions relating to measures for special support and services for those 1) who are mentally retarded, are autistic or have a condition resembling autism, 2) who have a considerable and permanent intellectual impairment after brain damage when an adult, the impairment being caused by external force or a physical illness, or 3) who have some other lasting physical or mental impairment which are manifestly not due to normal ageing, if these impairments are major ones and cause considerable difficulties in daily life and, consequently, an extensive need for support and service.

As can be seen the various forms of social support available through the Act of 1993 are open to persons with several types of disabilities, mental retardation being just one. If we talk about intellectual disability we see that persons with mental retardation, the type that has its roots during the developmental years, are eligible. But so are also those with an intellectual disability, which has developed during adult life. Autism, too often misunderstood as mental retardation, has been pointed out in this Act as a separate disability. While group 1 and 2 are diagnostic criteria in the classical sense, group 3 represents another way of identifying those who are eligible. Here the need for an extensive and permanent support, irrespective of type of disability, becomes the basis for deciding whether a person is eligible. The importance of this paragraph in the Act of 1993 is that it illustrates a shift away from criteria based on diagnosis of a disability in favour of basing the decision of eligibility on the person's need for support.

When we talk about eligibility it should be remembered that all persons with intellectual disability have the right to use the general welfare services. There is therefore no need to qualify to be able to avail of these. But if the person wants to have access to the supplementary support offered through the Act of 1993, he must of course be recognised as someone with mental retardation.

At one time, when the difference was great between social services for the general public and the special services offered by the residential institution to which one was admitted for a lifetime of care, this decision was most important. This situation does not exist today. The difference between social services and the special services is not that great and the same welfare organization finances and runs both services. Application for a service is today not for life, a request for housing can be for a limited period of a person's life. The decision of eligibility is therefore today not a dramatic one and although identification is based on psychological, social, educational and medical information, the request for support under the welfare state is received by an LSS-administrator who makes a decision with regard to the eligibility and what sort of support the person should receive.

Administrative prevalence

The number of persons in Sweden who in June 2000 requested support from the municipalities, was 0.4%. It should be remembered that this figure does not necessarily mean that it covers the entire group in the country. Even if prevalence is low, this figure represents those persons who have applied to a municipality for support according to the Act of 1993. This Act covers social services for pre-school children and school-children and their families, also social services for adults which offers welfare in the everyday life.

It should be remembered that these services are voluntary and that it is possible for persons to turn to other agencies, which run social services, for the general public. In that case a person is not necessarily identified as someone with an intellectual disability, only as a person with a need for support for example in his home or in his daily activities.

As education for children with intellectual disability is organised as part of the ordinary educational system, children receiving special education are found in this figure only if they have requested some form of additional social support. This is also the case for children who have medical needs. They turn to medical services for their support and can only be found included in this figure if they also have asked for social support from their municipality.

The statistics behind the figure of 0.4% is extensive and accurate. But as the structure of reporting of information is based on the Act of 1993 and used for the first time in the year 2000, it is difficult to make comparisons to previous reporting.

Policy framework and developmental pathways: a new socio-political idea

The question of finding ways for society to assist its citizens to lead a life of welfare, has been given attention in Sweden since the beginning of the 20th century. The economic depression of the 1930s gave new impetus and the question as to how to organise a welfare society was recognised as a major political task. This led to a programme of modern forms of social services.

Persons with a disability were of course hard hit by this depression and they, through the disability movement of the time, also expressed requests for welfare. As a response to this a public enquiry, the "Committee for the partially able-bodied", was set up in 1943. In 1946 it presented its suggestions. "Partially able-bodied" was the expression of the time, at least for those with a mild form of disability. The choice of term illustrates that the committee was concerned about the welfare of all persons with a disability, not only some diagnostic groups. The expression also showed some optimism as those with a disability were seen as persons with abilities.

As the modern welfare services had introduced new forms of delivering support to the general public, the committee was faced with two alternative ways of providing support to persons with a disability. Should their support be channelled through the traditional residential institutions common at the time, with roots in the society of 1850 and thereafter, or through the welfare services to be introduced 100 years later? The discussions of the committee ended with a recommendation that society should open up the welfare services so that they also had the responsibility to give their services to persons with a disability.

The expression “partially able-bodied” shows, however, that they only meant those with a mild disability. It was recommended that others with a more severe disability were to be served by traditional residential institutions. Based on the recommendations of this committee society took the first step away from the residential institution as a service. Deinstitutionalisation had begun. With the position chosen by the committee, a new socio-political idea was introduced. It was called the normalisation principle. A quotation from the report of the committee gives an idea of their thinking:

“... the agreed upon principle that the partially able-bodied to as great an extent as possible be included in the ordinary system of social services which are being developed in our country. ... It is hardly necessary to emphasise that this, even for the partially able-bodied themselves, must be seen as a basic right as a citizen; it is entirely in keeping with the very essence of democracy that equal human value and equal rights are put in the foreground. ... Psychologically this “normalisation” of conditions of life, education, employment exchange etc. of the partially able-bodied must be a great achievement.”

Here one finds three components, which together express the new socio-political idea. What is specified is the principle that welfare services, those with a task to guarantee the welfare of the general public, also should be available for persons with a disability. This was regarded to be a democratic right. In this way this idea expressed the view of persons with a disability as citizens and members of society. The committee also expressed an expectation that this way of organising services for the persons themselves should bring about a normalisation of their conditions of life.

The motive for this normalisation principle was, of course, to guarantee a good life and welfare for persons with a disability. But there were also societal motives of an economic nature. These were associated with the introduction of a welfare society, with social insurance and economic support as important forms of benefits. If the partially able-bodied were to become more productive and able to support themselves to a larger extent, demands on economic social support would decrease. One even went so far as to suggest that the existence of measures to increase the ability for the partially able-bodied to earn an income, was a basic condition for the realisation of a welfare society.

Here one also finds a position being taken on how to view persons with a disability. Their participation in the welfare society was seen as a democratic right, which granted, and confirmed, their role as citizens. As such they made up part of the general public, whose welfare was to be guaranteed by the new services which were to be established. It was, therefore, seen as natural to make the choice that even these persons should be allowed to avail of ordinary social services.

But even this democratic motive had an economic dimension. The day when a welfare society, with an ambition to guarantee welfare for the entire public, also perceives persons with a disability as citizens, all must be granted the right to have their needs provided for. If these needs should be realised through the provision of specially built residential institutions, with a standard seen as acceptable to a welfare society, society would be faced with an impossible economic task. One would not be able to build specially designed institutions for all! The only way to meet their needs for welfare was to open up the general welfare services (Ericsson 2002).

A shift between two traditions of support

The institutional tradition, which grew out of the conditions of the second half of the 19th century, was the natural and logical one at that time. The transformation from an old agrarian society into an industrial society made persons with a disability “visible”, a group among others. When families of these persons turned to society for assistance there were few public services to respond to the needs they expressed. A natural consequence was that private organizations for assistance were created. Later on public bodies also began to form disability services. The support from such an organization was delivered through a residential institution, where a group was taken care of, often in the countryside. Education was arranged for the “educable”, care for the “uneducable”. Their work was carried out with optimism and an ambition that persons would return to those communities from which they had originally come.

The normalisation principle of 1946 illustrates how a society 100 years later, with the conditions of the time, a democratic society, a disability movement and ambitions for welfare for citizens, turns to new forms of support. A community tradition, promoting community based services, becomes the natural and logical forms of support of this society. This transition from institutionally to community based forms of support can be seen as a shift between two traditions of support.

These two traditions differ in significant ways. The community tradition sees persons with an intellectual disability as citizens of society, with a right to welfare and participation in community life. The services to be used by them are the services of other citizens, that is, the welfare services used by the general public. Persons with a disability, their life and support, are seen from a citizen perspective in the community tradition.

The roles attributed to persons in the institutional tradition are those of the “pupil” (the “educable”) and the “patient” (the “uneducable”). As these roles put focus on the lack of competence of persons, the increase of competence becomes the major task of the institutional tradition. A competence perspective can be seen as the position from which persons with an intellectual disability, their lives and services are being defined. The consequence of this is an emphasis on special education and care as the main services to persons with an intellectual disability. It becomes natural to create special institutions, with special staff and special methods, to deliver those services. For a person to receive his support he has to be admitted to such an institution (Ericsson 1999a).

With the two traditions of support, deinstitutionalisation becomes a logical consequence and one finds the direction for development. On an individual level persons leave an institutional life for participation in community life. On an organisational level institutionally based services are being dissolved at the same time as community based forms of support, as part of the welfare services of society, are being developed as alternatives. On a cultural level a shift of perspective takes place. It is necessary that a citizen perspective be conquered, while a competence perspective is left behind (Ericsson 2002).

Four Acts of Parliament

These individual and societal motives have been the driving force behind the realisation of this new socio-political idea, aiming at the participation of persons with a disability in normal life. The basic condition for a realisation of this aim has, of course, been the extent to which the welfare society has become a reality for the general public.

As regards the field of intellectual disability, four Acts of Parliament, 1954, 1967, 1985 and 1993, have gradually introduced community based services, while institutionally based services were being dissolved. A notable Act of Parliament is the one of 1985 which, for the first time, clarified the right for everyone with an intellectual disability, not only those seen as “partially able-bodied”, to participate in community life. Then even those with an intellectual disability with extensive needs for support were recognised as citizens, with a right to use the services of the general welfare society.

These more than 50 years of transition of services ended in 1999, when the residential institution ceased to exist as a service. At the same time the regional organization which had run those institutions, was dissolved and responsibility was taken over by the municipalities who have the task of running services for the social well-being of the public. An important step towards the realisation of the normalisation principle of 1946 had been taken (Ericsson 2001).

This socio-political transition has been the framework for support to persons with an intellectual disability during the last 50 years. Much can be said about this transition (for an extensive analysis see Ericsson 2002), but here the actual development of community based services is being discussed.

Funding of Services and Role of Public and Private Sector

The welfare society in Sweden is based on the idea that it is the responsibility of society to contribute with assistance when for example unemployment, social crisis, disability, sickness or some other condition creates a hinder for a person or a family to earn an income and to lead a good life. Support from a number of agencies can then contribute to the welfare during a brief or a long period. These services are financed by taxation and they are organised by society. The size of taxation and the organization of services are decided by a parliament. If a service, for example support to the unemployed, is organised on a national level, the national parliament is responsible for taxation and the running of a service. When a service, for example the hospital, is run by a regional organization, the regional parliament has the responsibility and when a service is organised by the municipality, for example social services, the local parliament decides on the size of taxation and the type of service to be delivered.

The process leading up to a person receiving the support he asks for is a complex one. National Acts of Parliament provides the rules by which support is to be delivered and it defines the groups which are eligible. Parliament, on the relevant level, has to decide upon the financing of a service and the organization delivering this must be formed so as to reach out to the person with a disability in need of support. This welfare system does not in any way mean that everyone gets whatever he asks for. But as this process basically is a political one, with parties representing persons with a disability to a varying degree, it is open to the political pressure of organizations representing persons with a disability.

This means that disability services are publicly financed, without any contributions from the private sector. At present there is however a tendency that the role of private organizations is increasing. This means that they, side by side with public services, organise and run support, but these are still publicly financed. A consequence however of this interest from private organizations has been that public services have been challenged and that competition, as regards methods of delivering support, has increased. The interest in quality control has also increased.

Emerging service structures and models: three generations of community based services

Three generations of community based services can be identified. The first has a background in the traditional way of seeing persons with an intellectual disability as either "educable" or "non-educable", thereby separating those with a limited need for support from those with more extensive needs. The first type of community based services, during the 1960's and the first half of 1970's, were offered only to those with a limited need for support. These were easy to establish as the normal settings of a community were used. The housing and the places of work were those used by the general public. The ordinary schools were used for the special education of the time. Commercial services, places for recreation and welfare, services for health and social well-being could be used. What was needed was some few staff as these

persons were those with a limited need for support. Persons with the more severe disability were seen as being in need of the residential institution. Therefore, no attempts were made to offer them a life in the community.

The second generation of community based services were developed when all persons with a disability, even those with extensive needs for support, were given the right to a life in community together with others. Formally this took place with the Act of 1985. Demands for a community life came from persons who had grown up in their home and who, as adults, requested a life in community instead of an institutional life. As they had grown up in their family, they did not accept going to a residential institution. The closure of residential institutions for adults, starting at the middle of the 1970's, meant that community based services had to be developed in order to replace institutionally based services. By necessity these had to offer extensive support as those who had lived at the residential institution were those with the most extensive needs for support.

Today we see a tendency towards a third generation of community based services. As residential institutions no longer exist, those who request support are those who have grown up with their families. They are all well aware of their rights to participate in community life and to be partners in the process when services are being formed. In this way they are able to influence the course of their lives. When a person gets the opportunity to control his own life, he does not ask for special services, that is, special houses with special staff. This development is supported by the present Act of Parliament.

Now one can find examples of new disability services, which are a result of these new conditions. Personal assistance, introduced in the 1993 Act, is such an example and provides the person with a sum of money with which to purchase the support he requires from a group of assistants. As these are personal, their task is to see that the person can experience a good life within his own home. He can choose the assistants himself, together with his representative, and with such support be in charge of those who provide his assistance. As assistants are appointed for a person, not attached to any special house, he can choose whichever housing he finds most suitable from what is available in the community in which he wishes to live. In this way personal assistance illustrates that support is related to what is given by people, not what is provided in a building. Personal assistance can be given to people with extensive needs for support and the family can become involved in arranging housing.

This system of personal assistance contrasts with the group-home, which is a specially designed house for persons with an intellectual disability owned by society, with special staff attached, whose task is to provide support to those who are placed there. In this way one has recognised that support is not in the walls of the special house, but in the competence of staff who work there. When staff in this way is separated from the house, one must recognise that any house is possible to use by the person with the disability as long as he receives the staff support he needs.

As an example, four men left a traditional group-home and bought themselves a house and became the owners of their own home. Their personal assistants gave them the support they needed in their new house. In this way influence over their lives increased, they could buy the house they liked and they received the amount of support per month they needed. As the task of the personal assistant is to assist a person with a disability, support has become more personal. This has increased the possibility for the person to control his own life.

Support to the child and its family

When developing support, the ambition is to offer a life to the person with a disability, which is the same as others. As a consequence support is oriented towards giving the family support, in order to be able to live with its child at home during infancy and school years. When it becomes an adult, the family has become older and no longer able to give its support, the person gets the possibility to establish his own adult life.

The psychological needs of the family should not be neglected, as a child with a disability is seldom expected. In such a situation there could be disappointment and resentment. Other families, who previously have had similar experiences can then be someone to turn to for early information as to why this has happened and what can be expected from the child and its life in the future. There are also counsellors who can assist with "the first information".

When the child grows up in the family, this can be experienced as a burden on the parents, and then practical and psychological support is needed. Assistance can be given by a person coming into the family to deal with practical matters while the family gives its attention to the child. When parents want to give attention to themselves or to other members of the family, it can be desirable to have relief from others. This service can be received from an extra family or a group-home for short-term visits.

Early intervention indicates that not only the family but also the child is in need of support. As an infant it will have the same need of attention and care as other infants, but because of its disability there may be a need for extra support to cope with the various stages of child development. Pre-school activities, in the local day nursery, contribute to the child's play and social interaction with other children.

As all children with an intellectual disability have the right to education, schools and the education they offer must be organised for this to become a reality. For each child to have his educational needs satisfied it is understandable that there must be a variation of solutions on offer. Special schools are no longer recognised, instead the education of children with a disability takes place within the framework of ordinary school system.

But this does not mean that all children at all times are part of the ordinary classes of that school. The task is to create a situation when the child will gain educational experiences important for him. This can be achieved through the ordinary class or in a special setting. In reality the child's week will consist of the activities which are found suitable for him, these taking place in various settings of the school. Sometimes these will take place together with children who have got a disability and sometimes the activities take place together with others. A major experience is that the smaller the group in which the child takes part, the more attention the teacher can give the child thus enabling him to experience personalised education.

Support to adults

When the person has become an adult, compulsory schooling ends. If the person has the possibility of getting a paid job like most people, he will go to work. Even if the person has a disability, but still needs some limited support, he can have the possibility of getting a paid job, but a job where he receives some support from others. He receives a full salary, but this is subsidised by the national employment body.

If he cannot get a job because of his disability, he can instead take part in day services, organised as a series of daily activities with support. The idea with these is to give the person the opportunity to experience the normal life, that is to leave his home during the day and to take part in purposeful activities during the five days of the week. As this is a service, the type of activities should be related to the needs and requests of the person. For someone needing extensive support, the week can be filled with activities which give stimulation and pleasant experiences of value for his personal development. For those with a limited need for support, the days can be filled with productive work. Earlier on these activities usually took place in special day activity centres. Today, when there is an ambition to participate in community life, the tendency is to create settings in the ordinary community, specially organised for small groups of persons.

It is common that the child lives with his family during school years. But as he grows older it is usual that he leaves the family to get his own home. Because of his disability he is in need of support, this being limited if he only has a minor disability. In that case he can get an ordinary apartment of his own, like other young people, but with staff who provide support in his home

(through personal assistance, for example). If he is not self-sufficient and has got more extensive needs for support, a group home is an alternative. This can be a large apartment or a house where a group of usually 4-5 people live. In such a home there is also staff on duty around the clock, the number of staff being less if the needs of the persons are limited. But if the needs are more extensive, for example for persons who once lived at the residential institution, the number of staff needs to be higher.

The brief presentation given here can only be a general one. For each person there must be a personal choice of services, applying the alternatives, which are available at the time. The requests from the person and his family will of course influence how services will be formed. Contributions to the choice of services are also related to the degree and character of disability of the person. The cultural context will also influence services of the person, e.g. housing in the countryside being different to housing in the large city (Ericsson 1996).

Experiences of people with intellectual disabilities and their families

Persons and their families, a source of information

“... must be seen as a basic right as a citizen; it is entirely in keeping with the very essence of democracy that equal human value and equal rights are put in the foreground”

(from the Committee for the partially able-bodied of 1946, as translated in Ericsson 2002, p. 48).

In my analysis of change going on in Sweden as regards support to persons with a disability I have taken this quotation as a starting point. This comes from the public enquiry which produced the report which pointed the way towards a normal life for persons, away from residential institutions and institutional life. In 1946 this was of course a vision, without any substance. But after more than 50 years of change this idea becomes relevant in a process of evaluation of services.

The socio-political idea expressed in this quotation is also the key component of the community tradition. This attributes the role of the person with a disability as a citizen, with “equal human value and equal rights”. This becomes the citizen perspective from which one can view the life of the person and his services. As the issue of equality is paramount, the relationship between the person with a disability and the services organization is clarified. The person, with his representative, is a part of the process, which leads up to the support which is being offered to him.

In the model represented by the community tradition the process of support is opened by a request for support by the person and his representative. The response from the service organization should be the question: “what sort of life does the person want to lead?”. The content of the support process should be one, which forms and delivers the type of support, which makes a reality of the life requested by the person.

When the person becomes a member of the support process new demands are made on the type of services to be offered. The residential institution, centrally planned and with patriarchal relationships, coercion being just one, will not be the type of support asked for by the person. His experience of living with his family, in a community where he has grown up, has given him his view of the normal life. The schooling, housing and daily activities and other services for health and well-being which he has seen there, will be the ones which he asks for. Support therefore gets not only a personal but also a local character.

This has consequences for the issue of quality of support in this tradition. The question of whether the person lives a life of quality can be answered by relating the life lived by the

person, to the life, which once was requested by him. In this tradition quality becomes a personal issue, based on a personal criterion.

Before going on it should be said that several studies have of course been carried out in Sweden describing the everyday life of persons by using theoretically based methods of structuring the everyday life. But these are not the ones given attention here. With the community tradition and the role it attributes to the person with a disability, we need to be informed about how he views his services and the life, which is offered to him. Here two ways of collecting this information is given. In the first one a symposium, a conference or a long-standing committee is formed, the task of which is to give a platform for a group of persons to express themselves about their lives and how this is related to their support. The second way of collecting information is by interviews with persons.

Symposia and committees to bring information together

In the Nordic countries (Denmark, the Faeroes, Finland, Greenland, Iceland, Norway, Sweden and the Åland islands) NFPU (the Nordic association of mental retardation) has been a trans-Nordic forum for co-operation on issues relating to mental retardation. By tradition it had been an organization where professional people met for symposia and conferences to further work in the field of mental retardation. In 1987 NFPU formed a committee for persons with a disability with the task of finding forms for their participation in the organization. 5 persons from each of the 7 Nordic nations, with their representatives, met regularly over a 6 year period. Making this into a committee which was going to communicate with each other and which was to find forms of working together was a challenging task. But it was overcome as one found not only ways of translation between the Nordic languages. A process was also found which did collect the views of the committee on their participation in the organization and in their services.

It was very clear that persons requested participation in this Nordic organization. They also did express a desire to belong to organizations over which they had control themselves, not being part of organizations run by parents. They also wanted control over the services offering their support. This was expressed in a sentence, which was chosen as the final word of the committee: "we are not pieces of furniture - we are human beings!"

Another example of forwarding the views of persons to a wider audience, staff and other concerned groups, was the organization of a conference, consisting of 4 symposia. In each 3 persons participated. A symposium covered a subject and the members presented their views on the topic. The contributions for a symposium were summed up by the moderator (a person without disability) and it was documented. The members of the symposia had taken their task seriously and prepared a presentation. These varied in length but there was always a message in each contribution. As one of the presenters lacked formal speech he had his representative reading his views on life in a group-home.

Through the conference a picture was given of life being offered by services and how this life was viewed by the persons themselves. Many new aspects were brought forward, creating surprise among several in the audience. Creating a forum in the form of a conference with a series of symposia, was shown to be a very fruitful way of bringing persons with important experiences together.

Interviews to follow-up reforms

Municipalities and their new responsibility

As has been seen from my presentations, services in Sweden have gone through a period of reform. In reality there are two changes which have been carried out. The more spectacular is of course the closure of residential institutions. But there is also one where the regional county organizations have been closed down, handing over responsibility to local municipalities, those bodies in society which have the responsibility for social welfare services to the public.

A number of follow-up studies, on an organisational level, have been carried out to see to what extent new local services have been established. Apart from those we have in a series of studies asked persons concerned of their views of this reform. In one study in three municipalities persons were interviewed on two occasions to hear their experiences. Services are a relative phenomenon, growing out of prevailing conditions. As an important change during this reform, county handing over to municipality, new forms for delivering support need to be established. In this second study the task was to set up daily activities after the change had taken place. In two parts of this project interviews were carried out with persons concerned.

This is not the place to present all material. As it is fairly recent it is still in Swedish and as the material sums up a number of interviews, it is extensive. What can be said is that interviews is a method, if persons use speech as a means of communication, by which important information can be collected on the ongoing process of change. There are though demands on how interviews should be used, as a relationship need to be established characterised by trust on the part of the interviewee. The content of these interviews give an insight into the ongoing process of change as it is viewed from the perspective of those persons who are concerned. The tendency found in these interviews is that persons do not want to go back to previous conditions, neither to residential institutions nor to county services. They are instead pleased with the development which has taken place towards a closer participation in the local community to which they now belong in a more pronounced way than before. At the same time they are also critical on mismanagement and faults which they see in their new services and they do not hesitate to be frank about these.

Institutional closure

As regards the part of the reform concerning institutional closure, three interview studies have been carried out. They are presented here in brief (also in Ericsson 2002, p. 139-145) as more extensive presentations can be found elsewhere. The first is a study with interviews of persons who left the residential institution. The second study also concerns persons who left, but these are persons who do not use language as a means of communication. Therefore information was collected with interviews of staff in the new services. In the third study members of families to persons who left the residential institution are being interviewed.

Interviews with persons who started a new life

In a work which aims at an understanding of the change from institutionally to community based forms of support it is naturally desirable to listen to those persons who left in order to hear their views about the events which have taken place. But this is difficult as many of those who lived at the residential home were persons with extensive disabilities. This meant that several lacked speech as a way of communicating with others. Many also had a severe intellectual disability, which made it difficult to express the significance of the change, which had taken place. The way of getting an understanding of these persons' own thoughts in this series of studies was to interview the relatively small group who had speech, regarding what it meant to start a new life outside the residential institution. This study was conducted as part of the project, which documented and analysed the transition of services, which took place in Skaraborg County. Eighteen persons were interviewed by a member of the Skaraborg project, Sirkka Gilbertsson (Gilbertsson 1992).

As an interview was to relate the views of a person on his life after having left the residential home, a number of issues concerning everyday life, housing and a home, daily activities, leisure and relations to others, were to be covered. To make a person feel free to talk about his experiences, interviews were open but care was taken to cover all issues. The interview was carried out during a visit to the home of the person. From each interview quotations were collected, by writing them down during and after an interview, which were indications of the person's views of his new life. All interviews resulted in a collection of 307 quotations, which expressed these persons' perceptions of their new lives. As the quotations were the material for this study, these were sorted into categories and together with comments, presented in a text.

It is a positive picture of their new lives, which emerges. No one expresses a wish to return to the residential home. However, they do not recount a life of strong and intense emotions, nor one of dark or gloomy experiences. During the conversations, which took place it was instead the everyday events of daily life, which dominated, the pluses and minuses that are experienced by all, not just by this group of persons.

The positive experiences consisted largely of these persons having acquired something, which was their own, primarily a home where they are able to decide for themselves and to give their lives a personal touch. That this emerges as a dominant feature is perhaps natural, seen against the background of them previously being unable to encounter such experiences.

At the same time even these persons are faced with the annoying and problematic sides of daily life. The young man who summarised his experiences of dealing with financial matters with the words "*money, it's difficult, it is*" probably expressed a more general feeling and not just one experienced by the person who has left an institution.

There are also many expressions in these interviews, which with delicacy and nuance say something not just about their own but more general impressions. The role of recreational activities is well perceived by the one who said "*leisure, we spend together*".

One also wants to know more about the significance of some expressions. What do they really mean when they speak about the relatively young staff as "*the old maids*"? Is it an expression for warmth and tenderness, that is closeness, equality and positive relationships, or is it an expression for fear and respect for superiors, based on earlier experiences?

There is one quotation which stands out as particularly challenging as it can be seen as summarising this process of change. It is a comment made by a man who was pleased about receiving post in his own postbox which was outside his new house. His comment, when he went out to show it to the interviewer, was "... *it's good to have one's own postbox, but there is no name on it*". He had acquired a new life, which consisted of a considerably higher material standard. Regarding his own person he had, however, not become visible and publicly recognised in his local community. He, and all others who had been away for a long time, had a need to announce that once again one belonged to and participated in the life of that community.

The interviews show that these are persons who have profound views regarding the life they live and the support they receive. When one listens to them one also gets information. This is perhaps nothing one should be surprised about, but it needs to be said.

Interviews with staff

In order to gain an understanding of personal consequences this study was conducted at an early stage of the process of change at Carlsund residential home. The group concerned were the 24 persons who left during 1982. Two years later interviews were carried out with staff at the persons' new homes and their daily activities. A smaller number of interviews also took place with 3 persons and with 4 members of families. A total of 56 interviews were carried out. The study was conducted by a member of the Carlsund project, Maj Thorsell (Thorsell, Ericsson & Brusén 1986, 1988).

An interview began with the request "Describe what X:s life is like to-day. Focus preferably on the situations where you have seen change in a positive or negative direction. Remember that negative changes are as important as positive". X in this respect referred to the person the interview concerned. Each discussion contained several narratives, each in the form of some words or sentences, which expressed a change which had been observed. Each little narrative was taken as an indication of change. From each discussion a number of such indicators could be identified. The 56 interviews resulted in this way in a total of close to 600 indicators. When categorising them, indicators expressing similar ideas were grouped into dimensions. This resulted in 13 dimensions which were in turn grouped so as to describe similar phenomena in a category. In this way four categories emerged which together gave a picture of the daily lives of these persons after they had moved. These four categories, in bold

letters in the text, are summarised here. The wording of a category was chosen so as to describe the essence of the indicators they express. The dimensions which make up the category are presented in italics in the text.

Becoming a person: This was the category which emerged as most relevant. The picture which was found was that these persons now lived in smaller groups, with more personal relations to their staff. They became visible as a person, with their own personal needs and wishes. This was illustrated in the expression *staff have time for me too*. In the interviews there was a group of indicators which described positive exchanges between persons and staff and that there was time enough for staff to meet needs and wishes. This came to be described as *they do listen to us*. But in these personal relations there were also examples of how a person's wish to control his own life led to a situation when he wanted to argue for his opinion. The dimension which expressed this is entitled *now one dares say no*.

Finding a home: As the unit where the person had lived at the institution was planned like a modified medical ward, moving to a new house meant a big step. The home provided new experiences and a new way of life. Persons responded to these opportunities and created a home for themselves with a personal touch. In this way they acquired a private life. *Having one's own home* was a way of summarising the indicators which describe this. Of special significance was the kitchen and the free access to all that a home has to offer there. These were experiences which had not previously been accessible. The kitchen had therefore an important role to play, for these persons, as for everyone else. ... *with a kitchen* was the expression which summarised this new experience. That it is not entirely without problems to have access to a kitchen with its contents and the activities it offers, became apparent when one had to share a common kitchen. Food in the refrigerator had to be shared by many. There was also food purchased by the service organization. This raised the question of privacy and the freedom to use what was purchased for all: *whose is the food in the fridge?* Getting a house also implied that one was a resident, with an address and that one lived in a housing area like others. This also contributed to getting and keeping friends. This was summarised as *persons have personal relationships*.

Something to do all day: To offer daily activities that contribute to a good life for persons who had left a residential institution was not as easy and did not lead to the same positive consequences, as when the home was established. Few indicators say anything about the consequences of daily activities and those which are voiced are not all positive. *Passivity - my protest* was an expression which showed how persons who came to a day activity centre but who, when they did not experience activities which seemed purposeful, reacted with passivity and lack of interest. This became a protest, which put demands on a continued development of activities in order to be able to offer a good life also for persons who had left an institution. The positive activities that were recalled, were those which led to the person's participation in the activities which took place within the day activity centre. *I'm needed* was a way of describing this positive side of activities.

Dad comes even if it rains: In the person's home, in a house in a local housing area, it was more natural for a family member to make a visit. One visited one's son or daughter with a disability in the same way as when one visited another son or daughter. What went on in this home was the same as in any other home. In this way this type of contact with services became less dramatic. It was easier for a family member to make a visit and to contribute to what is going on when the competence one has in caring for one's own home can be seen as a contribution. *There's room for the family* is an expression, which describes this.

Contact also became more normal between family and a son or daughter. One could be passing by and just drop in for an short visit and a son or daughter could informally be invited home for a meal and a short visit. *Supposing I asked her to dinner?* was the expression which captured this feeling. With one's own home it had also become natural to have a telephone in order to keep in touch with one's family. It is easy to ring up and one does not have to speak in order to hear parents or siblings on the phone. *Phone-calls, a way of getting together* summed up this new form of contact. These social contacts were, of course, not as natural if one did not have a family that was interested in one's well-being. For these persons a desire

to acquire new friends developed. *Fellow human being wanted* became the expression, which communicated this aspiration.

The major tendency found among the personal consequences after these persons had left the residential home for new community based services, was expressed by the first category "becoming a person". Indicators of this were collected from interviews in the home as well as in daily activities. The individuality of the person was seen in the new setting offered by the new service. Seeing this personality also meant an awareness about social relationships, primarily to the family.

There are two aspects of the new life that could be expected, but comments on these were absent. One concerns the limited number of indicators relating to the daily activities of the person and when mentioned it was not only in positive terms. This is surprising considering the fact that this represents a separate service that offers activities to persons during five full days of the week. As the consequences of this service are hardly mentioned in the interviews, questions can be raised about its contribution to a good life for persons. One is also surprised about there being no mention in the interviews about participation in the life of local community, neither outside the home nor outside the day activity centre.

Interviews with families

Being a member of the family to a person who leaves an institution that is to close down, places one in a situation where one can be subjected to considerable stress. In the development of new services for one's son or daughter, brother or sister in a new community means that during a period one lacks knowledge as to what the future is going to be. It is not until one has seen the options available that one can understand what the closure of the residential home will imply for the person concerned. The purpose of these interviews was therefore to gain insight into the views of family members regarding this process of change. A total of 53 family members participated, parents, siblings and others, in interviews concerning 36 persons. A member of the project in Skaraborg County, Barbro Tuveßon, conducted the interviews (Tuveßon & Ericsson, 1996).

Four areas were covered by an interview. "Kind of support" concerned issues relating to the type of institutional care received by the person. Information about the new community based services was also covered. "Time for breaking up" covered the reactions of the family to this new situation during a period starting when information was given about the decision to close the residential home and ending at the time of the interview. "The relation to the family member" is an area in which the family could describe how the relationship was developed during the period beginning with the information about the closure of the institution. "The future" was the area in which the family could express views concerning the future for both the person and the family.

The interviews were recorded. This provided the basis for characterising the phases of the life of the family member and the reactions of the family, during the period which was covered by the study. One way of characterising the family reaction was to identify whether it had been negative, neutral or positive towards the person leaving the residential home. As the family reaction was identified for two occasions, after having received the first information about the closure and at the time of the interview, the development of a family reaction to this transition could be described.

There is one question to which an immediate answer was attained. It concerns whether relatives who had been negative when the process of change began, maintained their negative attitude after their relative had left. The answer is that the majority of those interviewed had changed their opinion. While 28% were positive prior to the move, 78% belonged to this group when the process of change had been accomplished. One finds therefore a group who changed their views when they had seen the new services which had replaced the institution and when they had seen the new life that was offered.

There is also a group who are not entirely positive. Admittedly it is small but represents those who, in spite of the higher standard in material and formal respects are not completely

satisfied with that which the persons have acquired. When they saw the alternatives to the institution, they sought other qualities which they regarded as more important if the option was to be considered suitable for their family member. A conclusion to be drawn is that it is not always enough, when creating new forms of support, that the formal and material requirements are met. It is also important to see that these are regarded as positive by others, in particular, by the family. If one is interested in their opinion they need to participate and be included in the process of change and to be able to influence the type of life which the son or daughter, sister or brother, is going to live.

Moving to a community near that of the family was regarded as an important factor. It was not so that all had come closer to the parental home, but many did come to live near each other after the move from the institution. This provided conditions which facilitated the development of an entirely new relationship between the person and his family. The previous more formal contacts which entailed travelling and visits to the unfamiliar environment of the institution, had been replaced by one where one was able to meet each other under spontaneous forms and in familiar circumstances.

A striking impression from these interviews was the very strong relationship of the family to the person in the institution. He was remembered as part of the family, even if he did not receive many visits. When this process of change was viewed from a life-long perspective it was clear that one had the person in one's thoughts, in spite of his being far away and having been unable to affect his life during several decades. What had taken place long ago was well remembered, for example a critical comment by a doctor or a headmaster, this having contributed to perceptions still held today. At the same time one took a responsibility in that one planned for the future, for the son or daughter, brother or sister, in order to guarantee that someone else would take responsibility when one no longer was able to do so oneself.

The commitment which was shown illustrated that the family felt a responsibility for the relative with a disability, "the person belonged to the family", even if he had not always been a part of its everyday life. For the organization responsible for support this is an important assertion. The person with an intellectual disability does not "belong" to the organization and should therefore not be accessible for any measures, which they wish to take. One has, of course, as a representative for a public service an important role to play in relation to these families. At the same time as one makes decisions concerning measures and contributions of support, one is also an intrusion, which can dramatically affect the life of the family. These factors are clearly illustrated in this study concerning this process of institutional closure and the person's move to new services.

DISCUSSION

Support to persons with an intellectual disability in Sweden today is characterized by extensive changes. An institutional tradition has previously dominated these services. But this has gradually been dissolved, opening up for the development of a community tradition. The most dramatic part of this change has been the closure of all residential institutions and the shift of responsibility from a regional county organization with special services to local municipality welfare services. This change is a logical one as the community tradition has grown out of the society of the last 50 years. The institutional tradition had its roots in the society of the 19th century.

When evaluating this change by asking persons with a disability, directly or indirectly, and their families the conclusion is clear. The general picture is that one finds the new forms of support desirable and one does not want to go back to previous conditions. The normal life, together with others, which once was a vision, has now become a reality. In this way support has become more personal giving opportunities for an increased involvement of persons and their families in everyday life. But this also leads to higher expectations of the quality of support. When this is not met there is critique.

Within the institutional tradition responsibility for what was seen as all aspects of life was taken over by the institutions, excluding municipalities from any responsibility. The present challenges are therefore concerned with the development of support for persons with an intellectual disability in the municipalities. The direction for this is being discussed as too much of ongoing services has merely been taken over from the regional special services. There is a need to leave such centralistic services behind, developing those which use the local resources of the community.

The responsibility of the welfare services of the municipalities was based on the idea of a citizen perspective. Therefore the physical and organizational restructuring which has taken place was a consequence of this. The task, not an easy one, is now to find the more democratic forms of support, giving a more inclusive role to the persons and their families.

REFERENCES

Ericsson, K., 1985a. *The origin and consequences of the normalization principle*. Presentation, IASSID Congress, New Delhi. Uppsala University, Department of Education. (<http://www.skinfaxe.se/ebok/delhi.pdf>)

Ericsson, K., 1985b. *The principle of normalization: History and experiences in Scandinavian countries*. Presentation, ILSMH Conference, Hamburg. Uppsala University, Department of Education. (<http://www.skinfaxe.se/ebok/hamburg.pdf>)

Ericsson, K., 1992a. *Community participation: The life of persons after leaving the residential institution*. Symposium, IASSID Congress, Brisbane. Uppsala University, Department of Education. (<http://www.skinfaxe.se/ebok/cbris.pdf>).

Ericsson, K., 1992b. *When all residential institutions are closed. On community alternatives and the lives they offer persons with handicap*. Symposium, IASSID Congress, Brisbane. Uppsala University, Department of Education. (<http://www.skinfaxe.se/ebok/abris.pdf>)

Ericsson, K., 1995. *Daily activities with support: Establishment and development of community based services in a changing society*. Memo. Uppsala University, Department of Education. (<http://www.skinfaxe.se/ebok/career.pdf>)

Ericsson, K., 1999. The shift between two traditions of support: Swedish experiences. In: K. Ericsson, ed. *Establishing CBR for persons with mental retardation. A task for the Sweileh Integration Project in Amman*. Uppsala University, Department of Education, 69-79. (<http://www.skinfaxe.se/ebok/amman01.pdf>)

Ericsson, K., 2000. *Deinstitutionalization and community living for persons with an intellectual disability in Sweden: Policy, organizational change and personal consequences*. Presentation, Disability Conference, Tokyo. Uppsala University, Department of Education. (<http://www.skinfaxe.se/ebok/tokyo.pdf>)

Ericsson, K. 2002. *From institutional life to community participation. Ideas and realities concerning support to persons with intellectual disability*. Uppsala University, Studies in Education 99.

Gilbertsson, S. 1992. What do persons say themselves? In: K. Ericsson, ed. *When all residential institutions are closed. On community alternatives and the lives they offer persons with handicap*. Symposium, IASSID Congress, Brisbane. Uppsala University, Department of Education, 24-27. (<http://www.skinfaxe.se/ebok/abris.pdf>)

Mansell, J. and Ericsson, K., 1996a. *Deinstitutionalization and community living. Intellectual disability services in Britain, Scandinavia and the USA*. London: Chapman and Hall.

Tuvelsson, B. and K. Ericsson (1996). Relatives' opinions on institutional closure. *Deinstitutionalization and Community Living: Intellectual Disability Services in Britain, Scandinavia and the USA*. In: J. Mansell and K. Ericsson. London, Chapman and Hall: 199-208.

Thorsell, M. Ericsson, K. & Brusén, P., 1988. Becoming visible! In: K. Ericsson, ed. *Key issues in the process towards community participation*. Symposium, IASSID Congress, Dublin. Uppsala University, Department of Education, 28-39. (<http://www.skinfaxe.se/ebok/dublin.pdf>)

Greece

Susana Padeliadu

Definitions, Legal Status and Eligibility

Definitions

Intellectual disability is only one of the terms currently used in Greece, coexisting with older terms such as mental illness, mental retardation, mental disability or mongoloid idiocy in certain legal papers. It appears that the definition is different depending on the services involved or the theoretical orientation of the people involved. Thus, in the educational field the prominent terms are the ones of mental disability and mental retardation while in the health/welfare field, the terms used most often refer to mental handicap, problems or illness. The most anachronistic terms are used in the legal papers and generally in law. The definition provided by Grossman (1983), is widely accepted and used by the psychologists involved in determining intellectual disability and the same definition is accepted by the health services as well. Therefore, intellectual disability is defined as significantly sub-average general functioning (IQ below 70), existing concurrently with deficits in adaptive behaviour, manifested during the developmental period. The instruments used more often are: WISC-R, WAIS-R, Peabody, Mental Gestalt, Raven and the Draw A Person test. However, the test mostly preferred is the WISC-R, since it is the only one standardized for Greece and it provides specific quotients needed for service eligibility. Test results are combined with information from observations. No definition is provided or suggested by law and classification is made based on the professional opinion of the people involved in the diagnosis.

Legal Status

As far as the legal status of adults with intellectual disabilities is concerned, their rights are protected under the Greek Constitution (articles 21 & 25). However, under the Greek Civil Law, there are certain categories of people who are denied specific rights and obligations. Based on the Civil Code, and specifically the article 1686, an individual who, due to permanent mental illness, is deprived by the use of reason and is not able to take care of him/herself or his/her assets, is placed under Judicial Prohibition and cannot participate in any legal act (i.e., sell, buy, sign a contract etc.). The court defines a relative as his/her guardian, and this person is then responsible for managing the income, the fortune and generally the affairs of the person with intellectual disabilities, according to the provisions of the law about juveniles in tutelage (article 1694). If the individual is not totally deprived of the use of reason and there are doubts on that issue, the person is placed under Judicial Care and someone else is defined as his/her representative (article 1705).

In order for a person to be placed under judicial prohibition or Judicial Care, an immediate relative and the family council (6 members of the family) need to apply. The juridical decisions are based on, and bound by, the findings of the 1st Level Health Committee, which is exclusively qualified to adjudicate on medical issues (State Council's Decision 1594/1994). In general people with intellectual disability are considered minors with no real rights and as legally incompetent to control their affairs and there is no system to allow legal appeal against the decision made and.

The representative for the law plays the key role, either at the family council level or at the court level. What needs to be underlined is that there is no safeguard against mistreatment of any case available either by the state or by any non-governmental organization.

Eligibility

To become eligible for services, a person with intellectual disabilities needs a diagnosis and a certificate from the First Level Health Committee of the district he/she lives in. The Committee consists of physicians of nearly all specializations. However, its synthesis does not include a psychologist, social worker, special educator or other non-medical specialist.

As far as the examination procedure is concerned, the Committee members do not administer any IQ test to people with intellectual disabilities. Based on the result of an IQ measurement that has to be administered in a public hospitals' psychiatric ward and a List of Illnesses in which disabilities correspond to percentages of handicap, (edited by the Ministry of Health), the committee examine the person with intellectual disability and decide the percentage of his/her handicap. In most cases, he/she is classified into definite categories of handicap that is 50%, 67% and 80%, because according to this classification he/she becomes eligible for certain services. For example, all the insurance and pension funds that provide handicap allowances are based on this committee's verification (in Greece there is not a common insurance and pension fund for all employed people, but several professional categories have one of their own). Moreover, the committee is qualified to judge the capability of a person to do a bread-winning job and to define the duration of the allowance provision. A person with intellectual disability needs the verification from this specific Committee to be eligible for all available public services, monetary and non-monetary ones.

The First Level Health Committee may state that the handicap of a person with intellectual disabilities is considered as a permanent condition and assign that the person can take the allowance for a lifetime. However, decisions are reviewed every 3 to 5 years as a way of ensuring against insurance fraud – the State appears inefficient in its ability to monitor whether people with disabilities are cashing in on more than two insurance policies for the same reason, which is mostly illegal. Consequently, a person with intellectual disabilities in order to be eligible for some services goes through a weary procedure, of which the examination is only a part, many times in his/her lifetime.

If a person with intellectual disabilities applies to the First Level Health Committee for an examination adducing the results of his/her IQ measurement and the application is rejected, or he/she is denied eligibility according to the committee's decision, he/she has the right to appeal against the decision within 20 days from the date of its announcement. During this period of time, he/she must ask for a new examination from the Second Level Health Committee, which will come to a definitive decision.

Eligibility for the disablement allowance, which determines the services people get, is based on three major criteria: (a) the percentage of their handicap, (b) the type of their insurance (according to theirs or their parents' job) and (c) the financial assets of the person and the other financial support that he/she receives. Specifically:

If it is assigned that the I.Q. of a person with intellectual disabilities is 30 or less, he/she becomes eligible for an allowance provided by the Provident Fund. This allowance is:

- 229,05 Euro per month when the person lives with its family,
- 151,13 Euro per month when the person lives in an institution,
- 206,20 Euro per month when the person receives for his/her disability an allowance from another fund which is not more than 29,35 Euro per month,
- 151,13 Euro per month when the person takes for his/her disability an allowance from another fund which is more than 140,87 Euro per month.

If it is assigned that the IQ of a person with intellectual disability is higher than 30, but the percentage of his/her handicap is equal or more than 67%, he/she becomes eligible for an allowance from the Provident Fund that is 170,21 Euro per month. It must be mentioned that it

is also required that the person doesn't live in an institution and he/she is not secured in other fund. Also, in case the individual receives a second allowance from another organization for the same reason, the extra amount of money is deducted from the Provident Fund allowance.

As far as total insurance and pension coverage is concerned, when the person is at least 67% handicapped, he/she has the right to choose between the Provident Fund services or the insurance fund services on the grounds of his/her or the parents' job (L. 2072/92). However, this practically never happens, because the Provident Fund services are so poor, that nobody chooses them if he/she has an alternative. Only the non-insured disabled people turn to Provident Fund services.

It must be noted that when the handicap of the person with intellectual disability is below 67% and he/she has no insurance (by his/her own or the parents' job), the welfare state ignores him/her and provides no financial assistance.

Additionally, people with intellectual disabilities are eligible for all the services and benefits that are provided to all people with special needs. Generally, these concern health care, vocational training, employment, housing, transportation and tax exemption.

Given the various definitions and various eligibility criteria from different agencies, information on the prevalence of intellectual disability lacks reliability. Unfortunately, there is no extensive national statistics or any integrated and extensive research initiatives in this area (Eurostat, 1993). The most valid and reliable data come from the census of 1991, although there are several issues raised, such as the data collection method used and the lack of training for the census takers. In 1991, the total number of people with disabilities living in non-collective houses was 232,571, while those living in collective house were 34,432. From those persons living in non-collective houses, 6% were persons with intellectual disabilities. From those living in collective households, 13.3% were people with intellectual disabilities. Half of the total population of people with intellectual disabilities lived in collective houses (6,407). For the ages over 26 the percentages rise (from the total population of people with intellectual disabilities living in collective houses, 1.9% are 0-10 years old, 13.6% are 11-25 years old, 32.5% are 26-50 years old and 52% are over 51 years old). In terms of age distribution, it appears that most of the people with mental problems in general fall into the 11-25 years old category. Here, it needs to be underlined that intellectual disability is the only category for which the percentage of people living in collective houses is so high (for physical disability, the figure is 9.9% with more than 80% of those being old (i.e. over 60?) and for sensory disability to the figure is 3.2% with more than 70% of them being old) (Balourdos, Chrysakis, Soulis & Yfantopoulos, 1998).

Policy framework

One of the major deficiencies of the present system of services offered to persons with intellectual disability in Greece is the lack of any sound knowledge of how many such people there are, who they are, how they cope with their disabilities and what services they use.

Social services in Greece are organized more with respect to target groups than with respect to other criteria. The public sector provides social services through the Ministry of Health and Welfare. The General Secretariat of Welfare is comprised of different Directories: the directory of public inspection, the directory of family and child protection, the directory of protection of people with special needs and of protection of the aged, the directory of housing and the directory of social work.

The Ministry of Health and Social Welfare provides social services either directly or through agencies that are funded and controlled by it, such as the PIKPA (Institution for Social Welfare and Care) and EOP (National Organization of Welfare). Based on the Law 2082/1992, EOP is in charge of the services provided to families and PIKPA is responsible for services to people with special needs and the aged population. Other state agencies involved in social services provision are the OAED (Organization of Labour's Employment), the Workers House (dealing with housing) that both belong to the Ministry of Labour. Further,

some responsibilities fall under the Ministry of Education, the Ministry of Agriculture and the Ministry of Justice (Cavounidis, 1996).

The state provides social services in the form of financial assistance, materials and services. In the area of people with special needs, state provisions involve mostly monetary help, vocational training and institutional care.

The special services and provisions which are planned and functioning especially for people with intellectual disabilities include the following:

- monetary provisions - provision of an allowance depending on the specific classification of intellectual disability,
- centres of care and rehabilitation for people with intellectual disabilities, providing shelter, food, health care and educational training,
- vocational training schools,
- centres for creative leisure and workshops,
- counselling centres,
- legislation aiming at the work integration of people with intellectual disabilities, including the obligatory employment of people with intellectual disabilities in all public organizations and in private companies, employing more than 50 employees.
- vocational training programs and support for the work integration of people with intellectual disabilities through the financial bounty for the companies employing them,
- programs of independent living.

The large majority of the above provisions and programs belong to the traditional public sector and are characterized by conservatism and lack of flexibility. Significant exceptions are the programs for independent living and social integration for people with intellectual disabilities, which are created (and often funded) by the European Union based on current progressive views on disability (www.disabled.gr, 2000).

In regard to services and provisions aiming in general at the needs of groups at risk for social exclusion, those come from either national agencies or European initiatives. Those services refer to:

- hospital and in general health care,
- provision of minimum financial support,
- support for people who need help in their everyday life.

Finally, non-governmental organizations produce policy for people with intellectual disabilities and play the role of pressure groups. Family organizations mostly focus on providing alternative services and on pushing the government for more financial support and more advanced measures. On the other hand, volunteers groups aim mostly at changing the social climate and the attitudes towards people with intellectual disabilities, and they provide informal support such as help at home, social events and walks in the city. They depend mostly on European funds and they do not receive any substantial support from the state.

The current lack of sufficient services for people with intellectual disabilities is filled in by the informal networks – still very strong in Greece – such as kinship and friends, through which everyday assistance and often employment is guaranteed. These networks have been going through a crisis during the past decade because of the changing financial needs for families

and the fact that more women are entering the career route. These informal networks will need significant support to fulfil their role and this support should avoid forcing the women back into their homes (Walker, 1983).

As for the church and the related charity organizations, they are traditional and aim towards securing funds for charity or exclusively institutional care.

Based on legislation introduced in the 1980s about the rights of people with disabilities to employment and vocational training, the policy proposed was not based only on monetary issues, such as income supplements but involved active measures such as vocational training programs. However, these proposed policies have not always been effective.

Although there are scarce data referring to the effectiveness of the state sector in provision of social services, there is general agreement that this provision has not been effective, and lately there is a concern regarding the role of local authorities, non-profit making and profit making organizations. The local authorities have only recently been involved in social services and there are several limitations restricting their contribution. One of the major limitations is the lack of financial resources. Furthermore there is limitation of legal identity restricting opportunities for collaboration with other agencies. Finally, since more involvement on part of the local authorities includes redistribution of funds and power there is also resistance on part of certain state agencies.

What seems to be on the rise is the role of the profit-making organizations in the private sector. Private profit making agencies come to fill in the gaps of the public sector. This does not mean that they substitute public agencies (since they still function) but they function in addition to the public sector.

Most of the policies in use involve people with intellectual disabilities under the general provision for people with special needs or the legislation for people with handicaps. These policies come from the Ministry of Health and Social Welfare, the Ministry of Labour and few from the Ministry of Education and Religious Affairs. The policies included refer to collective houses (institutions), vocational training, education and counselling-leisure activities plus passive measures, such as income supplements and waivers from transportation or taxes and loans. All of the passive measures depend on the personal income available and do not have any effect if the family of the person with intellectual disability is well off. Therefore, the general policies are guided by the idea of providing help to people not because they deal with intellectual disability per se but because in most cases intellectual disability is accompanied by poverty. The rest of the measures (active measures) are open to all people with intellectual disability.

The policies and guidance of the majority of the organizations involved in policy making and provision of services are either charity or parents and friends associations. Although in the past those organizations were oriented towards providing segregated services there is currently a trend towards integration and more normalization ideas. A major influence has come from the European projects initiated the last ten years, focusing on active measures and on social integration.

Funding of services and role of public and private sectors

Services for people with intellectual disabilities are funded mainly through national resources. This happens because the majority of social services are provided by ministries or agencies that are controlled by Ministry of Health & Social Welfare, as discussed in the previous section.

As far as the local authorities are concerned, they have recently been involved in social services provision and their role has not been significantly developed (Greek Association for Local Authorities and Development, 1995). The basic factor that cuts down the municipalities'

activities for people with intellectual disabilities is not the lack of competence or the lack of structures for social policy, but the limited financial resources that are available for this purpose. Furthermore, the local authorities' structures that are responsible for planning and implementing programs about the improvement of the quality of life for people with intellectual disabilities, do not function properly due to inefficient administration and settlement. The establishment and the staffing of these services were almost always occasional, organized through European initiatives that aimed to the restriction of social exclusion. These acts were funded from both the European Union and Greece (with the European community covering the 75% of the budget). Unfortunately, after the end of European funding, these departments function ineffectively or have been suppressed, due to the lack of financial resources (NCSR, 1996).

In regard to the private sector, the dominating features are charities, parent and volunteers associations. Their income comes from individual donations, members' contributions, selling handicrafts made by people with intellectual disabilities, organizing cultural exhibitions and occasional financial support from the state. Recently, certain services are granted from private companies for advertising reasons or for tax exemption. This area is still restricted and the rate of its growth is insignificant.

Emerging Service Structures and Models

Services provided for people with intellectual disability are found either within the services for people with special needs or within the psychiatric services for people with mental health problems. In the first case, the system has been more categorically structured; therefore it is relatively easy to find which services are exclusively for people with intellectual disability. However, in the second condition, the mental health problems, there is a greater confusion and concealment of the category of people with mental retardation. The medical orientation in psychiatry has led people with mental retardation to be treated as mentally ill while the lack of specific services for mentally retarded people has led to their inclusion in the services available, usually psychiatric services. Although this traditional mixed care setup has been criticized, there are still people with mental retardation served within the psychiatric services. In a recent study, it was revealed that a large number of the inmates in one of the largest psychiatric hospitals in Greece, were actually people with intellectual disability (Chatziioanidis, 2001). Moreover, many people currently diagnosed as adults suffering from psychosis, have been people with intellectual disability at a younger age and due to long institutionalization present psychotic symptoms. For example, we know from the reports of the Leros Project, that during the 1950s, adolescents with intellectual disability were admitted in the Leros Asylum and they have been recently de-institutionalized as mentally ill patients. Therefore, we will present both the structures serving people with mental health problems and those for people with special needs as well (Madianos & Stefanis, 1997).

In regard to diagnosis and counselling services, there are 40 Centres for Psychological Health (K.P.S.Y). Those centres provide services for people with mental retardation (diagnosis, parent counselling, psychological support).

There are also 32 Hostels for people with mental health problems and 84 supported apartments. It is assumed that in those structures there are people with mental retardation who are being served. There are also 61 Centres for vocational training and psychological support.

In terms of alternative housing provisions for people with intellectual disabilities the first initiative was under the Project Leros, which involved psychiatric hospitals and institutions. This first de-institutionalization project led to the foundation of a significant number of hostels, boarding houses, and apartments. A development of this program has been a newer initiative, from the Ministry of Health and Welfare, within the psychiatric field, named Psihargos. Since 1999, Psihargos has founded 55 hostels and 5 boarding houses. As it is mentioned in the Initial Planning of the Program, until 2005, 4 big psychiatric hospitals will close and the inmates will be placed in alternative housing (such as hostels and apartments) while 64 more boarding houses will open to serve people with moderate and severe intellectual disability.

The hostels are a transition structure where people can stay no longer than 36 months and where they are prepared for independent living in apartments or for returning to their families. The maximum number of people living in a hostel is 15 persons. As it has been planned, each hostel will create two apartments to move people on after the period of 36 months.

The boarding houses are structures for permanent stay with people with severe intellectual disabilities and serve a maximum of 20 people.

In all of these structures we find people with intellectual disabilities who, due to long term institutionalization, are currently diagnosed as being mentally ill and there is no differentiation of care for them.

There is a trend towards independent living although not financially supported by the state. However, large institutions move slowly, in an experimental phase towards establishing alternative structures. A common route is for the institutions to create within their establishment small units where people with intellectual disabilities are trained with the aim of moving to independent apartments. Furthermore, independent living structures were established through European funding but underwent a crisis when this funding was came to an end. However many of these schemes have taken legal identity and continue to exist with funding from the parents themselves. Unfortunately, there is absolutely no documentation of these alternative services and they do not belong to any regulatory network. It appears that a gap exists between the state policy implementation and the initiatives run by other groups. The lack of strong state support leaves the development on the good intentions of the people involved in each area. Based on our personal experience and knowledge, we know of more than 10 such cases for which the Ministry of Health and Social Welfare has no information.

Being more specific about Independent Living structure in Greece, the definition, the establishment requirements and the function of the independent living structures are specified by the law (L. 4681-96). According to this, a person with intellectual disabilities can be accommodated in the independent living units, only if it is medically verified that he-she is not suffering from severely challenging behaviour?).

People living in Independent Living Units are eligible for:

- healthy and comfortable living conditions,
- all the essential technical means to provide for his-her special needs,
- food provision,
- medical support,
- social and psychological support,
- links with those responsible for professional and social rehabilitation for people with special needs.

Nowadays, there are certain Units established that may host 36 persons at maximum. Specifically, 1-3 persons live in each apartment, where they sleep, cook, eat and cover their sanitary needs. A complex of 2-6 apartments consists a Section (2 – 18 persons), where places for common use are provided (kitchen, living room, dining room, laundry, storeroom etc.). A total of 1-6 sections are comprised in a Unit, where the same areas of central support are shared (administration offices, central storehouse etc.). The buildings of a Unit may not be located in the same block or district. In any case, it must be easy for all the residents of its sections to approach the areas of a Unit. Finally, it must be mentioned that legally it is not prohibited for Independent Living Units to be profitable. However, they all are funded by government or communal resources and have no profits.

In regard to services provided specifically for people with intellectual disability, there are 19 Institutions for chronic illness (which basically includes mental retardation) and 25 Centres exclusively for people with intellectual disability. Furthermore, there are 9 centres for special needs that provide day services only. The rest of the Centres mentioned above, as well as most of the Institutions for chronic illness, provide other services, such as prevocational or vocational training, psychological support, survival skills etc. Finally, there are 11 centres run by the Local Authorities that in most case focus on counselling services and psychological support (Madianos & Stefanis, 1997).

As was previously mentioned, the majority of the services available are located near Athens, in the Attica region. The National Centre of Social Research conducted a study on the children with disabilities and their families in the area of Attica (Kottaridi, Kappi & Adam, 2000). It was found that 37 centres are involved exclusively with people with special needs in general. Most of these centres (69%) are open 5 days a week. Ten centres (29%), seven of which are institutions, are open all week long. Most of them (77%) close during Christmas and Easter vacations (15 days each) and one month for summer vacations.

Anyone who wishes to visit the children can do that easily. In 17.1% of the centres a member of the family can spend the night at the centre if this is necessary.

From the 13 closed care centres (this is the Greek term for institutions), in 6 there are rooms for 2-5 persons, while in the rest the rooms serve 6-25 persons.

Most of the buildings are old and more than 90% function under the Ministry of Health and Social Welfare.

As it refers to legal identity, we can identify:

- Public Special centres, which are established by the state and are being funded through the Ministry of Health and Social Welfare or the Ministry of Education. The staff is public employees and the families do not pay any fees. Sometimes there is funding from other resources too.
- Private Special Centres are profit oriented businesses, and function with the permission from the Ministry of Health and Social Welfare. However, in some cases there is a gap between what is described in the permission and what is actually provided. Families pay the fees while part of those fees are reimbursed through the insurance funds.
- Private Special Centres, are non-profit oriented and are being run by non-governmental groups, parents groups or the church. The families do not pay fees but a minimal contribution. There are constant financial problems.

In total 54.3% of the special centres are private non profit organizations, 17.1% are state centres and 28.5% are private profit oriented organizations.

In terms of the funding provided, for the 77% of the centres there is mixed funding from various sources. The state contributes to 65% of the centres either directly or indirectly through the insurance funds. For about the 1/3 of the children served, the family covers the expenses involved. Non-governmental groups contribute less than 20%, while funding from other sources rises to 80-100%. This high contribution from other sources that are not steadily available appears to be a major constant problem.

From the 37 Special Centres in the Attica Region, 15 serve exclusively people with intellectual disability. In terms of type of services they are:

- closed care (institutions)
- open care (day programs)

- mixed care.

About 63% of the centres are open care programs. Their goals are treatment (38%), educational (9.5%) and the rest refer to social adjustment. Based on the evaluation from the directors of the programs, the above goals are partly fulfilled (50% of the time). Most often the services provided are called “medical” or “rehabilitation”, but in reality they are mostly social (i.e. during work therapy they actually do art and crafts). Educational activities are almost always informal prevocational training without guidance from the Ministry of Education or any special materials.

A general evaluation of services provided and of the needs projected by the staff involved indicates that services are medically-oriented and they focus more on rehabilitation than on psychosocial support.

In regard to client satisfaction, the parents in general are not satisfied: they think that the public closed care centres are terrible and they prefer the non-profit centres run through parents associations. The only parents who appear to be pleased with the situation are those falling into the lowest socio-economic rank. However, there are waiting lists for 60% of the special centres (Kottaridi, Kappi & Adam, 2000).

In summary, it appears that the development in the field of intellectual disability services in Greece is versatile and based both on old and new structures. Old, overcrowded institutions co-exist with new, alternative structures of independent living. However, there are certain issues that transcend all structures. On the negative side, there are long waiting lists to both new and old establishments, lack of availability of services outside the Athens area and two or three more big cities, low involvement of the local authorities, low priority of the issue in the agenda of the government and lack of financial support. On the positive side however, there is a slow but constant change of the state policy towards de-institutionalization, a growth of independent living structures for people with intellectual disabilities, a growing professional debate in favour of de-institutionalization, and most significantly an emergent, positive change in the social attitudes towards people with intellectual disabilities and their human rights.

Experience of people with intellectual disabilities and their families

Research on intellectual disabilities is very limited in Greece and especially documentation of the experiences of people with intellectual disabilities and their families is even scarcer in the Greek research literature. However, there are a few studies that can provide some relevant information. Those studies can be sorted into two groups: those who deal with the problems of families and the stress experienced by the families, and those who come out of implementing deinstitutionalization and present the experiences of everyone involved.

Parents experience extreme confusion regarding the child's problems and prospects especially during the first years of life due to lack of appropriate services and available information (Matinopoulou-Perri, 1990).

In a research conducted by the National Center of Social Research (Kottaridi, Kappi, Adam, 2000) in order to document the ideas held by the families of people with intellectual disabilities, a significant number of parents were interviewed. The qualitative analysis of these interviews revealed that:

Intellectual disability is considered the worst disability of all.

Parents often attribute their child's disability to God, whereas most of them feel closer to God now.

Parents believe that state/public services are of bad quality and they prefer private help. They feel helpless, alone and with lack of information. As they report, when they turn to public

services they face ignorance, suspicion, bad behaviour and harassment. Those with higher socio-economic background feel more disappointment and prefer to keep their children at home. They also feel overburdened and they do not trust the public services.

Parents believe that there is a negative social climate and lack of social acceptance. They also report that they themselves have trouble accepting their children with intellectual disabilities and that they proceed based on their belief in God and on the family support.

It is interesting that parents who have kept their children at home, say that they would prefer to send them in an institution if there were good institutions and those who have their children in institutions, they would prefer to keep their children at home if they had any support.

Parents worry extremely for the future and what the future holds for their children after their death and some of them even say they would prefer their children to "die before them" "or to take them along with an injection or something" so they will not suffer.

Referring to the problems of the families of people with intellectual disabilities, we have to focus on mothers' experience. Greek culture puts a high emphasis on the role of the mother, and assumes that the major and often sole responsibility of raising the child lies with her. Additionally, because of financial limitations, more women have to assume employment outside the house, and women have also started pursuing personal development and careers; the existence of these conflicting roles may be detrimental to the mother's emotional ability to cope with stress. This Greek cultural pattern, in which mothers assume sole responsibility for the household and child care, has often led to a lack of satisfaction on the part of mothers of both handicapped and non-handicapped children (Tsiantis, 1993).

According to the research study conducted by the Department of Elementary Education of Aristotle University of Thessaloniki, 44 mothers of children with Down's syndrome were interviewed to investigate the factors contributing to stress of mothers and the factors that they feel as supportive. Based on their open answers, mothers worried mostly about the health problems of their children and the consequences of their specific intellectual disability (38,6%), the acceptance of the child's disability by themselves (31,8%) and the education of their child (20,5%) (Padeliadu et al., 1994). The concern about education was found to be a life-long concern for the mothers in other studies as well (Matinopoulou-Perri, 1990). Significantly, they underlined problems regarding "whether their child will go to a special or regular school" "how will they decide about school placement" and "difficulties of attending the appropriate school due to large distances and lack of provided transportation means". Another issue that often came up in the mothers' responses is their disappointment from the attitudes of the parents of non-disabled classmates when they chose to send their child to an integrated school (Padeliadu et al., 1994).

Mothers of children with Down's syndrome also appeared to spend more time – than others – in educational and recreational activities with their children, reflecting on one hand the overloading for themselves and on the other hand, the lack of appropriate educational and recreational services in Greece, which probably forces them to assume full responsibility for all of the above (Padeliadu, 1998). They additionally experienced higher stress and this stress was related to the time demands of their children (Padeliadu et al., 1994).

In terms of the support available for these mothers, it appeared that the immediate and the extended family was the major support system for 75% of the mothers interviewed (Padeliadu et al., 1994). In Greek families, the system includes the parents of the spouses whose support may be financial, and by participation in the every day care of children. Furthermore, their support includes the emotional support plus the development of strong emotional relationships with the grandchildren (Mousourou, 1989). Despite the fact that the parents declared problems in their communication with the specialists involved (Matinopoulou-Perri, 1990), our mothers leaned for support to those same specialists and they appeared to trust them (Padeliadu et al., 1994). Another significant factor for their support was religion; not in terms of receiving material support from the church, but as a spiritual belief.

Concerning the psychology of mothers of children with Down's syndrome, it was observed that they had an external locus of control, revealing that they were feeling unable to control the events in their lives. Furthermore, their self-esteem appeared low and this may have a cultural explanation, since Greek society considers the birth of a child as a proof of the strength of the parents and as the fulfilment of the woman.

In regard to social acceptance, the mothers told stories about everyday rejection, stereotyping and negative attitudes. Some of them talked about people staring, making the holy cross or "spit in their bust", in order to expel the evil (Padeliadu et al., 1994).

Finally, a major agony of the parents was the goal of independency and self-reliance of their children (Matinopoulou-Perri, 1990). As their child grow older, there is a move of their interest towards employment (31,8%) and their future independence (20,5%).

As far as the people with intellectual disabilities are concerned, very little is known, and it comes from pilot projects implementing community living (Tsiantis, 1995). It has been found that even after only one year of de-institutionalization and introduction in community living, people who have been living for 18 years in institutions were literally transformed.

Helen, who did not talk to anyone, did not participate to any activity and was completely withdrawn when she was in the institution, after a year in community living, participated in taking care of the house, held specific responsibilities and participated successfully in vocational training. George, who was described as "lost in space" and with no vocabulary skills when in the asylum, managed to communicate orally and has won 2 gold metals in National Games of People with special needs. Ioanna, 30 years old, who lived in the institution since she was 6 years old and was described as withdrawn and often aggressive, was completely changed and participated in everyday life.

An issue that transcends the above stories and other personal stories too, is the issue of personal human relationships. After the introduction of people with intellectual disabilities to community living, they start developing better personal and social relationships. It seems that when living in the institutions, the model of discontinuous care provided by the staff, leads to discontinuous relationships, which are being reproduced by the people with intellectual disabilities themselves. However, when people are exposed to a new model of stable relationships they develop new social skills and apply them to normal social relationships.

References

- Balourdos, D., Chrysakis, M., Soulis, S. & Yfantopoulos, Y. (1998). Characteristics of the people with disabilities in Greece: Statistical data, research and policy implementation, *Mentoras*, 140-162.
- Cavounidis, J. (1996). Social Welfare Services and the Fight against Social Exclusion. In *Dimensions of Social Exclusion in Greece* (pp. 251-271). NCSR, Athens.
- Chatziioanidis, G. (2001). Deinstitutionalization: Alternative Structures for Rehabilitation of People with Special Needs. *Study presented in the web-site: <http://www.disabled.gr>*.
- Greek Association for Local Authorities and Development (1995). *Social Policy and Local Authorities*. Athens.
- Kottaridi, Y., Kappi, C. & Adam, E. (2000). Disabled Children and their families in Mediterranean countries. A preliminary study in Greece. *NCSR Working Paper 2000/12*. Athens.
- Madianos, M. & Stefanis, K. (1997). *Guide of Services of Mental Health, Psychosocial Rehabilitation and Support in Greece*. Ministry of Health and Welfare and Research University Institute of Mental Health. Athens.

- Matinopoulou-Perri, I. (1990). The problems that families with mentally retarded children face in Greece. *Journal of Social Work*, 19, 145-157.
- Mousourou, L. (1989). *The sociology of modern family*. Athens: Gutenberg.
- National Centre of Social Research (NCSR) (1996). *Dimensions of Social Exclusion in Greece*. Athens.
- Padeliadu, S. (1998). Time demands and experienced stress in Greek mothers of children with Down's syndrome. *Journal of Intellectual Disability Research*, 42(2), 144-153.
- Padeliadu, S., Papadioti, E., Prokovas, C., & Sandravelis, A. (1994). Mothers of children with special needs: factors of support and stress impacting on their role. Paper presented at the Panhellenic Conference on "Family and Family Policy in a Changing World", National Welfare Organization (EOP), Athens, Greece.
- Tsiantis, I. (1995). General Conclusions. In Tsiantis, I.(Ed.), *The 'children' of PIKPA in Leros*. Athens:Kastaniotis.
- Walker, A. (1983). Care for Elderly People: A Conflict Between Women and the State. In J. Finch and D. Groves (eds.), *A Labour of Love: Women, Work and Caring*. Routledge and Kegan Paul, London.

Web-sites

<http://www.disabled.gr>

Belgium

Geert Van Hove and Catherine Molleman²¹

The context: a small country with a complex organisation

Belgium is a kingdom near the North Sea. The official population on 01/01/2000 is 10,239,085 inhabitants. As a state it has a federal structure. There is the Flemish Region with 5.9 million inhabitants. The Walloon region has 3.3 million people (including a German-speaking Community of 70.000 persons). The Brussels Capital region has almost 1 million inhabitants.

This paper will focus on the situation in the Flemish Community, which is generally the best organised region with regard to services for people with intellectual disability. Flanders lies in the northern Dutch-speaking part of Belgium. Brussels is its capital, Brussels is also the capital of Belgium.

The Flemish Government and Parliament is responsible for 'person-related issues' within the Flemish Community (i.e. the inhabitants of the Dutch language area and the Dutch speakers in Brussels). These are policy areas in which the provision of services to the people is closely related to the language in which they have to be carried out, for example, Welfare, public health, education and culture. The Flemish government is also responsible for "territorial issues" such as the economy, infrastructure, agriculture, environment and employment, with the Flemish Region (i.e. the territory comprising the Dutch language area: provinces of West and East Flanders, Antwerp, Limburg and Flemish Brabant)

Although Belgium is internationally known for its 'community care' for persons with mental health problems in Geel, this paper will illustrate that, in contrast, a very specialised care system has developed for persons with intellectual disabilities. The specialised system was developed starting from psychiatric institutions like the 'Ghuislain Institute' in Ghent (founded in 1857) where children and adults with mental health problems and intellectual disabilities were brought together in the first modern psychiatric hospital for the country. Dr. Ghuislain the head-psychiatrist worked together with the Brothers of Charity to make ensure improved quality of life of persons who were marginalized in an industrial society. More and more these kinds of institutions appeared and were so well organised that the inhabitants of Flanders had less and less contact with the people living in these 'asylums'.

Definition, Legal Status and Eligibility

Definition

In Flanders the term 'person with a mental handicap' is still used. Here 'handicap' does not equate to the definition used in the third level of the former (1980) WHO-definition (i.e. in danger of discrimination), but rather to the medical definition of 'impairment'. (e.g. Down Syndrome) In accordance with neighbouring countries, the negatively coloured word 'mental' is being replaced with 'intellectual'.('verstandelijk'). People also try to avoid the use of the older terminology of 'handicap'. If they work with someone they take into account the

²¹ Geert Van Hove works at the Ghent University at the Department of Special Education. Catherine Molleman is a researcher with the Flemish Fund for the Social Integration for Persons with a disability.

interaction of problems on the individual level with the barriers and the threatening discrimination as organised in the organisation of our society. It has to be said that due to the Flemish culture of 'special care and special systems' the individual level still gets more attention than the barriers in society.

With regard to service provision (either through Flemish Fund or the special school system) it seems more and more obvious that people get a label of disability in an administrative way. Who is disabled and who is not depends as much on the criteria for access to specific provisions (and it is even dependent on the availability of services) as on any general criteria. To be entitled to a Flemish Fund provision e.g. the candidates have to be a 'disabled person' as it is defined by the legislation of the Fund. In accordance with the Decree of 1990 someone is disabled if he or she is confronted with a situation of long-lasting and substantial limitations of his/her possibilities of social integration due to reduced intellectual, psychological, physical or sensory capacities.

The administrative category of 'persons with a handicap' developed in the Flemish context from 3 important historical factors.

In Belgium education for all children is compulsory (basic law of 1914) and as a result, the Government and school boards were confronted with children who did not fit into the regular school system that focused on preparing children to develop their intellectual capacities and to work on the regular labour market. Out of this tension arose a basic law on special education in 1970.

In the sixties and seventies, starting from the special school system, a care system for people with disabilities was organised in an attempt to do better than 'the medical model' of old psychiatric institutions. A very specialised network of (mostly residential) facilities was organised to make sure that certain children and adults received the protection, care and support they needed, taking into account their problems to adapt to the expectations of an industrial and post-industrial society. On the other hand, members of society want to get protection from people with all kinds of problems. Samoy (2001 p.84) states that this network is organised in a 'categorical' way. (every facility claims a certain 'target group, working as if they could define a certain profile). So people got away from the medical model and 'total institutions' and they entered the world of specialised, categorical services. This brings us to the point that these special services seem to be very hard to change.

Because of the fact that the labour market plays an essential role in a capitalist society, the perspective of 'having a job' plays a central role in the life of most citizens. Persons with a label of 'intellectual disability' live in a conflicting position to the 'productivity discourse'. This paper attempts to discuss this topic including elements such as 'income replacement allowance', the category 'unable to work', the position of the phenomenon of 'sheltered workshops', new trends like 'job coaching and supported employment' in relation to the idea of an 'active welfare state'. (more information in 2.3)

Legal status

Persons with disabilities have, in general, the same rights as other Belgian citizens. However, Belgium has a law on 'prolonged minority' (law of June 1973) which applies to people with intellectual disabilities (Rentry, 2001). Until the beginning of the nineties, this was seen as the main way to protect people (especially people with so called 'severe mental handicap'). The diagnosis of 'severe retardation' in this situation is organised via a medical doctor and is based on following elements:

- the retardation has to be 'severe',
- the retardation has to be inborn or has to be manifest in early childhood,
- the situation has to have a bad prognosis.

In addition to these criteria, it has to be clear that the person is not in a situation to take care of himself and to manage his/her goods/property.

This protection makes sure that the parents keep the parental authority they would have if their son or daughter were under 16. This means that people with severe mental handicap cannot get married, cannot start a business co-operation and they can't donate or get goods out of a will.

In the beginning of the nineties, the Government came under pressure about this law (based on the argument that people either have rights or do not), and passed a law in 1991 on 'temporary government over persons'. With regard to persons with 'mild retardation' the court can decide to organise a specific package of protection decisions for a certain period. In most cases the protection goes back to budget matters or questions about ownership. A lawyer can be appointed to become a kind of mentor to follow the specified field. For people with severe disabilities the status of prolonged minority was maintained.

In practice, however, some services also try to negotiate with their 'clients' to organise a system of a 'double signature' on documentation concerning the budget of someone with a label of intellectual disability. This system makes sure that the 'client' cannot take money of his account without the double check of his or her professional guidance. This system is organised from a pragmatic point of view, but from a legal perspective it is obvious that this system is a very grey area.

Prevalence

Belgium and its Flemish speaking part in global follow the trends of most industrialised countries.

All the available statistics are delivered by the organisations in the care system: so, one, reliable overview is not available. Someone can be registered e.g. within his school career and leave the statistics when becoming an adult, to re-enter the field after some years within the Flemish Fund with a demand for support as a 'new client'.

Policy framework and services

Persons with intellectual disability and the Flemish school system

Responsibility for Education in Flanders lies with the Communities so within the Government of Flanders, the Flemish Minister of Education is responsible for almost every aspect of the Education policy from nursery to university education.

The Belgian constitution provides that everyone has a right to education with respect for fundamental rights and freedoms. With a view to secure this right to all children, education is compulsory. Compulsory education starts on 1 September of the year in which a child reaches the age of 6 and lasts 12 full school years. It finishes at the end of the school year in which the pupil reaches the age of 18 or when she/he – irrespective of age – has gained the certificate of secondary education. Students with special needs can get official permission to stay at school in special schools until the age of 21.

However compulsory education does not mean compulsory schooling - children do not have to go to school to learn. They can also be educated at home.

Children who are unable to attend school, mainly because of serious impairments, can be exempted from compulsory education. Till now official statistics show that only a very small group of children - 0.03% - get a measure that sets them free from compulsory education.

Most of these children attend 'day care centres for children who cannot attend school'. These projects are subsidised by the Flemish Fund, not through the Ministry of Education.

The Flemish Education Budget amounted to 6.51 billion Euro for the year 2000. This is 42% of the total Flemish budget.

Although Belgium already made use of special institutes and schools for children with disabilities mostly run by various religious groups (especially for children with visual and hearing impairment and children with intellectual disabilities) it was 1970 before any legislation on special education was established. This law put an end to the practices from the beginning of the 20th century where special schools existed together with special groups/classes in regular schools. This law had several important consequences:

The development of 8 different types of special schools on the primary school level (see Table 1 below) put the focus on the 'special characteristics of children'. By giving that much attention to the 'special' schools, teachers in regular schools felt that they were not prepared/trained to work with these children. Specialists (psychologists, special education specialists, speech therapists, physiotherapists, etc) entered the field and gradually took over. Following this 'culture shift' more and more children got a label and were sent to the specialists in the special system and parallel mainstream and special education systems were developed.

Table 1. Typology of special schools at primary school level

Type of special primary school	Definition
TYPE 1	delivers schooling to children who get the label 'mild mental handicap'
TYPE 2	delivers schooling to children who get the label 'moderate or severe mental handicap'
TYPE 3	delivers schooling to children who get the label 'emotionally disturbed, having behavioural problems'
TYPE 4	delivers schooling to children with physical impairments
TYPE 5	delivers schooling to children who are confronted with chronic diseases
TYPE 6	delivers schooling to children with visual impairments
TYPE 7	delivers schooling to children with hearing impairments
TYPE 8	delivers schooling to children with specific learning difficulties (dyslexia,...)

At the secondary school level, there are also several different levels of schooling available for those who are impaired in their physical, psychological, social or intellectual development. These different types of special secondary school are illustrated in Table 2 below.

Table 2: Typology of special schools at secondary level

Type of special secondary school	Definition
LEVEL 1	prepares students to live in a sheltered environment and to follow day care activities
LEVEL 2	prepares students to work in a sheltered workshop
LEVEL 3	prepares students to live independently in the community and to work on the regular labour market
LEVEL 4	organises the same programme as mainstream secondary schools but with special (e.g. therapeutic) facilities

From the seventies to the end of the eighties approximately 3 % of all children attended special schools. With this percentage Flanders was situated on the same level as e.g. the Netherlands. Since the nineties special schools have shown an explosive growth from 3.03% (32.930 children out of 1.051.162 students) in 1990 to 3.91% (43.268 children out of 1.062.685 children) in 2000.

Especially on the primary school level the growth was obvious. For children with intellectual disabilities the growth is presented in Table 3.

Table 3

Year	Type 1	Type 2
90 - 91	8,172	2073
95 – 96	9,915	2433
99 – 00	10,459	2.882
% growth	27.98 %	39.02%

Since 1970, financial subsidies were allocated to the schools providing special needs education and not to the children themselves. The special school system costs approximately 3 times more than regular schools.

Gradually, integrated nursery and primary education began to emerge as a result of co-operation between nursery and primary education and special education. In integrated education children with impairments (including those with learning or educational difficulties) attend lessons or activities in a mainstream school with assistance provided by special education. This can be a temporary or permanent arrangement and can apply to some or all of the lessons. This system of integrated schooling was introduced a number of years ago for children with intellectual disabilities, but sometime after such systems were introduced for other children with special needs. For children with a type 2 certificate (moderate or severe mental handicap), integrated schooling is only provided at nursery level. With regard to secondary education, young people with special needs can also be accepted into mainstream school, with the help of experts from special education.

Table 4 illustrates for primary school level, however, that integrated schooling is not well implemented for children with intellectual disabilities and in fact the majority of those receiving integrated schooling fall into the other categories of special needs.

Table 4: Number of children in integrated school environments at nursery and primary school level.

Year	Type 1	Type 2	Total over 8 school types
90 – 91	----	----	708
95 – 96	----	12	1.106
99 – 00	1	22	1.555

With the help of experts from special education young people with special needs can also be accepted by a school for mainstream secondary education through the system of integrated education.

In 1998 the Flemish Educational Council (Council where educational policy is prepared and discussed with representatives of unions, parent organisations, school boards, social/economic organisations and educational experts, ...) advised the Ministry of Education to introduce and implement 'inclusive education' as the Flemish school model for the future. Since the release of this advice the debate has continued and implementation is slow for a number of reasons:

1. Only recently, have some pilot projects of inclusive education been established, for example one parent organisation – 'Inclusion Flanders' – has a small project with about 20 children on primary school level. Another group of about 80 families ('Parents for Inclusion') recently founded a forum to meet and to exchange experiences starting with their isolated projects for their children.
2. The philosophy and conceptualisation of 'inclusive education' is in contradiction with the old frameworks of special education and special schools that are based on ideas about:
 - 'different types' of 'handicaps'
 - the paradigm that tries to rehabilitate children so that they can meet the standards of schools.
3. The teacher training system in Flanders still does not give much structural attention to the idea that a teacher will be "the teacher for all children" of integrated schooling. In general, teachers in postgraduate teacher training courses are trained to work with special needs children in special schools. Some teacher training institutes have started recently, within a modular system, to develop training packages that are oriented to integrated schooling and they organise some 'guest lectures' about inclusive education.
4. Still a lot of teachers in regular schools do not have experience with 'real teamwork' around one of the members of their class. Most of them were trained to work on their own with a group of children. In the old paradigm students are taken out of the group if they need 'therapy'.

On the macro policy level, the Flemish Government has tried to adapt its policy to the inclusion paradigm without having the full power over the policy of school boards. Some research projects (Ghesquiere, 2001) funded by the Government showed, for example, that the 8 different types of special schools did not have a solid scientific basis. It seems

impossible to differentiate students in such a way that everyone ‘fits’ in a certain type. Regional availability of certain types and pragmatic solutions for some children with some specific labels (e.g. parents of children with the label of autism are obliged to bring their children to the least bad option). In a recent policy paper the Flemish Ministry of Education launched the idea to encourage ‘more inclusive practices’ for children in primary schools of type 1, 3 and 8. The debate that followed this suggestion was ripe with ‘emotions’ – on one hand, some special school boards interpreted this policy paper as a first step to the closure of their schools and a way to cut their budgets. Some parents who had made the decision to send their children to special schools were fearful that their children would not get the specialised support in regular schools. On the other hand some authors illustrated the contradiction between the discourse of the inclusion paradigm and policy makers who continue to think in typologies of special needs. Some parents of children in inclusion experiments discuss the exclusion of e.g. children with a certificate to go to a type 2 school in this policy paper.

The Flemish Fund for the Social Integration of Persons with Disabilities

In the Flemish speaking part of Belgium the policy for the social integration for persons with disabilities is developed through the Flemish Ministry of Welfare. This Ministry has a close co-operation with the Flemish Fund for the Social Integration of Persons with Disabilities, which is the administrative body consisting mostly of officials. However, the policy and management board exists of a mixture of care providers, family organisations and unions. This mixture provides a series of distinct influences on the policy papers of the Ministry. Traditionally, the Ministry brings out a policy paper every two – four years. In the successive policy papers we can observe the same trends that are known as ‘renovating/new trends and ideas’ (not very clear – what is meant by this).

The most recent policy paper produced at the end of 2000, stated that everybody who is ‘in need’ for support should get the opportunities to get the support to participate in the community. The Flemish Fund and the Ministry have chosen to introduce a shift of accent from the residential care for persons with disabilities to the persons and their natural networks themselves. One of the most important elements within this shift is the introduction of ‘a personal budget’.

On the other hand the Fund has decided to renovate the management of ‘supply and demand’. In Flanders ‘waiting lists’ still exist as there is a structural deficit of ‘places’ e.g. in the residential services. The Fund has recently set up ‘central waiting lists’, with which the policy makers try to close the gap between people with a request for services and those who organise services and facilities. Table 5 shows the shortage of places in several services and facilities by representing the number of people on waiting lists.

Table 5: Number of people on waiting lists for different types of services.

Services in the community: Supported Living services	350 persons	25%
Semi residential services: Day Care Centres	233 persons	7%
Residential services:		
Group homes in the community	80 persons	22%
Respite care	11 persons	24%
Residential services for those who work	93 persons	8.5%
Residential services for those who cannot work	390 persons	5%

One interesting point to note from this overview is that the systems that offer less intensive support show the largest waiting lists and this observation can be related to the fact that within the Flemish culture priority is given to persons who need an intensive level of support.

Other issues arising from the recent policy include 1) an attempt to get rid of the old idea of 'total packages of care' and replacement of those packages with individually evaluated levels of support for each person. Within the system we can observe experiments with 'case-management'; 2) an attempt to make consistent the different options that are offered by service providers within the same region; 3) a resolve by the Government and the administration to work on the transparency and simplification of bureaucratic rules. It is essential to ensure that services can take initiatives with respect to what people ask for even if the request falls outside the 'little bureaucratic rules'; 4) the necessity for large service providers and parents associations to ensure that some of their staff members are given the opportunity to study and implement the distinctive new ideas and waves in the field. Within the Flemish Community we observe also the recent influences and growing power of self-advocacy movements. There are also some organisations for Life Long Learning that play an interesting role in the so-called empowerment process.

Funding Issues

Within the history we can observe that religious groups took the first responsibility to work with persons with (intellectual) disabilities. Within the 20th century service providers took an organisational form of 'not for profit organisations'. These organisations are organised through a board that takes the responsibility for the management of this organisation that gets his subsidies from the Government. The Flemish Fund pays the subsidies and controls the good management and quality of services. This control system tries to make sure that the not for profit organisation uses its budgets in agreement with its goals.

94% of the care system is organised through such private not for profit organisations, the rest are organisations of the Provinces or large communities who get subsidies from the government.

Persons with disabilities get the support they need in services or residential facilities without paying for the staff members. The only cost has to be seen as a kind of 'hotel cost' to pay the daily costs and to participate in activities. Everybody who lives in a residential facility has an amount of 'assured pocket money'. This is an amount of money service providers cannot claim.

Income

The income situation of persons with intellectual disabilities is organised on the federal level, especially for people who cannot get an income out of labour. The 'income replacement allowance' and the 'integration allowance' are two important elements that will be discussed in this paper.

Persons with the label of 'Intellectual Disability' often cannot get an income from employment. Currently, a person is entitled to an income replacement allowance for the disabled (Samoy, 2001, p.10) when his/her physical or mental condition causes a diminution of his/her earning capacity to one third or less of what a non-disabled person can earn in any job of the labour market. There is no distinction made between degrees of disability and in general, this benefit is meant for disabled persons who never worked or work very irregular hours due to the presence of a long-lasting and serious impairment. In confrontation with the situation on the labour market we can observe that the medical doctors of the Ministry of Health who are responsible for this evaluation base their ideas about work capacities more on the observable impairments and functional limitations than on a confrontation between the capacities and the demands of the market.

The integration allowance is based on a definition of disability that refers to the ability to perform activities of the daily life independent, the ability to communicate, personal hygiene skill, etc. Disability is measured with a scale especially designed for this evaluation. The allowance is intended to cover the 'extra-costs' resulting from functional impairments, but is often simply used in part as an additional income for people who get an income replacement allowance. Both assessments are often carried out together.

The fact that citizens with intellectual disabilities get an amount of pocket money is contra-productive for the integration of persons. It is cheaper to live in a residential facility with pocket money than to go and look for a house on the free market and to get support at home. People who live in the society and use a day care centre or supported living arrangements do not get that pocket money.

Many not for profit organisations are also dependent on 'fund raising activities' to build up their budgets. The National Lottery and individualised gifts with tax reduction certificate are the structural possibilities. Service clubs such as Lions and Rotary act as interesting partners in the fund raising sector. Most organisations use this system of fund raising to keep their budget in balance or to prepare new investments/new projects.

Service structures and models

It has to be said that all the services that are offered by the Flemish Fund have a supplementary character. The Fund is only active on the domains where the global policy and services do not fulfil their inclusive role. More and more we can observe a trend of inclusive policy, non-categorical services, for example, social housing projects, provide a service for ALL citizens. The Flemish culture with its parallel care system can be situated in the first stages of a paradigm shift from a categorical/specialist system to an inclusive system.

The Flemish fund gives subsidies to residential services as well as to services in the community. Since 2000, the Fund has also organised a system of 'personal budgets', a system which allows persons with disabilities to organise their private care packages and as such they become the employer of their support and care-givers. In 2001 316 budgets were allocated (the amount of budget varied from 7,436 Euro to 34,705 Euro for one year). Of these people 118 persons (37%) had a label of intellectual disabilities. The majority of people with intellectual disabilities are therefore using other forms of services. There are four main categories of services available in Belgium:

- Services in the Community
- Semi-residential services
- Residential Services
- Foster Care

These are described below and the numbers of people with intellectual disabilities using these services are illustrated in Table 6.

Services in the community

These are services that are offered in the community to ensure that families and persons with disabilities can participate in the community and can have a good Quality of Life.

Family support services can give educational and psychological support to families and parents who take care for a family member with a label of 'physical', 'intellectual', 'visual' disability, hearing impairment or who have a label of 'autism'.

Services of supported living give psycho-social support or assistance in activities of the daily life. Persons with a label of 'intellectual disability', 'physical or sensorial disability' can get a limited package of support.

Semi-residential services

Those services are given to persons who get support in the day-time, but stay in their family in the weekends and the evenings.

Most of the semi-boarding schools are linked to special schools. They give support to children and youngsters with labels as 'intellectual disability', 'emotional and behavioural problems', 'physical disability', 'sensorial impairments'.

For adults we can find day care centre programmes. Those Centres give support on several domains but their specific expertise is situated in the domain of adapted activities for adults who cannot work on the regular labour market.

Residential services

Minors who cannot stay in their family can get 24h support in boarding schools. Most of these initiatives are also linked to special schools.

Adults can get support in a wide variation of residential services. Those who work can live in residential services that are designed for them. In residential services for those who cannot work people get a home situation and an activity programme. People with an intensive need of support can live in nursing homes.

Group homes in the community are situated in between services of supported living and residential services for those who work. Those group homes are situated in the community, close to a residential facility, persons with disabilities can also participate in daily activities as organised by the residential facility. (residents of the group homes pay the costs for housing and living themselves, they don't work with the 'hotel cost system' of residential services)

Some families have to share the education of their children with foster families. Other families prefer to keep their children at home but they combine it with the respite care system. In the programme of some residential services families can bring their children to the institution to stay there for a weekend or a short period.

Traditionally the services of the Flemish Fund were organised on a 24hr hour basis. Since the beginning of the nineties more and more services in the community are organised. Through group homes in the community the Flemish Fund offered less intensive support packages, which was thought to be able to work more on a demand and supply strategy. However, we already mentioned the negative side-effect of the pocket money system - Some families decide to leave their family member in a residential facility because of this financial system and, in addition, many (older) parents hesitate to bring their children in the community because they fear that the support possibilities will not be sufficient in confrontation with the demands of the society. As a result, even in 2001, the majority of the budget was still allocated to residential services (approximately 400,000,000 Euros) compared to community care services (approximately 14,000,000 Euros).

Employment provisions for persons with disabilities in the Flemish speaking part of Belgium

To be entitled to Flemish Fund employment or services, a person has to undergo an evaluation from a multidisciplinary team to show that capacity to hold employment is reduced in relation to the demands of the open labour market. Applicants with an intellectual disability have to prove that the attempts they have made to find a job on the regular job market continue to fail. Once eligibility is established people can access a variety of provisions from

the Flemish Fund wage subsidies, vocational training, sheltered employment and supported employment (Samoy, 2001).

Table 6: Overview of services with percentage of persons with intellectual disabilities: number of people with intellectual disability using each type of service (and percentage of those using these services who have an intellectual disability)

	Persons with intellectual disability	
Services in the community		
Family support services	4,710	60%
Supported Living services	1,440	99%
Semi-residential services		
semi-boarding school	3,395	45%
Day care centre for adults	3,540	94%
Residential Services		
group homes in the society	360	100%
respite care	76	60%
boarding schools	4,800	60%
residential services for those who work	1,100	99%
residential services for those who cannot work	7,670	94%
Foster Family System	822	88%

In Flanders about 13,000 people with a disability find a job in a sheltered workshop (Samoy, 1998, p.160) About 60 to 70% of the employees have a label of 'intellectual disability'. Although these workshops were established to train people to find a job on the open market, research shows that in the middle of the nineties less than 1% of the workers were able to find a job on the open market. In addition, it is only since 1999 that employees in these workshops get the legal 'minimum income' out of their job -until than they worked for about 80% of the minimum income.

It is important to mention that a lot of people with an intellectual disability who get the extra label "not able to work" enter a career in day care activity centre. A lot of those centres offer industrial activities and job coaching projects. Activities in the community are available and people who 'cannot work' , work there but they cannot get an income from this work.

Since 1999 and after many experiments, supported employment services have been available in Flanders. They have the task to guide people from a process of vocational training /extra-schooling, job analysis and solicitation and on-the-job training to a job on the open labour market. The vocational training is often organised through one of the 13 (in 1999) Vocational Training Centres that are specifically organised for people with disabilities.

Conclusion

As we can observe, the Flemish system of services is in a transition period. It is interesting to question (from an ideological point of view) whether a compromise between the old residential model and the new services promotes a higher quality of life to the people. On the other hand, it is necessary to question whether two systems can be managed from an economic point of view.

References/sources

<http://www.ond.vlaanderen.be/berichten/onderwijsinvlaanderen/onderwijsB5engels.pdf>

http://belgium.fgov.be/abtb/population/en_20203.htm

<http://belgium.fgov.be/debelgen/01001.htm>

<http://www.fracarita.org/nl/europa/belgie/museum/MuseumCollectie.html>

<http://www.vlafo.be/engels/index.html>

<http://www.vlafo.be/nederlands/mededelingen/pers28022002.html>

http://www.vlafo.be/nederlands/vlaams-fonds/publicaties/handicap_en_arbeid.htm

RENTY, J. (2001), De verlengde minderjarigheid. Is er een fundamentele contradictie met het nieuwe paradigma?, onuitgegeven licentiaatsverhandeling Universiteit Gent, 200-2001 (promoter: G. Van Hove)

SAMOY, E., LAMMERTYN, F. (1998), Sociaal beleid ten behoeve van mensen met een handicap, Acco/Leuven.

SAMOY, E. (2001), Definitions of disability, paper: Contribution from Belgium to the EU-project on: 'Undertaking a Comparative Analysis and Assessment of the Policy Implications of Alternative Legal Definitions of Disability on Policies for People with Disabilities', Department of Government, Brunel University/UK

KENNES, R. (ed.) (2001), Inclusief beleid voor personen met een handicap. Voorbeelden uit de beleidspraktijk, Acco/Leuven

DEVISCH, F., SAMOY, E., LAMMERTYN, F. (2000), Barrières voor sociale integratie van personen met een handicap, Departement Sociologie/K.U.Leuven.

VAN HEDDEGHEM, I., DOUTERLUGNE, M., GHESQUIERE, P. (2001), Het zorgverbredend vermogen van de school en de uitstroom naar het buitengewoon onderwijs, paper, HIVA/ Katholieke Universiteit Leuven.

VAN HOVE, G., VAN DEN ABBEELE, A., WILSSENS, M. (1999), Onderzoeksrapport m.b.t. de implementatie van de AAMR-systematiek, Universiteit Gent.

VAN HOVE, G. (2001), De school van de toekomst zit verscholen in de school van vandaag, Perspectieven, jg.63, 3, 12-18.

VANDERPOORTEN, M., (2002), 'Maatwerk in samenspraak'(Policy paper to be discussed in the Flemish Parliament before the summer of 2002)

The Netherlands

Carla Vlaskamp and Petra Poppes

Introduction

In this paper, several topics are discussed. All topics could be discussed more extensively, in a historical perspective, with more detail or from another point of view. For all topics several rules and regulations could be put forward and discussed. The Netherlands is a country where much is regulated, and several departments have made rules, regulations, memoranda and even laws that are related to persons with intellectual disabilities. In short, the topics are very broad and the selection made is open to discussion.

Definitions, legal status and eligibility

Definitions

In governmental papers, the term 'persons with intellectual disabilities' is used. The definition of Luckasson *et al.* (1992) is used in most 'official' papers, this definition describes persons with intellectual disabilities as persons with

- significant impairment of intellectual functioning
- significant impairment of at least two adaptive functions
- age of onset before 18 years.

Although this is the official definition (or description), a variety of terms are commonly used.

In practice, there are several terms used, like severe subnormality, mental handicap, feeble-minded persons, intellectual handicap. For several categories of persons, like persons with profound multiple disabilities, there are also several terms in common use, for example, 'multiple complex handicapped'. Especially within the medical circuit, outdated terminology is frequently used. Only recently, the Health Department outlawed the use of the term 'idiots' (for persons with profound intellectual disabilities).

Legal Status

In principle, adults with an intellectual disability – regardless of severity of intellectual disability – are afforded the same civil rights as any other citizen. However, most persons with severe or profound intellectual disabilities (and even some persons with a mild disability) are considered unable to execute these rights and have a legal guardian (a parent, brother or sister) who is legally responsible for the person. A formal representative can also be appointed by court to represent the person. Most services believe, that if a person is capable of giving consent (for example related to work or living situation), they should be offered the support/care they choose. As a consequence, there are still persons who are restricted in their freedom to go where they please 'because it is in their best interest'. Especially persons with challenging behaviour, persons with profound multiple disabilities and persons with profound intellectual disabilities and autism are among those who have a very restricted life. With regard to children, the situation is clear: parents are legally responsible for their children.

Eligibility

Persons with an intellectual disability have a legal right to services. In the Netherlands, there are a number of organisations, frequently based on religious beliefs, which provide services for sometimes more than a 1000 persons with intellectual disabilities. They exploit both residential facilities, institutional annexes, group homes, supported living houses and several forms of day services: sheltered workshops as well as farms, cycle shops, toy shops etc. These organisations are largely funded by our central government and services are obliged to provide for persons with intellectual disabilities.

In The Netherlands persons with intellectual disabilities are entitled to receive care when they have been indicated for it. Until recently local governments decided whether or not a person would obtain some sort of care or funding. The local governments weren't bound to central regulations. This meant that there were discrepancies between regions in Holland. Since January 2001 indications for care are provided by the central government (Landelijk Centrum Indicatiestelling Gehandicaptenzorg). This means that an indication is formulated independently of the providers of care or the organisations that fund care. An indication is given when a person belongs to the target group. This is determined on the basis of an IQ-test and/or a clinical observation. Subsequently the individual needs of a person with intellectual disabilities are mapped out. The indication advice consists of a description of the type of care and the amount of care that is needed, and the way parents or legal guardians would like the care to be funded (in kind or in the form of a personal budget with which the person can purchase care). With this indication advice the person with intellectual disabilities can go to the organisation that funds care. These organisations are obliged to allocate the care that is needed (LCIG, 2001). There are, however, waiting lists for day services, for community houses and even for residential facilities. There are also persons that have a personal budget, in principle they can try to buy the services they want and need, but they face many obstacles, especially administrative processes that are very slow, and shortages in housing, personnel, and jobs (Stoelinga & Zomerplaag, 2002).

Service providers use eligibility criteria, but these criteria are not standardised. There are services that 'specialise' in either severe or just mild disabilities. Services can refuse persons on certain grounds, for example by telling them that there is no hoist so a person cannot be moved and therefore he or she is refused. There are services that refuse persons with a pervasive need of support because they are more expensive to support - as such they "specialise" in providing care for those with mild levels of disability. There are, all in all, too few community houses and even too few places in residential facilities. Also, there are long waiting lists for places in day services.

Prevalence

In 1995, there were approximately 102,000 persons with intellectual disabilities in the Netherlands (VGN/NZi, 1996; Haveman, 1998). Based on those figures, it was estimated that the number would increase to 111,000 in 2000. Further research in 2000 estimated higher numbers (120,000) of persons with intellectual disabilities (Beltman, 2001, RIVM, 2002). The number of persons with intellectual disabilities is certainly increasing, especially in the group of persons above 50 years of age. There is also an increase in the number of persons with severe or profound disabilities. This is a growing population, due to improved neonatal care and immigration rates (over half of all children with profound intellectual disabilities are of foreign descent).

There are as many children with intellectual disabilities as there are adults and elderly. Also, it is not true that there are far more persons with mild intellectual disabilities than severe disabilities, numbers for severe and profound intellectual disabilities are even higher (Haveman, 1998). Research has shown that there are approximately 49,400 people with mild to moderate intellectual disability, 48,000 with severe intellectual disability and 11,000 with profound intellectual disabilities (Beltman, 2000).

Policy frameworks and the development of services from 1985 onwards

The policy concerning care for persons with intellectual disabilities, has, generally speaking, developed from segregation towards integration and inclusion.

From 1985 onwards, the government introduced measures that aimed at more freedom of choice for the person with the disability, and more independence from and flexibility in the services offered. This was in accordance with changes in policy, where health care was reorganised on a more free-market basis. In 1991, a governmental memorandum called 'Verstandig Veranderen'(Sensible Change) said that a client oriented budget should be introduced. This memorandum was followed by a long-range plan, called 'De Perken te buiten' (Outside the pale) that stated, that persons with an intellectual disability are citizens just like every other citizen in the Netherlands, and that they should be given the same opportunities and choices, and were entitled to support wherever they were limited in executing their civil rights. There were two points that struck as special in this plan: first, all children should be enabled to visit a school (up till then, it was common practice for children with intellectual disabilities not to go to school but visit a day care centre, compulsory education didn't apply to them), and second: the government prohibited the building of new residential facilities, and the reconstruction in existing facilities. From 1995 onwards, partly because of the good economic climate, a lot of money was spent in order to implement these long-range plans.

To enable children with intellectual disabilities to receive education in schools, several schools for special education and day care centres started to co-operate. These co-operations are subsidised and supervised by the government. Their aim is to develop suitable curricular activities for children with (profound) intellectual disabilities from the age of four. It is anticipated that these co-operations will produce an advice about a suitable curriculum in August 2003. This advice will be formalised in the form of a new law. That means that all children from the age of four will have a right to education and that for all children from the age of five education will be compulsory, regardless of their intellectual and functional disabilities. It will still be possible to ask for an exemption from compulsory education, but the assumption is that it will be less easy than it has been up until now (Ministry of Education (OC & W), 2000).

Besides this the government is taking steps to prohibit the building of new residential facilities, and to reconstruct existing facilities. Private initiatives (e.g. several parents received funding so they could buy a house together for their disabled children) were stimulated. Several initiatives around supported employment have been developed and an occupational training package is now available. Also, there has been a general move away from large institutions to smaller group homes (up to 24 persons per home) and community houses (4-6 persons per house, still with a professional present on a daily basis). The size of the institutions is mainly reduced by moving part of the population to an annex of the institute. These clients still use facilities of the mother-institute, like day services. On a smaller scale, institutes are realising a form of supported living (1-4 persons, living independently). These clients, mostly individuals with mild and moderate intellectual disabilities, live in a home of their own and receive care when necessary. They also benefit from supported employment.

In the present situation, 'special categories' like individuals with severe or profound mental and multiple disabilities, elderly with a mental disability and persons with mental disability and challenging behaviour, are 'left behind' in residential facilities. Although these service users would probably benefit from a community setting, most policy makers believe that because individuals with profound disabilities need more staff support and require greater expenditure per person, they are 'better off' in residential facilities. It is still very difficult (both financially and practically) to establish community support services for individuals with high support needs. So, changes have led to improvement for persons with mild and moderate mental disabilities although the process is slow. In a densely populated country like the Netherlands, it is not easy to buy land or to rent or buy a house. There has been an explosive increase in the costs of housing, prices have almost doubled in less than five years. Therefore, it has

increasingly become very expensive to buy houses for persons with intellectual disability in the so-called normal community. Besides this, the funding to enable people with intellectual disability to live in small community houses and receive 24-hour care does not cover the costs (Stoelinga & Zomerplaa, 2002).

Still, the process is continuing and will not stop. At the same time, the situation for persons with profound and multiple disabilities, has deteriorated. This group of people still lives in residential facilities, but because of the transition towards community care, facilities have stopped to invest: buildings are in a state of decline, there is a lack of trained staff, etc.

One might still expect a fast decrease of places in a residential facility because most individuals with mild and moderate intellectual disabilities moved out of the residential facilities to a community setting. The reality is, that even if many clients move out into the community, residential institutions will not vanish to exist, as there are still waiting lists. In 1996 there were 6410 people with intellectual disability on the waitinglist, in 2000 there were still 6019 (Stoelinga & Zomerplaa, 2002). To many parents, the most important is that their (grown-up) child has a supported place, either within or outside a residential facility. As long as there are far more clients than places in group homes or community services, residential facilities will still be necessary.

Right now, we have large organisations that offer different forms of support: residential, day activity centres, supported living and supported employment, and 'ordinary' housing within the community. The multi-location organisation is typical for the Dutch - they favour a consensus model. It is also a form of 'control' from the organisation over its smaller units.

This type of organisation can be understood if keeping in mind that we still do not have a sound system of client held budgets. In our system, the vast majority of the budget is still made available to the facility. Although client held budgets are believed to be important for a real change in our support system, this is still a slow development. Even if a client is allowed a budget, he or she is likely to find him or herself on another waiting list. Furthermore, research shows that a personal budget is not enough to buy the care that is needed for a person with intellectual disability (Stoelinga & Zomerplaa, 2002).

Funding of services and service models

Funding

In Dutch legislation, a collective responsibility is laid down towards persons with mental disabilities. The financial regulations allocate budgets to facilities, both residential and non-residential. The height of the budget is related to the number of clients for whom the facility cares. With a few exceptions, like persons with severe challenging behaviour, the amount of money per client is the same. The facility is responsible for the distribution, and can therefore decide if they want to spend extra money on staff, if they find it necessary to buy new equipment or if they want to use extra money on housing, etc.

Recently, all service providers are forced to indicate the level of support a client needs. This system of 'level of severity of support' will in the near future determine how much money is allowed to a facility (or a private person). The same system will apply for the system of personal budgeting, although this budget is still limited and not by far enough to provide for all clients wanting such a personal budget. The system of personal budgeting is still functioning next to the 'normal' financing. It shows that we still lack legislation that fits the support-paradigm (Stoelinga & Zomerplaa, 2002). There are memoranda and plans, but no legislations. This new legislation and related budgeting is important if a change is really to happen. An annotation to this remark: the strong influence of the government is not only slowing this process down. When the government wants to stimulate supported living, they can put financial pressure on facilities. But next to the movement towards supported living there is a movement (for example by parent associations) towards the relative security of living in a sheltered world like the residential facility.

Service models

The Dutch government is funding services on the one hand and private persons on the other (via a personal budget). There are several services for persons with intellectual disabilities and their families, and most of these services are funded by the government. In table 1 you can find an overview of services provided in The Netherlands.

Table 1: overview of services

Services	Description
Services for parents/family whose children live at home	Family support services
Semi-residential services	Medical day care centres for children; Day care centres for children; Day care centres for adults
Work	Supported employment services; Social work places
Residential services	Group-homes; Community homes; Supported living services; Residential facilities; Respite care; Foster family services
Schools	Schools for special education; Schools for regular education

Services for parents/family whose children live at home

When a child with intellectual disabilities lives at home with his or her parents, the parents can call upon family support services. There are services that support parents in daily life activities (e.g. someone comes in to help out during dinnertime), services that provide medical support and paramedical services. Psychosocial support can be given to parents and families to come to grips with having a child with intellectual disabilities. Parents and families can also receive educational and psychological support regarding rearing a child with intellectual disabilities. Also, there are special houses where children with disabilities can stay for a couple of nights per month and services that provide trained nanny's to look after the child when the parents are not at home.

Semi-residential services

These services are provided to people with intellectual disabilities during the day.

Medical day centres treatment to children from the age of 0 up to the age of 13. The children return to their homes in the evening. The target-group of medical day centres are children who's development is (likely to be) disturbed by a combination of physical, psychological and social factors. Treatment is aimed at the child and its parents.

Day centres for children provide services for children with intellectual disabilities between the ages 2½ and 18. The activities of a day centre for children are aimed at giving the child the opportunity to optimal cognitive and physical development.

Day centres for adults are visited by persons with intellectual disabilities from the age of 16 and older. Usually they start going to a day centre, when they are too old to go to school or a day centre for children. Day centres want to provide meaningful activities during the day. A wide range of activities are carried out in the day centres, for example: making candles or soap, toys, cards, copyprint, art, woodwork, etc.

Work

Supported employment services try to provide persons with intellectual disabilities with a paid job, for example in a cycle-repair shop, or assisting in a gift- or toyshop that is often related to a facility. They support the person with disabilities and his or her employer.

Social working places provide work for persons with intellectual, physical or psychological disabilities who can only work when the environment is adapted to their special needs. It involves industrial work, like packing or wrapping industrial goods, etc.

Residential services

Group homes exist in a wide variation. There are group homes for children, for adults, for the elderly, for teenagers, etc. The homes vary in number of residents (up to 24 persons per home), the amount of support that is given, etc. During the day the residents go to school, day centre or work. There are group homes situated in the community, almost always close to a residential facility and there are group homes that are situated on the grounds of a residential facility. Community homes also vary regarding the people who live there, their age, the amount of support they need, etc. Community homes house up to 6 persons per home.

Supported living services are available for people with mild to moderate intellectual disabilities who live in a home of their own (1 to 4 persons per home). They receive care when necessary. When a person wants to live independently, he or she will be trained to do so by supported living services.

In residential institutions/facilities residents receive support 24 hours a day. Residential facilities offer overall care: a place to live, work or activities during the day which are adapted to special needs, leisure activities, medical care, psychiatric care, support. A rather 'new' development at residential facilities is the so-called reversed integration, where part of the grounds of the former institute is sold to private persons. Some of the persons with an intellectual disability (most of them persons with profound disabilities and elderly persons with intellectual disability) continue to live within the grounds of the former institution, and non-disabled persons build houses next to them. Instead of going into the community, the community comes to them.

Respite care is a service that parents can claim when their child still lives at home. Most group homes have places to enable a person to stay there for the weekend or for a couple of weeks. Some parents place their child with foster parents.

Schools

The education system in The Netherlands is divided in education for children with and for children without disabilities. Schools for children with disabilities are called 'schools for special education'. There are schools for children with mild intellectual disabilities (MLK) and schools for children with severe intellectual disabilities (ZMLK). Recent developments enable children with disabilities to go to 'regular' schools. At the moment mostly children with Down's Syndrome visit 'regular' schools. Experts from schools for special education support regular schools. An ambulatory special education teacher supports the child with an intellectual disability at a regular school.

Numbers

There are 140 residential facilities that provide for 34,000 persons, and 675 smaller group homes for adults (for up to 24 persons) that provide for 18,500 persons (Beltman, 2000). There is limited information on the number of persons (adults) that still live with their parents, in three provinces in the Netherlands (there are 13 provinces) there were 2,573 persons living at home in 1995. These provinces were among the least populated. One could therefore expect at least 15.000 persons living at home. There is no reliable information on the number of persons that live in a community home or who live independently.

There are approximately 49,400 persons with a mild or moderate intellectual disability - most of them live at home with their parents but move to a group home, community house or a form of independent living when they are grown up. During childhood, the majority will visit a school for persons with mild intellectual disabilities (MLK-schools) In 1998, these schools had 40,426 students. Some go to regular schools. As grown-ups, they either hold a job (supported or otherwise) or are unemployed. A small number visits a day centre for adults with intellectual disabilities.

Around 48,000 have a severe intellectual disability, most of them live at home with their parents till adulthood. Most of them go to school: there are 103 schools for children with severe intellectual disabilities (ZMLK), they teach a total of 9229 students. Few children will go to a day centre for children with mental disabilities. Right now, ZMLK schools and children's day centres have started a process towards further co-operation and integration. This also includes children with a profound mental disability.

If the child grows up, parents face a problem in finding suitable housing facilities, as most facilities (residential and communal) have a waiting list. Most of the adults with a severe mental disability visit a day centre during daytime.

Almost 11,000 persons have a profound intellectual disability, and approximately 9000 of them can be classified as profound multiple disabled. As a child, most of them live at home. A small number visits special schools. Around 1500 children with profound multiple disabilities go to a day centre where education and therapy are provided in an interdisciplinary way. As adults, most parents still feel forced to find a place for their child in a residential setting. A small but increasing number of parents join forces and buy a house for their children. If they have obtained a personal budget, they can buy the professional support they feel is needed.

With a personal budget, parents have started to buy houses for their children; they want to provide their children with the type and the amount of care they believe is necessary (Baarfeld & Ramakers, 2001). This is a system that functions right 'outside' the regular system. Parents can hold their child's budget and even become 'director' of their child's personal support plan. These initiatives are rather new, so little is known about efficiency and efficacy of these plans: for example can parents manage to keep investing time in this form of communal housing, will parents of different children manage to work together and share the same ideals. It is known through research that a personal budget usually does not cover the costs (Stoelinga & Zomerplaa, 2002).

Also new is a system where children with intellectual disabilities can go to foster parents. This form of care is still underpaid for the foster parents. Most foster parents are persons who used to work professionally in services for the intellectual disabled.

Experience of people with intellectual disabilities and their families

Research on the effects of de-institutionalisation is scarce in The Netherlands. Research that has been done (Overkamp, 2000; Stoelinga & Zomerplaa, 2002), show that integration of clients in de-institutionalised surroundings has increased, but not to the extent that the government anticipated in its policy. Clients do make use of social facilities but they are seldom integrated in the 'normal' social life or the labour market. Social contacts outside the institutional world and the family circle, remain limited (Overkamp, 2000; Stoelinga & Zomerplaa, 2002). Research that aims at the effects of de-institutionalisation on all parties involved, is carried out by University of Groningen, dept. Special Education, supervised by prof. dr. H. Nakken. As this research follows the actual process, publication of the data is not due within the next year. The research shows the slowness and treachery of the process. The outcome of the de-institutionalisation process is still unclear and up until now the most important question has not been answered: under which conditions do we obtain the best effects of de-institutionalisation? In many situations the transition itself cannot be discussed. It is declared to be the best- there is hardly room for discussing different options with regard to

the best conditions. The conditions are usually set, so we should study the effects of de-institutionalisation given set conditions. Also, the effects of de-institutionalisation on the quality of life of special categories of people, such as: persons with challenging behaviour, persons with profound (multiple) disabilities and elderly people, should be object of research. They seem to profit the least of the recent developments.

References

- Baarfeld, F. en Ramakers, C. (2001). Kleinschalig wonen met een PGB. Evaluatieonderzoek naar kleinschalige woonzorgvormen die door ouders zelf worden opgezet voor mensen met een verstandelijke handicap. Nijmegen: ITS.
- Beltman, H. (2000). Buigen of barsten? Hoofdstukken uit de geschiedenis van de zorg aan mensen met een verstandelijke handicap in Nederland 1945-2000. Proefschrift, niet gepubliceerde uitgave van het Noordelijk Centrum voor Gezondheidsvraagstukken.
- Haveman, M.J. (1998). Epidemiologie in de zorg voor mensen met een verstandelijke handicap. In: ten Horn, G.H.M.M., Buntinx, W. et al. (red.): Handboek mogelijkheden. Vraaggerichte zorg voor mensen met een verstandelijke handicap. Maarsen: Elsevier, I 8.1-1 – I 8.1.-29.
- Luckasson, R., Coulter, D.L., Polloway, E.A., Reiss, S., Schalock, R.L., Snell, M.E., Spitalnik, D.M. and Stark, J.A. (1992). Mental Retardation. Definition, Classification and Systems of support. Washington: AAMR.
- Overkamp, E.H. (2000). Instellingen nemen de wijk.: een analyse van het beleid inzake de deconcentratie van instellingen voor mensen met een verstandelijke handicap en zijn empirische effecten. Assen: Van Gorcum.
- Rijks Instituut voor Volksgezondheid en Milieu (2002). Data available on: <http://www.rivm.nl/vtv/data/kompas/gezondheidstoestand>.
- Stoelinga, B. & Zomerplaag, J. (2002). Knelpunten in de samenleving. Raad voor de Volksgezondheid en Zorg. Zoetermeer.
- Stoelinga, B. & Zomerplaag, J. (2002). Beleidsontwikkeling verstandelijk gehandicaptenzorg. Raad voor de Volksgezondheid en Zorg. Zoetermeer.
- VGN/NZi (1996). Landelijke registratie zorg- en dienstverlening aan mensen met verstandelijke beperkingen. Landelijke tabellen 1995. Utrecht: Vereniging Gehandicaptenzorg Nederland, Nationaal Ziekenhuis Instituut.

England

Julie Beadle-Brown, Jim Mansell, Paul Cambridge and Rachel Forrester-Jones

Introductory note

The UK consists of four countries, which now each have their own government departments and varying degrees of autonomy in social and health care. It should not be assumed, therefore, that arrangements in Scotland, Wales or Northern Ireland are the same as in England. Within each country, the major organisational characteristic of importance for social and health care is that some services (education, housing, social care) are provided by local government agencies of different types, whereas health care and social security are provided by central government through (different) regional and local organisations.

In terms of law and policy, common practice is that Government intentions and guidance without the force of law are expressed through *White Papers*; these are often produced after an expert committee, usually named after its Chairperson. Legal imperatives are expressed through *Acts of Parliament*.

Definition, legal status and eligibility

Terminology

The terminology used in England to label people with intellectual disabilities varies between different organisations and in different situations. For example, in the criminal justice system terminology ranges from “mental defective” in the Sexual Offences Act (1956) to “mental impairment” and “severe mental impairment” in the Mental Health Act (1983). Within the social security system the terms “severe mental impairment” and “severe learning disability” are used. “Intellectual Disabilities” is the term adopted internationally mostly by the academic world. Some service user organisations such as People First, prefer to use the term “learning difficulties”. However, the Warnock Committee (a Government committee reviewing policy on special education in the 1980s) suggested that the term “learning difficulties” should be used to refer to specific problems with learning in children that might arise from a number of different things such as medical problems, emotional or behavioural problems, language impairments, etc. This term is often used to encompass disabilities such as dyslexia, ADHD and dysphasia. The most commonly used term in the UK and that used by the government and in most professional and academic circles is the term “learning disability” and “people with learning disabilities”. For practical purposes, this term equates to intellectual disability (Australia and New Zealand) and mental retardation and developmental disability (North America).

Despite the variety of terminology used, most of the labels imply the same underlying definition, although with slightly different connotations. Within the legal system: The term “defective” is used in the Sexual Offences Act (1956) and is defined in the Mental Health (Amendment) Act 1982 (Schedule 3) as “a state of arrested or incomplete development of mind which includes severe impairment of intelligence and social functioning” (cited in Gunn, 1996, page 17). As Gunn (1996) points out this definition is similar to that used in the Mental Health Act 1959, for the term “severe subnormality”. It is also the same as the definition of “severe mental handicap” in the Sexual Offences Act 1967 and in the Juries Act, 1974 (Gunn, 1996, page 17) and is the definition used by the World Health Organisation, although is considered rather outdated now (Emerson, Hatton, Felce and Murphy, 2001). Within the professional and academic world the definition most often used is that of the American

Association on Mental Retardation recently extended and clarified by the British Psychological Society (2001). As the British Psychological Society's publication "Learning Disability: Definition and Contexts" (2001) and Emerson et al.'s Learning Disability: The Fundamental Facts (2001) both illustrate, there are three core criteria:

- significant impairment of intellectual functioning
- significant impairment of adaptive/social functioning
- age of onset before adulthood

All three criteria must be met for a person to be considered to have a learning disability.

This definition is adopted in the White Paper "Valuing People" (Department of Health, 2001) although expressed in less clinical terms:

"A significantly reduced ability to understand new or complex information, to learn new skills (impaired intelligence), with;

A reduced ability to cope independently (impaired social functioning);

Which started before adulthood, with a lasting effect on development."

Intellectual disability in England is a medico-legal definition: it depends on the judgement of a psychiatrist. The BPS guidelines point out that due to the difficulties in assessing adaptive/social functioning many psychiatrists concentrate solely on intellectual functioning, assuming that if significant impairment in IQ (usually below 70) is found then similar levels of impairment in adaptive/social functioning are likely. However, as the BPS guidelines state, this is not necessarily the case for everyone and they recommend that "classification of learning disability should only be made on the basis of assessed impairments in both intellectual and adaptive/social functioning which have been acquired before adulthood".

Legal status

Within the UK adults with a learning disability are afforded the same civil rights as any other citizen. However, since the UK has no written constitution, these rights are mainly derived from common law (ie from decisions made in individual cases over many years) or from specific statutes. There is usually scope for application of judgement, so that often people with intellectual disabilities may in fact experience discrimination. In recent years, there have been increasing attempts to protect disabled people from discrimination. The Human Rights Act (Home Office, 1998) and the Disability Discrimination Act (Department of Health, 1995) both address basic rights. More specific laws address the quality of care services (the Care Standards Act, 2000; the Education Act (1981) giving force to the Warnock report). These laws are supported by a framework of policy and guidance, with quasi-non-governmental organisations involved in enforcement. For example a Disability Rights Commission set up in 2000, helps all disabled people to access their full legal rights, a National Care Standards Commission monitors quality of care and there is extensive government guidance such as the "No Secrets" policy document (Department of Health, 2000d), which offers guidelines for policies and procedures to protect vulnerable adults.

There is no clear legal framework dealing with decision-making by or on behalf of adults with intellectual disabilities in the UK. This has been given much attention, with the recent government papers on consent to medical treatment (Department of Health, 2001b) and guidance for seeking consent from people with learning disabilities (Department of Health, 2001c). No one can legally give consent on behalf of an adult with a learning disability and they should be assumed capable of giving consent unless incapacity is demonstrated (Department of Health, 2001c). If a person is capable of giving consent then they should be helped do so and their refusal to engage with a particular intervention cannot be overridden by professionals claiming that their action is "in the person's best interests" or reflects a "duty

of care". However, where a person cannot give consent there is no legal provision for anyone else to give consent on their behalf. Thus, much common practice is of untested legality (for example, restraining a person who is aggressive might be a common assault). Services rely on very general legal principles –such as the duty to care, the common-law power to protect a person from harm – in the absence of clear legal guidance. For children, the situation is much clearer (Lyon, 1994 for Mental Health Foundation)

Eligibility

There are several important issues here: a) people with a learning disability, like anyone else in the UK, generally have no legal right to services; laws empower public agencies to provide or pay for service, but generally do not require them to do so in individual cases. Even where there is a legal entitlement – as there is for example to education for all children, irrespective of their level of disability – this can be met by very limited and inferior provision. b) eligibility criteria for local government services – education, housing, social services - are created at local level and can vary from authority to authority; this leads to geographical inequities and the present UK government is about to issue guidance to begin to standardise definitions and assessments (consultation paper, Department of Health, July 2001) (though still leaving considerable discretion to local authorities about the extent to which they provide services). c) one critical issue is that people are entitled to free medical and nursing care provided through the National Health Service but not to free social care, which is often charged for by local authorities. This creates perverse incentives for agencies in the same area to try to shunt costs onto other organisations.(although this was available in the past). Most social care has to be paid for from personal contributions (e.g. from personal savings or from benefits

Prevalence

There is no single official statistic that indicates how many people with a learning disability live in the UK. Government statistics are based on those receiving services and may not include those who, for example, live with their parents and receive no official services. . If people have not come to the attention of services at some stage in their life then they are unlikely to be included in any statistical estimate. Even for those who do come to the attention of local or health authorities, local case registers often fail to use standard definitions of intellectual disabilities.

In "Valuing People" the government estimates that, in England, there are 210,000 people with severe and profound learning disabilities and 1.2 million with mild/moderate learning disabilities (25 per 1000). Emerson et al., (2001) summarise prevalence rates from recent epidemiological research, which has put prevalence of severe learning disabilities at between 3-4 per 1000 of the population. They point out that studies that have screened whole populations (as reporting those known to services) report a higher prevalence of 6 per 1000. Figures for mild learning disabilities are much more variable but in general suggest that there are less than 10 per 1000 people in the population with a mild learning disability (only people known to services included). Once again, studies that have screened whole populations have found much higher incidence rates for 25-30 people per 1000).

In terms of future numbers, it is estimated that the number of people with severe learning disabilities will increase by approximately 1% per year for the next 15 years (Department of Health, 2001).

Policy Framework

Within the UK (see Mansell and Ericsson, 1996), alternatives to institutional care started to be considered in the 1950s when the Report to the Royal Commission on the Law Relating to Mental Illness and Mental Deficiency (1957) recommended that there should be more places for people with mild intellectual disabilities in residential homes - more as a way of relieving pressure on the already over-crowded hospitals, rather than as a the result of any ideological convictions. The responsibility for community services lay with local government rather than

central government and so little was done about setting up community alternatives until the mid-1960s, when a series of scandals in institutions revealed ill-treatment and squalid conditions. In response to this, the government White Paper (Department of Health and Social Security, 1971) "Better Services for the Mentally Handicapped" was published and encouraged the development of community care for people with mild and moderate intellectual disabilities within England and Wales (Scotland and Northern Ireland have a different legislative system and were in general much slower to develop community services). The other political influence at this time was a public lobby for the abandonment of hospital care by the Campaign for the Mentally Handicapped. This lobby was influenced by the examples of community care in the US and in Scandinavia as well as research evidence from work by Tizard (1960; 1964) demonstrating that community care produced better outcomes (Mansell and Ericsson, 1996).

Mansell and Ericsson (1996) report that the first units that developed in the community were large (20-25 person) units but that by the middle of the 1970s the first examples of supported housing in ordinary houses started to appear. However, government policy did not really address the issue of whether all people with learning disabilities should be supported in the community until, at the beginning of the 1980s, the Report of the Committee of Enquiry into Mental Handicap Nursing and Care, (1979, cited in Mansell and Ericsson, 1996) recommended housing-based services as the main future model of care. At this point the Department of Health funded some demonstration projects (Mansell et al., 1987; Felce, 1989) and the King's Fund (1980) introduced the concept of "An Ordinary Life". In 1983, the government published the Care in the Community Circular recommending further demonstration projects and funded the Care in the Community Initiative (Cambridge et al, 1994).

The momentum of community care continued through the 1980s and concern over the increasing numbers of people entering residential care (in particular older people) led to a series of reports such as the Griffiths report (1988), the Audit Commission reports (1986 and 1987) and the House of Commons Select Committee (1985). These reports led in turn to the 1989 White Paper "Caring for People: Community Care in the next decade" and to major reform in the 1990 Health and Community Care Act. This transferred financial responsibility for residential care solely to local authorities (they became the lead agency responsible for care for people with intellectual disabilities). It emphasised the use of hospital care for short-term treatment and assessment rather than long-term care, introduced the purchaser/provider split and encouraged the transfer of provision of care to private and voluntary organizations. It also introduced the necessity for better community care planning, case management and consumer choice. However, throughout the 1990s, the decision as to whether to provide community-based models or institutional care remained with health and local authorities, rather than any legislative or policy commitment from central government (Mansell and Ericsson, 1996).

The remainder of this section will consider the most recent policy developments within the UK and their effect on services for people with intellectual disabilities. Section 4 introduces some of the intervening policy decisions with respect to service structure and organisation in particular.

General policy relevant to people with intellectual disabilities

There have been three strains of more general policy over the past decade, which have had an influence on the lives of people with learning disabilities. Firstly, there has been general Home Office legislation such as the Human Rights Act (1998). This came into force in October 2000 and although there is no specific reference to people with intellectual disabilities, the Act gives a way for human right infringement cases to be heard in the UK rather than having to go to the European Court of Human Rights. The Act is based on the European Convention on Human Rights and as such adopts the rights (both Absolute and Qualified) used there. The Act should create more awareness of rights, especially in people supporting those with intellectual disabilities, and ensure that these people receive the benefits of such an Act being in place.

Secondly, general Disability legislation such as *The Disability Discrimination Act (1995)* has enforced more equal opportunities and anti-discriminatory policies benefiting all people with disabilities. One of the most important implications of this act for people with learning disabilities has been with regard to improved physical access to all public areas and improved access to appropriate treatment in hospitals.

Thirdly, there have been a number of general Community Care policies that have aimed at improving the independence, protection and quality of care for all people receiving community care. *Modernising Social Services (1998b)* identified six areas where current social services needed to be modernised: Protection, co-ordination, inflexibility, clarity of role, consistency and inefficiency. It identified the main aims of more modern services for adults as promoting independence, improving consistency and providing convenient user-centred services. Services for children were to focus on improving protection, quality of care, and improving life chances. This White Paper emphasised the need for social services to adhere to the Best Value initiative (discussed more fully in following sections) and led to a number of further policies in an attempt to modernise social services.

Already in existence but not well used was *The Community Care (Direct Payments) Act (1996)*, which allowed Local Authorities (LA) to provide a cash payment to enable people to purchase their own services to meet an assessed community care need. The aim of direct payments was to improve independence and empowerment of all people receiving community care but included people with a learning disability. It was one vessel by which the government hoped to modernise social services as outlined in *Modernising Social Services*. However, the scheme was not compulsory and uptake, especially for people with a learning disability, was very low. This was mainly because the guidance offered with the Act stated that in order to be eligible for a direct payment a person must be “able and willing” to manage a direct payment, although could receive help in doing so. Many local authorities focused on the “able” rather than the “assistance” and assumed that people with learning disabilities could not manage a direct payment. However, recent guidance (Department of Health, 2000c) issued made it very clear that this was not to happen and the *Health and Social Care Act (2001)* made it compulsory for LA to offer a Direct Payment Scheme. The “Valuing People” White Paper (Department of Health, 2001 d) also focused on the need to promote the use of Direct Payments for people with learning disabilities and this is to be part of the remit of the Valuing People Implementation Support Team.

Another follow-on from Modernising Social Services was the adult protection guidance issued in 2000: *No secrets: Guidance on developing and implementing multi-agency policies and procedures to protect vulnerable adults in the community (2000d)*. One of the main recommendations is for a multi-agency approach to adult protection and in particular to dealing with abuse and this guidance now forms the basis of many in-services Adult Protection policies.

Finally, the *Care Standards Act (2000a)* aimed at improving consistency and quality of care across services - Of its six key provisions that most relevant to people with intellectual disabilities was probably the setting up of an independent National Care Standards Commission (NCSC, with equivalents in Wales, Scotland and Ireland). The original remit was mostly with children but in England the NCSC also took on the role of regulating care of children, adults (including those with intellectual disabilities) and independent health care. Some of the other key provisions related to protection of vulnerable adults by requiring the Secretary of State to maintain a register of individuals unsuitable for work with vulnerable adults. It also gave a new power for ministers to issue guidance on residential care and in 2001 the Department of Health released several documents relating to the Care Standards Act, including National Minimum Standards for Care Homes for Younger Adults and Adult Placements, for Care Homes for Children and for Care Homes for Older Adults. Finally, the Care Standards Act (2000) had implications for training of the social care workforce and for how funding systems operated.

Policies specific to people with intellectual disabilities

The main piece of policy related to people with intellectual disabilities is the recent *White Paper (Department of Health, 2001d)* "*Valuing People: a new strategy for learning disability in the 21st Century*". It lays open a "new vision" incorporating four key principles: Rights, Independence, Choice and Inclusion and with this it advocates a complete move to community care for everyone with a learning disability. It talks about new national objectives for services "to provide clear direction for local agencies" and From April 2002 there will be a new Learning Disability Development Fund (although part of this new fund will not be new money but rather money released from the long-stay health funding. Money will also be provided to help implement the White Paper.

The White paper outlines 11 objectives all of which are based around improving the life chances of people with intellectual disabilities in line with the four key principles above. There is an emphasis on the promotion of Direct Payments for people with intellectual disability, on promoting supported employment, on improving day services available, improving workforce training, on the use of Person Centred Planning and on partnership working.

At present implementation is in the very early stages but recent publications by the Department of Health have provided extensive guidance on the use of the Person-Centred Approach and on Partnership. Every local authority have had to set up a Partnership Board to co-ordinate strategic planning and service development. These boards bring together public, private, community and voluntary sectors and must include representation from people with intellectual disabilities and their carers. They will be responsible for implementing the long-term changes outlined in *Valuing People* in each local authority and person centred planning will play a significant role in bringing about the significant changes in organisational culture and practices that are needed. The implementation of person centred planning is to be a priority of the Implementation Support Team, who will co-ordinate with others to provide training, materials and opportunity for discussion and feedback and to identify sources of support for local development.

The other recent development signalled by the 2001 White paper has been the new Learning Disability Awards Framework (LDAF) set in the context of the work of TOPSS, the National Training Organisation for the Personal Social Services. Initiatives are underway to provide training for care staff and managers working in community care services, including those for people with learning disabilities, requiring a new focus on the skills and training of the social care and health workforce (Department of Health, 1998; Brand, 2000). Around 75% of social care staff are unqualified, difficulties are experienced in recruitment and retention and the work attracts low status and low pay.

In terms of more specific policy, in 1993 the Department of Health published a project group report on "*Services for People with Learning Disabilities and Challenging Behaviour or Mental Health Needs*". This report recommended, among other things, the need for highly individualised service planning, based on accurate records and assessments, and service delivery, using small, community-based staffed houses rather than large residential homes or centres and small-scale alternative day services rather than large day centres. Hospital services should only be used on short-term assessment and treatment basis and not for long-term care. Effective joint commissioning and inter-agency working was seen as essential to high quality services for this group of people in particular.

Similar conclusions were drawn in a report published by the Mental Health Foundation in 1997, focusing on children with intellectual disabilities and challenging behaviour. This stressed the importance of access to a range of services, including specialist provision and the need to plan services "reflecting the cultural, racial and religious diversity of society". Like the Mansell Report (Department of Health, 1993) this report also emphasised the importance of strategic planning (e.g. for transition to adult services), of multi-agency working, individualisation and the provision of local services, if children cannot be provided for within their own home.

Funding of Services and role of public and private sectors

Five trends can be identified in the UK approach to funding services for people with intellectual disabilities since the beginning of the 1970s.

Growth in specific disability-related benefits

Over time, there has been increased differentiation within the social security system, so that people with disabilities can claim specific additional benefits intended to offset the extra costs of their disability. In learning disability, the most of important of these were the introduction of mobility allowance and of attendance allowance, which offered substantial sums to people with severe disabilities.

Erosion of universal public service principle – charging, privatisation

From the election of the Thatcher government in 1979 there has been a sustained process of shifting provision of services from public agencies to private (to create the “mixed economy of welfare”). Coupled with this have been annual cost reduction programmes for public agencies which have led to much more widespread charging for social care services. Although health care remains free, there has been a major shift of service provision from the health service to local authorities and therefore increased costs for people with intellectual disabilities and their families.

Shift from rights-based to discretionary cash limited benefits

As part of its attempts to constrain public expenditure, the UK government has systematically replaced rights-based social security entitlements with discretionary cash-limited benefits. For example, a social security entitlement to housing benefit which has been important in funding many residential places in the community is currently being replaced by a discretionary benefit managed by local authorities and with a cash-limited budget set by central government.

Repeated attempts to constrain social security use for care (eg housing benefit)

Much of the deinstitutionalisation movement in the UK was funded by people in institutions accessing both the level of funds paying for their institutional care and social security entitlements as well. Increasingly the government department responsible for social security has sought to constrain the use of social security for care in these circumstances.

Increased attempts to individualise funding – dowries, direct payments – as tool to change services and to individualise services

Individualised funding was invented at the end of the 1970s as an incentive to public authorities to remove people placed in institutions. As they did so, they would receive the ‘dowry’ payment associated with each person. This was typically the average cost of the institutional place. The bridging costs of this arrangement were met by central government. Following the adoption of the care management model at the end of the 1980s, this principle has been extended from notional individual allocation to real individual allocations which can be spent in more imaginative ways than block grants in the past. The most recent version of

this policy is the creation of direct payments to individuals with which to purchase their own care.

Emerging Service Structures and models

Service structure and organisation:

As previously mentioned, government funded reports were recommending the development of social care markets before the 1990 community care reforms, along with reviews of funding arrangements. The Audit Commission (1986) recommended that local authorities should be the lead agency in the care of people with intellectual disabilities and that parallel funding mechanisms were necessary. The need for joint working between LA and Health Authorities in securing a needs based allocation of funds was recognised as essential in a world of rapidly changing needs and values (The Audit Commission, 1987) and integrated purchasing and service development was also emphasised by '*Community Care: Agenda for Action*' (Department of Health, 1988). In 1989 the Audit Commission took this concept a step further by suggesting joint management of services by health and local authorities with '*a joint manager..... responsible for a jointly funded budget*' (Audit Commission, 1989, para. 66), in other words, local joint commissioning. However, although joint working was obviously desirable, the 1990 community care reforms *Caring for People*, (Department of Health, 1989) made little progress in removing the organisational and funding disincentives to joint working.

It was not until 1998 that *Partnership in Action* (Department of Health, 1998), signalled the Government's intention to promote joint commissioning through:

pooled budgets between health authorities or Primary Care Trusts and social services departments

lead commissioners, with funds transferred and functions delegated

integrated provision

In addition to joint working and joint commissioning, an important change was in how contractual relationships operated following the 1990 community care reforms (*Caring for People*, Department of Health, 1989). These reforms introduced a market paradigm for managing community care. This was predicated primarily through the separation of purchasing from providing, with social services as lead agencies, responsible for commissioning services, community care planning and care management, promoted through the rhetoric of user and carer choice, competition, and cost-effectiveness. This led to increasing inequities and fragmentation in the organisation and delivery of community care (Cambridge 1999) and more recently to a cycle of regulation. While social services purchased and commissioned care, the provision of care was to be taken on by private and voluntary organisations and Social Services/Local authorities were to work collaboratively with all other agencies (health authority, education authorities, housing agencies, advocacy services, etc.) to negotiate packages of care that would meet individual needs.

In terms of purchasing services, a system of competitive or select list tendering was employed in local authority services, where contracts were awarded to the lowest priced tender for a specific service. This, however, did not guarantee the quality of services and from 1998 the Government's Best Value initiative (DETR, 1998) was made central to implementing wider changes in the personal social services (Department of Health, 1998 and 1999), including performance monitoring, national standards, partnership working and consultation. Best Value is a system of purchasing designed to replace previous systems and is related to notions of cost effectiveness and value for money, which have been central themes of British social care policy for the last twenty years (Knapp et al, 1992). In addition to changes in purchasing criteria, Best Value is also a process, related to performance management, performance review, service review and inspection.

Finally, in terms of day-to-day management of service provision, some of the important developments have included person-centred planning (outlined in Section 2) and care management. The term “Care management” was first introduced in the Griffith report (1988) and adopted as a key concept in the 1989 White Paper. It was defined as the “responsibility for ensuring individual needs are regularly reviewed, resources are managed effectively and that each service user has a single point of contact”. It was viewed by the Audit Commission (1989) as the “lynchpin of an individual, needs led service” and seen as a system of working rather than as a group of individuals (Greig, Cambridge and Rucker, 1996). Unfortunately, however, it has not developed into the influential system initially envisaged, mainly due to a lack of consistency in operational model adopted across authorities, differences in role definition in particular, and a lack of suitably trained people to act as care managers leading to enormous caseloads in some areas and an inability to effect change on an individual or a service level. Despite this, care management is still seen as central not only to the process of ensuring Best Value (Cambridge, 2000), to the success of Joint Commissioning (Cambridge, 1999) but also to recent developments around person-centred planning.

General statistics on learning disability services.

The most recent government figures from Personal Social Services (Department of Health, 2000b), reports that in March 2000, there were 53,431 places for adults with learning disabilities in Local Authority staffed homes, voluntary, private, small homes and dual registered homes. There were 3,670 places for people with learning disabilities in nursing homes and private hospitals (out of a total of 193,621 total beds). In March 2000, the local authorities in England supported a total of 30,900 people with learning disabilities: 6,300 in Local authority staffed homes, 22,000 in independent residential homes, 1,000 in independent nursing homes and 1,600 in unstaffed homes and other accommodation. In terms of the actual number of homes available, there are 8,568. 8, 537 of these are staffed residential accommodation – 543 are local authority staffed homes, 3, 928 are small homes for less than 4 people, 2,106 are staffed homes from voluntary sector and 1,960 are privately-run staffed accommodation. Thirty-one homes are unstaffed or other types of accommodation.

Day service provision: Meaningful statistics here are much harder to come by. The White Paper (Department of Health, 2001d) estimates that while in 1971, there were 24,500 places available in Adult Training Centres, there are now estimated to be 84,000 adults with a learning disability receiving community-based services but these include home help and meals as well as day care. Of these 49,600 are in receipt of social services day services (many still within adult training centres). 6,630 patients use NHS day care facilities. Most of the information on prevalent service models comes from the research literature (see following section) rather than local or central government publications.

Future demand: Felce (1999) provides figures on residential provision through time and across countries within the UK and concludes that there is a severe lack of residential provision both currently and from future perspectives. Emerson and Hatton (1998) suggest that a further 20,000 – 25,000 places are needed to meet current demand, never mind future demand. There appears to be no such research for day service provision. As previously stated, the 2001 White Paper estimated that the population of people with learning disabilities would continue to grow by 1% per annum for the next 15 years with obvious implications for both residential and day services.

Service models: residential services

As outlined earlier, in the UK the larger institutions were first of all replaced by larger homes of 25-30 people within the community and later with smaller staffed houses usually with 7-8 people in older homes and 2-6 people in newer homes (Mansell, 1996). Over the years many comparisons have been made between the community and institutional provision and between different models of community provision, generally with the result of any model of community care provides better quality of care/quality of life than institutional care (Emerson et al., 2001). More recently, research comparisons have shown that small group homes were better than hospitals, hostels and larger group homes in physical development, the extent of

residents' personal possessions, improved behavioural competence, increased engagements in domestic and other activities and greater community presence or use of community activities (Hatton and Emerson, 1996; de Kock et al., 1988; Felce and Repp, 1992, cited in Felce, 1999).

The most recent development in service provision to be used in the UK has been supported living which generally embodies five principles (Kinsella, 1993):

- Separate housing and support,
- Focusing on one person at a time,
- Providing as much choice and control for services users as possible,
- Zero rejection and
- A focus on relationships and acting in a way which complements the natural supports rather than simply replaces them.

Supported living means organising support for people in their own homes, to reflect their culture, wishes and changing needs. People do not have to live alone but can choose where they live, who they live with and who supports them. There is little formal evaluation of supported living (Emerson et al., 2001) but what there is has suggested that outcome is better in terms of variety and frequency of community based activity, greater choice, greater community participation. However, methodological issues in this work led Emerson et al (2001) to compare 63 adults in supported living residences, 55 adults in small group homes (1-3 co-residents) and 152 adults in larger group homes (4 – 6 co-residents). They found that participants living in supported living had greater choice, participated in more community activities but experienced fewer scheduled activities, were more at risk of having their home vandalised and were at greater risk of exploitation than those in small group homes. They also had larger social networks, had more people in their social networks who were not staff, not family and did not have intellectual disability, than those in large group homes. They were also thought to be at less risk of abuse. Within the UK, there has always been a culture of providing a large range of service models (Department of Health, 1983) and supported living is seen as one model of service provision (Mansell, 1998). Problems of isolation even within the community, abuse and inconsistency in quality of care are as likely to occur within a supported living context as a staffed housing context – further evaluation is needed to really draw conclusions about its ultimate usefulness as a wide-spread model of service provision (Simmons, 1997).

In terms of prevalence of the different models of service provision most of the larger types of services still exist but as can be seen from the government figures above, the largest single type of residential provision (in terms of number of homes) is now small group homes of less than 4 people. However, it is only when we look at research over the past 5 years that we can really get some idea of the service models in use and the number of people using them.

For example, out of 41 people with severe intellectual disabilities and severe challenging behaviour, Felce et al. (1998) found that 5 were living in family homes, 17 in community housing, 17 in hospitals and 2 in hostels. Felce (1999) compared residential provision between England and Wales and found that group homes were generally larger in England than in Wales.

The government statistics quoted above do not include people supported to live independently in ordinary community housing or in adult family placements but. Braddock et al. (2001) concludes from the available literature that this accounts for no more than 10% of people who live outside their family homes. The emphasis of recent policy has been to help children with intellectual disabilities remain in their own family home as long as possible and the number of children in residential care decreased from 30% in 1970s to 3% in 1980s (Braddock, et al, 2001). As such there has been a decrease in the number of adults residing

in large residential or hospital accommodation because they continued to live with their family into adulthood. Braddock et al., estimates the rate of out-of-family residential placements for adults in England at 1.68 per 1000 aged 16 and over. However, as the increased population of people with intellectual disabilities age, this will cause a crisis in residential provision in the future.

Service models: Day services

The type of large day centres that are still very visible around Britain today often started as Adult Training Centres or Occupation Centres, and had an industrial or commercial outlook. In 1970s there was general recognition that these services offered little stimulation or financial reward and so there was pressure to change the services provided. In 1980s the focus of many of these day services changed from employment to social education and some became known as Day Opportunity Services, but they were still criticised for dealing with people in large groups, and failing to meet the needs of individuals, especially those with complex needs or challenging behaviour. The aim of many of these day centres was to train people in skills that would procure people employment but the skills taught did not necessarily reflect the jobs available. However, these Centres filled a very necessary function of providing daily respite for carers and at least some activity and social contact for the people who attended them. As such the speed of change was very slow.

In 1993, the Kings Fund conducted a national consultation and found that the “majority of people with learning difficulties still spent their most of their waking hours in congregate settings in special services with lifestyles largely dictated by the limited choice offered by those services”. In 1997 this was followed by a People’s First conference from which the overwhelming response was “Day Centres should not waste people’s time or people’s lives” (Whittaker and McIntosh, 2000). The pressure towards more individualised, community-based and rewarding day services intensified, from both political and user sectors. One possible alternative which has been expanding within the UK and which the government advocate as one way to help people lead “fulfilling lives” is supported employment.

Supported employment grew out of frustration with traditional day centres and sheltered employment schemes (Beyer and Kilsby, 1997). The aim of supported employment is to “place, train and maintain” and although several variations in the model are available, the main elements are the same:

- vocational profiling;
- canvassing of employers until suitable job found to meet profile;
- analysis of job tasks and work culture;
- job training provided and support faded until person is stable;
- continued monitoring, problem solving and career development.

As for supported living, there is little evaluative work at present, but what there is tends to show that supported employment results in more jobs in the community, greater financial gain, wider social integration (Forrester-Jones, 2001_ Forrester-Jones et al, 2001) increased worker satisfaction and increased quality of life (Beyer and Kilsby, 1997, Forrester-Jones et al., 2001). There are no official figures of the number of people in supported employment in the UK but Beyer and Kilsby (1997) report that the number of supported employment services had risen from 5 in 1986 to 210 in 1995 and that an estimated 5,084 people were in supported employment at that time. There are now over 230 supported employment agencies in the UK (Association for Supported Employment, 2002 www.afse.org.uk).

The experience of people with intellectual disabilities and their families

Within the UK there has been a recent emphasis in policy on empowerment for people with intellectual disabilities, on social inclusion and on family care giving. *Valuing People* (Department of Health, 2001) encouraged a new vision encompassing four key principles – rights, independence, choice and inclusion. It talked about better life chances including more choice and control but it also talked about supporting carers. Caring for a family member with a learning disability has now become more widely acknowledged as a life long commitment and an important resource. Since the later 1990s, a culture of consultation has sprung up, with people with intellectual disabilities appearing on advisory boards, government committees, consulted through advocacy groups about service development and taking part in their own reviews and care package development. Many research funding bodies want to see service users involved in the research and there is now beginning to develop a strain of research that includes people with intellectual disabilities as researchers, not just as a member of advisory boards. However, there is little published evaluation of this involvement and in many cases service users are only really involved at a tokenistic level, especially within service development. It is also problematic that by nature of the communication impairments associated with intellectual disabilities, in general only those with milder levels of intellectual disability are involved at this level.

There has, however, been several studies worth mentioning where people in the UK have been involved in service evaluation or review process. One example is a Joseph Rowntree Foundation funded project on a user-controlled Best Value review of direct payments by the Wiltshire and Swindon Users Network (with Wiltshire Social Services and University of Bath Research and Development Partnership).

There have also been a number of recent studies where researchers have made every effort to interview more severely disabled people using a system of total communication (Forrester-Jones et al. in press) with good results in terms of responsiveness. They found that users within services reported high levels of satisfaction with the quality of their accommodation and the care provided (especially the living environment, social milieu and independence). However, they also found that some people experienced bullying, did not like the social regime and reported feelings of loneliness and boredom.

However, most research on quality of life and outcome for people with intellectual disability has focused on either objective measures of quality of life or life satisfaction for those who were more able. In fact, most research on quality of life is framed as a way of evaluating service provision or contrasting service models. For example, as prevalent service models or views of what constituted good practice changed, the focus of the quality of life literature changed in the UK as well as the US. Initially, research focused on the comparison between institutional care and initial staffed community homes (Lowe and de Paiva, 1991; Emerson and Hatton, 1994;), then between larger and smaller community homes (Hatton and Emerson, 1996; de Kock et al., 1988; Felce and Repp, 1992.), and more recently between community homes and supported living (Howe et al., 1998). The general finding was that quality of life improved with the move to community care and with more autonomy and independence but the methodological and practical difficulties of assessing quality of life reliably has left many caveats in this work.

Even with more recent service models, research has found areas of poor quality and the issues that gave rise to the scandals of the 1960s and 70s that eventually lead to the demise of the large institution, remain all too prevalent in many services today. Prevalence of abuse is still relatively high, largely unreported and difficult to prosecute (Brown and Barry, 1994; Brown, Hunt and Stein, 1994; Brown, Stein and Turk, 1995). Service users often experience long periods of inactivity, especially those with more severe levels of disability (Emerson and Hatton, 1994; Simons, 1998; Felce and Perry, 1995; Felce et al., 1998) even in services where staff have been trained in specific methods to improve engagement in activity. Social exclusion is still very much a problem, especially for those with challenging behaviour and in many areas, people with more difficult/complex conditions such as autism or challenging

behaviour are sent away to larger specialised services or experience placement breakdown more frequently.

In terms of day activity, there has been some recent work around the development of supported employment and alternatives to the traditional large local authority run day centres still seen in many parts of the UK. In general, supported employment results in more jobs in the community, greater financial gain, wider social integration (Forrester-Jones, 2001; Forrester-Jones et al, 2001; Sinnot-Oswald, Glinner and Spencer, 1989) increased worker satisfaction and increased quality of life (Beyer and Kilsby, 1997, Forrester-Jones et al., 2001). The Changing Days project (Whittaker and McIntosh, 2000) illustrated a very general level of dissatisfaction with day centres and a desire for more creative and meaningful day activity. "Valuing People" reflected these findings in its proposals for major changes to day services. Person-centred planning was seen as essential in service delivery in the future and there was a particular focus on employment and opportunities for work. Mencap expanded on these proposals in "A life in the day: the modernisation of day services for people with learning disability". However, currently the majority of people with intellectual disabilities in the UK still attend traditional day services (Just under 50,000 receiving social services day services, mostly in the form of adult training centres, Department of Health, 2001) with little opportunity for employment (approximately 6000 people with an intellectual disability were in employment in 1995, Beyer and Kilsby, 1997), due to limited funding and difficulties in staff recruitment.

There are a number of specific service user groups where there has been some research in terms of differing experiences.

Women's health-related issues have been flagged up in recent years –The 1998 Mencap report entitled "The NHS - Health for All?" found that women with learning disabilities are severely disadvantaged in terms of preventative health care, in particular regular screening. Similar findings are reported in WHO/IASSSID/Inclusion International Healthy Ageing report (2000). Recent work by McCarthy on women with intellectual disabilities' experience of the menopause found that women had a lack of knowledge about the menopause and had little opportunity to discuss these sorts of issues. Most of the distress they went through, if they experienced distress at all, was down to physical factors rather than psychological factors (McCarthy, 2002). McCarthy concluded that women needed education with regard to the menopause and staff and carers needed to be sensitive to the symptoms and facilitate access to medical care, while GPs needed to work in partnership with the women and their carers. Earlier work describes women's experience of sexuality, sexual relationships and sexual abuse (McCarthy, 2000a and b). Research focusing on how women's reproductive health needs are met, is currently underway.

Research around the experience of older people with intellectual disabilities focuses mainly on physiological and medical changes (such as the work on dementia or Alzheimer's e.g. Moss and Patel, 1997; Holland et al., 2000) and there is little work in the UK on their experience in services. Cooper (1997) found that those over 65 with an intellectual disability have greater physical and psychiatric morbidity than younger people but have less access to health, respite and day services. Walker et al. (1995) found that of the 102 older people that they interviewed, none of these were in touch with an advocacy project. Hogg et al. (1988) talked about the double jeopardy – discrimination on grounds of both age and disability. In many places older people with intellectual disabilities are encouraged to use "ordinary" services for older people, where in reality they are not welcome and become victims of discrimination. There are two different models of care used in the UK – one for older people and one for people with intellectual disabilities (growing dependence versus ordinary life, cf. Walker et al., 1996) and during deinstitutionalisation it was often older people who were left in institutions because it was assumed they could not adapt to community life. Even more recent work by Robertson, Moss and Turner (1996) has shown that only 33% of Community Care plans made mention of issues relating to older people and these were mostly around service planning. In general there is widespread variation across the UK in how older people with intellectual disabilities are viewed and provided for (Department of Health, 1997; Fitzgerald, 1998).

Race issues. For many years people of ethnic minorities, were reported to have been anglicised in particular in institutionalised settings (Walmsley and Downer, 1997). In more recent years attempts have been made to respect the cultural, religious and dietary needs of people with intellectual disabilities from ethnic minorities but they are still subject to the double discrimination of being disabled and of an ethnic minority. Downer and Ferns (1998) describe the most common experiences for Black people with learning disabilities as being ignored as a Black person and treated as if white, so that culture is disregarded. They also experienced being called racist names, not having religious beliefs taken seriously, loneliness, lacking in confidence, lack of autonomy and respect.

There has also been some research on differences between ethnic minority and white people, for example, a recent study by McCrother et al. (2002), compared South Asian and white adults in Leicestershire, UK on prevalence, morbidity and service need. In terms of their experience, South Asians showed lower use of psychiatric services, residential care and respite care. They used community services as extensively as whites but felt that they had greater unmet need especially with regard to social services.

Those with challenging behaviour are often particularly susceptible to exclusion both from services and within services. When institutions are closing, people with challenging behaviour (along with those with the most profound disabilities) are less likely to gain community placement from institutions, often being the last people to move out in any resettlement process (Hill and Bruininks, 1984; Wing, 1988). They are also the most likely to be re-institutionalised (Eyman and Call, 1977; Hill and Bruininks, 1984 and Intagliata and Willer, 1982; Allen, 1999). Many people with challenging behaviour are placed in a service outside their own area. Exclusion from community services is often put down to client characteristics (such as severity or nature of challenging behaviour) but as the Mansell Report comments, exclusion appears to be caused as much by agency policy and service characteristics as by the nature of the challenge presented by the individuals (Department of Health, 1993). Whatever the reasons for exclusion from local services, the effect of exclusion is often maleficent on both the individual themselves in terms of the almost complete obliteration of their social networks and on the family. Out-of-area placements, often lead to the gradual dissipation of family ties, due to the distance and cost required to visit. Even when included in services, those with challenging behaviour tend to have less consistency in provision - this is usually due to placement breakdown (Pagel and Whitling, 1978 ; Sutter, 1980).

In terms of service provision, the Mansell report (1993) and Don't Forget Us (MHF 1997), emphasised the need to consider people with challenging behaviour as having the same needs as everyone else and more recent policy such as Valuing People (Department of Health, 2001) emphasise a policy of zero-rejection in terms of community care. However, scarcity of adequate provision in many areas means that those with challenging behaviour still do not receive the support they need to make

Although there is a general assumption that people with challenging behaviour have a poorer quality of life than other people without challenging behaviour, there is little research evidence that this is the case - a limited study of quality of life (Beadle-Brown, Murphy and di Terlizzi, in preparation) found that those with challenging behaviour tended to have poorer proxy ratings on a measure of quality of life, but the usual methodological cautions apply. Because those with challenging behaviour also have communication problems, they are generally not included in quality of life studies, so we don't have very reliable accounts of their experience.

As mentioned above there has been a renewed emphasis recently on family carers and on the support they need to provide what often amounts to life long care. The Carers and Disabled Children Act, 2000 meant that from April 2001, carers could request an assessment of their needs as a carer and local councils could offer services to the carer, not just the person they cared for. It also made it possible for direct payments to be made available to parents of children with intellectual disabilities so that they could be the services their children needed directly. In "Valuing People" (Department of Health, 2001), this life-long commitment is acknowledged and money was made available to fund a national learning disability information centre and help line in partnership with Mencap. Extra financial help was also to be made available in a variety of ways. At same time as VP was published, the Department of

Health issued "Family Matters: counting families in." In this it was noted that carer's organisations estimate that there are 6 million carers in this country but how many of these are family carers of people with intellectual disabilities is unknown. Carers in general are thought to experience higher levels of stress, poorer financial situation, poorer health, isolation, poorer housing and marital breakdown (Beresford, 1995, cited in "Family Matters"). Situation is even worse for minority ethnic and black families who experience high levels of unmet need, poverty, poor housing and social isolation and lack of support as well as a lack of information of culturally appropriate services (Baxter et al., 1999; Nocon, Department of Health, 2000; Chambara et al., 1990, all cited in Department of Health, 2001b). Families experience heightened difficulties around times of transition and as the carers themselves become older.

Even local and national provider organisations have recognised the importance of families in providing real social inclusion for people with intellectual disabilities e.g. "Valuing People: Valuing Families – towards an agenda for social inclusion" is published by Home Farm Trust for People with Learning Disabilities. This reports findings from research work and carer consultation within UK. As mentioned above, national statistics suggest that the situation of those caring for people are very poor, including higher costs but lower incomes than non-caring families. However, most of the research is from children – little research on those caring for adults with intellectual disabilities. However, a Mencap report (2001) focused on the needs of families caring for children and adults with profound and multiple learning disabilities and found that "60% of parents spent more than 10 hours a day on basic physical care, 48% received no support from outside the home to help with their care tasks, 78% received no support or less than two hours per week to help them cope at home with their caring tasks, 37% had contact with eight or more professionals and 80% thought professions were poorly or very poorly co-ordinated" (cited in Valuing People: Valuing Families page 12).

In terms of the psychological costs of caring for someone with a learning disability, there exists some research around stress in parents – for example, the work of Pahl and Quine (1984) and Quine and Pahl (1989) on stress and coping in mothers. Pahl and Quine (1984), suggest that parents with children with intellectual disabilities experience stress well above the average for families with non-disabled children, that mothers carry the main burden of care compared to fathers who provide and ask for little help. And that parents who experienced most stress were those whose child had multiple impairments and/or had challenging behaviour. This was combined with environmental 'family adversity' including poverty, poor housing, ill health and social isolation. Pahl and Quine concluded that parents urgently want more information on many different aspects of caring, and need clear assessment procedures, family relief schemes such as respite care and specialist services such as specialist social workers (1984:141 - 144). Quine and Pahl (1989) also highlighted the considerable financial costs involved in caring for a child with severe intellectual disability and the difficulty parents found in "managing" their child with intellectual disabilities, such as dealing with incontinence, fewer self-help skills, poor communication skills, and the inability to read, write or count was increased when their child also had challenging behaviour. In terms of the psychological stress experienced and the coping mechanisms employed, Quine and Pahl found that one of the most important child variables affecting mothers' stress was behaviour problems. Coping resource variables included financial and social support, marital satisfaction and social networks.

There has also been some research on the mental health of carers – Olsson and Hwang (2001) found higher depression scores in mothers of those with autism compared to mothers of those with ID without autism, fathers of those with autism, fathers of those with ID and mothers and fathers of those without ID. Chen et al. (2001) found that caregiving for later-life mothers (over 65 years) was more detrimental to physical and mental health than for mid-life mothers (55-64 years).

There is also some work around older carers which shows that older carers are more likely to experience social isolation and to end up caring for their son or daughter until they can no longer physically do so (Walker, 1998, cited in Home Farm Trust, 2002). Recently there has been some resources for ageing parents made available – e.g. Life Time of Caring website – aimed both at older parents and service providers working with older parents of people with an intellectual disability. There are also a number of very active service user, parent or

advocate organisations such as Mencap and Scope, which serve as an information resource, service provider, advocate organisation, etc.

References:

- Allen, D. (1999) Success and failure in community placements for people with learning disabilities and challenging behaviour: An analysis of key variables. *Journal of Mental Health*, 8, 3, 307 – 320.
- Audit Commission (1986) *Making a Reality of Community Care*, London: HMSO.
- Audit Commission (1987) *Occasional Paper Number 4*, London: HMSO.
- Audit Commission (1989) *Occasional Paper Number 9*, London: HMSO.
- Audit Commission (1992) *Community Care: Managing the Cascade of Change*, London: HMSO.
- Beadle-Brown, J., Murphy, G and di Terlizzi, M. (in preparation) *Quality of Life for the Camberwell Cohort: a brief report*
- Beresford, B. (1995) *Expert Opinion: A national strategy of parents caring for a severely disabled child*. The Policy Press.
- Beyer, S. and Kilsby, M. (1997) Supported employment in Britain *Tizard Learning Disability Review*, 2 (2), 6 – 14.
- Braddock, D., Emerson, E., Felce, D. and Stancliffe, R.J. (2001) Living Circumstances of children and adults with mental retardation or developmental disabilities in the United States, Canada, England, Wales, and Australia. *Mental Retardation and Developmental Disabilities Research Reviews*, 7, 115 – 121.
- Brand, D (2000) Modernising social services: implications for the development of staff training in learning disability services, *Tizard Learning Disability Review*, 5 (2), 36-43.
- British Psychological Society (2001) *Learning Disability: Definitions and Contexts*.
- Brown, H. and Barry, G. (1994) Taking advantage: sexual abuse of adults with learning disabilities. *The criminal lawyer*, Feb/Mar, 5 – 7.
- Brown, H., Hunt, N. and Stein, J. (1994) Alarming but very necessary: working with staff groups around the issues of adults with learning disabilities. *Journal of Intellectual Disability Research*, 38, 393 – 412.
- Brown, H., Stein, J. and Turk, V. (1995) The sexual abuse of adults with learning disabilities: report of a second two-year incidence study. *Mental Handicap Research*, 8 (1), 3 – 24.
- Cambridge, P. (1999) The state of care management in services for people with mental retardation in the UK, in eds. N Bouras, *Psychiatric and Behavioural Disorders in Developmental Disabilities and Mental Retardation*, Cambridge, Cambridge University Press.
- Cambridge, P. (2000) Using “Best Value” in purchasing and providing services for people with learning disabilities *British Journal of Learning Disabilities*, 28, 31-37.
- Cambridge, P., Carpenter, J., Beecham, J., Hallam, A., Knapp, M., Forrester-Jones, R., & Tate, A (2001) *Twelve Years On: the Outcomes and Costs of Community Care for People with Learning Disabilities and Mental Health Problems*, Canterbury: Tizard Centre, University of Kent at Canterbury.

- Cambridge, P., Hayes, L., & Knapp, M. (1994) *Care in the Community: Five Years On*, Aldershot: Arena.
- Chen, S. C., S. Ryan-Henry, et al. (2001). Health status of mothers of adults with intellectual disability. *Journal of Intellectual Disability Research* **45**(Issue 5): 439 - 450.
- Cooper, S (1997) Deficient health and social services for elderly people with learning disabilities. *Journal of Intellectual Disability Research*, 41 (4), 331-338.
- de Kock, U., H. Saxby, et al. (1988). "Community and family contact: An evaluation of small community homes for adults with severe and profound mental handicaps." *Mental Handicap Research* **1**(2): 127-140.
- Department of Education and Skills (1978) *Special Educational Needs (the Warnock Report)* London: HMSO.
- Department of Education and Skills (1981) *The Education Act 1981* London: HMSO
- Department of Health (1989) *Caring for People: Community Care in the Next Decade and Beyond*. London: HMSO.
- Department of Health (1993) *Services for People with learning disabilities and challenging behaviour or mental health needs: Report of a project group*. (Chairman: Prof. J.L. Mansell) London: HMSO.
- Department of Health (1993) *Services for people with learning disabilities and challenging behaviour or mental health needs: Report of a project Group (Chairman: Prof. J.L. Mansell)* London: Her Majesty's Stationary Office.
- Department of Health (1993) *Services for People with learning disabilities and challenging behaviour or mental health needs: Report of a project group*. (Chairman: Prof. J.L. Mansell) London: HMSO.
- Department of Health (1995) *Disability Discrimination Act* London: HMSO
- Department of Health (1996) *Community Care (Direct Payments) Act* London: HMSO (<http://www.hmso.gov.uk/acts/acts1996/1996030.htm>)
- Department of Health (1997) *Guide to Direct Payments* (<http://www.open.gov.uk/Department of Health/directp.htm>)
- Department of Health (1998a) *Partnership in Action – new opportunities for joint working between Health and Social Service Departments* London: HMSO
- Department of Health (1998b) *Modernising the Social Services (CM 4169)*, The Stationery Office, London.
- Department of Health (1999) *A New Approach to Social Services Performance*, Department of Health, London.
- Department of Health (2000a) *Care Standards Act*
- Department of Health (2000b) *Community Care Statistics 2000* (Residential Personal Social Services for Adults, England).
- Department of Health (2000c) *Guide to Direct Payments* (revised)
- Department of Health (2000d) *No Secrets: Guidance on Developing and Implementing Multi-agency Policies and Procedures to Protect Vulnerable Adults from Abuse*, London, Department of Health.
- Department of Health (2001a) *Health and Social Care Act*

- Department of Health (2001a) *Valuing People: a new strategy for learning disability for the 21st Century*. London: HMSO
- Department of Health (2001b) *Family Matters – Counting Families In*. London: Her Majesty's Stationery Office.
- Department of Health (2001b) *Reference guide to consent for examination or treatment*, Department of Health: London (available at www.Department of Health.gov.uk/consent)
- Department of Health (2001c) *Seeking Consent: working with people with learning disabilities* Department of Health: London (available at www.Department of Health.gov.uk/consent)
- Department of Health (2001d) *Valuing People: a new strategy for learning disability for the 21st Century*. London: HMSO
- Department of Health and Social Security (1971) *Better Services for the Mentally Handicapped* London: HMSO
- Department of Health and Social Services (1983) *Care in the Community* London: HMSO.
- Department of Health. (2001) *Care Homes for Older People: National Minimum Standards*. London: The Stationery Office.
- Department of Health. (2002) *Care Homes for Younger Adults and Adult Placements: National Minimum Standards: Care Homes Regulations*. London: The Stationery Office.
- Department of the Environment, Transport and the Regions (1998a) Compulsory Competitive tendering: changes to regulations and guidance. DETR, London.
- Downer, J, and Ferns, P. (1998) Self Advocacy by Black People with Learning Disabilities in Ward, L. (Ed) *Innovation in Advocacy and Empowerment for People with Intellectual Disabilities* Chorley, UK : Lisieux Hall Publications. Chapter 10, pp 141 – 149.
- Emerson, E. and C. Hatton (1994). *Moving Out: Relocation from Hospital to Community*. London, Her Majesty's Stationery Office.
- Emerson, E. and C. Hatton (1998). "Residential provision for people with intellectual disabilities in England, Wales and Scotland." *Journal of Applied Research in Intellectual Disabilities*, 11(1): 1-14
- Emerson, E., Hatton, C., Felce, D and Murphy, G. (2001) *Learning Disabilities: the Fundamental Facts*. The Foundation for People with Learning Disabilities.
- Emerson, E., Robertson, J, Gregory, N., Hatton, C., Kessissoglou, S. et al. (2001) Quality and Costs of Supported Living Residences and group homes in the United Kingdom. *American Journal on Mental Retardation*, 106 (5), 401 – 415.
- Eyman, R and Call, T. (1977) Maladaptive Behaviour and community placement of mentally retarded persons. *American Journal of Mental Deficiency*, 82, 2, 137 – 144.
- Felce, D. (1989) *The Andover Project: Staffed Housing for Adults with Severe or Profound Mental Handicaps*, British Institute on Mental Handicap: Kidderminster.
- Felce, D. (1999) The Gerry Simon Lecture, 1998: Enhancing the Quality of Life of people receiving residential support. *British Journal of Learning Disabilities*, 27, 4 - 9.
- Felce, D. and A. Repp (1992). The behavioral and social ecology of community houses. *Research in Developmental Disabilities* 13: 27-42.

- Felce, D. and J. Perry (1995). The extent of support for ordinary living provided in staffed housing: The relationship between staffing levels, resident characteristics, staff:resident interactions and resident activity patterns. *Social Science and Medicine* **40**(6): 799-810.
- Felce, D., K. Lowe, et al. (1998). "Service support to people with severe intellectual disabilities and the most severe challenging behaviours in Wales: Processes, outcomes and costs." *Journal of Intellectual Disability Research*, 42: 375-389.
- Fitzgerald, J. (1998) *Time for freedom: services for older people with learning disabilities*. London: Centre for Policy on Ageing and Values into Action.
- Forrester-Jones, R. (2001) Friendships and Social Integration Through Leisure: Commentary. *Tizard Learning Disability Review* Vol 6, Issue 4. Pp 28-32
- Forrester-Jones, R. (in press) 'Individualised communication in research with people with intellectual disabilities' *Journal of Intellectual and Developmental Disability*
- Forrester-Jones, R. Carpenter, J. Tate, A. Cambridge, P. Beecham, J. Hallam, A. and Knapp, M. (in press) The Quality of Life of People Twelve Years after Resettlement from Long-Stay Hospitals: Users' views on their living environment, daily activities and future aspirations. *Disability and Society*.
- Forrester-Jones, R., Heason, S., Jones, S. and Di'Terlizzi, M. (2001) *Support Networks of People with Learning Disabilities using IMBY Employment (a supported employment agency). Report on an evaluation to assess the impact of the new provision of supported employment on the lives of service users*. Canterbury, Tizard.
- Forrester-Jones, R., Heason, S., Jones, S. and Di'Terlizzi, M. (2001) Support Networks of People with Learning Disabilities using IMBY Employment (a supported employment agency). Report on an evaluation to assess the impact of the new provision of supported employment on the lives of service users. Canterbury: Tizard Centre.
- Great Britain. (2000) *Care Standards Act 2000 : Chapter 14*. London: Stationery Office.
- Greig, R., Cambridge, P. and Rucker, L. (1996) Care Management and Joint Commissioning in Harris, J. (Ed) *Purchasing Services for people with learning disabilities, challenging behaviour and mental health needs*, Kidderminster: British Institute of Learning Disabilities. Chapter 2, pages 5-20.
- Gunn, M.J. (1996) *Sex and the law: a brief guide for staff working with people with learning disabilities* London: Family Planning Association.
- Hatton, C. and E. Emerson (1996). Residential Provision for People with Learning Disabilities: A Research Review. Manchester, Hester Adrian Research Centre.
- Hill, B. and Bruininks, R. (1984) Maladaptive Behaviour of mentally retarded individuals in residential facilities. *American Journal of Mental Deficiency*, 88, 380 – 387.
- Hogg, J, Moss, S and Cooke, D. (1988) *Ageing and Mental Handicap* London: Chapman and Hall.
- Home Farm Trust (2002) *Valuing People: Valuing Families. Towards an agenda for social inclusion*
- Home Office (1998) *Human Rights Act* London: HMSO
- Howe, J., R. H. Horner, et al. (1998). Comparison of supported living and traditional residential services in the state of Oregon. *Mental Retardation* **36**(1): 1-11.

- Intagliata, J. and Willer, B., (1982) Reinstitutionalisation of mentally retarded persons successfully placed in family-care and group homes *American Journal of Mental Deficiency*, 87, 34 – 39.
- King's Fund (1980) *An Ordinary Life: Comprehensive Locally-Based Residential Services for Mentally Handicapped People* London: King's Fund Centre.
- Kinsella, P. (1993). *Supported living: a new paradigm*, National Development Team.
- Knapp, M., and Beecham, J (1990) Costing mental health services, *Psychological Medicine*, 20, 893-908.
- Knapp, M., and Cambridge, P. (1997) The cost dimension in commissioning and providing services for people with learning disabilities, in Eds N. Bouras and P Donlan *Challenges and Change: Commissioning and Providing Services for People with Learning Disabilities*, Brighton: Pavilion and SEIPH.
- Knapp, M., Cambridge, P., Thomason, C., Beecham, J., Allen, C., & Darton, R. (1992) *Care in the Community: Challenge and Demonstration*, Aldershot: Ashgate.
- Lowe, K. and S. de Paiva (1991). Clients' community and social contacts: Results of a 5-year longitudinal study. *Journal of Mental Deficiency Research* 35: 308-323.
- Lyon, C. (1994) *Legal Issues Arising from the Care, Control and Safety of Children with Learning Disabilities who also present Severe Challenging Behaviour*. London: Mental Health Foundation.
- Mansell, J (1996) Issues in Community Services in Britain in Mansell and Ericsson (Eds) *Deinstitutionalisation and Community Living* London: Chapman and Hall, Chapter 4.
- Mansell, J. (1996) The cost and quality of community residential care by Raynes, N.V., Wright, K., Shiell, A. & Pettipher, C. *Journal of Intellectual Disability Research*, 40(5), 482-483.
- Mansell, J. and Ericsson, K. (1996) Introduction: towards deinstitutionalisation in Mansell and Ericsson (Eds) *Deinstitutionalisation and Community Living* London: Chapman and Hall. Chapter 1.
- Mansell, J., Felce, D., Jenkins, J et al (1987) *Developing Staffed Housing for People with Mental Handicaps*, Tunbridge Wells: Costello.
- McCarthy, M. (2000). Consent, abuse and choices: Women with intellectual disabilities and sexuality in R. Travstadóttir and K. Johnson (Eds). *Women With Intellectual Disabilities: Finding a Place in the World* London, Jessica Kingsley: 132-156.
- McCarthy, M. (2000). Sexual Abuse and Women with Learning Disabilities in Atkinson, M; Walmsley, J; Cooper, M; Rolph, S; Aspis, S; Barette, P; Coventry, M and Ferris, G. (Eds) *Good Times, Bad Times: Women with Learning Difficulties Telling their Stories*. BILD Publications: 47-66.
- McCarthy, M. (2002) Responses to Women with Learning Disabilities as they go through the Menopause *Tizard Learning Disability Review*, 7 (1), 4-12.
- Mencap (2001) *No Ordinary Life: The support needs of families caring for children and adults with profound and multiple learning disabilities*.
- Mental Health Foundation (1997) *Don't forget us: children with learning disabilities and severe challenging behaviour*.
- Mental Health Foundation (1997). *Don't Forget Us*. London, Mental Health Foundation.

- Moss, S. and Patel, P. (1997) Dementia in older people with intellectual disabilities: symptoms of physical and mental illness and levels of adaptive behaviour. *Journal of Intellectual Disability Research*, 41 (1), 60-69.
- Olsson, M. B. and C. P. Hwang (2001). Depression in mothers and fathers of children with intellectual disability. *Journal of Intellectual Disability Research* 45(Issue 6): 535 - 543.
- Pagel, S. and C. Whitling (1978). Readmission to a state hospital for mentally retarded persons reasons for community placement failure. *Mental Retardation* 16: 25-28.
- Pahl, J and Quine, L. (1984) *Families with mentally handicapped children: a study of stress and service response* HSRU, Canterbury
- Quine, L and Pahl, J. (1989) *Stress and coping in families caring for a child with severe mental handicap: a longitudinal study* ISAP and CHSS, Canterbury
- Robertson, J., Moss, S & Turner, S. (1996) Policy, Services and staff training for older people with intellectual disability in the UK. *Journal of Applied Research In Intellectual Disabilities*, 9 (2) 91-100.
- Rojahn, J. (1994) Behavior Problems Inventory: Nisonger Centre for Mental Retardation, Ohio State University.
- Sharard, H.E. (1992) Feeling the strain: job stress and satisfaction of direct-care staff in the mental handicap service *The British Journal of Mental Subnormality*, 38, 32-38.
- Simons, K. (1998) Getting a foot in the door: the strategic significance of supported living. *Tizard Learning Disability Review*, 3 (2), 7 – 16.
- Simons, K. (1998) Getting a foot in the door: the strategic significance of supported living. *Tizard Learning Disability Review*, 3 (2), 7 – 16.
- Sutter, P. (1980). "Environmental variables related to community placement failure in mentally retarded adults." *Mental Retardation* 18: 189-191.
- Tizard, J. (1960) Residential care of mentally handicapped children. *British Medical Journal*, 2 April, pp. 1044.
- Tizard, J. (1964) *Community Services for the Mentally Handicapped* London: Oxford University Press
- Walker, C., Walker, A. and Ryan, T. (1996) Older People with learning disabilities leaving institutional care: A case of double jeopardy. *Ageing and Society*, 16. 125-150.
- Walmsley J., and Downer, J. (1997) Shouting the Loudest: Self Advocacy, Power and Diversity in Ramacharan, P., Roberts, G., Grant, G. and Borland, J. (Eds) *Empowerment in Everyday Life: Learning Disability* London: Jessica Kingsley Publishers.
- Whittaker, A. and McIntosh, B. (2000) Changing Days *British Journal of Learning Disabilities*, 28, 3 – 8

Glossary of terms/service typology

Apoyo familiar (ESP) Familienunterstützender Dienst (GER)

Domiciliary service for families with intellectual disabled children. Provides practical, educational and psychological assistance for parents and supports the integration of the child into society.

Care Management (UK)

Process of core tasks including assessment, service planning and review or process for co-ordinating services and inputs from different agencies and sectors around individual needs.

Community Care (UK) Atención Comunitaria (ESP) Community Care (NL)

Services that give support to persons with intellectual disability and their families in the community. The term is often used in a general way referring to living facilities in the community in contrast to large institutions.

Community learning disability team (UK)

Multidisciplinary team of e.g. social work, psychological and nursing staff, responsible for the care for people with learning disability in a local district.

Daily activities with support (SWE)

A day service for persons with a mild as well as those with a severe disability. This is realized through a week filled with purposeful daily activities. As the activities are related to individual needs, the content of the week will be personal.

Day Centre (UK) Centros de Día (ESP) Dagverblijf voor volwassenen (NL) Tagesstätte (GER)

Facility that provides activities and support during the day-time, focusing on social education for people with intellectual disability who do not work in sheltered workshops. Often directly linked to a sheltered workshop.

Direct payments (UK) Pagos directos (ESP) PGB Persoonsgebonden/volgend budget (NL) Persönliches Budget (GER)

Monetary provisions that are received by people with learning disability to buy the care and support they need themselves.

Early intervention (UK) Atención temprana (ESP) Frühförderung (GER)

Service that offers furtherance and care for babies and young children with intellectual disability or developmental delay. Treatment is often provided in the child's home and is aimed at the child and its parents.

Freie Wohlfahrtspflege (GER)

Term that subsumes third sector welfare work organisations in Germany. The provision of social services is given to six welfare work organisations in each state following the principle of subsidiarity.

Group home/Staffed house (UK) Viviendas tuteladas (ESP) Kleinschalige woonvoorzieningen (NL) Aussenwohngruppe (GER)

Community situated living facility for a smaller number of people with learning disability (approx. 2-8 persons in the UK and Sweden, up to 6 persons in the Netherlands and Germany, max. 10-15 persons in Spain). In some countries (GER, ESP) directly linked to a larger residential service. Usually group homes are staffed 24 hours per day, although in Sweden the term group home is also used to refer to the living situation of people with limited support needs living with some friends without staff.

Institution (UK) Instituciones Residenciales (CAMP) (ESP) Residentiele voorzieningen (NL) Anstalt (GER)

Large, facility which is not community integrated and which offers general care for residents including a place to live, work, activities during the day, medical and psychiatric care. In the UK term is usually used to describe the old long-stay 'mental handicap' hospital.

Intellectual disability/Learning disability (UK) Retraso Mental (ESP) Verstandelijke beperkingen (NL) Geistige Behinderung (GER)

Intellectual ability that is significantly lower than the mean (measured by IQ), accompanied by a significant impairment of adaptive functions, in accordance with AAMR definition.

Local authority (UK) Autoridad local (ESP) Örtlicher/Überörtlicher Sozialhilfeträger

Social administration on local or regional level that generally holds responsibility for the planning and implementing of programmes and social care services.

Mainstreaming for children with special educational needs (UK) Aulas de integración (ESP) Integrationsklassen/Integrative Schule (GER)

Regular school in which children with and without intellectual disability attend lessons and school activities together, with assistance provided by special education.

Mixed economy (UK) Economía mixta (ESP)

Term used to describe a diversification of relationships between the public sector organisations, local government and various statutory and voluntary providers of community care.

Normalisation (UK, SWE) Normalisatie (NL) Normalisierungsprinzip (GER)

The right of people with intellectual disability to live a life as normal as possible and a lifestyle comparable to people of the same age and cultural background. In Sweden in 1946 this became the socio-political idea that the desirable development for persons with a disability is to live a normal life, with the support from general welfare services. This became the starting point of the deinstitutionalisation process in Sweden and other countries.

Personal assistance (SWE)

A person with a severe disability is allocated funding to be able to choose his/her personal assistants, their task being to give support in everyday life to this person.

Person centred planning (UK) Zorgplanning/Vraaggestuurde zorg (NL) Individuelle Hilfeplanung (GER)

Assessment-based process that aims to clarify the individual needs, desires and involvement of a person with learning disability in order to create a support arrangement that meets this needs and desires.

Private housing with support (SWE)

The person has his own home, by renting or by purchase, and receives his staff support from social welfare services.

Residential home/Hostel (UK) Miniresidencias (ESP) Gezinsvervangend tehuis (GVT) (NL) Wohnheim (GER)

Living facility for a larger number of people with learning disability (approx. 8-20 persons in the UK, 15-20 persons in Spain and 24 persons in Germany), often community situated and providing continuous staffing 24 hours.

Sheltered workshop (UK) Centros Ocupacionales (ESP) Social werplaats (NL) Werkstatt für behinderte Menschen (GER)

Work facility for people with intellectual disability who, for several reasons, are not able to take part in the regular labour market. People do not receive a normal salary and the aim is to train people in skills that prepare them for regular employment.

Special hospital (UK)

Hospital for serious criminals. Residents are in several cases people with mild or moderate intellectual disability.

Special needs unit (UK)

Unit within a day centre for people with severe or profound intellectual disability or other complex needs such as challenging behaviour.

Special School (UK) Centros de Educación Especial (ESP) School voor speciaal onderwijs (NL) Schule für geistig Behinderte (GER)

Special school or education centre for children with intellectual disability.

Supported employment scheme (UK) Empleo con apoyo (ESP) Begeleid werken (NL) Integrationsfachdienst (GER)

Service that provides support for people with intellectual disability in finding and maintaining employment on the regular labour market.

Supported living (UK) Ayuda a domicilio (ESP) Begeleid zelfstandig wonen (NL) Betreutes/Unterstütztes Wohnen (GER)

Service that organises support, e.g. psycho-social support or assistance in activities of the daily life, for people with learning disabilities living in their own, community integrated homes. Users of supported living receive care when necessary and wanted.

The new paradigm/Ordinary living (UK) Burgerschapsparadigma (NL) Selbstbestimmungsparadigma/Bürgerschaftsparadigma (GER)

People with intellectual disability are part of the community as any other citizen. They have the right to make their own choices and to exert control over their own lives. Their life has a perspective and is not reduced to medical or physical care only. Because of their disabilities, they need and have a right to support, both by their own social network and by professional staff.

